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May 3, 2010

To Live Means to Suffer:
Exploring the Identity of Chronic Pain Conditions

In writing about chronic pain, I have learned that language fails to capture the sensation of pain and of suffering, an unsurprising notion but nevertheless frustrating for a writer, such as myself, who suffers from a chronic pain disorder. For nearly a decade, I have tried to push my pain onto a page, and my pain has pushed back. I have tried to write about pain simply because I want to write honestly about myself, and pain is tied deeply to my sense of identity, to my voice. Pain is unavoidable in my personal narrative, but remains inexplicable. I considered, perhaps, that I should attempt to write about pain academically, instead of creatively, utilizing scholastic insight to inform my conception of the pain experience. I wanted to read how others, academics, scholars, authors (those with an impressive command of language) wrote about pain, what words they put to use. My research of chronic pain conditions began with sociological texts, many of which contained interviews with patients. The interviews failed to capture the essence of embodiment, and I wondered whether these patients were being asked the wrong questions. This ultimately led me to conduct my own interviews. In an exploration of the relationship between identity formation and chronic illness, I conducted and transcribed three interviews, resulting in compelling illness narratives that support the sociological conclusions made in the discourse surrounding pain.

As I began to write this paper in December of 2009, it felt dishonest not to include my own struggle with chronic pain. This paper is the product of my own pain. It is my

means to uncover the implications of my own body. I could not leave out my story. My battle with chronic disease began seven years ago, at age twelve, a seventh grader at Herbert Hoover Middle School. I was living then at the second home I have ever lived, 551 Yale Street, Portola District, San Francisco, California and at that time it was new to me: its Victorian smells and the prosaic groan of its basement stairs, its droplet moldings which I read with my fingertips like Braille. It was October, but in California, seasons are meaningless, leaves and weather don't change shape. I was roughly four foot eleven inches.

This is the point most left on my timeline, the beginning of my illness narrative. There are few things that anchor that year: I began menstruating, a dog named Dahlia joined my family, I got sick. The year is endowed with importance, with symbolism. There is certainly a before-and-after of my twelfth year of life. It is what could be regarded as my "fall," from innocence, from childhood, from health. It somehow, and perhaps this paper will serve as an explanation, was a rebirth into my current identity, an identity that defines itself as a person in pain. I became a person who, although not constantly, lives consistently with pain. I am good at pain; I know it well. Joan Didion writes in her essay "In Bed," of a relationship with her migraine: "I have learned now how to live with it, learned when to expect it, how to outwit it, even how to regard it, when it does come, as more friend than lodger. We have reached a certain understanding, my migraine and I." Reading Didion, I'm inclined to retract my statement. I do not want to have a friendship with my pain. I wish pain was a stranger, or even an acquaintance, cordial but easy to dismiss. I wish pain not to be my friend, but also not to be an enemy. I wish I were neutral towards pain, towards suffering, that I could laugh at it, tease it, toss

it around like a soccer ball. But the fact is I am, at times, not much bigger than pain. Like a freckle on my hand I wake up with it, shower with it, and I cannot shake it.

"In the context of a chronic disorder, the illness becomes embodied in a particular life trajectory, environed in a concrete world. Acting like a sponge, illness soaks up personal and social significance from the world of the sick person,"(Kleinman, 31) writes anthropologist Arthur Kleinman in his book *The Illness Narratives*, in which he explores this very subject: the consuming nature of chronic illness. The illness itself becomes endowed with emotions, with memories, with overpowering significance. The person can lose him/herself in the illness, and can see everything in their life as a product or cause of it. "The chronically ill are somewhat like revisionist historians, refiguring past events in light of recent changes," (Kleinman, 48). The illness is the subject of their biography, "the plot lines, core metaphors, and rhetorical devices…structure the illness narratives," (Kleinman, 49).

The year before I got sick, my dentist found a horizontal tooth in my chin and I had surgery to remove it. My mother had joked then, said that I had the healthiest, most normal little body and this tooth was my little fluke. Who knew brewing inside this healthy little body was a sluggish tooth, resting on its side? The tooth had lost its way. That year before I got sick, I had a healthy, normal body, a vaccinated, nurtured little body. Granted, I was a headachy child, which is rare, because most children complain of tummy pains, but my stomach was without event, without grievance, at least at that point on my time line.

Now, eight years later, this minor oral surgery works its way into my pain narrative, as does my trip to Mexico in July of that same year. These are questions

doctors predictably ask, each specialist trying to discern whether it is something they can solve. Have you had any major surgeries? (Is this a complication that occurred? An infection?) Did you leave the country around that time? (Did you drink the water? Might it be a parasite?) When did you first start menstruation? (Are these simply unbearable cramps?) Tell me about that year of your life. (Is this caused by stress? By trauma?) I have been to enough dumbfounded specialists to know that these are not the causes. That there are seemingly no causes. This is an important part of my narrative.

Those who have not been required to repeat a pain narrative cannot understand the consequence of one. Lynne Greenberg, author of *The Body Broken*, developed an illness narrative to recite to each doctor she visited:

> I am in pain from the moment I wake up until the moment I go to sleep. On a scale of 1 to 5, my pain never falls below a 3 and will rise at some point to 5 nearly daily and stay there for hours. These spikes are unrelenting, stare-at-the-ceiling, wait-it-out pain. Its sinews unfurling, the pain whips through the middle of my head. It feels like an ice-cream headache—the sharp deep freeze of eating or drinking too much of a cold substance too quickly. It is heavier than an ice-cream headache, though; it feels as if an enormous weight lies along the tendon, crushing this central route, tearing my head in half. When spiking, the pain radiates out from the center and disperses. The ice cream has melted, not just freezing my forehead but dripping down to encompass my entire head symmetrically, pooling finally behind my eyes. Sometimes the pain is intense that even the skin of my face, particularly around the eyes, hurts like a bruise. My eyes also burn and smart and sting.

This is the mantra of the chronically ill. We know how to rate our pain on a scale. We know the descriptors doctors want to hear: throbbing, burning, stinging, sharp, dull. We know the questions they will ask and preemptively answer them: Heat, not cold, alleviates the pain. I have no appetite. I cannot sleep. It lasts for ten days without resolve. It comes on steadily, fades sedately. These details become character traits, personalities. We lose ourselves in these details.

The specifics of my very first encounter with chronic pain are surprisingly hazy; there are deep cavities in my memories. I can, however, list the chronology of the medicine that shadowed my pain. I remember my pediatrician suggesting a tacky, fruity syrup as a remedy. Then chalky tablets that dissolved in a mug of water. I could not yet swallow pills, so my mother buried every prescription in strawberry ice cream. The vestiges of each medication, each drugstore drive-by, reside in a bathroom cabinet at my parents' home. It is a graveyard that I imagine most chronically ill have: a memorial of every drug that failed to cure. I don't remember these remedies not working, but I am certain they did not work. I don't remember, that seventh-grade year, the pain softening in my stomach, thawing, but I am certain that it eventually did.

My body, vacated, went back to its life as a healthy body. It ate whatever it pleased. It played clarinet, it studied algebra. It slept full eight-hour sleeps. It was a fluke, we knew, a ten-day fluke like my lazy tooth, like my infrequent headaches. The pain in my stomach returned just six weeks later, the next notch on my timeline. This one led to a trip to an emergency room, to intravenous morphine, to a few more doctors probing and disseminating. Thus began the pattern, the ebb and flow of pain that would infiltrate my life for the next nine years, for who knows how long there after. More importantly, thus began the recreation of my identity, which needed to stretch, to dismantle to engage a new, sick being. I have not *become* my illness, but the illness joins me in my living. Its presence lingers even when I am not in pain; it threatens to come back at any moment. "The undercurrent of chronic illness is like the volcano: it does not go away. It menaces. It erupts. It is out of control. One damned thing after another," (Kleinman, 44).

Kleinman writes in his discussion of a badly burned patient, that while one of her problems might be "the insidious medical complications of the course of her chronic [pain]" another problem, one perhaps even more important, is "the life trajectory that her illness had marked and inexorably shaped" (Kleinman, xii). This is unavoidably and uniquely true for the chronically ill. Those with a common cold or a violent flu, those who have broken an ankle or even stubbed their toe, perhaps suffer just as much, momentarily, as a person in chronic pain, but their pain does not last and therefore does not create a "biographical disruption" (Lawton, 3) which is an important and agonizing part of the chronic pain experience. But chronic pain is not an interruption through which a patient lives, recovers and returns to their previous life. People with pain confront a new identity, of a person who experiences, and will always experience, pain. Poet Adrienne Rich considers this, "You ask me how I'm going to live / the rest of my life/ well nothing is predictable with pain…But I'm already living the rest of my life/ not under conditions of my choosing/ wired into pain."

Didion insists, "It was a long time before I began thinking mechanistically enough to accept the migraine for what it was: something with which I would be living, the way some people live with diabetes." Those who are chronically ill suffer two tragedies, the pain itself, and also the construction of a new, unwanted identity. They are not themselves *without* illness and they cannot be themselves while in pain. Themselves, ourselves, myself becomes something new. "I wanted to dance on tables, to breathe freely, to play with my children, to have sex, to teach. My mind at this stage was utterly self-involved and myopic: me, me, me, me, I, I, I, I," (Greenberg, 81).

Chronic illness brings with it an embodied experience that the healthy do not have bear. The chronically ill cannot forget their bodies. They are always conscious because their body, their pain, refuses to be ignored. “For the chronically ill, details are all. To cope with chronic illness means to routinely scan minute bodily processes, (Kleinman, 47). This can be explained as a “daily quest for control,” (Kleinman, 47). No wonder exhaustion is a frequent symptom of chronic pain, as is depression (Kleinman, 69). Pain is demoralizing, especially unexplainable or unsolvable pain. “Surviving itself is a kind of success,” says one of Kleinman’s patients (Kleinman, 83). “It controls me,” complains another, “It’s limiting,” (Kleinman, 91).

Chronic pain is disturbing because it implies that there is no cure, that it is something which will truly exist forever. It carries with it currents of failure. “It doesn’t end. It tortures,” (Kleinman, 184). Graveyards of pharmaceutical rejects do not expand exponentially, but just the opposite: the healing process slows as we grow with our pain. The rush to find a cure ceases. We come to know our pain as part of our body. I read once in a psychology class that it takes less than ten minutes to adapt to a smell. If you enter a rancid room, your senses will relax after a few minutes. Pain is not like that. It is not something you forget, or get used to. “I have found that my strategies are simply efforts to ignore the ever-present, omnipotent foe. None of the methods ever cures me,” (Greenberg, 196). It is “the interminable waiting to exit and reenter normal everyday life, the perpetual uncertainty,” (Kleinman, 181).

This uncertainty is in itself painful, confusing, debilitating. It is why we cannot rate our pain on a scale of one-to-ten. “I found these questions ridiculous. I filled in all the little boxes, but I think the questions are superficial. You really want to know the

impact my…illness has had?" Kleinman quotes a patient (Kleinman, 183). Even an illness narrative lacks the true nature of pain because it is scripted; it is catering to the expectations of our doctors. Language fails to capture embodiment. Chronic pain is unquantifiable, and often unconfirmed even by medical testing. One of Kleinman's patients valued the surgeries performed on his back because the procedures "created icons of his travail, scars that he can show people, that he can touch to assure himself that there is something physically wrong with his back," (Kleinman, 68). If there are no scars, it is difficult to defend yourself, to know it is not in all in your head. "I used to think that I could rid myself of this error by simply denying it, character over chemistry…for I had no brain tumor, no eyestrain, no high blood pressure, nothing wrong with me at all," Didion recalls of her first years suffering from migraines.

Not all chronically ill patients can find validation in western medicine. Diagnoses rely on typical results from past patients, following expected patterns of pain. Their x-rays should show standard deviations from the average body. We rely on a doctor's endorsement to trust that our pain is real. If our pain is not visible, not tangible, then we are further alienated from the healthy world. Without a diagnosis, we do not feel justified in our pain. The recognition, the legitimization of pain is crucial when pain is so twisted with identity, because without detection, it is not just the pain we cannot define, but ourselves. There is a need to broaden "the definition of pain from the Cartesian proposition which inevitably acts to divorce mental from psychical states and tends to attribute single symptoms to single causes," (Bendelow, 275) so that both doctors and patients understand that the reality of an illness does not exist exclusively in a diagnosis.

The reality of pain is this:

1. “The relationship between injury and pain is highly variable.
2. Innocuous stimuli may produce pain.
3. The location of pain may be different from the location of the damage.
4. Pain may persist in the absence of injury after healing.
5. The nature and location of pain changes with time.
6. Pain is not a single sensation but has many dimensions.
7. There is no adequate treatment for certain types of pain, especially idiopathic pains in which there is no sign of tissue damage and no agreed cause,” (Bendelow 60).

Having scars, or x-rays, give a sufferer “cultural cache,” (Kleinman, 102) which is valuable, because it results in sympathy. For the chronically ill, sympathy runs out, but the pain does not. “Migraine headaches were, as everyone who did not have them knew, imaginary,” Didion proclaims, because those not in pain are incapable of feeling it. It is not communicable. “Nothing so tends to prolong an attack as the accusing eye of someone who has never had a headache,” (Didion).

Studies of fibromyalgia, a chronic muscular pain condition, conjure these themes because it is difficult to locate medically. However, those who suffer from it know it is undeniable. “They repeatedly find themselves being questioned and judged either to be not ill, suffering from an imaginary illness, or given a psychiatric label,” (Werner, 1036). In this case, these patients crave an identity that characterizes them as truly, legitimately ill. This kind of pain is shameful, stigmatized, and results in patients blaming themselves for their condition, mimicking their doctors’ reaction. They have a “loss of self” (Lawton) without a construction of a new identity; they lack the tools to build one. Often labeled hysterical, fibromyalgia patients have chronic “but invisible” pain. They constantly feel “at maximum capacity” and get worn out after simple tasks like bringing the groceries in from the car. Because they are constantly faced with doubt and accusations from doctors and family alike, their attitudes towards patients with similar

symptoms are unusually harsh. They describe the other patients as “whiners and complainers” and decide that there is “an essential difference between my pain and theirs…” (Werner, 1035). The message that these patients repeat is this: “This is not something I have chosen,” which is not a surprising reaction given how often they are confronted with blame. While it is not something that they have chosen, it is certainly something that they cannot ignore.

“The healthy body tends to be experienced as an ‘absent presence’ in the context of every day life, and only becomes the subject of conscious attention when illness and other dysfunctions set in,” (Lawton, 11). Of those not in chronic pain, Kleinman writes, “there are no great moments to the illness or the life…Our pains, like our joys, are small, interior, simple,” (Kleinman, 87). But the sick carry a passion, an anger that the healthy do not know. It is a knowledge “of the human condition, giving an edge to life,” (Kleinman, 87). Our pains are not simple, not easy, not forgotten. Our pains are a threat, although not necessarily biologically, to our lives. We feel “decayed, eroded” and most literally, weakened (Kleinman, 112).

Greenberg imagines that “unlike literary criticism, medicine did not have to contend with metaphors with multivalent interpretations and associations. Doctors offered the surety of black-and-white truth. Just the facts, ma’am. We were going to get to the bottom of this pronto!” but she is wrong. Because pain is fluid, unsettled, medicine fails to apprehend it. Greenberg discovers this later in her book, “Pain, I realized, does not fit into the tamed heartbeat of iambic pentameter. It pummels through borders. Unremitting, it refuses closure and explodes rhyme and reason. All-consuming, it does

not permit the luxury of metaphoric or chiasmic thinking, tropes or symbols, wit or pun. Its sound is unsound, dysphony, a wail, a silence," (Greenberg, 38).

It is not just that pain is unstable and borderless, but the ways in which people experience pain vary. There is a "dialectic between [the] social world and personal experience," (Kleinman, 99) which affects our illness narrative. "The unique details of…life together with the shared cultural aspects constrain…illness experience. Pain symbolizes both. Treatment requires the exploration of both," (Kleinman, 99). Factors that affect how we experience pain involve: "Attention given to pain stimuli, prior pain experiences, attitudes toward pain, and social comparison and social learning within ethno-cultural situations," (Bendelow, 275). It is unsurprising to see differences in how men and women react to pain. They may have been taught early on to handle it differently. Often, men are expected to be stoic while women are predictably more unnerved and frenzied.

For some patients, pain is not considered a negative response. For many, although not the chronically ill, pain is seen as a sign of health, "providing the system of warning the body and could even be seen…as productive, as successful…Positive qualities of pain perception were associated with acute, short-lived," (Bendelow 283) the exact opposite of pain for the chronically ill patient. It is not the result of any one cause; it is neither acute nor short-lived, and in fact, those are the very factors that make chronic pain uniquely insufferable.

"Understanding pain and suffering is, of course, as much a social and cultural process as it is scientific," (Bendelow 60). This is true of any illness, whether it is diagnosed or fails to be. Those who seek to define and control pain may confront the

limits of contemporary western medicine simply because pain is subjective. Only someone in pain can explore it to the fullest, and even then it is difficult to truly understand it. Pain is consuming, distracting, in a way that defies intellectualism. It is not something that can be captured in an x-ray, a questionnaire, or even, a narrative. Language fails to portray pain. All that can be said, after ten pages of pondering, is that chronic pain is a condition unto itself because it expands beyond the body. The way we live day-to-day, the way we think of ourselves, is not merely affected but defined by illness, creating a significant chasm between ourselves and the rest of the world.

The gap between the healthy and the sick silences the sick, stigmatizing their disorders, problematizing their identities. It is only fair to give them a chance to speak. I was inspired to interview the ill because I was unsatisfied with the interviews I read. One article I used for research presented hybrid-narratives, combining the stories of many patients. This defeats the purpose of interviewing: condensing a person's identity, their history, into a prototype. The questions asked of these patients demanded them to be self-aware, did not let them wander into their memories, but rather required them to discuss their conceptions of themselves. This seemed unfair. If my overriding question regarded language, I wanted to allow the interviewees to use their own language in any way they pleased.

Jeannie

"My therapist uses that same one," she says, eyeing the voice recorder on the table in front of us. I ask her if it is okay to use one, if she minds. "No. I don't mind." Her mouth closes around the word 'no,' squeezing very small, and with her eyes so big she

looks animated, like a Margaret Keane painting. I press the record button. For a pseudonym, she suggests “Inoculation,” and laughs. I wonder how to read into that, decide to address it later. I ask her for something more believable. “Jeannie.”

Jeannie was fourteen when she started having pain. There was one instance at a movie theater: she was stuck on the third floor and couldn’t move her legs. She waited for her mom to get off work to pick her up. Her mother bought a movie ticket to get through the door. She could not stand on the escalator. There was another on a cross-town bus, homeward bound. She missed her stop. Pain was debilitating. Jeannie describes it as a shrill pain, which is a word she applies to her mother, too. She revises the word “shrill,” replacing it with “stiff.” “You just can’t move.” It was six months before they diagnosed it as arthritis.

Treatment consisted of corticosteroid injections in her thigh. She is prideful that she administered the shots herself. She was skin-and-bones at fourteen. I struggle to not picture her thigh, which I imagine blindingly white and lanky. She describes herself as sickly, as fragile. “I wasn’t dainty; I was gangly, like frail.” Her pain improved but did not cease to rule her life. She gained weight. Her face rounded, cheeks bloated. Her belly pouched. She had to watch her salt intake. “Like, looking at photos, there are two things: I don’t look like me. That’s not my face! And that look, I’m faking it. I was uncomfortable.”

At school, Jeannie had few friends as it was, but with her newly rounded, stiff body, she felt even more alienated. In the hallway, no one spoke to her. No one offered to help. No one swung her locker closed for her, opened doors for her, helped her carry books. “I knew they could see me. I was a freak. Not human and no one said anything.

They just ignored me. Even my friends, no questions. When I would freeze up, they barely knew to be concerned." Within a year, Jeannie transferred schools. "They sucked. That's the kind of people they were. It was so lonely. And I was so far from fitting in."

The loneliness was not something unique to school. Jeannie was reluctant to do anything outside of her home. She missed a lot of school. She struggled to describe what it was like to be so alienated from her own body. There were many days that she remained in bed, not to be reminded. If she did not move, it did not hurt. But that was her only relief. Her sister was heading to college, and Jeannie snagged her bedroom. From her sister's bed, she had a view outside and could watch cars come and go from her narrow driveway. Many hit the planters alongside their house.

Her parents, who had long been sleeping in separate bedrooms at each end of a long Victorian hallway, had declared they would divorce when Jeannie and her sister had both moved out for school. But they divorced prematurely; her dad moved out when Jeannie was sixteen. "Serena," her dad's girlfriend, was "not so serene. My dad is way too good for her." Jeannie was alone with her mother in the house she grew up in, which they threatened to sell but have yet to do. Both her parents were producers, had won Emmys. "My dad's apartment was beige. Beige floors, beige walls, beige furniture except for the red suede couch. His cognac above the fridge. Dad was a bachelor."

Jeannie stopped taking her injections, which made her feel worse than the pain, she claimed, because they made her stand out, made her ugly. She did not ask her doctor, or tell her mother. "You aren't supposed to do that, because, you have to wean on and off. I didn't have the means to wean." When she stopped her injections, Jeannie instantly felt sick, and was in pain, and had no resources to fix it. But to start giving herself

injections again also made her feel sick. She could not win. “I told my therapist who made me tell my mom. She was angry. But I was angry. It sounds bad, but I just wanted to feel like myself again. And look like myself.”

Flora

Flora describes the pain as a dull ache. “Occasionally, it gets so, if I move from standing to sitting, it’s not so dull. It’s sort of a, sharper pain. It’s evolved a little. For eleven years I had a band of lower back pain. Like a belt. Now it’s different. It’s in the hip.” Flora knows her pain started fourteen years ago because she was pregnant with her second child. She was in yoga class when her hip began to hurt. “I told my doctor, which is rare for me, because I never tell the doctor anything. I thought it was arthritis.” Flora describes her pain as having come and gone for eleven years. I ask her about those first three years and she tells me, with a laugh, “It took me that long to find the pattern. I remember looking at a survey in a doctor’s office and realizing, it’s not acute. Something didn’t just happen. It comes and goes and has a life of its own.” At that moment of origin, her hip and back x-rays were fine. She says it’s hard to identify as someone with chronic pain, that she was surprised that I asked to interview her. “I used to think of people with chronic pain as complainers,” she laughs, “it was psychological. Low-level depression. I have all these associations. Now that it’s me, I don’t think those things are true. I have realized that this is what it looks like.” Flora discusses the relationship between the mind and the body, that it is a complicated mix, “there really are things they can’t understand. I don’t look down on people who can’t manage the physical pain part. I think I used to.”

I ask Flora whether she had ever been diagnosed, if they had ever found anything in tests or x-rays. “Recently, this past year, I went through this time—I usually have some breaks where I’m fine—but I went through this time from May to November, where I didn’t have any breaks. Then it was chronic-chronic-chronic. I got so frustrated and worn down. I went in for more tests and work-ups. This time there were some physical findings. Arthritis on this particular back joint. The MRI of my spine was fine.” Flora reports that eleven years ago, the doctor told her it was disc irritation and nerve endings, “causing irritation. But she was wrong about that. I don’t show disc problems. There’s spasming muscles, related to the hip joint wear and tear.” They told Flora nothing was likely to show up on x-rays. They told her they knew this condition, that it did exist, and they weren’t surprised there were no findings. “I wasn’t that bothered.” But she doesn’t feel like she’s been diagnosed. “There are tests to have, things to rule out.” Flora thinks treating pain, even if you don’t have the answers, is the right route, as long as you don’t feel that the treatment is off. “You have to keep asking questions. A lot of people don’t get an answer.”

In the years since, Flora has come up with her own theories of pain, theories she tries to convince her doctors. “I try to find patterns, what sets it off. Hormonal patterns. People asked if it could be stress. It’s not that I don’t think it’s stress. But if I get stressed when I’m hormonal, it hits my back. And if I get stressed at another time, it doesn’t. There’s not a linear causality, you know. They don’t believe it. They don’t make sense. I’ve had a hard time.” Flora used to search for physical things that set it off, “I’ve had to get used to that it just emerges.” Flora stops talking and waits silently for another question. Then she says, “They thought it was rheumatoid arthritis. Because the arthritis

on my hip joints was so even. But I looked at the symptoms. That didn't make sense to me." I ask her what she does when she hears a diagnosis or theory that she doesn't agree with. "Well, I feel that way about bad news. A gut reaction. Sometimes I keep it to myself." Flora doesn't feel she's at a point in her pain where she would try steroids. "The progression hasn't been that bad." Flora gets a bigger picture from alternative healers, and takes "Western medicine with a grain of salt. But that's because of my dissatisfaction. Had my regular doctor given me something that worked, then maybe. I'm going to keep searching. Alternative healers haven't given me a diagnosis I can hang my hat on, but they give better ways to cope with it."

I look over my notes and ask her what treatments she's tried. First, Flora tried yoga, pilates, and physical therapy, acupuncture, homeopathy, massage therapy. Muscle relaxants, a pain killer, "vitamin regimes," an energy worker. "I looked for a specialist. I have been referred to another physical therapist. I'll follow up with that." In physical therapy, they work on strengthening her core, which is not strong enough to support her back. "I don't keep up as well as I should. Partially because when the back pain comes, I can't, I can't work on the stomach muscles without setting it off." Ice relieves Flora's pain, and a certain anti-inflammatory. Flora shyly admits to attending meditation retreats, which relieve her pain within five days.

Her bouts last two and a half weeks, but the pain creeps in between bouts. Once, she was pain-free for five months. I ask about how her routine changes when she is in pain. "I can't do the amount of exercise I like to do. Something that involves walking, like the grocery store, I can't. Sometimes, my evenings where I might do something more

active, I am too worn out by the pain." Flora pauses. She tells me she has never missed work. "I have to lay in bed or sit in my car until medicine kicks in."

When she plans something that she can't do while in pain, she worries about whether she will be hurting. "What will I do? I've never had it go away long enough where it's even gone." She says it is more bearable now, both because it is less painful and she has found better ways to cope with it. Because Flora's pain could be addressed with ibuprofen, she struggled to get an appointment with a pain specialist. Her general physician was hesitant to give her an appointment. "She was underrating how disturbing it was." She mimics her doctor: "You know what will happen if you go to this pain specialist? You'll have to get counseling and take anti-depressants. You know that don't you?" Flora was upset. "Clearly there's no reason for your pain. You're just psychosomatic. I don't want to be considered to be malingering. Or depressed."

Flora, in some ways, would be relieved if it was psychosomatic. "Everyone with chronic pain worries that its something waiting to declare itself. Cancer. So, there is some relief when the medical tests are fine. Sad that there isn't any answer. But it's comforting to know I'm not getting worse. Not deteriorating. But if it is psychosomatic, am I just a really neurotic person? In our culture, we judge that." Flora referencing asthma, "Stress, of some sort, is involved in the typical illness. So yeah, it's complicated."

William

William does not think he can help me. He says he is not right for this, asks me a few times what it is I am writing about. He does not think he can of any help. "Let me just stop you," he asks after the first question, "You're writing about pain? You want

details?" I tell him I am looking at the relationship between illness and biography. "You mean psychologically?" he asks. "I know what happens to me. I know what it feels like. But I don't think about that. Maybe you'll discover something that I don't know."

William started to feel pain at fifteen, working in his dad's lumberyard. He used to try to show off how much he could lift, "I tried to be a hero. Are you getting this?" I tell him I am jotting down notes, but I am recording it, too. "Oh good. That's right." His dad also suffered from chronic back pain, so he was unsurprised when he started to feel it. When he took a job as a janitor at a dormitory in Minnesota, "It was kind of dramatic." He could not wax the floors; "I couldn't bend down without hurting. By the end of the day, I quit. I was afraid I would hurt myself. It wasn't worth a dollar-fifty an hour." It would hurt periodically for a day or two. At school, William took to sleeping on the floor if his back was hurting. "It seemed to help. It wasn't hard. I got used to it."

"Is this helping?" he asks again. I encourage him to continue. Fifteen years ago, he was advised not to play basketball. He sat out for six months. When he finally played again, he ended the game bent over, unable to walk straight. "If I really felt it, I was bent over. I could straighten my posture if I went for a walk for half an hour. I was okay laying down." The pain would last two weeks to a month. "When it starts, it can be sharp. Not, outrageous or like I need morphine or anything like that. It's always in my lower back. Some of the disk is missing—is it the disk—something is missing and its pushing on the vertebrae—it is a disk. It's a nuisance. It's a warning." I ask him how they found out that it was a disk. "I got in a big tube, an x-ray." I prompt him, "C-T Scan, MRI?" "Yes! A Cat-Scan. What's the other one? There's one other. I'll ask Gail. I was scared, claustrophobic. I moved around and it didn't work. I couldn't help it." He was not sure

whether his x-rays have changed overtime. He fusses over the words—vertebrae, cartilage, disks.

William's pain affected two vacations, once on a history tour of Spain and Portugal. He felt compelled to take the tours, coming all this way; he did not want to spend his trip in a hotel bed. "People would look at me. Doesn't that hurt? Or You need surgery. But it got much better." William recalls another vacation, in1988, the last time the Dodgers won the World Series, he went to Shasta with his wife. "I could not walk a block without needing to sit down. I could only walk one block. I could get up, and walk another block. Luckily it was only a few blocks long. I spent my vacation in restaurants. I'm sure it was a lot of fun for Gail."

William was writing for the L.A. Times. He did not want his employer to know. "I didn't want to give them any reason—I didn't want to be less valuable. I couldn't walk more than a block. If I knew I was going someplace in the office, I would look and see if I could lean against something, or sit down. After I'd walked the equivalent of a block. A desk I could lean against, pretending to look around the office for somebody, or the bottom of a stairway, a rail or something, where I could lean a minute before I went upstairs. I knew in my head where all these places were. In the Times building, I could walk a couple hundred feet to the elevator—I had lunch upstairs—inside the elevator there was a rail against the side. If I could lean forward, with my back bent over. Especially if there was no one in the elevator. When I got to the cafeteria, it was only a short way to where the line started and there was a tray—a counter, a railing, metal bars—where you push your tray. I could lean on that. I would pay my money. Then it was easy to get a chair. I knew I needed to lean on those things to you know, stand up."

Once, William received an assignment to cover a Russian astronaut. William could not remember his name. For the interview, William could sit down, but they were at Disneyland. William looked for opportunities to sit down all over the park. The astronaut's wife noticed him, and remarked that he had a health problem. "No, I'm fine." He did not want people to know. "More recently—Is this okay, is this what you want?" William interrupts. I tell him it is perfect. He does not see how intently I am listening, how engaged I am. He does not know this is exactly what I am looking for. How pain permeates life, pain makes you pretend. Pain makes you a phony, inhuman, makes you lie. Pain makes you fail.

"I saw an internist. They tried anti-inflammatory, then physical therapy, then an epidural cortizone injection. And then the last alternative was surgery. That was the routine. What they all did." A doctor set him up on a table. As I'm transcribing, I notice that the recording has me laughing a lot. I am not sure why. I laugh until he continues his story. I imagine he is pulling a funny face. "He pulled up my shirt. Stuck a needle in me. It lasted about two hours. Just two hours and then the pain was back." William found an office that was known for healing professional athletes. "Top doctors, top internists. People come from all over the country." He saw a pain management specialist who gave him epidurals. "My last one was four years ago. I haven't had a serious problem in four years." "He took me into an operating room. I was in just a robe. He gave me an anesthetic. He had a screen where he could see something, he could follow the right veins. Find the right place. It was cutting edge technology. That's why he was more successful."

But William still gets an occasional twinge. When he feels these, he lies down, watches television. “I don’t like it. It happens often enough that I don’t worry about it. If I’m doing something, I stop. Sorry, Gail, this is your job now. I lay down. I can’t lay in bed all day.” According to his chiropractor, William is supposed to walk every day for the rest of his life. He does not do that, but walks frequently. He jogs, which he thinks is making him stronger. William’s physical trainer, who he calls his coach, told him to buy new shoes, that his old shoes could hurt his back.

William already knew the exercises he was supposed to do, holding his knees to his chest while lying down. “I used to help my dad with these exercises. I would push his knees to his chest.” Physical therapy is hard, because for William it takes up to three times a week, and each appointment eats up an entire day. I move to my next question when William interrupts, “That’s frustrating. I don’t like that. It takes so much time. I need time to myself. To do my work.”

William says that he feels fortunate, “it’s never been 24-hour chronic. Some people, they can’t escape it. It’s different for everyone. It can hurt when they’re lying down.”

Analysis & Methodology

I struggled deciding whether to present these narratives as purely stories, or to write them up as interviews. I wanted to show how Flora, Jeannie, and William acted and reacted when discussing their pain. The interview process felt integral to my paper, but not necessarily central to their narratives. The act of being interviewed changed the narrative for each of them, just as their narratives might change when being told to their

doctor. William and Flora were surprised I asked to interview them; Jeannie was not. This may be because Jeannie is the only one with a firm diagnosis: arthritis. William was overtly concerned that he was not a person with chronic pain, and was hesitant to commit to the label. Flora also alluded to her aversion towards the idea that she might have chronic pain. All three said they were much better now, much further from being chronically ill. All three were reluctant to give me pseudonyms, perhaps because they felt so closely tied to these narratives. They did not want to attribute these narratives to a fictitious person. These stories were, after all, their biographies.

Each interview was distinct in pace, pattern, and content. Jeannie's was up-and-down, teary at moments and riotous at others. Full of high school anecdotes, it was gossipy. Flora's was theoretical. She mused about what it means to be in pain, how much she disdains Western medicine, how distant she feels from her previous perception of the chronically ill. And finally, William, who was thoroughly impressed by the technology that diagnosed him, who hid his pain from his colleagues, so prideful that he would sooner quit than admit to suffering.

I noticed, while transcribing the interviews, that there was something uniquely heartbreaking about the life of someone with chronic pain. This is hardly a surprise, but what was heartbreaking turned out not to be the pain itself. The descriptors of pain remain stilted and constricting, "dull," "sharp," "stiff," but the narratives of their lives are compelling and complex. Instead, it was the *effect* of that pain on each of their lives that was upsetting: the way it disrupted vacations, broke down friendships, interfered with careers, and perhaps most interestingly, intruded on theologies.

Kleinman writes about the way illness is placed in a life trajectory, “environed in a concrete world.” This is important to note. The sociological analysis of chronic pain must be accompanied by its real-life existence in a person’s life. By writing about “biographical disruption,” Lawton tells us little, but read William’s account of an elevator ride, and one can understand the disruption of a personhood. While one cannot feel William’s pain, they suffer with him anyway, because the pain becomes embarrassment, a sense of invalidity. Lawton can write about a “loss of self,” but Jeannie had to change schools, suffer her parents’ divorce, to inject her thigh daily with a needle. Jeannie lost all her friends. It does not feel fair to extract sociological theories from the narratives acquired in my interviews, because the stories speak for themselves. They are strong narratives that those interviewed seemed to know well, their pain weaving in and out of time. Every moment of their lives is anchored by pain, and every moment of their pain is anchored by their lives. Take for example, Flora’s measure of when her pain began: her second pregnancy. Or the timing of William’s miserable trip to Shasta calculated by the World Series. These are ten-year stories, fifty-year stories. Can they be condensed into the phrase “prior pain experiences?” I ask them to tell me about their pain and they tell me about their lives: Flora’s yoga retreats, Jeannie’s father’s girlfriend, William’s janitorial job. It is impossible to separate the two, when illness and biography merge to become a harrowing life narrative that defies language, and to some extent, defies analysis.

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