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# CHRONIC: Misunderstanding, Misdiagnosis, and Misinterpretation

A thesis submitted to

Regis College

The Honors Program

in partial fulfillment of the requirements

for Graduation with Honors

by

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## Preface and Acknowledgements

At Regis, we strive to be men and women for and with others. This piece stands for all the people crippled by chronic pain, sifting through enormous medical files, searching for a diagnosis that does not exist. More than that, it advises readers on how to stand in solidarity with people struggling with disabilities, especially invisible ones. This thesis follows in the Jesuit tradition by pursuing justice, honesty, and equality. I use my voice and my own story to expose deeply ingrained flaws within the American medical system; a system claiming to serve people while profiting off their harm.

I pour love and truth into this piece. By examining pain, a subjective sensation, under an equally subjective microscope, I hope to shed light on the nature of pain and how we treat it. I confront myself with research, I ask myself questions, and I examine if my reality is a true reality throughout the piece. The intention behind this body of work is shedding light on an oft-ignored topic while also shedding light on a suffering individual. I am fortunate enough to be a white middle-class American and that identity plays a large role in my experience. As a woman, speaking on the basis of sex rather than gender, I experience unique roadblocks within the American medical system. This piece will explore the nature of those roadblocks and will speak in binary terms about men and women (male or female, masculine or feminine, etc.) on the basis of medical anatomy. This language is not meant to exclude non-binary or transgender folks. The content of this research, sex bias systematically disadvantaging women in the American medical

system, is rooted in binary language based on the anatomical differences between the sexes. Though gender expression also plays a role in medical treatment, this research specifically addresses how sex-anatomy influences American medicine.

This work belongs to me, just as it now belongs to readers, but a piece of it also belongs to my incredible advisors, Alyse Knorr and Amy Hazel. Both of these incredible women contributed to the piece in numerous ways, giving their time and love to my writing. Professor Knorr used an expert hand to guide my thinking and writing while Amy Hazel applied an expert eye to each and every sentence. The members of the Regis University Honors Board, Drs. Howe and Narcisi, also deserve a thank you for their unwavering support. By dedicating themselves to the Honors Class of 2020, they aided in the development of several wonderful theses, including this one. Without the help of these people, this thesis would not stand as it does today. Their dedication to this work, and to me, has never gone unnoticed. Each of these people deserves a thousand thank-yous for their efforts.

...

Dear reader, I place in your hands a story very close to my heart. Yes, I seek to expose deep-seated problems in the medical industry, but I also seek to expose myself. In pursuit of truth, I strip down every memory, read every doctor's note, and piece together a story that lived in my shadow until now. I hope this body of work can either comfort, commiserate with, or console those who walk this earth mis- or undiagnosed. For those healthy readers, I hope it offers a much-needed window into the life of someone with an

invisible disability. Perhaps one day all this pain will be a distant memory, but today is not that day. Readers, today we begin with a fantasy.

## Call Me Ish-Michelle

Did you ever kind of want to faint in public. Like just for the attention. That might be crazy, but I'm a middle child. I don't just want attention; I have to earn it. What better way than non-fatally collapsing on the floor with a flourish? Dr. Win-Kuang Shen, a cardiologist for the Mayo Clinic, explicitly writes that often, "fainting is not a reason for concern."<sup>1</sup> She means that symptomatically, fainting is not generally a reason to go to the hospital or immediately see a doctor. Typically, it's related to low blood sugar. If I ever fainted in public, I could feel confident that my health remains intact while also appeasing my flair for the dramatic. I always thought to faint in public was the perfect nonconsequential drama, maybe inspiring a bystander to open a group chat and text her friends, "oh my god this is so crazy the girl in front of me at Starbucks like literally just fainted."

Perhaps other people never wondered what would happen if they collapsed in the middle of a Starbucks, but I thought about it all the time. When I was younger, I saw women in movies fainting, perhaps in a courtroom, into the arms of a loved one who doted on them, brushed their hair out of their face, and held them tenderly until they regained consciousness. If one googles it, as I have, one finds that these moments are

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<sup>1</sup> Win-Kuang Shen, "Mayo Clinic Q and A: When Does Fainting Require Medical Attention?," Mayo Clinic (Mayo Foundation for Medical Education and Research, April 13, 2018), <https://newsnetwork.mayoclinic.org/discussion/mayo-clinic-q-and-a-when-does-fainting-require-medical-attention/>



colloquially called the “Faint and Carry.” There are many *YouTube* playlists dedicated to the phenomenon. What would people do for me if I raised a hand to my forehead and fell backward in a crowded Starbucks? Would a hero gently lift me from the floor and move me to one of those weird loveseats, waiting patiently for me to flutter my eyes open, asking, ‘where am I?’ while a rosy blush warms my cheeks?

Turns out, no. Fainting in public is not like the movies, not that that is a huge surprise. It’s not one fell swoop and no handsome partner clutches you as your legs crumble. People don’t tenderly wait for you to wake up while brushing your hair out of your face. More often, friends lean close and yell ‘get up!’ until I regain consciousness. One time, I blacked out after stepping out of an elevator into my boyfriend’s apartment lobby. I tumbled onto the marble-ish tile, blackness in my eyes, sweat rolling down my back, when I felt my boyfriend’s hand gently on my shoulder and heard him whisper in my ear, “people are staring.” So not only could I feel suspended in space and time, trying to bring the light back to my eyes, I could also feel self-conscious about how the cold sweats accompanying the blackout might have smudged my makeup.

I never had my Dorothy moment, when she wakes up surrounded by family after her trip to Oz. People feel embarrassed for me, and for themselves in turn. They aren’t trying to rob me of my Hollywood moment, obviously. They react with panic, an emotion rarely associated with romance and stardust. They shake you and yell at you and more than anything, want you to wake up. They want the moment to be over so they know you’re ok and so strangers stop pausing as they walk by to ask, ‘what’s going on?’

When I realized the Dorothy moment would never come, I started hiding my blackouts. My face grows cold and sweat collects around my hairline turning to ice. I find a wall, get to a chair, get to an empty bathroom stall before the wall tilts sideways. *Is the wall tilting?* I need something stable, something to hold when my eyes close so I know where I am. *Are my eyes closed?* The wall tethers my body to the empty bathroom as I sink into the infinite blackness. So long as I can feel the wall, I won't fall into the roaring ocean rising in my ears. *The wall? Where's the...*

Breath is all I can smell, see, hear, taste, and feel. Darkness wraps around my brain and the roaring ocean in my ears drowns out the knocking on the door. The tides of my lungs pull me in and out of the ice-cold water rippling around my neck and teeth. *Am I swimming? Is there ground or am I a part of this body of water, bleeding into the ice blue cold making it red, filling the empty black air with white and purple waves?*

There's nothing. No time, no air, no space. *But there must be air, right?* My breath moves with the roaring ocean in my ears. There's nothing here, but over *there?* Over *there* is the green light of water from upside down. Sunlight streaming through dense currents in broken rays, twinkling and playing in golden beams. Over *there* is the iceberg peaking over my ocean. I can feel the iceberg. My ocean pours into that iceberg and crashes against the hard surface. My hands feel the cracks, grabbing at the ice. My arms meet my hands and pull, using every muscle and every breath to lift my ears out of my ocean. My breath matches the tide and the crashing water calms against the ice. *In and out. In. Out.* The iceberg feels smooth now. I open my eyes and the cold black fades

away. White hands pushed against a white wall greet me and I remember this isn't the ocean, this is an empty bathroom stall. I'm alone on the cold tile floor and I don't even want to think about the last time it was cleaned.

...

I wish I'd only fainted in public once. I wish now that I'd never fainted at all. In 2015, I fell into that blank space often, crashing into parking lot gravel or the clean marble floors of museum lobbies. That cold black ocean lingers in my tingling finger-tips and the unpredictable tide moves in steady, restrained motions across my eyes threatening to drown me even still, 5 years later. I can't escape my fear of that ocean. I master my breathing and push the tides deeper inside. I take pills every day, pills I'll have to take every day for the rest of my life so that my ocean does not turn to fire and eat me alive. I burn from the inside out while ice traces webs across my skin and wait, rigid in time, while the elements fight over my bones. My body-- a body that belongs to the elements and to the medicine and to the sterile hospital hallways.

In 2014, I sacrificed this body to doctors and medical records and test results. Like an offering, I laid on the vinyl altar of a doctor's observation room. One more test, one more appointment, one more procedure, and the burning inside my body would alight from the spark of truth and a fire would rage, burning the old, broken body to offer me a new one. I laid on that altar for years, awaiting a fire no one could light. I yearned for the flames of enlightenment, for an answer to my sacrifice - all in vain. After waiting for so long, ice stiffened my neck and my toes, slowly circling my heart, tickling the back of my

brain. I needed to start my own meager fire to thaw this body and save my heart while seeking the answer to no direct question. Today, I share the story of my sacrifice and I begin with fire.

...

“Oh my *God*, this burns.”

The hair salon smells like artificial blueberries. No one seems to have heard my comment. I know bleach is supposed to burn, but I expect *this*. I glance around at the stylists and bounce my foot on the bar of the salon chair. There’s a stylish man wearing ripped black jeans and a shredded beige t-shirt sweeping hair off the floor. I open Twitter and refresh my feed. Again.

My stylist, Tiffany, reappears from the back of the salon to check on me. She lifts the plastic wrap twisted around my head and sighs. She tilts her platinum-haired head to the side, musing to herself that she didn’t expect it to take this long.

“You ok sweetie? We’re going to need to do like 15 more minutes. Think you can make it?” She folds back the plastic and places the mass of hair back on my damp neck, undoubtedly noticing how sweaty I am. I regulate my breathing and nod back at her. *In and out. In. Out.* My phone buzzes under the plastic cape draped over my shoulders. I’d texted everyone in my recents seeking solace while the bleach soaked through my scalp. It’s a friend who’d bleached her hair before:  
I forgot to warn you. Do a crossword  
puzzle or something

why the fuck would I have brought  
a crossword puzzle to the salon  
idk just like keep yourself entertained  
it does burn tho

I switch to Instagram, having exhausted Twitter. It's the kind of burning that makes you wring your hands, makes your tonsils feel swollen in your throat, and makes you whimper so loudly your stylist has to come back and wash the bleach out immediately. She took me squirming from my chair and gently sat me at the salon sink, carefully running her long fingers and cold water over my scalp. She pushes her fingers into my brain and my toes curl before relaxing at the soothing pressure of her fingertips. The water runs over my ear. I breathe again, finding comfort in this pain I created, different from the mysterious pain rooted in my belly and twisted around my ribs. This pain will give me my body back in a burst of purple flame, gently falling in waves around my face.

...

**A Doctor's Note:** "MICHELLE is a 17 year old alert; friendly; cooperative girl... Prior labs and endoscopies have been normal. She is significantly disabled from her symptoms currently. She has many symptoms that are concerning for possible depression, which may not have been present when abdominal symptoms started, but

seems to be contributing to their severity and the degree of disability she is now experiencing.”

...

“Normal.”

All the tests, scans, and reports say the same thing. The situation seems simple. The records all point me toward the door, toward a new doctor with new treatments and new prescriptions. Every test comes back normal and every doctor reports that everything looks *normal*, every. single. time. Everything is normal except the knives carving into my side, dancing on my ribcage. Everything looks great except the broken glass sliding down my throat and slicing my heart open until I cannot breathe. Everything looks fine except the circles under my eyes and the cheekbones cutting out of my face, pushing past my skin, sharpening their points with every lost pound or lost minute of sleep. The pain keeps me awake. The pain pulls at my hair as my neck curves back, the taut muscles of my throat holding in screams. The pain cuts and shreds my stomach, clenching it so tightly my abs take a definite shape, prompting friends to ask, ‘have you been working out?’ I grow my nails long so when I clench the sheets, claw my neck, or squeeze my bony fingers into fists I can create a pain I can see. My shadow grows thinner and begs to disappear, but by all official accounts, I’m absolutely normal.

There were missed classes and doctor’s appointments. I knew the differences between the hospital parking lots and learned how to drive there wringing my hands and biting my lip. My friends sprouted and bloomed while I wilted away, the dying flower

that gets picked out of the bouquet and thrown onto the street. I wanted to pretend I was in the spring of my youth, despite the cold gnaw of winter biting at my ears. My peers were bursting with life while I tried to keep my petals from blowing away under hospital air vents. I tried gluten-free, dairy-free, low-histamine, and low-acid diets. Sometimes, I tried all those diets at once. I tried diets recommended by my nutritionist that felt random and punishing. I tried prescriptions and supplements and appetite amplifiers and muscle relaxers and pain killers and anti-nausea medication given to cancer patients. Nothing I tried mattered. All the pills, the diets, the meditation, the prayer-- it all killed me just the same.

The doctors told me I worried my pretty little head about nothing. The tests are fine! By all accounts, I should have been too. I was lost. In this period of our lives when we build confidence and become young adults, I shriveled and felt worthless. When we all stopped being girls and grew into women, I felt small. I wanted to ruffle my feathers and fly with the rest of the pack only to find my wings had been clipped.

The bleach cascades down my roots into the salon sink and the truth is, I want it to burn. I burned it so I could feel pain I inflicted on myself. I want to be an agent of destruction instead of a victim. After years of this torment, I had grown to hate. I hated this body, I hated telling people I was ok, and I hated seeing myself looking lost in the mirror. I grew into a mangled woman wearily searching for answers that don't exist and I wanted nothing more than to put her out of her misery.

...

I'm not getting better anytime soon. There are no answers waiting for me. This book doesn't end with a hopeful last page about triumph over disease. Those books are a hell of a lot more fun to read, but this game I'm playing is systematically rigged against me. It's rigged against all the people like me-- people silently suffering from chronic pain disorders, especially women.

This story spells out the rules to the healthcare game we're all playing. In the game, there are few winners and many, many losers. I, even with my enormous amounts of identity and financial privilege, am one of the losers. I am so grateful to my parents and the life they worked to give me. I am endlessly thankful that their struggles gave me the tools I need to work, continue school, and test treatments while undergoing acute, unexplained physical trauma. No amount of privilege has taken my pain away. I can only imagine what condition I'd be in if those privileges were never afforded to me.

There are people worse off than me. Sometimes it seems like people only want stories filled with greatness, stories that expose how much the human spirit can withstand. That's why people read nonfiction books written by celebrities instead of ordinary people like me. As the doctors say, I'm normal. I name myself now as a person suffering from chronic pain. I claim this story as mine, but this kind of story belongs to hundreds of thousands of women across the country. Sufferers like me only recently began using the power of voice to speak out about this very normal issue. We are people excluded from medical research, ignored by the medical community, and haunted by disbelief. I didn't feel like I had the power or the authority to tell this story. I didn't know



who would believe me. I didn't know if my truth belonged to anyone besides me. I've found in my research that maybe the doctors are right; maybe I am normal. Perhaps my pain is entirely normal according to American healthcare. This broken body is normal because American healthcare is broken too. This story is ordinary because my pain and problems are far more common than I originally believed.

This story is ordinary because about 20% of the American population suffers from chronic pain, as I do. That's about 50 million people and those are only the cases researchers know about.<sup>2</sup> Who knows how many people who can't see doctors or never report their pain suffer as well. Other contemporary sources estimate that up to 25% of the population suffers<sup>3</sup> or even up to 100 million Americans.<sup>4</sup> This costs the United States roughly \$560 billion every year in disability programs, lost productivity, and medical bills.<sup>5</sup> Research finds that women are 3 times more likely to suffer.<sup>6</sup> This pervasive problem is not on the margins of the human experience. It is happening every minute of every day to the people everywhere around us.

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<sup>2</sup> James Dahlhamer et al., "Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults — United States, 2016," *MMWR. Morbidity and Mortality Weekly Report* 67, no. 36 (2018): pp. 1001-1006, <https://doi.org/10.15585/mmwr.mm6736a2>

<sup>3</sup> Laurie Edwards, "The Gender Gap in Pain," *The New York Times* (The New York Times, March 16, 2013), <https://www.nytimes.com/2013/03/17/opinion/sunday/women-and-the-treatment-of-pain.html>

<sup>4</sup> Tracy Middleton, "'I've Been In Almost-Constant Pain For Nearly 20 Years'," *Women's Health* (Hearst Magazine Media, Inc., June 11, 2019), <https://www.womenshealthmag.com/health/a19977855/living-with-chronic-pain/>

<sup>5</sup> Linda Searing, "The Big Number: 50 Million Adults Experience Chronic Pain," *The Washington Post* (WP Company, October 21, 2018), [https://www.washingtonpost.com/national/health-science/the-big-number-50-million-adults-experience-chronic-pain/2018/10/19/30831828-d2e0-11e8-83d6-291fced2ab1\\_story.html](https://www.washingtonpost.com/national/health-science/the-big-number-50-million-adults-experience-chronic-pain/2018/10/19/30831828-d2e0-11e8-83d6-291fced2ab1_story.html)

<sup>6</sup> Edwards, "Gender Gap"

A fourth of the American population suffers from chronic pain. I'm part of a huge community of people who have no idea how many sufferers there are. I thought I was alone and that something was wrong with me, other than the physical trauma. As I found out, I am not alone. There are many thousands of us, completely disregarded and left to navigate a system without a map. I assumed my case was extraordinary, only to be proved wrong by mountains of research and testimonials. If readers won't be interested because my circumstance isn't the most extreme example, I hope this will pique their interest- what's happening to me, this quiet disorder that weakens my body and plagues my brain, is happening to someone you know too. She's keeping herself guarded for the next relapse, the next episode, all the while assuring you and everyone else that she's completely fine, if she even mentions it at all. She doesn't want anyone to think she's weak, or different, or anything but normal. This girl is present in each one of our lives even if we do not know it. Read on for her.

## A Scale from 1-10

“Can you verify your name and birthday for me?” the nurse asks, her fingers poised over the keyboard of a desktop computer.

“Hart. H-A-R-T.” I tell her my birthday.

She asks a few more questions. She takes my vitals. “Alright. You can lay down, the doctor will be right in.”

There’s not much hanging on the walls. I check my phone. The date under the time reads ‘February 8, 2015.’ Tomorrow I’m supposed to go to a black-light mixer. I calculate in my head how many pills I’ll have to take beforehand. I didn’t use to have to do that, but everything happened so quickly. A week of missed classes turned into weeks of feeling nauseous, bloated, tired, and sick. What little energy I had went to digesting, or attempting to digest, meager meals of plain rice and vegetables. My pediatrician was at a loss for why my appetite collapsed, and she recommended I see a GI specialist. That recommendation brought me and my parents to the Gastrointestinal Department of the Saint Louis Children’s Hospital.

I don’t talk and my father muses about the medical equipment hanging by the door. We’ve visited this same observation room a few times in the last few weeks. It’s

always freezing. The walls are pale yellow and the vinyl observation table sticks to my thighs. My mom sits in one of the plastic chairs placed against the wall, scrolling through her phone.

The doctor walks in. “Hey there, Michelle. Bummer to see you back here.”

She has enormous watery blue eyes and wears her brown hair back in a ponytail. She has a gentle voice and a reassuring head nod to accompany sympathetic and thoughtful questions. Of all the doctors I have seen, she was one of the first and one of my favorites. I’ll call her Dr. Blue for now. We speak for a bit before she asks me to lay flat on my back. She wants to hear any updates, tells us about the last few lab tests, and quietly listens while my father talks about how on the internet it says stool samples are diagnostically useful, so maybe....

Dr. Blue nods and says, “we aren’t worried about parasites in Michelle’s case, which is what a stool sample could typically help us with.”

She pulls on a pair of blue surgical gloves and asks me to lift my shirt so she can do a physical exam on my stomach.

“How much does this hurt?”

She pushes her fingers into my lower left abdomen. I wince, squirming under the pressure. “It’s ok. It’s...tender.”

“Can you rate it on a scale of 1-10?” Dr. Blue asks, probing the area.

I consider her question. It's one I've gotten a lot more since all this started. I never want to answer 10, no matter how much it hurts, because pain can always get worse. Right? I can't say this is the worst pain I've ever felt because that cements the scale and presumes I'll never feel a worse pain in my life. How can I be sure of that? She holds the pressure on my side, waiting for an answer.

"Um... maybe 5?" I say, uncertain.

"Ok. How about here?" She shifts her hands to just below my navel and presses down. I flinch, curling my body inward.

"That's a lot... it's not... the worst, but that spot is definitely more... sensitive," I say. A tear rolls down my cheek.

"Michelle, if it hurts, it hurts," my dad says from across the examination room, coming closer to hold my hand. My mom watches from her chair, shifting her eyes between me and the doctor. Dr. Blue nods and sits back down.

"Well," she says, "we've done all the testing we can do. By all means, you should be fine. Maybe wait a bit and see if it clears up? I'll keep up with your prescriptions if you want?" She cocks her head at me, sympathetic, but unsure how to proceed. I nod. She turns to the computer to fill out the prescription order, verifying the pharmacy with my mom.

"Can I get a copy of all her files?" my dad asks.

They talk about adding more papers to the hefty files we already have on the dining room table. They say everything is fine. All the tests, all the blood work, all the x-rays, and ultrasounds; they're all fine.

Everything is fine, it seems, but me. I still sit on the vinyl examination benches, shivering in paper gowns. My heart beats softer day after day because every step toward getting better feels like a step in the opposite direction. I want to feel the "normal" that all the tests insist upon, but the codes running my bodily program are soaked in blood. My system has shorted out and I'm drowning in the sparks.

...

Elaine Scarry, in her book *The Body of Pain* writes, "physical pain does not simply resist language but actively destroys it."<sup>7</sup> I used to tell people my pain was like trying to squeeze juice from those plastic, decorative grapes realtors use to stage homes. No amount of pressure pops the grape, it only warps the plastic into distorted, unloved bubbles until they \*pop\* back to normal. Much of this story devotes time to making pain tangible, trying to reconstruct the language of pain. My pain rides waves of pressure until I cave into something distorted, popping back to normal after the tide crashes. My pain curves vines around my waist that tighten like boa constrictors, releasing after forcing all the air out of my lungs. My pain lays weights on my ribs and lights a fire on my back.

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<sup>7</sup> Nicola Twilley, "The Neuroscience of Pain," *The New Yorker* (*The New Yorker*, July 9, 2019), <https://www.newyorker.com/magazine/2018/07/02/the-neuroscience-of-pain>

Does saying that make it any more imaginable? Can any metaphor, analogy, word-painted-picture, or scream communicate just how much this hurts when no one can see any sign of injury?

Pain is subjective, personal, and untransferable. That means it is next to impossible to properly communicate one's pain to someone else. Pain is subjective to the point of incomprehension. Metrics have been developed to avoid this problem, like rating pain on a scale of 1 to 10, or specific words doctors use to clarify; like acute, dull, burning, throbbing, twisting, etc.<sup>8</sup> Part of the problem of pain being subjective, however, is that each person can react to the same symptom, or kind of pain, differently. Some people walk on a broken ankle, barely registering the symptoms and some might take to their beds after a sprain. Each of us humans, though genetically similar, is an individual and feels pain individually.

“To have great pain is to have certainty,” Scarry wrote. “To hear that another person has pain is to have doubt.”<sup>9</sup> Though we understand our own pain perfectly--it fucking hurts--how can we convey it to others effectively? I feel so strongly about my distorted body and if there were just some way to *show* it I know my situation would be different. Blood is a wonderful indicator of pain. If only I were always doused in blood. But instead, the pain that rides in certainty in my chest leaves no mark. If pain destroys

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<sup>8</sup> Twilley, “Neuroscience”

<sup>9</sup> Twilley, “Neuroscience”

language, what mutilated words communicate the certainty of pain? Pain, always, is clearer to the individual than to anyone else, becoming a thorn in the side of the metrics above. How can doctors effectively treat such a subjective problem? To the best of their ability, they have to put together the pieces of the puzzle and determine what's best for their patients, just as one would go about any problem. This works relatively well when it comes to something like a muscle spasm. They could prescribe a painkiller to those without a history of abuse, recommend a chiropractor, outline the benefits of acupuncture, etc. Even if the doctor doubts the patient's reporting of his or her pain, each of the methods above can fix the problem without consequently-huge negative side effects, aside from the painkillers. Chronic pain, however, is a different kind of pain.

In the case of the muscle spasm, a patient may have overused their left shoulder playing football with friends one sunny afternoon. For this example, the patient's name is Frida. Frida suddenly feels waves of pain in her shoulder. Oh no! Frida goes to the doctor and explains that after playing football, her shoulder hurts. The doctor fills out a prescription for a low-dose painkiller Frida can use for the next three days and advises Frida to avoid the use of that shoulder. The muscle needs time to rest and the painkillers help her go about her day without feeling distracted by the pain of her healing muscle. Frida takes her pills responsibly, avoids using her left shoulder, and feels better. This would be the medical system working at its finest: identifying a problem, treating it, and



keeping the patient comfortable while the problem is fixed. Assuming Frida does not have a chronic pain disorder, the pain will go away as if there was never a problem at all.

Let's imagine the pain doesn't go away. Two weeks later, Frida feels waves of pain in her left shoulder. Remembering what her doctor said before about resting the muscle, she takes over-the-counter painkillers, like Tylenol, for a few days and avoids using that arm. But as soon as she stops taking painkillers, her shoulder hurts. Oh no! Frida goes to the doctor again, but now the problem becomes harder to solve. After resting the muscle this long, Frida should not still be experiencing pain. The doctor orders lots of tests, x-rays, and ultrasounds, all of which come back negative. Stumped, the doctor says there's nothing more to do and the muscle pain has no physical explanation. Perhaps the problem is mental and Frida should see a psychiatrist. The doctor sends Frida away and wonders for only a moment, *I wonder what that could be*, before moving on to the next patient.

It is possible, based on the fictional circumstances I designed to demonstrate this example, Frida's situational pain has developed into a chronic pain disorder. How does that happen? She's a perfectly normal person, playing football with her friends on a sunny afternoon! Think of pain like a faucet. Something in the body isn't right, so it signals that something is wrong by turning on the faucet in accordance with how bad the problem is. Get a paper cut, the body turns the faucet handle just a little bit. Fall off a

motorcycle and break an arm, the body turns the faucet a lot. Nonetheless, like in bathrooms anywhere this faucet can develop a leak. A leak in the pain faucet, in other words, is the difference between chronic pain and regular pain. Frida hurt her shoulder, a typical injury, and her body turned the faucet on just enough to communicate to her that she should rest her shoulder. After she rested it, her body turned off the pain faucet, but it developed a leak! Now, Frida has to fix the leak in her pain faucet AND find a way to stop the pain in her shoulder because really, it's quite annoying and she thinks she'd be a lot happier if her shoulder didn't hurt all the time.

This example hugely oversimplifies how chronic pain or chronic problems develop, but it illustrates how someone like Frida can develop a chronic pain disorder and how that differs from regular pain. In later chapters, I introduce a few real-life Fridas. For now, hypothetical Frida helps demonstrate the development and presence of chronic pain more simply as she removes the complex day-to-day factors that make chronic pain even more complicated. More importantly, Frida could be anyone. Chronic pain is so pervasive and unbiased, it can strike anyone at any time. I am a Frida. In the blink of an eye, I morphed into a sick and struggling young woman and just like Frida, no doctors can tell me why or how it happened.

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Chronic pain, or pain that lasts for longer than three months, is typically defined as pain that extends beyond the time something should typically take to heal.<sup>10</sup> Dr. Irene Tracey, one of the premier pain researchers in the world, says the current information on chronic pain is somewhat off base. We need to look at it another way, as we just did with Frida. We cannot look at chronic pain as a symptom to treat. Dr. Tracey believes that once a patient has “gone chronic...pain is the disease, rather than a symptom.”<sup>11</sup> Rather, pain can be more than a side-effect of a larger problem. Pain itself is the problem.

Bodies on high alert for pain feel pain more intensely. A theory stands that the body, when made aware of pain, anticipates it and is predisposed to feel it more intensely. The cycle is self-fulfilling. Chronic pain sufferers continue to get the brain signals that say, “Danger! Pain!” so their nerves rewire themselves to be more sensitive. The medical community considers this a “neurological glitch” and refers to it as central sensitization.<sup>12</sup> Pain like this has gone chronic, as Dr. Tracey would put it, and rerouting those signals still remains next to impossible. Nevertheless, pain resulting from a glitch is no less real than pain resulting from injury. That glitch creates the leaky faucet Frida now has to deal with. Pain does not derive from nowhere, but when it comes to chronic pain, determining the cause of pain becomes more complicated due to the relationship between pain and

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<sup>10</sup> Twilley, “Neuroscience”

<sup>11</sup> Twilley, “Neuroscience”

<sup>12</sup> Middleton, “Almost-Constant Pain”

anticipation. Scientists at Oxford are trying to work toward eliminating both the subjectivity of pain and determining where exactly the pain comes from. Neuroscientists study MRIs given while people experience pain. The idea is once we can neurologically map pain, it loses its subjectivity. Mapping it also allows doctors and researchers to begin breaking down pain into elements, rather than a nebulous body, locating where in the brain pain derives.<sup>13</sup> This research is still in very early stages, however, and needs years' worth of work before it can be used in a medical lab.

Chronic pain feels everlasting, there's no cure, and because it acts differently than other kinds of pain, doctors still don't fully know what causes it. So for someone like Frida, she isn't *just* in pain all the time, she also has to begin navigating a complex medical system that really has no way of accommodating her.

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Why does it matter? When there are cancers and heart attacks and hypertension, diseases that claim lives every day, why should anyone devote special attention to this problem? For one, it's a very common problem among American adults. Data from the CDC reports that 50 million American adults suffer from some kind of chronic disorder.<sup>14</sup> That study excludes children, though other research finds that 1 and 5 children suffer

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<sup>13</sup> Twilley, "Neuroscience"

<sup>14</sup> Dahlhamer, "Prevalence of Chronic Pain."

from chronic pain, meaning like adults, 20% of children suffer.<sup>15</sup> Regardless, both of these studies unintentionally exclude people who haven't, or couldn't, report their pain. That means more people than researchers can account for likely struggle with chronic pain.

Chronic pain can affect anyone regardless of their physical health, like the generally healthy Frida. Physical strength and prowess do not always change how chronic pain ravages the body. Even people at their physical peak can be debilitated by chronic pain. Olympian Kathleen Baker, backstroke swimmer for the USA team, suffers from chronic pain and says, “during a flare, it feels as if someone is stabbing me in the stomach. I can barely move through the water.”<sup>16</sup> One can be perfectly healthy and still suffer. One can be sick and strong at the same time. Though some demographics are more likely to suffer, pain is unbiased after it strikes. It hurts. It sometimes won't go away. And it affects a whole lot of people.

Even if the estimates are a little off, one in five Americans chronically suffering from something or other costs a whole lot of money. Estimates range from \$560<sup>17</sup> – to

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<sup>15</sup> Rachael Coakley, “Your Child and Chronic Pain: How to 'Dial down' the Agony,” The Washington Post (WP Company, November 11, 2018), [https://www.washingtonpost.com/national/health-science/your-child-and-chronic-pain-how-to-dial-down-the-agony/2018/11/09/7d141a02-e12c-11e8-b759-3d88a5ce9e19\\_story.html](https://www.washingtonpost.com/national/health-science/your-child-and-chronic-pain-how-to-dial-down-the-agony/2018/11/09/7d141a02-e12c-11e8-b759-3d88a5ce9e19_story.html)

<sup>16</sup> Kristen Mascia, “Our Pain Is Invisible But We're Not': 6 Chronic Pain Warriors Share Their Stories,” Women's Health, October 22, 2019, <https://www.womenshealthmag.com/health/a26679435/chronic-pain-in-women/>

<sup>17</sup> Searing, “Big Number”

\$635 billion<sup>18</sup> every year in medical bills, government aid, and lost productivity. For context, the bill on chronic pain is more than the combined cost of other conditions like heart disease and cancer.<sup>19</sup> As a generally less fatal condition, chronic pain does not receive the resources other conditions do and consequently costs America a lot of money.

Because chronic pain is a different kind of problem than other diseases, that is to say generally non-fatal, fewer resources go toward the education, treatment, and management of chronic pain. So for 20% of the American population, there are not many resources for handling the sometimes debilitating pain people like Frida, or myself, feel every single day. What resources we do have focus entirely on how to manage the problem, as opposed to actually curing it. In other words, Frida can find resources to comfort the pain in her shoulder, but she likely won't find a way to fix the leak causing the problem. She sure can try, though, which brings us to part of why chronic pain in America specifically can be such a big problem – healthcare costs.

Chronic problems sometimes take time to develop. Take Lyme disease for example, a bacterial infection often borne of tick bites. Jerry got bitten by a tick. Oh, no! His friends help him remove the tick with tweezers, but a few hours later, there's a rash where his tick-bite was. Double oh no! But Jerry has good insurance, so he goes to see a

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<sup>18</sup> Twilley, "Neuroscience"

<sup>19</sup> Twilley, "Neuroscience"

doctor who says that it could be Lyme disease. The doctor prescribes Jerry some antibiotics and Jerry never thinks about the tick-bite again.

What if Jerry doesn't have good insurance? What if Jerry sees a few bumps on his arm where the tick-bite was and ignores it? Going to the doctor about a little rash on his arm is not worth it. After a while, Jerry faces different, seemingly unrelated problems. His head feels foggy and he's more tired than usual. His joints hurt and he feels strains on his muscles whenever he tries to exercise like he used to. Suddenly, he begins convulsing on the floor and his sister rushes him to the hospital. Though usually, it takes years to receive this diagnosis, Jerry's rash makes it clear to doctors that he has Lyme disease. Notwithstanding, because he couldn't go to the doctor because he doesn't have good insurance, the disease mutated and became chronic, or late-stage Lyme disease.<sup>20</sup> This means he'll have chronic problems, largely pain but also cardiovascular issues, indefinitely. In summary, because Jerry didn't have good insurance and didn't see a doctor about a rash on his arm, a normal bacterial infection mutated into a chronic problem Jerry will live with forever.

If Jerry lived somewhere with a different healthcare structure, like Canada which has universal healthcare, he might have gone to the doctor and gotten antibiotics that

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<sup>20</sup> John N Aucott, Ari Seifter, and Alison W Rebman, "Probable Late Lyme Disease: a Variant Manifestation of Untreated *Borrelia Burgdorferi* Infection," *BMC Infectious Diseases* 12, no. 1 (January 2012), <https://doi.org/10.1186/1471-2334-12-173>)

would have prevented any mutation of the disease. Jerry doesn't live in Canada, he lives in America where healthcare can be quite expensive. There are thousands of people like Jerry who face choosing between their health and their financial well-being. While researching a story for *The New York Times* about how cuts in government funding affect family planning clinics, reporter Nicholas Kristof witnessed a young woman come to a clinic for a follow-up STD test after discovering she had chlamydia. She had already been treated, but clinics strongly recommend follow-up tests to ensure treatment eradicates the infection. Budget-cuts meant the previously free test now costs \$94. After hearing this, the woman left the clinic saying, "I can't afford that."<sup>21</sup> Her decision to prioritize financial security over physical health is not uncommon. Budget-cuts like this force thousands of people to make the same choice as this young woman. When care becomes too expensive it also becomes inaccessible, putting people at risk.

This woman had an infection from a virus that likely will not mutate into a chronic illness because she already received treatment. Jerry, on the other hand, waited to treat his infection and now has a chronic illness that causes chronic pain. What's the difference between chronic pain and chronic illness? It's like squares and rectangles. All chronic pain could be called a chronic illness, but not all chronic illnesses involve chronic

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<sup>21</sup> Nicholas Kristof, "At a Clinic Threatened by Trump's Rules, She Asks, 'Why Attack Women?'," *The New York Times* (*The New York Times*, July 27, 2019), <https://www.nytimes.com/2019/07/27/opinion/sunday/women-health-trump.html?searchResultPosition=7>



pain. Something like asthma is a chronic illness, while something like arthritis is both chronic pain and chronic illness. An estimated 50% of Americans suffer from at least one chronic disease, which accounts for 86% of the healthcare budget.<sup>22</sup> That's a lot of people and a lot of money. How did this many people get sick? Because American healthcare prioritizes treating the sick as opposed to keeping people healthy.

What exactly is the difference between treating the sick instead of maintaining a higher standard of healthy people? Why would doctors focus on people *without problems*? This concept requires rearranging the American way of thinking a little bit. Doctors don't need to see healthy people all the time to ensure they remain healthy. That's a waste of everyone's time. Keeping healthy people healthy, however, is something that could be done in America, but the healthcare structures are not designed to function that way. For example, if flu shots were cheaper and easier to get, then doctors would have to treat fewer people who actually contract the flu. People can choose for themselves if they want to pay for themselves and if they don't want to, they can get the flu. The punishment seems to fit the negligence. How much is a flu shot? For someone like Jerry who doesn't have good health insurance, flu shots can be up to \$50 a shot. If the parents in a family of 6 want flu shots for their whole family so they can all

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<sup>22</sup> Matthias Müllenbeck, host, "What If We Paid Doctors to Keep People Healthy?" TEDTalks Health (podcast), March 26, 2018  
<https://podcasts.apple.com/be/podcast/what-if-we-paid-doctors-to-keep-people-healthy-matthias/id470623173?i=1000408386116>

stay healthy, it could cost them up to \$300. If that's too much money for them, and they don't get the shots, they are all more likely to get the flu. And because 6 more people have the flu than before, they can each infect someone who wouldn't have gotten the flu and those people can infect more people and so on. As Dr. Manish Sadarangani, British Columbia Children's Hospital Director, explains, "by being vaccinated an individual is not only protected from being infected themselves but they then also cannot pass this infection onto other people, where it may cause severe disease."<sup>23</sup> This cycle of avoiding shots or vaccines risks herd immunity.

The American Academy of Pediatrics defines herd immunity as, "protection from contagious disease that an individual benefits from as a result of living in a community where a critical number of people are vaccinated."<sup>24</sup> Communities with the critical number of people vaccinated protect those in the area who may be more vulnerable to disease. The critical number of people vaccinated depends on the disease. For an extremely contagious disease like measles, 90-95% of the population must be vaccinated while a slightly less contagious disease like polio requires 80-85% instead.<sup>25</sup> To return to the previous example of flu shots, when more people get flu shots and become immune, people who cannot get flu shots are less likely to get the flu by association. Making flu

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<sup>23</sup> "Herd Immunity: How Does It Work?," Oxford Vaccine Group, April 26, 2016, <https://www.ovg.ox.ac.uk/news/herd-immunity-how-does-it-work>

<sup>24</sup> Rhea Boyd, "It Takes a Herd," AAP.org (American Academy of Pediatrics, April 18, 2016), <https://www.aap.org/en-us/aap-voices/Pages/It-Takes-a-Herd.aspx>

<sup>25</sup> "Herd Immunity"

shots cheaper and easier to get could mean that a family of 6 gets flu shots and won't get the flu and thus won't infect anyone else. Ensuring that people have access to flu shots means everyone becomes healthier as a result, which is an example of American healthcare working to keep people healthy instead of treating people after they're already sick.

Here's another example. If the average American could get a cheap, easy to schedule physical once a year, doctors could warn patients at risk of diabetes, or other diseases, and recommend ways for them to avoid the disease altogether.<sup>26</sup> Patients could have easier access to things like prescriptions for inhalers or allergies, which would avoid patients coming into the hospital to be treated for asthma attacks or allergic reactions. This kind of healthcare limits the severity of problems people experience and limits perfectly manageable conditions from exploding into more dangerous problems. The American healthcare system functions differently, making preventative care like flu shots and physicals harder to get which in turn creates a treatment methodology that treats the sick as opposed to keeping people healthy.

Scientists like Dr. Matthias Müllenbeck, a leader for strategic partnerships in the field of oncology and immuno-oncology for Merck KGaA, want to emphasize that preventative healthcare can change the lives of Americans suffering from chronic disease

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<sup>26</sup> Müllenbeck, "Paid Doctors"

and could decrease the number of Americans facing chronic problems in general. How many cases of diabetes could doctors have prevented by seeing patients before it was too late?<sup>27</sup> Doctors must, of course, continue to treat the sick. Nevertheless, a redesign of American healthcare to prevent illness and keep people from getting sick in the first place could radically shift the standard of health in the U.S.

What about the affordable options that do exist within American healthcare?

Many of those options are less than perfect. According to Dr. P.J. Parmar, a physician in Denver, only 20% of the doctors in the city take Medicaid and many have caps on how many patients they'll see each month. Almost half the doctors in the country won't see Medicaid patients at all.<sup>28</sup> Availability cannot meet demand and low-income patients sometimes have to wait months for a doctor's appointment, while someone with better insurance can be seen much sooner.

Not getting a timely appointment leads to problems getting worse, so what are the options if you're on Medicaid and a doctor who takes your insurance won't be available for another month or two? Maybe, if the problem is bad enough, one could pay out of pocket for an appointment, thinking it worth it to pay more now to avoid more cost build-up in the future. But healthcare costs in the U.S. aren't just astronomical, they also

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<sup>27</sup> Müllenbeck, "Paid Doctors"

<sup>28</sup> P. J. Parmar, host, "How Doctors Can Help Low-Income Patients (and Still Make a Profit)" TEDTalks Health (podcast), February 12, 2019, <https://podcasts.apple.com/us/podcast/how-doctors-can-help-low-income-patients-still-make/id470623173?i=1000431386266>)

aren't transparent. Typically, one does not know how much any given appointment or procedure will cost, both during and directly after. One cannot weigh the cost-benefit of paying out of pocket for the appointment. Even if an appointment were affordable, who knows how much treatment could cost. The CEO of ClearHealthCosts Jeanne Pinder asks, "imagine if you could afford the diagnosis, but not the cure."<sup>29</sup> Why even bother with a doctor for useless information? If one can't afford the cure, is it even worth knowing the diagnosis? Is it better to stay behind an opaque curtain, oblivious to bodily malfunction? The rest of the developed world ensures that sick people will not be buried in debt receiving treatment. The incentive to keep people healthy by affording them financial benefits does not exist in America.<sup>30</sup> Sick people stay sick because they may not have the means to get better. The financial ramifications of engaging with American healthcare cause sick people to stay sick. Sick people staying sick threatens productivity costs, herd immunity, and more.

Now, what in the world does that have to do with Jerry? Jerry doesn't have good insurance, so he didn't go to the doctor. If Jerry had Medicaid, he could potentially wait months for an appointment and by then the Lyme disease would have mutated anyway. Jerry thinks *this rash looks pretty bad, I'll pay out of pocket to see a doctor*, but he has no

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<sup>29</sup> Jeanne Pinder, host, "What If All U.S. Health Care Costs Were Transparent?" TEDTalks Health (podcast), February 20, 2019, <https://podcasts.apple.com/gb/podcast/what-if-all-us-health-care-costs-were-transparent-jeanne/id470623173?i=1000432913367>

<sup>30</sup> Pinder, "Health Care Costs Were"

idea how much an appointment will cost and the cost at one doctor's office can be wildly different than that of another.<sup>31</sup> How does he choose where to go? What if he makes the wrong choice, goes to an office that's far more expensive than the one in a different zip code, finds out after the appointment how much seeing the doctor cost him, and cannot afford the antibiotics the doctor prescribed? The bacteria mutates even though Jerry knows exactly what's wrong. To return to the much, much bigger point, why is chronic pain a problem in America specifically? The problems Frida and Jerry face are why.

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**A Doctor's Note:** "Michelle cries daily because of the pain and is "a mess."

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There's another layer to the problem of chronic pain in America. We understand now why the American healthcare system struggles to accommodate patients struggling with chronic pain. Women have an even more unique relationship with chronic pain than their fellow American males. Here are some fast facts about chronic pain in women from the *Journal of Law, Medicine, & Ethics*:

1. "Women are more likely than men to develop a chronic pain syndrome after experiencing a trauma similar to that experienced by men."<sup>32</sup>

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<sup>31</sup> Pinder, "Health Care Costs Were"

<sup>32</sup> Diane E. Hoffmann and Anita J. Tarzian, "The Girl Who Cried Pain: A Bias against Women in the Treatment of Pain," *The Journal of Law, Medicine & Ethics* 28, no. 4 (2001): 14.

2. Men are more likely than women to receive narcotics as opposed to sedatives after the same procedures.<sup>33</sup>
3. Women are more likely than men to report pain, but their pain reports are much more likely to be assessed as “ ‘emotional,’ ‘psychogenic,’ and therefore, ‘not real.’ ”<sup>34</sup>

This offers 3 crucial takeaways. Women are more likely than men to suffer from chronic pain, men’s pain is treated differently than women’s pain, and women’s pain is often dismissed by medical professionals. Of the 50 million American adults who suffer, about 56% of them are women. Other data suggests that women are sometimes up to 3x more likely to suffer from chronic pain.<sup>35</sup> This data is why it’s so important to address women’s chronic pain separately than men’s. Women and men do not experience pain the same way and the medical system systematically makes it more difficult for women to manage their pain. Women take longer to receive diagnoses, there’s very little research data on chronic pain in women as opposed to chronic pain in men, and doctors often discount a woman’s ability to self-report her symptoms. I’ll be delving into each of those points more thoroughly throughout this piece, but first, it’s important to establish how men and women’s pain differs on a physical level.

Men and women are not identical. Clearly. This is not to say anything like men are from Mars and women are from Venus. Here on Earth, men and women not only

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<sup>33</sup> Hoffmann, “Girl Who Cried,” 17.

<sup>34</sup> Hoffmann, “Girl Who Cried,” 21.

<sup>35</sup> Mascia, “Our Pain”

experience pain differently, but their kinds of pain are quite different. For women, pain becomes a part of normal bodily function. Things like childbirth, the varying pains of menstruation, or even the side effects of birth control become a normal part of the female experience. In other words, this link normalizes pain in women as part of what makes them women. Men, on the other hand, are more likely to experience pain as “a sign of injury or disease.”<sup>36</sup> When symptoms of pain appear, women must determine if that pain comes from a natural biological process or from an abnormality, while men may not need to compartmentalize their pain in that way. While navigating the medical landscape, this difference plays a huge role in how to report pain and how that pain will be received. I cannot count the number of times I saw a doctor and listed my symptoms only to be asked if I was pregnant. Men have the benefit of being able to completely avoid that entire line of thought. Their sexual organs are less important when it comes to pain unless they’re seeing a doctor about STDs or kidney stones. A man will not be asked about his penis if he has a headache, typically.

Sometimes symptoms for either men or women overlap and conditions that sound too similar, or too overarching, can be impossible to correctly diagnose. Too many symptoms do not equate to a more specific problem. In fact, in many ways, the more symptoms one has the vaguer the problem can be. *New Yorker* contributor Lidija Hass writes that too many unclear symptoms are called “nebulous” symptoms because they

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<sup>36</sup> Hoffmann, “Girl Who Cried,” 16.



can be attributed to so many disorders or diseases.<sup>37</sup> Nebulous symptoms can also be called somatization disorder, which is just a modernized word for hysteria. Hysteria in the very recent past was a catch-all term for any problem any woman had. Depression? Hysteria. Fainting? Hysteria. Feeling enormous pain in your stomach for 6 years without a diagnosis? Seeking attention as a result of hysteria. This new term, nebulous symptoms, modernizes the idea of hysterical women while still functioning as a tool to treat women's symptoms with a combination of disbelief and dismissal.

Kathleen Hanna, an American punk singer with Lyme disease, had too many problems, so to speak. When she explained her symptoms to a doctor, he said the completeness of her symptoms, the fact that they were gastrointestinal, respiratory, and neurological, meant that no one problem could be the cause. So the doctor simplified the problem--"she must be having a panic attack."<sup>38</sup> This, of course, is a thinly veiled continuance of the 'hysterical' diagnosis that trapped women in rest homes for decades.

Rest homes were medical facilities designed to treat women with hysteria, or any illness really. Charlotte Perkins Gilman writes about staying in a rest home in her famous short story "The Yellow Wallpaper." Women needed to rest their heads because as one doctor in the 1800s said, "the mind of a woman is always threatened with danger from the reverberations of her physiological emergencies."<sup>39</sup> The danger he refers to is the

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<sup>37</sup> Lidija Haas, "Memoirs of Disease and Disbelief," *The New Yorker* (*The New Yorker*, July 9, 2019), <https://www.newyorker.com/magazine/2018/06/04/memoirs-of-disease-and-disbelief>

<sup>38</sup> Haas, "Disease and Disbelief"

<sup>39</sup> Marina Koren, "The Pioneering Female Doctor Who Argued Against Rest," *The Atlantic* (Atlantic Media Company, July 10, 2019), <https://www.theatlantic.com/science/archive/2019/07/menstruation-women-suffrage-voting-nineteenth-ame ndment/593260/>

normal bodily functions every woman experiences from about the ages of 13-50. Dr. Jacobi, a pioneering female doctor who fought against rest treatment in the early twentieth century wrote that rest recommendations lacked “experimental proof,” relied on “exaggeration of fact,” and served “many interests besides those of scientific truth.”<sup>40</sup> In her view, rest treatments weren’t medical at all, but a deliberate attempt to bar women from classrooms and offices and keep them in the home. Doctors today still advise women to rest, relieve themselves of any stresses, and insist that women’s physical pain directly translates to delusional mental states. Though medicine progressed by leaps and bounds since Dr. Jacobi’s fight to end rest treatment, when it comes to the general treatment of women as opposed to men, there’s still a long way to go. Bed rest remains a common recommendation for pregnant women despite the fact that according to the Mayo Clinic, restricting movement later in the pregnancy can cause severe health risks and make the birth itself even more difficult.<sup>41</sup> Over a hundred years after Jacobi’s argument and even after premier medical institutions recommend avoiding bed rest, doctors continue to prescribe it as a way to treat women.

Problems like diagnosable hysteria, improper treatment, and the assumption that women’s pain can only symptomatically translate to problems with their uteruses are why women struggle to talk about their pain, generally speaking. After one doctor doesn’t believe you, or questions your motivations for vocalizing your pain, it becomes difficult

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<sup>40</sup> Koren, “Female Doctor”

<sup>41</sup> “Coping with Bed Rest and Pelvic Rest during Pregnancy,” Mayo Clinic (Mayo Foundation for Medical Education and Research, February 8, 2020), <https://www.mayoclinic.org/healthy-lifestyle/pregnancy-week-by-week/in-depth/pregnancy/art-20048007>

to believe anyone will trust you to report your pain accurately. Pain can be hard to talk about also because of how many opinions people have. Kerri, a yoga instructor with fibromyalgia, found it difficult to begin speaking about it publically. She says, “I inevitably receive unwanted ‘advice.’ *Have you tried this?* people will say.” When anyone finds out about her condition, she finds judgment often attached to their reactions. The choices she makes become a medical choice rather than a personal one, at least in the minds of others. She says people ask, “You still drink?” and judge her for her habits after she says yes, as if her consumption habits change her ability to manage her own body. She continues, “it makes me feel like I’m living in someone else’s body sometimes.”<sup>42</sup>

It can be difficult to talk about what makes one different than others. Talking about an illness or disability makes the condition seem like a vulnerability. Others, who have no experience navigating the broken medical landscape, feel they can solve the problem of our pain whilst we can’t. The constant ‘advice’ or reprimandings not only assumes a superior role over the sick person, but also pokes at that vulnerability suggesting if only you did things differently, all your problems would go away. The easy remedy to that is acting ‘normal.’ Sick people in my experience want to seem like there’s nothing about us that would make us different than anyone else. It becomes tricky to navigate when to tell people that though I may look fine, I am broken on the inside. I want to be something else. And as a young woman, I am meant to be something completely different. Michele Lent Hirsch, author of *Invisible: How Young Women with*

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<sup>42</sup> Mascia, “Our Pain”

*Serious Health Issues Navigate Work, Relationships, and the Pressure to Seem Just Fine*, finds that Western society expects young women to be “air-brushed beacons of sparkling youth.”<sup>43</sup> Perfect, perky, healthy. Finding a place within that expectation when I am deeply imperfect, bitter, and unhealthy is more difficult than it seems.

The assumed image of young women as sparkling and youthful damages the self-image of sick women. Sick women tend to mask their pain rather than confront this societal expectation. I hide the pain, smother the differences, wear clothes that are too big so people cannot tell just how thin I am, or just how small I feel. I reveal nothing. If you cannot see it maybe it isn't there. The terror of holding an evil in my blood only boils at the thought of other people knowing, treating me like glass, expecting less of me despite the reality that I literally don't have as much to give. Hirsch writes, “do you reveal anything to your boss? Or do you just hope nobody sees you as different? Even if it means working extra hard and hiding a big part of yourself.”<sup>44</sup> Why push myself? Why work two jobs while being a full-time student? Why push the limits of what I'm capable of when I know that this body can only take so much? Maybe I'm punishing myself for what this body has done to me. Maybe I'm showing myself that I am not weak. Maybe I'm trying to prove to no one that I can do more than most people my age even with an illness. But then I wonder if I'm just hiding. What if I push myself so I can hide behind a veil of accomplishments? Am I pushing myself beyond what I'm capable of so people

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<sup>43</sup> Michele Lent Hirsch, *Invisible: How Young Women with Serious Health Issues Navigate Work, Relationships, and the Pressure to Seem Just Fine*, read by Frankie Corzo (Boston: Beacon Press, 2019), Audible audio ed., ch 12. 0:16-0:38

<sup>44</sup> Hirsch, *Invisible*, ch 30. 5:17-5:34

will never assume any part of me is different? So people will never know the deep truths buried in my veins and twisted around my throat? Then part of me has to admit that I am hiding in plain sight while the rest of me asks the question, *how many people actually know me?*

## Pesky Hormones

**A Doctor's Note:** "Michelle is a "basket case" per mom."

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"We think prescribing you antidepressants is the best next step forward," my primary care doctor says. It's 2016, months into my search for a diagnosis. My mom sits on the other side of the observation room while I look up from my lap at the doctor.

I hold her gaze and narrow my eyes. "What are the side effects?"

"Pardon?" the doctor says. My mom looks up at me from her seat with a warning glance. *Watch your attitude*, her look tells me. She stays quiet despite an obvious hesitation over my authority in the situation. I push forward with my questions.

"The side effects. What are the side effects of the antidepressants?" I ask again.

She looks confused and says, "Well...there aren't really any side effects. There's some sleep deprivation and maybe some mood swings. You'd--"

I cut her off. "No. I'm not depressed. I don't want antidepressants."

My mom looks as though she's about to say something, but bites her tongue. I face my doctor, assured in this conviction. She mulls over my steady response to her suggestion and crosses her arms.

“Then I’m not sure how we can help you,” she says.

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In the previous chapter, I provide an overview of chronic pain in America and why women struggle uniquely with chronic pain. That summary built an important foundation for the discussion about women and chronic pain. This chapter will take a closer look at the relationship between women and medical science, explaining how and why physicians treat women’s bodies more poorly than men’s. The bias and sexism women face from doctors does not derive from any one doctor’s particular opinion about women. The problem stems from a systematic injustice within the medical research industry. Scientists and researchers do not have enough research on the female body to understand female symptoms because the majority of medical research only uses male test subjects. Why?

According to Maya Dusenbery, author of *Doing Harm*, studying men is not only cheaper and simpler, “men were the chosen ones because women’s bodies were thought to be too complicated.”<sup>45</sup> Because of this, research began to exclude women. For example, one study at Rockefeller University looked at the relationship between obesity and breast or uterine cancer. That study did not have a single female subject or patient. For comparison, The American Cancer Society reports that 1 in 883 men will get breast

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<sup>45</sup> Maya Dusenbery, *Doing Harm: the Truth about How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick* (New York, NY: HarperOne, 2019) Kindle edition, 32

cancer<sup>46</sup> while breast cancer occurs 1 in every 8 women.<sup>47</sup> That means there is a 13% chance any woman can develop breast cancer. The chance any man can develop breast cancer is 0.113%. This is not to say that doctors should not study male breast cancer. However, this particular study does not examine the relationship between obesity and breast or uterine cancer in men, their research is meant to apply to the entire population. In a congressional hearing about this study's lack of female participants, former Rep. Olympia Snow of Maine said, "Somehow, I find it hard to believe that the male-dominated medical community would tolerate a study of prostate cancer that used only women as research subjects."<sup>48</sup> This particular study is not an isolated example. Many medical studies use almost exclusively male subjects or patients, assuming the results apply to the entire population. As more and more researchers look into women's symptoms or reactions to drugs and treatment, the medical community finds that men no longer can act as the default. There is not enough of this research and women remain largely misunderstood by the medical community due to the assumption that their bodies act the same as men's.

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<sup>46</sup> "Key Statistics for Breast Cancer in Men," American Cancer Society (American Cancer Society, Inc., January 8, 2020), <https://www.cancer.org/cancer/breast-cancer-in-men/about/key-statistics.html>

<sup>47</sup> "How Common Is Breast Cancer?: Breast Cancer Statistics," American Cancer Society (American Cancer Society, Inc., January 8, 2020), <https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html>

<sup>48</sup> Dusenbery, *Doing Harm*, 25



Caroline Criado Perez, author of *Invisible Women: Data Bias in a World Designed for Men*, analyzes the idea of the male default, that men are the foundation and what works for them will work for everyone else. Her book looks at how that can cause catastrophic harm to others, from seat belts and medicine to how snowplows plan their routes. For medical purposes, Perez's book looks at how medical research rests largely on the male body. She explains there's a trickle-down effect when it comes to how medicine treats men. She says, "the way we have researched them, the way we treat them, the way we diagnose them has been based on research on men--women get misdiagnosed."<sup>49</sup> It all starts with research. Research allows the male body to act as a proxy for all bodies.

Research continued this way in part because no one outside of the medical community knew about this data gap. Recent media coverage, however, brings this oversight into public consciousness. John Oliver, in an exposé about American medical treatment, found clips of male researchers saying to women, "you are me with pesky hormones" and "we're studying all the fundamental things in you without this sort of nuisance stuff."<sup>50</sup> His reporting finds that medical research views men as women without all the annoyances. Those so-called annoyances explain why in the 1990s a study on cancers of the breast would have only male subjects. Reporting like this emphasizes the

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<sup>49</sup> Roman Mars, host, "99% Invisible," 99% Invisible (podcast), July 23, 2019, <https://99percentinvisible.org/episode/invisible-women/>

<sup>50</sup> John Oliver, "Bias in Medicine," *Last Week Tonight with John Oliver* (New York, New York: HBO, August 18, 2019)

existence of a long ignored research gap. The work of Oliver and Perez begins to question why doctors, people typically with the best of intentions, ignore women. It's maddening that part of the answer is that doctors didn't realize they were. Women were seen as more complicated than men. They were perceived to have more hormones and because of their menstruation, were too complex and messy to study. Part of the foundation of medical testing is that the test can be repeated and that there's a control group. For those who may not know, here is a run-down of what a control group means and is used for:

If scientists want to test a new sleeping pill, for example, they will put half of their subjects in one room and the other half in a room with the exact same conditions (temperature, light, layout, etc.). One group will be given the new sleeping pill. The other group will be given a sugar pill that should have no effect or nothing at all. This way, the scientists can compare how a group that took the pill reacted versus a group that did not. Almost all of their findings will come from this basis of comparison.

The reasons researchers have a problem with using female subjects stem from the idea that the experiment must be able to be replicated exactly and with a predictable control group. With women, their monthly cycles 'complicate' how repeatable a study is. Would all the new subjects, for the next round of testing, need to be at the exact same place in their monthly cycles as the women from the first trial? Because of continuity

issues derived from this, women are left out of testing altogether, so as not to complicate the repeatability of a medical trial.

This testing strategy is quickly being recognized as a public health problem. Without testing women, doctors cannot treat women effectively. The medical community is beginning to move in the right direction, but it was only in 2016 that the National Institutes of Health began requiring researchers to include female subjects when their research applies to both genders.<sup>51</sup> Only four years of research include women, while the basis of medical knowledge rests on hundreds of years of established research that largely excludes women altogether. Those four years are a step in the right direction, but it will take decades before there's enough research for doctors to understand women's symptoms more fully. This lack of research means that women cannot be effectively treated, which despite this new measure from the NIH will likely remain the case for years to come.

Why exactly do women need to be studied specifically? Why is it that research on men cannot apply to women-- aren't men and women just two versions of 'human'? Shouldn't their base-level biology be more or less the same? In some ways, yes. In others, not at all. For example, what if the sleeping trail from earlier in this chapter only

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<sup>51</sup> Joanna Klein, "Fighting the Gender Stereotypes That Warp Biomedical Research," The New York Times (The New York Times, May 30, 2019), <https://www.nytimes.com/2019/05/30/health/gender-stereotypes-research.html>

used male subjects. They complete several trials and find that the drug has no effect. It did not help the subjects sleep or cause any notable change, for better or for worse. The drug is useless. The scientists store the data, gripe about the lost time and money, and begin on a new project, perhaps trying to figure out how to make the useless sleeping pill effective. Or they begin working on a new drug entirely, leaving that useless sleeping pill in the past.

Now let's say it's 10 years later. Researchers are developing a sleep drug for women. They develop a formula and find that researchers in the past discarded this exact chemical composition, claiming the drug was useless. The new scientists read the report from 10 years ago and see scientists only tested the drug on men. The new scientists repeat the same experiment with female subjects and report huge success. The new scientists high-five and begin the process of getting this new, female-targeted drug, on the market.

This example massively oversimplifies the medical testing process, but it illustrates an important overall point: some drugs work better for women than men. And some drugs work better for men than women. This is the case with a lot of antidepressants.<sup>52</sup> Because of this, only using men in medical drug testing halts the

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<sup>52</sup> Tammy Worth, "Drugs That Work Differently in Women and Men: Everyday Health," EverydayHealth.com (Everyday Health, Inc., February 19, 2015), <https://www.everydayhealth.com/news/drugs-work-differently-woman-than-man/>

development of drugs that could be enormously useful to women. Those drugs will never reach the market and thus cannot reach female patients in desperate need of proper treatment.

Neurobiologist Daniela Pollak says in an interview with *The New York Times* that “we live in a world where the assumption is that males are the standard, the reference population, and females are the ones that are odd.”<sup>53</sup> Men acting as the standard for medical research endangers the female population, making it nearly impossible to effectively treat women at the same rate doctors treat men. The research means the odds are stacked against women. In a poll of neuroscience subjects, women were outnumbered by men 6 to 1.<sup>54</sup> Men’s brains in neuroscience are 6 times more supported by research than women’s. By making women “odd,” doctors create a problem for themselves. Female variability when it comes to hormone cycles does not have to be a setback. What needs to change to help this problem is forcing scientists to see variability as a positive challenge, not a roadblock hindering their research.

On that note, women are not found to be more hormonal than men. The assumption has continually been that, on the research level, female rats were too hormonal, variable, or unpredictable compared to male rats. This was because they get periods. The belief that female mice must be tested at each stage of their estrous cycle to

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<sup>53</sup> Klein, “Fighting the Gender”

<sup>54</sup> Klein, “Fighting the Gender”

achieve accurate results, or that female mice are more variable than male mice, is in no way empirically based. A study published in the *Biology of Sex Differences* finds that in female rats there was not significant enough variability, at every stage of the reproductive cycle, to warrant the conclusion that female rats are more hormonal or more driven by hormones than the male counterparts.<sup>55</sup> The study determines that excluding females entirely from studies is lazy research, for experiments could merely be designed to make the menstrual cycle a non-issue. A meta-analysis of 293 articles published by *Neuroscience & Biobehavioral Reviews* shows no greater variability in females than males and the study concludes that particular attention to the estrous cycle is unnecessary.<sup>56</sup> In other words, saying that females must be excluded from studies because their bodies skew the research on account of hormones is unfounded and points to laziness and sexism within scientific and medical research.<sup>57</sup> Dr. Brian Prendergast, professor of psychology at The University of Chicago, worked on both of the above projects and ultimately found that testosterone can actually play a larger role than female hormones like estrogen depending on the group hierarchies in place.<sup>58</sup> The assumption that hormones stand in the way of viable female test subjects then becomes obsolete.

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<sup>55</sup> Jill B. Becker, Brian J. Prendergast, and Jing W. Liang, "Female Rats Are Not More Variable than Male Rats: a Meta-Analysis of Neuroscience Studies," *Biology of Sex Differences* 7, no. 1 (July 26, 2016), <https://doi.org/10.1186/s13293-016-0087-5>

<sup>56</sup> Brian J. Prendergast, Kenneth G. Onishi, and Irving Zucker, "Female Mice Liberated for Inclusion in Neuroscience and Biomedical Research," *Neuroscience & Biobehavioral Reviews* 40 (March 2014): pp. 1-5, <https://doi.org/10.1016/j.neubiorev.2014.01.001>

<sup>57</sup> Becker, "Female Rats Are Not More"

<sup>58</sup> Klein, "Fighting the Gender"

This research proves that women are not more complicated than men. More factors than biological difference contribute to the exclusion of women from medical research. Biologists and doctors systematically minimized women in the 19th century after women began demanding more rights. Medical theory shifted, disenfranchising women by claiming they were psychologically inferior--hysterical, emotional, irrational, etc. Their brains were the complements to male brains--ambitious, aggressive, logical. The reason women's brains were so disordered, according to these 'scholars,' was their reproductive systems. Dr. Rebecca Shansky, director of the Shansky Lab for neuroanatomy and behavior, argues that this history contributes to why studies still avoid using female animals.<sup>59</sup> This standard, set at a time before women had basic rights, lasts today. Despite the new research that promotes a less sexist attitude toward female research subjects, there remains a stigma around women. Today, instead of merely claiming that the female brain or body is inferior to men, researchers claim that the female body is too complicated to empirically prove results.

Research forms the foundation of medical treatment. It is the first step of many when it comes to diagnosis, treatment, care, and prevention. When half of the population is systematically excluded due to unsubstantiated claims that their bodies are too complicated, half the population faces risks that are completely avoidable. A medical

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<sup>59</sup> Rebecca M. Shansky, "Are Hormones a 'Female Problem' for Animal Research?," *Science* 364, no. 6443 (May 31, 2019): pp. 825-826, <https://doi.org/10.1126/science.aaw7570>

practice that threatens half the population must be examined more closely. How can doctors take an oath to do no harm when each day they put women at risk? How can women trust medical professionals to help them once they know how little research has been done on the female body? The answer is simple. They can't.

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There were days after I took all my pills and drove my carpool to school that the energy of living became too difficult. I'd leave my homeroom or first-period class and walk past the beige lockers to the front office. Shoulders hunched and with my right hand resting on my stomach, I'd call my mom. Our school nurse who wasn't really a nurse, but a woman in the front office, had assumed the responsibility of tallying the days I've missed. She tisks while dialing my mom's number.

"Hi, this is Carol Amad from Nerinx Hall. I'm calling for Patricia?" she says briskly. I watch her pause as my mom confirms.

"Yes, I'm calling for Michelle. She's not feeling well again and wants to head home. Would you like to speak with her?"

She hands me the phone.

"So you're not feeling good?" my mom says with sympathy in her voice.

"No...my stomach hurts and I feel really dizzy and I just want to go home."

"Are you sure you can't make it for the rest of the day?" she asks.

"I really want to go home and lie down," I say, glancing back at Mrs. Amad who's jotting something down in her notes.



My mom asks to speak to the nurse again and tells her it's ok to send me home.

“Is she safe to drive herself?” Mrs. Amad asks.

My mom must answer yes because, after a few more quick words, Mrs. Amad gently directs me to the binder on the front desk to sign out.

“Write the time and the reason. We hope you feel better,” she says.

She heads back to her notes and picks back up her pen. I walk back down the empty hallway and grab my stuff from my locker. I text my carpool that I can't make it through the rest of the day so they know to find new rides.

Ok so I left because the baby is  
trying to kill me. If yall still need  
a ride lemme know I have no problem  
coming back

“The baby” was code. For a long time, because we didn't know what was wrong with me, my friends and I called my disorder “the baby.” When other people started to notice I had to miss class, or was losing weight, or fainted in the hallway, my friends alluded to pregnancy so they didn't have to try explaining something even I couldn't even define. My friend Molly, one of the passengers in my carpool, told me about it on a spring afternoon on our way home from school.

“When people ask, like, what's up with you...I've just been saying that you're pregnant or talk about how you were born premature,” she says, her hands fiddling with the cardboard sleeve around her Starbucks coffee cup.

“Oh?” I flick my eyes over to her and smile, flipping on my blinker and pulling into the left turn lane.

“Yeah, there’s like nothing actually wrong with you so I wasn’t sure what to say,” she says, sipping her mocha.

My doctor took me off coffee with my most recent diet, so I sip my iced green tea latte and laugh. “They believe you?”

She snorts. “Michelle. Think of the *drama!*”

I mull it over. “No one will ask me about it if that’s the rumor... Yeah. Yes. Ok, I like it,” I say.

The rumor meant that people might talk about it, but not to me. Being the subject of the rumor mill at an all-girls high school was nothing compared to unexplained nausea, sleep loss, and condescending doctors. Ever since then, we coded whatever *this* is as “the baby.” The shorthand made it easier to talk about and a little less scary when we were talking logistics, like if my carpool needed me to come back after leaving early so they had a way to get home. It wasn’t usual for me to leave school after the first period, but return to the parking lot pick-up lane at the end of the day to drive my carpool home.

I reach my car in the parking lot and sigh when I finally settle in the seat. I need a few deep breaths to calm my nausea before starting the drive home. The grey skies finally open and a patter of rain settles on the car. *Listen to the rain. Breathe...and listen...to the rain.* The drops fall slow and heavy, making loud and distinct thunks on my windshield. *Breathe.* I turn on the wipers and throw the car into reverse. I pull out of my parking spot

and hold my breath until the stop sign at the exit. *Breathe...and listen...to the rain.* I check that there is no one behind me and briefly close my eyes, gripping the steering wheel. The knots in my stomach grow into vines rooting me into my seat. I clench my thighs and breathe heavily as I continue to drive. My hands, slick with sweat, grip the steering wheel with white knuckles. I lean toward the rain, peering out of the windshield. The vines wrap tighter around my kidneys and sneak up my throat, threatening to twist around my tongue, pulling it back toward my tonsils. *Breathe...and listen...to the rain.* I start squirming in my seat as the vines pull tighter, my breath becoming short and quick. My face starts to sweat as panic pushes into my feet and I begin gasping for air. I start whimpering to myself in the car, twisting my hands on the wheel.

*Breathe...and...listen...to...the...rain*

Finally, I pull up at my house. My hands lay slack. My forehead meets the steering wheel. I pant out a couple of long breaths. The front door is unlocked. My step-father appears in the kitchen right off the entryway.

“Not feeling good today?” he asks.

I shake my head and hold back tears. “I’m going to go upstairs,” I say.

He walks over, pulls me into a tight hug, and rubs my back. “Make sure to tell your mother you made it home. Let me know if you need anything,” he says.

I trudge up the stairs with my dog, Stella, on my tail. She follows me into my room, but won’t stay because eventually, I’ll close the door and she doesn’t like spaces that aren’t an open concept. I throw my bag against the bookcase and pull off my black

Converse high tops. She watches from the doorway. I settle crisscross on the floor and beckon her to me, patting the floor with my palms.

“Stella!” I say.

Her ears perk up and she bounds over, pushing her nose into my face. I wrap my arms around her to hang off her neck. She’s a golden retriever and when we rest like this she towers over me. After enough time, she sits and lets me lean on her with more of my weight. She can tell when something’s wrong and though she won’t usually let us hang onto her like this, today she snorts and groans, but lets me hold her. She slowly shifts to the ground and lays flat with my head on her ribcage, my hands still wrapped around her neck. She won’t stay with me like this for very long. But she’ll take away the pain she can and will lick my hands until I start to smile and will then try sniffing my face until she maybe gets a laugh. Then she’ll wait until I change into sweatpants and pull myself into bed before she leaves the room to go back downstairs.

I stay in bed for the rest of the day, occasionally getting up for water or the bathroom or to see Stella. Day turns to dusk and as daylight falls from my room, someone knocks.

“Come in,” I grunt.

“Hey, Shelly.”

It’s my mom. She’s wearing her blue work suit and still has her black leather portfolio in one hand. She comes over to the bed and sits on the left side, perching near my hip. She rubs my shoulder and asks, “How’s it going?”

“Fine,” I say before rolling back to the other side of the bed, away from her.

“Well, it’s not fine...Right? Because you’re home from school so...”

“It’s the same thing it always is, ok? It’s fine,” I growl, tears biting the backs of my eyes.

“I know. I’m sorry your stomach hurts,” she says.

“Yeah. Me too,” I say, my voice wavering under the weight of tears.

“I’m going to change and see what John’s cooking up for dinner.”

She stands and pauses to look back at me before leaving the room. She sighs before she asks, “Is there anything I can get for you?”

“No,” I say curtly, staring at her from the bed.

She nods, leaving my dark room for the brightly-lit hallway on the other side. She closes the door behind her and goes to change into grey fleece sweatpants and a light green zip-up fleece jacket. She’s always cold. After running downstairs and kissing her husband, she jogs back upstairs and knocks on my door.

“What!?” I pause my show and angrily glare at the door.

She pushes the door open and places a small yellow plastic bowl on my bedside table. It’s filled with oyster crackers, those small circular ones people put in soup.

“I think you should eat something,” she says.

I start to cry. She rushes over and sits again on the side of the bed. She pulls me into a hug and I cry harder.

“I want this to be over. I can’t DO this anymore!” I wail into her shoulder.

She rubs my back and says, “I know.”

“I want to be better. I don’t want to be sick anymore. I can’t do this anymore. I want this to be done,” I whisper, my voice thick with tears. I sniffle and look up at her. She hugs me tighter.

“I know,” she says. She wants this to be over too. She doesn’t want to do this any more than I do. She keeps rubbing my back until I stop crying. I wipe my eyes and fall back onto my pillows. I thank her for the crackers and she promises to check on me later. With an ‘I love you,’ she leaves the room, closes the door behind her, and goes back downstairs to eat dinner with her husband.

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My mother and I spent many evenings apart like this, her downstairs eating dinner with her husband and me upstairs trying to eat a bowl of crackers by the light of my laptop screen and the Christmas lights I hung over my bed. Sometimes, I would be frustrated and I would cry and she would hug me. And sometimes I was mean and an asshole to the woman who wanted nothing more than to see her daughter healthy again, who was willing to do anything to see it happen. The woman who took off from work to go with me to doctor’s appointments. The woman who spent hundreds of dollars on ways to make me feel better. The woman who left her heart open to me as I turned away, wallowing in pain and misery.

My mother’s sister wrote me a letter after things had been bad for a while. The letter was for a retreat I went on with my Senior class and was meant to be about my

growth, but a lot of the letter addressed how the years wore away for me more slowly, and how my mother had to watch her daughter wear away with them. She asks me in the letter to see that my mom would lift me out of a bed of thorns, sparing no time tending to the scratches on her arms. My aunt reminded me, “when things get tough, as life always does, try to remember that there is an army of people that love you and will do anything to help you.” It was a gentle reminder that the struggle I go through is not just mine. It affects my family, my friends, and the people in my life closest to me. All these people were willing to march for me, with my mother at the front with her sword poised and ready.

Both my parents gave me and my other siblings so much and without the privileges my mother provided, I’m not sure I could have made it to college. I was sick and tired and mean and ungrateful, yet she continued to pick peonies from the garden outside and leave the blooms in a vase on my nightstand. She works as a lawyer for Washington University in Saint Louis, a university that feeds directly into Barnes-Jewish Hospital, the biggest hospital in Missouri and one of the top twenty hospitals in the United States. She practices medical law, on cases involving things like HIPAA, and because of that was near some of the best doctors in the world daily. If it weren’t for her connections and her healthy relationships with coworkers, I might not have received the care I did. Her job opened doors for us. She was the hero, pioneer, and advocate I needed. She found me new diets and doctors and treatments when I didn’t have the energy to do it

myself. I didn't have the kindness of heart to recognize how difficult it is to be the parent of a sick child, and how my pain and cruelty were also her pain and sacrifice.

The difference between a clean, well-run hospital and an over-crowded budget hospital is like the difference between a Tesla and a 2001 Honda Civic. Both cars run, but one offers a lot more features and is a hell of a lot better to look at. My mother got me access to the Tesla because of her hard work and professional accomplishments. The fact that I'm still looking for a diagnosis after all this time, riding in one of the best cars in the world, points to the larger problems in place and shows that even in the best circumstances, with the best care, and with incredible support, people in this country still suffer from unknown maladies. I can only imagine the pain I'd be in today if the circumstances were different and I'd been stuck in the Civic.

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Data bias in research, intentionally or otherwise, risks the lives of American women. Though we may not think it, women are more likely to die of a heart attack than men.<sup>60</sup> By using men as the default in data collection and medical research, doctors know very little about heart attacks in women. Many doctors never learn about female heart attack symptoms as differentiated from male symptoms. Therefore, doctors cannot effectively treat a female attack. They cannot identify the symptoms and then cannot diagnose the problem. As Caroline Perez, who I mentioned earlier in this chapter, explains, "female

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<sup>60</sup> Mars, "Invisible Women"



heart attack symptoms are seen as atypical, even though they are very typical for women.”<sup>61</sup> As a result, women and doctors assume that the symptoms associated with male heart attacks are the *only* symptoms of a heart attack. For men, heart attack symptoms look like tightness in the chest and chest pain. For women, heart attack symptoms look like abdominal pain, shortness of breath, nausea, lightheadedness, fatigue, or indigestion. Those symptoms are considered abnormal.

Male heart attack symptoms acting as the default creates a dangerous problem for women. Because a typical female heart attack appears as symptomatically abnormal, women falsely read their own bodies when having a heart attack. They assume the ‘normal’ symptoms apply to them the same as they apply to men. This means when women do experience heart attacks, they likely won’t seek medical attention. Their negligence derives from ignorance. Many are completely unaware they’re going into cardiac arrest.

Take for example a patient named Nancy. Vidhi Doshi reported on Nancy in a piece for *The Atlantic* about heart disease in women. Nancy had stomach pain. After it persisted for 4 days, she went to the hospital. The doctor thought it was gallstones, kept her overnight for observation, and then sent her home. When she got home, she had chest pains and called the doctor immediately. She returned to the hospital after just having

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<sup>61</sup> Mars, “Invisible Women”

been released to treat the chest pain. There, doctors discovered she'd had two heart attacks in five days. She died two days later.<sup>62</sup>

Women who seek medication attention for heart attacks often do not receive proper care. Perez says that for those who seek medical attention, “doctors don’t realize that women are having a heart attack.”<sup>63</sup> The lack of research on women means doctors are unfamiliar with the symptoms classically related to female heart attacks. The data gap between men and women directly corresponds to the maltreatment of heart disease in women. Women are dying because scientists exclude them from medical research. Women are dying because medical research calls their hormones too “messy” to study.

The lack of research creates a cultural barrier to the problem as well. Harlan Krumholz, the editor of the *New England Journal of Medicine*, began studying heart disease in women after noticing the male bias. He explained the problem simply, “this is a man’s disease.”<sup>64</sup> Culturally, heart disease belongs to men just as something like breast cancer belongs to women. Think for a moment about how often on TV a male character has a heart attack. There’s Roger Sterling from *Mad Men*, Richard from *Gilmore Girls*, Coach from *Cheers*, Dan from *Roseanne*, etc. Can you think of even one where a heart attack strikes a woman? Heart disease as far as TV, and to some extent medicine, is

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<sup>62</sup> Vidhi Doshi, “Why Doctors Still Misunderstand Heart Disease in Women,” The Atlantic (Atlantic Media Company, October 26, 2015), <https://www.theatlantic.com/health/archive/2015/10/heart-disease-women/412495/>

<sup>63</sup> Mars, “Invisible Women”

<sup>64</sup> Doshi, “Why Doctors”

concerned is the trademark disease of a “hardworking capitalist man.”<sup>65</sup> Women have no place in the discussion.

Most U.S. medical textbooks do not differentiate between male and female heart attacks. Research continues to exclude female subjects from studies on heart disease. Women’s symptoms become abnormal. Doctors call their symptoms unusual. As a result, heart disease has become the number one cause of death for women in the U.S.<sup>66</sup> Nancy experienced symptoms very typical for women experiencing a heart attack. The doctors, because of faults in their education, could not treat her according to her needs. Her ‘abnormal’ symptoms lead to an avoidable tragedy if only American healthcare prioritized women in the same way it does men.

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<sup>65</sup> Doshi, “Why Doctors”

<sup>66</sup> Doshi, “Why Doctors”

## Are We There Yet?

About 2 hours South of Saint Louis, Missouri, past the small towns and big forests with tall trees is a lake. A huge, spectacular lake. Every summer, my father loaded up our bright blue minivan with tents, sleeping bags, and folding chairs. In the backseat, my brother and I wriggled and fought between eating bagels, apples, and blueberry muffins. We bounced along to the radio and watched the big trees fold into the curve of a dusty, gravel parking lot just past the sign that reads “Lake Wappapello.”

My father was left alone to unload the car and he trudged across the campground before throwing our stuff in the open space beside our cousins’ camper. We were already inside, sitting in the kitchenette watching *Scooby-Doo* on the portable television. He’d set up the tent, inevitably on a rock that would dig into either his or my back later, and we’d pretend to help. The boombox from the basement didn’t get great radio service but between the Beach Boys, the Moody Blues, and the Supremes, our ears and feet had no trouble finding music.

Those songs were a gift from my father. He and my mother filled our house with Simon and Garfunkel on vinyl, but when he left, he took some of the music with him. The divorce left us with silence ringing in our ears, but he built a new home and before moving anything else plugged in the record player. He provided the soundtrack for my childhood, playing his music in the new house and letting me pick the radio station in the

car. We were driving into a new decisive era for a broken family and music seemed to be the universal language communicating to all of us that an unconventional family is no less whole than a nuclear one.

After the divorce, I heard a lot of the Moody Blues. I remember listening to the lyrics and hearing a plea for love. A lost idea of what he had. We'd sit side by side on the couch and eat cantaloupe, shifting our attention between the music and whatever movie was on ABC Family. The noise drowned out the sadness in our hearts and I came to realize it's harder to feel sad when your heart is dancing. But some songs, like "Isn't Life Strange" asked us to stop dancing and just listen to the music, sitting alone in the house, together.

So we'd go to the lake. We'd let family and fireflies and muddy water lap at his toes to nourish the soul inside. He'd sit in a folding chair and I'd stand beside him, sharing a bag of cherries. Lake food we called it. We'd take a cherry, throw the stem into the lake, and suck the pits clean. Then we'd let the pits soar, keeping pace with the waterline, toeing that piece of soft earth left behind by small waves. Cherries weren't as fun at home. Having a bowl of pits on the counter lacks ritual. At the lake they were different, a specialty made just for him and I. They'd crash into the water and create nickel-sized ripples that we watched spread across the surface, marking it as ours.

We ate a lot of cherries that way, lakeside. He'd have the boombox and everyone else would be off somewhere else. The cherries were ours and the ripples they made were our claim to this place and this time. I look back on those lakeside afternoons and hear

something different in the music. We swayed to “Isn’t Life Strange,” in the house and I thought of my mother. I’d keep the beat in my heart and curl myself in his lap. But now, the tune sounds different.

“Isn't life strange

A turn of the page

A book without light

Unless with love we write

To throw it away

To lose just a day

The quicksand of time

You know it makes me want to cry, cry, cry”

I’m not sure he was thinking of her. I think he was thinking of us. Our time at the lake was love written, it was days kept and moments savored. The cruel quicksand of time swallowing his kids was strong competition for the muddy water we splashed around in. Maybe if he could teach us to conquer the lake, we could compete with the quicksand. We could stay afloat and continue to be his children, holding the pages still.

So he taught me to throw in the cherry pits. Making the lake and the moment ours. It wasn’t something to cry about, it just was.

Eventually, we stopped going to Lake Wappapello. The blue van still runs, but not well. My brother doesn’t talk to my dad anymore. I am too sick now to go camping. But my father and I still like to eat cherries and see how far the pits can fly. We let them soar

into the backyard off the porch and pretend we can see the ripples, pretending we still have the lake.

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After I'd been sick for a while, we reached out to new doctors. We went to new facilities, tried new types of medicine, and got new tests done. This kind of repeat testing with multiple consultations is not uncommon for women suffering from chronic pain disorders. For example, a report from the Overlapping Conditions Alliance (OCA) finds that 50% of women suffering from endometriosis have at least 5 separate consults before getting diagnosed.<sup>67</sup> Women with chronic pain are familiar with looking further than a second opinion for a diagnosis and I was no exception.

We read blog articles and listened to anecdotes from our friends and family, trying to figure out which stone we left unturned. Around this time, in 2016, a new health movement sparked and new tests were being offered every day, from new kinds of allergy testing to DNA tests that tracked smaller mental or physical problems back to the core of who you were. These tests are exhausting and make it very hard to be a client advocating for his or her health.

We tried fructose testing in the fall of my Senior year of high school. A friend of my mother's knew someone else who had a sister who had symptoms like mine and was diagnosed through a hydrogen breath test. When you're a sick person, stories like these

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<sup>67</sup> Mary Lou Ballweg, "Chronic Pain in Women: Neglect, Dismissal, and Discrimination: Analysis and Policy Recommendations," *Overlapping Conditions Alliance*, May 2010, pp. 1-40, <http://www.chronicpainresearch.org/Resources>. 24

arise all the time. Everyone has an anecdote and everyone has a remedy to add to the list of unchecked boxes at the bottom of the “Get Well Soon” to-do list.

“Have you tried this? My boyfriend’s sister’s friend’s sister was sick for like months and then some doctor tried this new thing and she was fine in, like, 3 days” or something along those lines. Most of these suggestions are unhelpful and symptomatically, getting information this second-hand means it is very unlikely my condition matches your boyfriend’s sister’s friend’s sister. That said, when you are out of options and out of ideas, and too exhausted to find new treatments yourself, these suggestions at least lead to new avenues worth exploring. So I, along with my father, went to a pristine doctor’s office one winter morning to get a breath test determining the amount of hydrogen in my breath.

The test measures the amount of hydrogen on your breath which determines if there’s too much bacteria in the body. For example, bacterial overgrowth in the small intestine causes abdominal pain, bloating, indigestion, etc. The entire list of symptoms targeted by this test is not a perfect fit for me and my case, but our insurance covered the test and I cannot emphasize enough how exhausting finding new medical tests can be. When someone throws you a bone, you take it.

We waited in the clean lobby until a middle-aged blonde nurse called me back to start the test. I had to drink a cup of water and sugar and for the next three hours periodically blow into a breathalyzer or drink more of the sugary concoction. The breathalyzer analyzes my breath for hydrogen gas and if the percentage of hydrogen gas



in my breath is too high, I may have a bacterial overgrowth somewhere in my GI tract. I drank the first Styrofoam cup the nurse gave me, blew into the breathalyzer, and took my seat outside in the lobby, waiting until she called me back again. I brought my backpack with me, anticipating the length of the test, and pulled out my used copy of *Lord of the Flies*. My father, sitting next to me, pulled out his copy of *The Post Dispatch*, St. Louis's daily newspaper.

“Ready to settle in?” he asked me, half-laughing.

Neither of us wanted to spend our morning in this small lobby on the second floor of an office building. I was wearing my school uniform and scheduled the appointment early enough to make it in before my second class that day. I shifted in the vinyl seat and perched my black high top Converse sneakers on the edge of the coffee table covered in old issues of *People*. My palms started to sweat and I could feel my breath tightening in my chest. I shifted again, planting my feet on the floor and sinking lower in the chair. A drop of sweat rolled down the back of my neck. My stomach tightened and clutched my heart, curling vines around my waist and squeezing my organs tighter. I tried to keep my breathing even.

“Pop, I’m going to hit the bathroom real quick. I’ll be right back,” I say.

He glances up from the newspaper and sees the restroom sign right outside the lobby door.

“Try not to get lost,” he says, going back to the newspaper.

I roll my eyes and cross the lobby, pulling open the glass-paned door and after a few more steps, crash into the bathroom. I clutch the sides of the single white sink and glance into the mirror positioned above it. A ghost looks back at me. A ghost completely drenched in sweat. *Can ghosts sweat?* My chest heaves with the effort it takes to breathe. I splash water on my face and sit on the toilet, hoping for quick relief. No luck. The vines wrap tighter, snaking around my waist and puncturing my torso, twisting around my kidneys and liver. I haven't moved from the toilet. I don't think I can.

Suddenly, there's a knock at the door. "Honey? You need to blow into the...the thing again." My dad pauses at the door. "Are you ok?"

"Yes, I'm ok! I'm coming," I yell.

I grit my teeth and pull myself into a standing position. With a hand clutching my side, I limp out of the bathroom and into the lobby, following the nurse back into the examination room. She has me blow into the breathalyzer. She looks me up and down, frowning.

"Are you ok?" she asks.

"I'm not great," I say, struggling to keep my breath even. "Is this normal?"

"Everyone can react to the sugars differently. We still have about 2 hours left, think you can make it?" She asks, turning away to record the metrics on the breathalyzer.

"Is there any way we can finish the test more quickly?" I ask. She shakes her head. I wince as I get up from the medical observation table.

"I certainly don't want to come back. I guess I'll have to make it." I say.

She helps me back to the lobby. My father leaps out of his seat when he sees me and helps me sit down. He follows the nurse back to the observation room. He comes back a few minutes later.

“Honey, do we need to go to the hospital?”

“No, we’ve got to finish the test,” I say.

“Something’s wrong,” he says, folding his newspaper in half. “You don’t have to finish the test. Do we need to go to the hospital?”

“No. Let’s do this. Today. Please?” I look up at him from my chair. He bites his lip and strokes my hair. He nods.

“Whatever you want to do,” he says. “You call it and we’re out of here.”

“I’m going to try the bathroom again,” I say, forcing myself up.

Again, the bathroom provides no comfort. I fold up on the toilet and the vines stretch across my chest and grip my neck. I force my breaths to sink lower, curling up on the bathroom floor. *God, I hope they clean these in the morning.* I push my hands into the cool white bathroom tile and groan under the weight of the pain. Sweat dampens my hair and my hands claw at the tiles. My father comes to get me for the nurse again. She makes me drink another Styrofoam cup. I go back to the bathroom and sit with my back against the wall in the bigger of the two stalls. My head falls on my knees.

We spend the rest of the morning like this. The nurse calls for me, my father knocks on the bathroom door, I push myself away from the cold white tiles, and he helps me into the observation room. Nothing makes the pain go away. I claw at the vines

twisting into my spine and groan into the bathroom walls. Tears begin to fall. My whimpers don't seem to do anything. *Can anyone hear me? Does it matter if they can?* I start whimpering louder. I kick the wall and pull my hair away from my neck, clutching clumps and pushing my fists into my temples. It's so hard to breathe. Each inhale punctuates itself with sharp, squeezing pain and I begin to wonder, *is it worth it to keep trying?*

At least I'm alone in the public bathroom. I draw comfort in knowing that my dad stands on the other side of the door and that I sit alone on the floor, so no one sees or bears witness to this immense pain. The nurse helps me out of the bathroom for the final breath test. She promises to call us soon.

My dad helps me into his blue van and we drive home. I can't go to school. My dad helps me into bed. I pass out from the pain and wake up in a pool of sweat hours later. I breathe normally again. I check my phone and see texts from my friends wondering where I am. I missed a call from my mom. I call into the house and my dad runs up the stairs.

"Did you take off work?" I ask. My uniform is damp.

"Don't worry about that. How are you feeling? Do you want anything?" he asks, kissing my forehead. I'm already starting to fall back asleep. When my friends text me asking how the appointment went, I tell them about the breathalyzer and laugh about how long it took. When they ask why I never came to school, I tell them I wanted to skip to

avoid my French quiz. If they ask how I'm feeling, I tell them I'm so glad I got to take a day off.

We get the results back later that week. They are perfectly normal. I am perfectly fine.

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Maybe there's a reason we call patients patients. Misdiagnosis is hard and requires an enormous amount of patience. For women, it is very common and a very, very long road. The OCA report also finds that 40% of women with chronic vulvar pain need 3 consultations before getting a diagnosis.<sup>68</sup> Typically, it takes months to years before women suffering from chronic pain conditions get any kind of diagnosis.

Getting those first, second, and fifth appointments is not easy for everyone. The more opinions one must collect, the more privilege plays a role in finding a diagnosis. Not all people can afford that many appointments, that many co-pays, devote that much time to sitting in doctor's offices. Insurance can stand in the way of finding a diagnosis, considering almost half of the doctors in the country won't see Medicaid patients.<sup>69</sup> These appointments begin to weigh down on patients, as the bills accumulate and the confusion grows. After one or two misdiagnoses, how can you trust that any other will be accurate? Which doctor will be *the* doctor and how can a patient tell?

There are a lot of reasons why patients get misdiagnosed. One is purely an accident. Often, symptoms can add-up to any number of diagnoses. Once, my eye doctor

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<sup>68</sup> Ballweg, "Chronic Pain in Women," 24

<sup>69</sup> Parmar, "How Doctors"

told me my optic nerves tilted inwards. In her words, either they had always been that way or it was brain cancer. I had to get an MRI to be sure. Every little thing in our bodies, like the tilt of our optic nerves, can be just the way we are made or needs a test to ensure there are no abnormalities. Medical tests are one way to easily prove a diagnosis. Those tests are administered based on the collection of symptoms any one person has. However, these tests are not as black and white as something like a take-home pregnancy test. They have to be interpreted. As I said, there are a lot of reasons why patients get misdiagnosed. The interpretation of these tests brings us to the second reason: money.

An expose in *The Atlantic* highlights how financially beneficial it can be for a doctor to intentionally misdiagnose a patient. The way some hospitals work, doctors are compensated for how many tests they perform on certain machines, performing certain procedures, prescribing certain drugs; things like that.<sup>70</sup> These doctors can receive bonuses for meeting and surpassing billing targets, bills that come from those tests, prescriptions, and procedures. The problem with this method is that doctors are no longer incentivized to treat patients according to the patients' best interest, but according to the financial benefits that come with treating the patient in a certain way.

One doctor was compensated for every EEG performed. An EEG (electroencephalogram) is the test that attaches a bunch of wires to your head so a machine can read the electric activity in your brain. Mark Ruffalo wears one in *Now You*

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<sup>70</sup> Olga Khazan, "Why Some Doctors Purposely Misdiagnose Patients," *The Atlantic* (Atlantic Media Company, August 26, 2019), <https://www.theatlantic.com/health/archive/2019/08/when-doctors-purposely-misdiagnose-patients/596068/>

*See Me* while Morgan Freeman explains to him how the Horsemen completed a magic trick. Professor X of the *X-Men* movies wears a cool dystopian version of an EEG from his wheelchair. Both Eleven and Will from *Stranger Things* wear the headsets for EEGs while scientists try to understand their sinister connection to The Upside-Down. By being compensated for every EEG performed under his care, this doctor increased his pay with an additional \$115,000 a year.<sup>71</sup> A test that for many patients was unnecessary, not covered by all insurers, and often led to misdiagnosis for the children he treated for epilepsy.

Another woman went 3 years before discovering she had Epstein-Barr and herpes-6. She was tired and sick all the time. Life became unhappy. There's an idea in the medical field that our unhappiness leads to our problems. In my experience, it is the other way around. Being sick all the time takes away the things in it that make you happy. This woman wrote, "my journey to a proper diagnosis was long and involved a lot of doctors, a lot of waiting, and a lot of disappointment."<sup>72</sup> After the herpes diagnosis, she was told she had chronic fatigue. "At one point during my search for a diagnosis, I saw a psychiatrist who said I might have an anxiety disorder. That made me feel like it was all in my head and like I could've been better years ago if I had just learned how to calm myself down. But I knew it wasn't in my head—I knew it was more than she thought, and the medication she gave me didn't work."<sup>73</sup> We have to know ourselves, trust

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<sup>71</sup> Khazan, "Why Some Doctors"

<sup>72</sup> Zahra Barnes, "Excruciating Stories of Women Whose Diseases Were Misdiagnosed," *Women's Health* (*Women's Health*, June 11, 2019), <https://www.womenshealthmag.com/health/a19936894/misdiagnosis/>

<sup>73</sup> Barnes, "Excruciating Stories"

ourselves, and feel confident in our knowledge about our own bodies. When doctors try to insist the problems are all in your head, it becomes more and more difficult to trust oneself. Not only that, but hearing someone reduce enormous physical pain to anxiety makes it difficult to trust the doctor as well. Am I just being written off because I'm a woman? Or is there a logical reason you sent me to a psychiatrist for pain management? If I have more faith in the factuality of my horoscope than my diagnosis, we have a problem.

The woman from above continues, "being sick for so long, especially without knowing why, is exhausting. Worse yet, fighting it all the time is exhausting."<sup>74</sup> I'm tired. We're all tired. And yet the responsibility falls entirely on us to battle the systematic flaws in the medical network while battling the conditions that ravage our bodies. All I want every day is an answer, but at this point, the only thing I'm confident about is that I'll never get one.

I rode to so many doctors' offices in my father's blue van. Even when I was younger, I remember sitting in that car while it rattled toward my orthodontist appointments. He carted me to different specialists, different testing labs, and different hospitals. I would fold my arms around my torso and look out the passenger-side window while neighborhoods across St. Louis rolled by. Sometimes we listened to the radio and other times we sat quietly listening to the melody of the engine. Everything in my life had been so simple. No one could anticipate these changes or how hard it would be to find a

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<sup>74</sup> Barnes, "Excruciating Stories"



diagnosis. There was no way to predict that now, 6 years after this all started, I'd still be undiagnosed. Those Moody Blues lyrics hit me differently now. Even just the title, "Isn't Life Strange," feels true in a way I never understood as a child. I nod along to lyrics:

"To throw it away

To lose just a day

The quicksand of time

You know it makes me want to cry, cry, cry"

How many years, days, and minutes have I thrown away digging through quicksand? How many hours have I wasted crying about the life I lost all those years ago? How, after so many years of being undefinable by so many, can I trust one doctor to define me? Is it possible I live now in fear of the thing I covet most? Is it possible that after this trauma, I can never trust a doctor enough to give me a diagnosis?

## Some People Want to be Sick

**A Doctor's Note:** "She is described as being 'an emotional mess.'"

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I walk into the doctor's office and immediately feel anxious. This particular hospital in Saint Louis has a reputation. Fights and gunshots echo in the parking lot while fluorescent lights glow yellow from the ER windows. Maybe I'm projecting onto the hospital and the real reason I'm nervous is the possibility that these doctors won't be able to help me. At this point, in 2016, I'm running out of options. We walk into the crowded lobby and take the stairs up to the GI floor.

The PA who takes me back is young with long black hair and a beautiful honey complexion. She sits down with me and nods as I run through my list of symptoms. I've been through them so many times now the list sounds robotic. The observation room is small and crowded because both my parents accompanied me. Her kind eyes look at me from behind rectangular, black plastic glasses.

"First thing," she says. "I think you should start birth control. You said you have trouble eating during your period and you lose a lot of weight that way, correct?" she waits for me to nod. "We can fix that. I'll write you a low-dose prescription for a pill a lot of young girls start with. I think it will really help even out the months for you."

“That sounds...great, actually. Yeah, I would love to try that,” I say. This was the first new suggestion we’ve gotten in months and I feel a balloon in my stomach swelling, excited by the possibility of new, possibly beneficial, treatment.

My Catholic mother looks a little skeptical and my father looks at the tile floor, as he does every time we discuss my reproductive health. This new treatment doesn’t deviate from the normalization of women’s pain, reducing my problem to my uterus and hormones, but it does bring a hopefulness I haven’t felt in a long time. The PA excuses herself, letting us know the doctor will be joining us shortly. My feet dangle off the vinyl observation table and I swing my legs. The doctor comes in and shuts the door behind her.

“So!” she says. “What’s going on?”

I repeat the list of symptoms. She’s a shorter woman with her brown hair cut into a bob. She doesn’t sit the entire time she’s there. I get through an abbreviated list of my symptoms when she interrupts me.

“Hang on. I talked to my assistant and its IBS,” she says, almost triumphantly.

“Why do you think that?” I ask, caught off-guard by how quickly she reached a diagnosis after so many doctors struggled. She had only been in the room for a minute, maybe less.

“You’ve got all the symptoms...cramping, bloating, difficulty sleeping. It’s IBS.” She’s wearing a blue t-shirt.

“That’s interesting...I’ve just seen so many other doctors and they said that IBS was unlikely and told me I wasn’t a traditional candidate for that diagnosis,” I said, wringing my hands.

“You’ve come to me, that’s what it is. I’m an expert in this, I know it when I see it,” she says, starting to look annoyed.

“Ok, and I get that. But...if 4 other doctors said it wasn’t IBS, I don’t know how you can tell me it is so quickly,” I say.

“Look,” she says. “You’ve done all the tests. There’s only one more test I can think of to try to see if it’s IBS. But, I’m telling you, that’s what you’ve got.”

“What’s the test?” I ask. My mom continues taking notes and my father stands behind me, his hand over his mouth, nodding along to my comments so far.

“It’s called Anorectal Manometry. We’ll insert the end of this...well basically like a balloon...into the anus and you’ll concentrate on exerting some pressure to blow it up,” she says. “We can do it right now.”

“You...want me...to blow up a balloon...” I couldn’t even get the words out. I looked at my parents in disbelief. My mom looked confused. I cleared my throat.

“Um...no I don’t think so. That’s like...we’ve just met...I haven’t...” I stammer out.

*Where’s the nice PA?*

“This test is not a big deal. It’s very common. I know this is your first appointment, but I’m a doctor, and this is what doctors do,” she shot back.

“I just don’t think I’m comfortable with...” I start tearing up, my voice is shaking.  
“I don’t think I want to do that today.”

“If she’s not comfortable, she’s not comfortable,” my father says, chiming in from behind me.

My mom pipes up, “Michelle, you can do it right now. Your dad and I can leave the room.”

“No!” I push back my tears and sit resolutely on the vinyl table. “I’m not doing that today. I’m sorry, no.”

“Honey,” the doctor says patronizingly. “This is an option we can do right now. We can get you diagnosed today. If you don’t want that, be my guest,” she says, crossing her arms.

“Thank you,” I say. “I think I will.”

We rush out of the office. My mom scolds me as we’re leaving.

“Michelle, we have to be looking at every option and if she says that could be it then –”

I cut her off. “Mom! No. None of the other doctors we’ve seen have thought it was IBS. They explicitly said it wasn’t. I do not know that doctor. I have never seen her before and I do not want her to stick a balloon up my butt so I can blow it up like a circus animal,” I pause. “That appointment was humiliating.”

We stand across from each other in the hospital hallway. My eyes are still wet from tears and I’m breathing heavy, self-righteous breaths. She pulls me into a hug. “I know. I

get it. I'm sorry, I just want everything to get better for you." She sighs and says she needs to get back to work and she's parked on the other side of the building.

"I'll see you at home later," she says, squeezing my shoulder.

She walks away from my father and I. I turn to him.

"That was like...crazy right? Am I crazy?" I ask. We start down the hallway, headed to the stairs.

"Baby, if you're not comfortable..." he laughs. "That's what matters! You weren't comfortable! You've never seen that doctor before. And...all these other doctors, you know, they're saying over and over 'it's not IBS' so I think she was a little quick with that."

"Right!" I say, racing down the stairs. "She talked to me for like 20 seconds and knows everything about me?"

"She...she wasn't right. And it's good we went, but...Yeah, she was..." he laughs again. "It was 30 seconds wasn't it?" He stops me at the bottom of the stairs. "That wasn't how we wanted that to go. We didn't get what we were looking for. If we want to do the test, you know, we'll do the test. But her pushing that on you today, before even talking to you...that wasn't the right way to do it." He pulls me into a hug and kisses the top of my head.

"Let's get out of here before someone steals the car," he says.

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Did I ever take the test? Why was I so resolved not to take it then? No, I never took it. There are a few reasons why. First, the test is rather ineffective. The National Institutes of Health published an article on their government website in 2015 on how accurate anorectal manometry tests were, and how likely those tests were to lead to a diagnosis. Their study finds that the test considered 90% of healthy patients “abnormal” and the article concludes that anorectal manometry tests are “of limited utility.”<sup>75</sup> Did I want to see a rude doctor again so she could administer a test that acts as a confirmation basis for any doctor performing it due to the 90% chance it will read as abnormal regardless of my health? Pass.

Second, I had never heard of this test. We had been seeing doctors who tried everything – urine, blood, ultrasounds, endoscopies, colonoscopies, biopsies, x-rays. You name it; we tried it. I found it hard to believe that this doctor’s colleagues, who frankly worked within much more highly regarded medical institutions, would have overlooked a test she told me was so common. Aside from our experience in the medical community, none of our research had ever pointed to a test like this. No one’s friend’s brother’s classmate had taken a test like this, as far as we knew.

Third, anal tests are not done on the spot. They require planning and usually take long enough to warrant their own appointment. At the very least, patients are advised to eat lightly or avoid eating altogether a few hours before the test. I looked up the advised preparation for anorectal manometry. According to the website for a clinic in Cleveland,

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<sup>75</sup> Ugo Grossi et al., “Diagnostic Accuracy Study of Anorectal Manometry for Diagnosis of Dyssynergic Defaecation,” *Gut* 65, no. 3 (March 2016): pp. 447-455, <https://doi.org/10.1136/gutjnl-2014-308835>

aptly named Cleveland Clinic, there are two very important steps required of patients before this test.

1. One must stop all eating or drinking at midnight the night before.
2. 2 to 3 hours before the appointment, the patient should clear out the bowels with an enema.<sup>76</sup>

Other clinics that offer the exam say more or less the same thing, at the very minimum insisting that patients abstain from eating or drinking at least 2 hours before the procedure. The fact that this doctor insisted we could do it on the spot, getting my diagnosis in 10 minutes after years of searching, felt wrong. I needed to listen to my gut, ironic as that is.

Lastly, and perhaps most importantly, she made me uncomfortable. She did not listen to me. She spent very little time with me and concluded far too quickly that she knew more about my body than me. I trusted myself, and had spent enough time with a variety of doctors, all with varying degrees of comforting bedside manner, and knew that this doctor wanted to write me off with a bullshit diagnosis to include me in her yearly list of triumphs, a part of a statistic that makes her hospital look better.

All that brings me to the point of this story. Doctors are not infallible. Doctors exist to care for us and if we don't feel cared for, they are not doing their job. Now, some doctors struggle with bedside manner, a noted problem within the medical industry that often leaves patients, especially women, feeling a little stricken. That said, part of what

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<sup>76</sup> "Anorectal Manometry Test Details," Cleveland Clinic, January 18, 2015, <https://my.clevelandclinic.org/health/diagnostics/12760-anorectal-manometry/test-details>



makes doctors useful is their separation from emotion and logic. I have seen doctors that do not communicate well, that do not like me, that do not show an ounce of emotion, and I have had no problems with most of them. I am a tough patient. I've been around the block enough times to earn a little respect from the doctors.

Doctors do typically know more than the average patient about medicine. This is part of why patients trust their doctors. They are professionals, but they can still violate trust and misuse their power. One doctor, currently serving time in prison for administering unnecessary chemotherapy to 553 patients, abused his position and made clients feel inferior to him. When one patient did more research, the doctor asked "if [the patient] had fellowshiped at Sloan Kettering like he had," shutting down the patient and continuing the maltreatments that would eventually land him in jail.<sup>77</sup> Yes, doctors do know more than patients. Doctors also need to listen more to their patients, especially women, and understand that though it may feel like it, they are not gods and patients are not their underlings. Patients deserve to be heard and doctors must start granting patients the benefit of the doubt, trusting in the patient to tell the truth.

When a doctor tries to insist on doing something that makes the patient uncomfortable, that the patient knows does not sound right, without offering any other options, or the chance for the patient to do research, something is wrong. These are the moments when the most important thing a patient can do is to be his or her own advocate. It's hard. Your body hurts like hell and more than anything in the world, you want to

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<sup>77</sup> Khazan, "Why Some Doctors"

know why. I wanted so badly to hear the words, “you’ve been diagnosed with...” but I didn’t trust this doctor. And trusting my gut saved me from an invasive, ineffective, and frankly very strange test that would have undoubtedly granted me a false diagnosis for an incurable condition.

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Women who have worked their way through the American medical system have heard doctors say “it’s all in your head” before prescribing Tylenol. This kind of brush-off bullshit is called by Sasha Ottey, the founder of The National Polycystic Ovary Syndrome Association. “health-care gaslighting.”<sup>78</sup> It’s doctors insisting that either the problem is made up or insisting that the patient is not reporting the problem truthfully. Ottey, when defining health-care gaslighting further, uses the example of food diaries. I had to have one when my doctors were trying to put me on diets, looking to see if I felt notably worse after eating certain foods. “People who are following an eating plan and present their diaries to their physicians or nutritionists will be told, ‘You left something off. You’re lying. You’re not doing enough,’” says Ottey.<sup>79</sup> The doctor who tried to give me an anal manometry also critiqued my eating habits, saying I wasn’t doing enough to make myself feel better.

Noted facts like women being more likely to have debilitating chronic diseases, though not necessarily life-threatening ones, do not seem to change the perception that

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<sup>78</sup> Ashley Fetters, “The Doctor Doesn’t Listen to Her. But the Media Is Starting To.,” *The Atlantic* (Atlantic Media Company, August 13, 2018), <https://www.theatlantic.com/family/archive/2018/08/womens-health-care-gaslighting/567149/>

<sup>79</sup> Fetters, “The Doctor Doesn’t”

women cannot self-report. There continues to be “the sense women are not very accurate judges of when something is really, truly wrong in their bodies”<sup>80</sup> and that leads to women’s symptoms being dismissed as well. Their symptoms are “brushed off as the result of depression, anxiety, of the all-purpose favorite: stress.”<sup>81</sup> As I’ve said, doctors tried to prescribe me anti-depressants, they sent me to therapists, they warned me about my busy schedule; they cared about my brain more than my body and constantly told me once I got out of my head I’d be cured.

Some conditions link the brain and the body. Anxiety and stress can make your stomach hurt. I know I’ve felt nauseous and queasy during a break-up or before a presentation I wasn’t prepared for. The problem is not acknowledging the mind-body connection as it pertains to medicine. The problem comes from assuming that any medical abnormality a woman faces comes strictly from her head. That minimizes women’s symptoms and dismisses their authority over their bodies. Porochista Khakpour, author of *Sick: A Memoir*, remembers a doctor condescendingly telling her, “sometimes people subconsciously want to be sick.”<sup>82</sup> The doctor does not believe her. Doctors across the country tell women they’re looking for attention. Sickness brings something to us that our typical lives did not. This doctor’s comments made Khakpour acknowledge, “I am a sick girl,” she writes. “I know sickness. I live with it. In some ways, I keep myself sick.”

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<sup>80</sup> Dusenbery, *Doing Harm*, 4

<sup>81</sup> Dusenbery, *Doing Harm*, 4

<sup>82</sup> Haas, “Disease and Disbelief”

<sup>83</sup> In other ways, she desperately needs doctors to see her and treat her and recognize that something in her body doesn't work. Something other than her brain, that is.

Women like me seek to explain that they are, or were, *normal*. That's what I am doing here. I will tell my story. I weave in my sense of self. I detail eating cherries with my father and hugging my mother. I do this to establish that I am a normal person, a person worth reading about, believing, and inspiring change. I need readers to sympathize with me. I want readers to see in me a friend, sister, daughter, or mother so that my pain is transferable. In many ways, it's my job to make people believe me. That's what writers do. But maybe it's worth considering, why don't people believe me? Why do I need to convince anyone that I am worth his or her time? Why do I need to convince anyone that I don't want to be sick?

Am I hysterical for refusing to go on antidepressants because I am not depressed? Am I crazy to say a diagnosis is bullshit when a qualified doctor gives it to me? Am I resisting treatment and keeping myself sick when I sneak a cookie on my gluten-free diet; a diet that made no sense in the first place? Why should I, the person laden with physical trauma, have to constantly defend myself, my state of mind, my sanity, to the people who are supposedly trying to protect me?

Being sick comes with an intense need for connection to those going through the same thing while still maintaining individuality and a sense of self separate from the sickness. Undiagnosed people, like myself, suspend themselves in a medical landscape

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<sup>83</sup> Haas, "Disease and Disbelief"

designed to treat diagnosable problems. As a writer for the *New Yorker* puts it, “an incurable chronic illness of unknown origin that ravages the sufferer while remaining suspect and all but undetectable to those around her has the hallmarks of horror.”<sup>84</sup> It’s maddening. The crazier it makes you, the more consumed one is by the horror, and the more likely it is that doctors will write you off as precisely that, crazy.

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A contributor to *the Atlantic* went with his wife, Rachel, to the ER because of intense abdominal pain. Quickly, the staff diagnoses her with kidney or gall stones, asking questions that serve to prove their theory. None of the staff seem interested in how her being female could change the reasons for her abdominal pain and no one administers a physical or gynecological exam. The doctor checked in just once, assessed her pain to be stones of some kind in a matter of seconds, and continued on to the next patient without any further assessment. The pain feels so torturous that eventually the staff administers an ultrasound. They find a large mass, an ovarian cyst. She needs surgery and a different doctor “couldn’t believe that they left me here all day. He knows how much it hurts.”<sup>85</sup> The staff in the ER did not believe her. This problem is not unique to Rachel, or unique to me. Staff do not believe women and do not treat them as quickly as men for problems like acute abdominal pain. In the ER, on average men will wait 49 minutes for

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<sup>84</sup> Haas, “Disease and Disbelief”

<sup>85</sup> Joe Fassler, “How Doctors Take Women’s Pain Less Seriously,” *The Atlantic* (Atlantic Media Company, November 4, 2015), <https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/>

an analgesic while women will be waiting for 65.<sup>86</sup> Those 16 extra minutes are excruciating. Waiting under fluorescent lights with an IV stuck in your arm, looking at the medical equipment hung on the wall, listening to the screams and cries of fellow patients while knowing if you were a man, you'd have gotten treatment 16 minutes ago doesn't make someone like me more patient. It makes me want to scream louder. Those 16 minutes come with a price. They come with the feeling of health-care gaslighting and, as Rachel puts it, "the trauma of not being seen."<sup>87</sup>

Women going to the hospital for heart attacks are 7 times more likely than men to be misdiagnosed and have their symptoms completely ignored.<sup>88</sup> One woman went to the ER for a heart attack and the doctor, after calling her a drama queen, told her, "it's not my job to tell you what's wrong with you, it's my job to tell you what it's not and it's not your heart."<sup>89</sup> She later saw a different doctor and it was conclusively, without a doubt, a heart attack. Doctors make us feel small, and that's because they have an obscene amount of power over us. Dr. Alexandra Moffett-Bateau, a scholar of African American studies and its intersection with gender, found after a run-in with the doctors, "this belief that I was making things up, that what I was saying wasn't real, that I must be seeking drugs...what happens is you start to develop a ton of fear around going to the doctor."<sup>90</sup> Black women especially suffer under the current medical system. Black women are 3 to 4

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<sup>86</sup> Fassler, "How Doctors"

<sup>87</sup> Fassler, "How Doctors"

<sup>88</sup> Oliver, "Bias in Medicine"

<sup>89</sup> Oliver, "Bias in Medicine"

<sup>90</sup> Oliver, "Bias in Medicine"

times more likely to die during childbirth than white women. Why? According to Dr. Neel Shah, senior author of *Understanding Value-Based Healthcare*, Black women who express symptoms of pain are less likely to be believed about the reality of that pain.<sup>91</sup> We all know that childbirth is a pretty painless activity, but what excuse is that for not believing women?

Comedian Wanda Sykes discusses in her standup routine how difficult it can be for Black people to get proper pain medication. She says, “white people get opioids like tiktaks... It amazes me how many opioids you motherfuckers have...I had a double mastectomy, you know what they sent my Black ass home with? Ibu-fucking-profen.”<sup>92</sup> And she’s right. African Americans are 34% less likely to receive opioids than white people.<sup>93</sup> Why? The same reason doctors send women home from the ER without properly examining them. There’s a bias in the medical community against women and especially against women of color. Wanda Sykes makes it funny, but her point remains. These biases leave people suffering and endangered. More needs to be done to solve it, measures that the medical community has not taken because not enough people have demanded it. Today, dear readers, we demand it.

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<sup>91</sup> Oliver, “Bias in Medicine”

<sup>92</sup> Sykes, Wanda. *Not Normal*, Netflix (Netflix, 2019)

<sup>93</sup> Oliver, “Bias in Medicine”

Lined up in a row on the counter are 4 ibuprofen, 3 Tylenol, 2 lansoprazole, 2 Hyoscyamine, 8 digestive supplements, and 2 pills I found in my pill basket. I'm not sure what the last 2 are, but I honestly don't care. I grab the first off the line.

My brother wanders into the kitchen and grabs his morning pills from the cabinet. He takes them to manage his ADHD. He glances at the counter and raises his eyebrows.

"Jesus," he says.

I shoot him an exhausted glance and shrug. I brace my hands against the kitchen island while slowly washing down the drugs set before me. He leaves the kitchen and as I watch him go, I think about when neither of us took any medicine. I remember our twin bodies bouncing around the backyard without drugs in our blood. I wish we could both go back to before these little white and blue and red and yellow dots controlled us. How luxurious it was to rise in the morning with no obligation, facing the day as a pure body. Now we're both polluted, floating in a toxic river of drugs we'll be taking for the rest of our lives. I can't imagine a scenario where neither of us takes these pills. We're trapped in these bottles, 'saved' by these chemicals. It scares me to think about what I'd be reduced to if I didn't have these pills every day. I remember the days before I became dependent on these chemicals and I can't return to the pain and misery. I can't. I won't. It also scares me to think about how the polluted river of my body will eventually destroy me from within.

All those fears don't matter in the every day of my life. Every day, just as my brother does, I wash away my body with the toxins of my river. My fears about addiction,



dependence, health, all slip into the river as the pills bring light to my eyes. The medicine says, “until tomorrow,” when the rapids of my soul will call back the chemicals to soften the jagged edges of the rocks under the water. Each day those jagged edges reappear, threatening me before the pills come to my rescue. Each day stays the same. Each day continues.

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I was once asked, after detailing my condition to a friend, if I was simply more sensitive to pain than other people. I granted that it was a possibility, but there was no proof or indication that that was true. If anything, I felt I represented the opposite as someone who suffered from mono for months without changing my routine or going to the doctor. I didn't even know I'd contracted the disease until much later from a blood test. Regardless, his question is worth dissecting and points to a fundamental problem in the way we discuss and imagine pain. Perhaps I do feel pain more than others and am naturally more predisposed to it. Does that make my experience any less valid? Why diminish my pain, which is very real and consuming for me, by suggesting that if someone else had the problem I do, they would feel it less? Many diseases are worse for some people than others, it is true. Pain tolerance, while very difficult to measure, varies from person to person. While I acknowledge that my same symptoms could be experienced by a different person in a completely different way, does that mean I'm not

worth treating? I am somehow exaggerating, lying, weak, or hysterical about the pain I feel. This was a person I trust, someone who knew me quite well. Why is it, when we talk about pain, that we always feel ours is worse than that of others? Back in the second chapter, I established that pain is “inherently, stubbornly subjective.”<sup>94</sup> That subjectivity makes it hard to discuss pain in general, but it leads to other issues as well.

One of those issues is how bias affects the treatment of pain due, in part, to the subjective nature of pain. Bias, unconscious or otherwise, can cloud the judgment of every single person in the process of treating pain, from the friends or family we first tell to the doctors and nurses who have the power to heal us. These biases contribute to Black patients being less likely to be prescribed medication for the same level of pain as white patients. These biases contribute to men being 25% more likely to receive opioids for pain than women.<sup>95</sup> These biases hurt people and diminish their pain, which in turn diminishes the person.

The question my friend asked me, while rooted in unintentional sexist bias, ignores that “pain that gets performed is still pain.”<sup>96</sup> If I am subconsciously amplifying my pain, a pain I very much wish would go away, does that minimize how painful it feels? That pain still affects my life and soul. That pain exists to me and is still pain, no

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<sup>94</sup> Twilley, “Neuroscience”

<sup>95</sup> Twilley, “Neuroscience”

<sup>96</sup> Leslie Jamison, “Grand Unified Theory of Female Pain,” *The Virginia Quarterly Review* 90, no. 2 (2014), <https://www.vqronline.org/essays-articles/2014/04/grand-unified-theory-female-pain>

matter where it comes from. Why should I have to convince anyone that my pain is real, regardless of the reason for it?

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**A Doctor's Note:** "The pain is described as twisting, or sharp like "being stuck with a chopstick" ... She feels hungry, but oral intake leads to significant pain, so she has not been eating much. She has lost weight... She is missing many activities due to pain."

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Disbelief happens to anyone and everyone. Even tennis star Serena Williams ran into problems with disbelief when she gave birth.<sup>97</sup> She had to have an emergency C-section, which went well, but after the surgery, she felt short of breath. She worried about blood clots, which had been a problem for her in the past. The interviewer from *Vogue* explains, "because she was off her daily anticoagulant regimen due to the recent surgery, she immediately assumed she was having another pulmonary embolism."<sup>98</sup> Williams grabbed the nurse and explained the situation, communicating that she needed a CT scan. The nurse assumed a pain medication from the birth was confusing Williams. After she insisted, a doctor performed an ultrasound of her legs. Williams said, "I told you, I need a CT scan and a heparin drip." They eventually did a CT and found blood clots in her lungs causing a cough that reopened Williams wounds. For this, they gave her a blood thinner. The tennis player underwent surgery again and "they found that a large

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<sup>97</sup> Rob Haskell, "Serena Williams on Motherhood, Marriage, and Making Her Comeback," *Vogue* (*Vogue*, January 16, 2018), <https://www.vogue.com/article/serena-williams-vogue-cover-interview-february-2018>

<sup>98</sup> Haskell, "Serena Williams"

hematoma had flooded her abdomen, the result of a medical catch-22 in which the potentially lifesaving blood thinner caused hemorrhaging at the site of her C-section.”<sup>99</sup>

These problems escalated after doctors and nurses ignored Williams, assuring her she was perfectly fine. Serena Williams, a famous professional athlete, struggled with a medical emergency made worse by the fact that the medical community did not believe in her ability to read her own body.

It’s not just doctors that don’t believe women. Friends, family, strangers...we have to convince everyone that our sickness is real, something difficult to do when you don’t have a diagnosis. Being a young woman makes being sick more difficult. My invisible disease hides beneath a thin, young, spritely appearance. Who would guess that beneath my skin runs poison? Who would guess that I have to take pills every morning when I’m out doing yoga? Michelle Lent Hirsch, who I mentioned earlier, writes, “being young and female was inextricably linked to my experience. That I looked bright-eyed and feminine affected how others responded to me too. Often, people thought that I looked great or pretty or young and that I therefore couldn’t possibly be sick.”<sup>100</sup> If one doesn’t look sick, people struggle to believe one suffers. When appearance and reality don’t correlate, treating an invisible illness becomes all the more difficult.

In fact, some studies show more attractive women struggle more to be believed for their pain. There’s a stereotype that beauty equates to strength and health. Young beautiful women are never assumed to be unhealthy, in other words. The study I

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<sup>99</sup> Haskell, “Serena Williams”

<sup>100</sup> Hirsch, *Invisible*, ch 2. 0:14-0:34

introduced in chapter 2 from the *Journal of Law, Medicine, & Ethics* finds that within the healthcare industry, attractive people are assumed to experience pain less intensely, experience less discomfort per their symptoms, and struggle less with disabilities than people who may be less conventionally attractive.<sup>101</sup> Now, do attractive people benefit from the current American societal structure in other ways? Yes. Articles from *Vox*, *The Atlantic*, *Business Insider*, *Science*, and others have found that people considered less conventionally beautiful can make 13% less than their more attractive but similarly capable peers.<sup>102</sup> The same bias that aids attractive people socially or in their careers works against them when it comes to chronic pain. Bias within the medical industry runs deeper and in more ways than perhaps we imagine.

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<sup>101</sup> Hoffmann, "Girl Who Cried," 18

<sup>102</sup> Derek Thompson, "The Financial Benefits of Being Beautiful," *The Atlantic* (Atlantic Media Company, January 11, 2014), <https://www.theatlantic.com/business/archive/2014/01/the-financial-benefits-of-being-beautiful/282975/>

## Burning Phoenix

Maybe there was a kind of glamour I always thought came with being a sick girl. As I mentioned in chapter 1, that kind of damsel in distress narrative had been sold to me since day one. I, a twin and a middle child, saw how much attention Snow White got after she ate the poisoned apple. *Awesome*, I thought, sitting in front of the wood-framed floor TV we kept upstairs, watching the seven dwarves gather around her, weeping and cherishing her memory before putting her in a glass coffin. A coffin made of glass. How fucking badass. And then a prince shows up?!? That's *eight* people! Eight people paying attention to nothing but the sick, young, beautiful girl displayed in a glass box, literally hoisted on a pedestal. And while my brother got yelled at by my parents for talking back and my sister read alone in the living room, I thought, *it must be cool to be poisoned and have so many people care about it*.

Enough movies and books shape her, the sick girl. Her archetype as a glowing, perfect young woman wiser for the fact that sickness struck her during her physical prime. In *A Walk to Remember* when Mandy Moore tells Shane West that she has leukemia, he responds, "no. You're 18. You--you're perfect."<sup>103</sup> West cannot fathom that this woman he fell for, so beautiful and youthful, could be sick. Her youth solidifies her

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<sup>103</sup> *A Walk to Remember* (Di Novi Pictures, 2002)

perfection. Young sick girls fall into this uncanny valley of what people think young beautiful girls need to be. And audiences eat. this. shit. up.

I did a quick Google search. I typed “books and movies where boys fall for the dying girl” and the first result was a compiled list from *Vulture* ranking 18 “Terminal Romance” movies from worst to best. This weird glamorization of love turned longing after the death of a betrothed has its own movie genre; that’s how widespread this myth is. Terminal romance movies are so defined by the sick girl dying at the end that the reason *Vulture* ranks *The Fault in Our Stars* as the best Terminal Romance movie is, “finally, a cancer-ridden teen girl who makes it to the final credits!”<sup>104</sup>

Illness in young, beautiful girls inspires hundreds of movies and instills the idea of “terminal romance” into the minds of young girls. Some of these movies are explicitly marketed to teen audiences like *Me and Earl and the Dying Girl* and others proudly reside in film cannon like *Moulin Rouge!*, wherein Nicole Kidman finally admits her love for Ewan McGregor just before she dies of tuberculosis, wrapped in a sparkling flapper dress with a full face of makeup.

Granted, many of these movies are not well-reviewed. Nevertheless, audiences consume them, digest them, and internalize these romantic ideas about what it means to be young, beautiful, and sick. I got sick, but didn’t feel glamorous. I had people who

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<sup>104</sup> Brian Moylan, “18 Terminal Romance Movies Ranked, From Me Before You to The Fault in Our Stars,” *Vulture* (*Vulture*, June 9, 2016), <https://www.vulture.com/2016/06/18-terminal-romance-movies-ranked.html>

wanted to help me, but the last thing I wanted was for loved ones to see me weakened by my body, if they knew I was sick at all.

When people are sick, they need more care and attention. The culturally ingrained idea that women are needy and men can provide for them is exasperated when a woman becomes sick. Porochista Khakpour, author of *Sick*, in an interview with *Women's Health*, talks about how men want to care for her, thinking she's something they can fix:

I'm needier when I'm ill. I literally need things—rides to appointments, help making meals. But that doesn't mean I'm looking for someone to save me. I've also had the experience where, when ill, my DMs are filled with guys who want to fix broken birds. I think they find it titillating, or a challenge: *Here's a woman who's fragile—how can I solve this problem?*

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Eventually, she finds these men are confronted by their own mortality after spending time with her and leave. This is not the case for all couples. I have been lucky enough to have a wonderful boyfriend who seems undaunted by all the times I cancel plans in favor of staying in. Khakpour's point is that culturally, sick women seem like a challenge, something fixable, and something romantic when in reality being sick polarizes romanticism altogether.

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**A Doctor's Note:** She cries frequently. She spends most of her day in bed.

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<sup>105</sup> Mascia, "Our Pain"



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There are some people, if it's fair to call TV and movie characters people, that say they wouldn't change a thing if they could go back and ensure their lives were different. Movies like these, with the sick girl drawing her final breaths as a love interest leans over her hospital bed, love the moment when the meandering boy, finally grounded in his life and his goals because of meeting this girl, asks her if she wishes she had never gotten sick. Their conversation goes something like this:

'If things could be different...if you could change all this, be a different person, would you?' he asks, two hands clasped around one of hers.

She looks up from the hospital bed, circles under her eyes, and whispers from chapped lips, 'If things were different...I never would have met you.' And then she falls into a coma.

Literally, in *A Walk to Remember* Mandy Moore says to Shane West, who sits perched on her hospital bed, his hand lightly brushing her neck, "maybe God has a bigger plan for me than I had for myself... Like you were sent to me because I'm sick. To help me through all this. You're my angel."<sup>106</sup> Come on! Not to judge any sick person that thinks this way. Being sick, simply put, is hard. Certain mentalities aid the process of coming to reality and facing the path ahead of you, like God or fate. But what these movies do is equate sickness with spiritual enlightening. They make it seem as though this poor sick person wouldn't rather be anywhere else, doing anything else, than sitting

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<sup>106</sup>*A Walk to Remember*

with her love interest. What the sick person is most grateful for is never modern medicine for keeping her alive. It's the boy sitting in front of her. It makes it seem as though people rely so heavily on fate and are so consumed with the cards fate dealt them, they wouldn't even consider going back and asking fate for a new deck.

I used to have great cards. Before all this started, I felt confident in the deck fate dealt me. I guess I got too cocky because everything changed so fast. The cards I have now are better than they used to be, but if I could get a new hand I'd do it. When I was 16 and all this began, it was hard to hide my pain. It read on my face. Today, I attend classes and go to work with pills in my purse. I take vacations and stroll down pedestrian walkways looking completely normal. I consumed the test results and to most people, there's no indication I'm anything but fine. It's all a facade. It's the walls I erected so no one knows about my ice-black ocean. The walls hold back the waves, stopping them from crashing over my heart and spreading to my finger-tips. These walls are fragile. I monitor them every day. I take a carefully determined mixture of medicine in the morning to support these walls. The landscape of this body intentionally reads as calm on the surface. No one needs to know that below the still waves rests a whirlpool, threatening to suck me under at any misstep or miscalculation.

If I could change everything I would give myself a healthy body before the genie even finishes saying, "you get three wishes." While I've been sick, I have tried to be grateful for the support systems around me. Still, there is always a part, lingering in the back of my head, asking *what if it all was different?* I do not want this. I am not better for

this. I am not happy about the knowledge I've gained along the way. For years, my body raged against my skin and killed the soul inside. I don't have to think for a second about the person I've become because of this physical trauma. There's a girl in another universe, in another timeline, that lived this life of mine without getting sick. I would love to meet her.

If things were different, maybe I wouldn't be where I am. I would not have the same friends. I would not have met my boyfriend. I would be someone different, but there is no evidence that that girl is worse off than I am now. That girl could have gone to the same college I went to. That girl could have made the same friends and could have Facetimed that same boy for months before falling in love with him. That girl could have lived the same life, but really lived it. She could breathe without pain in her chest. She could have spent the wasted hospital nights with singing friends at a backyard barbeque. She could have danced under the fireworks at a 4<sup>th</sup> of July party and laughed into the sparkles. She could have lived without dying at the same time.

And if she didn't? What if she didn't go to the same college and made different friends and fell in love with someone else? What if she never felt pain wrench her from sleep or knock her down just as she stood tall again? I value this life of mine, with all the pleasures and pains and people that populate it, but when I look through that window, I think *I could like her life too.*

## Phoenix Rising

*Breathe.* I grip the railing in front of me, my hands slippery with sweat. My vision fades in and out, pulling me into darkness before I push myself back into the present. I take another breath. The girls I'm babysitting don't seem to notice anything unusual. It's 2016 and we're in line at the St. Louis Science Center, waiting for their turn in the spaceship simulator. They're next.

*You can sit down once they are on the ride. Breathe.* I lean over the railing and almost fall over the side. *Breathe.* They're bouncing up and down, but they're moving in slow motion. *Blink. Breathe.* Blood rushes in my ears and I sway, hunched over. A woman behind a velvet rope mouths something to me. I can't see her face. My eyes are open, but the world is black. The noiseless sound pushes against my ears as I hand her the tickets for the ride. I turn my back on the girls and focus my eyes long enough to spot a bench on the other side of the line. *Back straight. Breathe. Walk.* The world is black but I walk straight, crashing into the bench and closing my eyes. The hallway is spinning. My ears can't hear, but they flood with waves. I no longer feel a body, but I feel cold.

*Breathe. Sit up straight. Breathe.*

The girls exit the ride and rush over to me, shouting over each other about the spaceship and virtual stars. I smile at them, wiping sweat from my upper lip.

“Sounds awesome! Want to head back and get frozen yogurt?” Frozen yogurt always, at least briefly, distracts 8-year-old girls.

They beam at each other and race toward the exit. I lift myself from the bench and follow them, rushing to keep up.

I can’t do this anymore.

...

**A Doctor’s Note:** “She is afraid of stopping [medications] because of fear that her symptoms will worsen, although she cannot say they actually help with the pain.”

...

I wish the solution to the bias, the misdiagnosis, disbelief, the pervasive problem of chronic pain in America, was simple. To some extent, it is. The culmination of all the solutions, however, will take deep systematic changes within the medical community, as well as changes to how patients and doctors alike view chronic pain. In the first chapter, I mentioned that chronic pain inherently differs from other kinds of pain. Dr. Irene Tracey, neuroscientist elected to the UK Medical Research Council in 2016, said, “pain is the disease, rather than a symptom” after pain has “gone chronic.”<sup>107</sup> After pain itself becomes a problem, the treatment of it changes.

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<sup>107</sup> Twilley, “Neuroscience”

Currently, American healthcare is woefully unprepared to confront that change. Pain management, or treatments that emphasize treating pain as a condition rather than a symptom, receives little attention from the medical community. More or less, the medical community ignores pain management for chronic conditions in women specifically, as conditions that largely affect biologically female patients are under-researched and steeped in bias. A 2001 survey by the Association of American Medical Colleges found that only 3% of medical schools taught separate courses in pain management, which has not changed much today.<sup>108</sup> That's just for pain in general. It wasn't until 2016 that the Mayo Clinic, one of the premier research and treatment centers in the world, began taking specific initiatives to make sex differences emphasized in their curriculum.<sup>109</sup> This is a good start, but there needs to be more.

There needs to be cultural training so medical professionals can understand how pain affects different people differently. That cultural training would significantly cut bias within the medical community. Many of the problems with doctors disbelieving women that I outlined in chapter 5 can be treated with cultural and bias training. Most doctors are completely unaware of their bias. Training them to recognize it will change how they treat women and people of color.

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<sup>108</sup> Ballweg, "Chronic Pain in Women," 17

<sup>109</sup> Ethan Grove, "Mayo Clinic Co-Sponsors Landmark Summit on Sex and Gender Based Medical Education," Mayo Clinic (Mayo Clinic, October 16, 2015), <https://newsnetwork.mayoclinic.org/discussion/mayo-clinic-co-sponsors-landmark-summit-on-sex-and-gender-based-medical-education/>

There also needs to be diversity in medicine so white men aren't making all the decisions for people whose bodies look nothing like theirs. There needs to be a commitment to the health of the patient rather than the financial gain of a treatment. Ideally, American healthcare could shift to a preventative system rather than a reactionary one, taking measures to keep people healthy with affordable appointments and vaccines. By doing so, doctors can intervene and prevent the chronic illnesses that develop over time, like diabetes.

All this requires big changes and may seem impossible to implement. This requires a complete paradigm shift when it comes to how American healthcare can serve the population. There are resources, frameworks, and people already working to implement each of these measures. These changes are possible. The medical industry must be pushed to begin making these changes for the good of all Americans, not just those with chronic pain conditions.

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The industry won't change until Americans demand it. People in power *should* be doing more to rectify all the problems I've outlined throughout these 7 chapters. Now that reporters are starting to take note, it will be more difficult for the industry to continue ignoring sufferers of chronic pain and the obvious issues American healthcare has with treating women. That said, until patients and doctors begin asking for change, it won't happen. Hard as it may be, I have to tell this story. If my community continues to allow

American healthcare to drive the narrative about the treatment of chronic pain, people will continue to disbelieve our pain. The power of my story, of any of the stories belonging to people in the chronic pain community, is in the agency it grants us to control the narrative. The medical industry took away my body and my voice. This body of work takes back both of those things, starting with me naming myself and granting myself the power of voice.

The rise of voices affected by chronic pain can light a fire that will rage across American healthcare. Once suffering people speak out about how healthcare mishandles chronic pain, others can begin to listen. Part of why this problem persisted for so long is because many patients don't feel they had the authority to speak. Talking about it changes the conversation. It means we can stop wondering, 'do you believe me' and rather can ask, 'Why don't you believe me?' Creating a new conversation where patients can use an authoritative voice puts pressure on the industries ignoring the problem. Sparking this conversation prompts reporters and researchers to ignite a fire under American healthcare.

I know it's hard to talk about. Half of this body of work details why it's so hard to talk about it. In an ideal world, healthcare professionals would implement many of the changes I've suggested over the course of this piece without people demanding they do so. It pains me to recognize that people suffering, who have more than enough on their



plate, will have to bear some of the weight when it comes to creating change. That should not be our responsibility. Nevertheless, once more people talk about their pain, more people can understand just how common and pervasive the problem is. Once more people understand, the more likely it is that people like John Oliver dedicate an entire episode of television on a major network to bias in medicine. Without testimonials from patients across the medical spectrum, the bias in medicine never would have received this kind of attention.

He, and reporters like him, bring levity to the situation, making it approachable to people outside of the problem. He brings on comedian Wanda Sykes to give a voice to women of color and hear the suggestions of people who suffer. He gives her the floor as she explains that the medical community needs to standardize care, offering the same treatment to patients suffering from the same problems. She emphasizes the importance of doctors and medical students receiving cultural and bias training before working in the field. She pleads for more diversity in medical schools. Lastly, she encourages patients to be their own advocates.<sup>110</sup> By coming on Oliver's show, she acts as her own advocate in a big way. Sykes makes her experience in American healthcare public, sourcing from her experience ways to improve healthcare for all.

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<sup>110</sup> Oliver, "Bias in Medicine,"

Sykes recommends concrete solutions as a woman who experienced bias in medicine first-hand. Her experience, and mine, makes her a unique kind of expert. We aren't doctors and we don't have specialized degrees in public health, but we have years worth of field data. We have our stories. Oliver, by giving Sykes a platform on his show, indicates how important storytelling is to solving bias in medicine. For those of us who vomit in public bathrooms, wash off our faces, and return to the friend's birthday dinner acting as though nothing happened; we need to begin talking about what's happening to us. There is strength in numbers.

Gaylyn Henderson, the founder of *Gutless and Glamorous*, has some advice for us who struggle to talk about it. She says, "you're afraid you'll be an outcast; that you'll never be able to wear a bikini again; that you'll never find love, or even love yourself again. I promise, you will have all those things. But it's going to be a process."<sup>111</sup> We have to give ourselves to that process. I know that most of the time all I want is to seem normal. Michelle Lent Hirsch, an author I've revisited a few times thus far, writes about the pressure sick people feel to appear the same as anyone else. She notes that "having an invisible health issue or disability comes with its own set of terrors."<sup>112</sup> Those terrors derive in part from concepts I've already explored, like health-care gaslighting or the trauma of not being seen. The pressure to remain silent about what makes one 'different'

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<sup>111</sup> Mascia, "Our Pain"

<sup>112</sup> Hirsch, *Invisible*, ch 30. 5:05-5:10

acts as a terrible weight. Silent suffering feels like a protective blanket, shielding sick people from judgment or the perception that we cannot be normal. That protective blanket feels comfortable now, but it damages the long-term goal of changing the system working against women suffering from chronic pain.

Whether it's to friends, family, or doctors, the health-care gaslighting and trauma of not being seen make it feel like no one is listening. When I began this journey, I felt completely ignored by my doctors. I felt like they steamrolled over me, reading my chart as opposed to listening to me. I felt like the systems in place to help me discounted me as soon as I didn't fit the model of a perfect or easy patient. Generally, American healthcare needs to change more than patients do. We can't help that we are sick. That said, patients struggling to feel heard or struggling to get diagnosed must advocate for themselves. I have to remind myself every time I leave a doctor's appointment in tears that my body is worth more than dismissal. My body deserves to be heard, treated, and believed. My body and I are worth the doctor's time. This can be hard when it feels like I have to somehow cater to the doctor, manipulating my language, symptoms, and feelings to make the doctor listen to me. What I have to remember, and other patients must remember too, is that doctors serve me, not the other way around. I am not picky for choosing healthcare professionals that make me feel valuable. I am lucky to have the resources to make such

choices. I have every right to fight for my body and defend it. I know this body better than anyone. I must trust it and myself.

Defending one's health and one's body isn't easy. Even for those at their physical peak, avoiding the doctor and opting to suffer silently feels easier than prioritizing health. Shannon Miller, a 7-time Olympic medalist in gymnastics, had ovarian cancer, but when she went to the doctor she reported feeling fine, not wanting to complain about what seemed like typical 'female' problems. She says in a podcast interview, "I had three of the primary symptoms of ovarian cancer--bloating, sudden weight loss, severe stomach aches--and I could chalk every single one of those up to either regular women's issues or, oh, I ate something wrong."<sup>113</sup> Putting one's health first presents women with a huge challenge, for reasons I discussed in chapter one. For women, questions about the female body accompany pain. *Is this a problem I need to worry about? Or is this a 'woman' problem?* Shannon Miller's story demonstrates a lesson many Americans need to hear. Listen to one's body. For women specifically, remember that presenting a doctor with medical concerns is not complaining. Doctors are employed to treat patients, though it often may not feel like it.

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<sup>113</sup> Jonathan Van Ness, host, "Can We Make it the Magnificent 8? with America's Most Decorated Olympic Gymnast Shannon Miller" Getting Curious with Jonathan Van Ness (podcast), July 2, 2019, <https://www.earwolf.com/episode/can-we-make-it-the-magnificent-8-with-americas-most-decorated-olympic-gymnast-shannon-miller/>

We also must remember that doctors are human like we are. We all make mistakes at work, regardless of how long we've worked with our company or how much education we may have received. To err is to be human. With doctors, however, we expect infallibility. We want to take their word as law. Nevertheless, they make mistakes too. Only their mistakes have no safety net. Very few of us make choices every day that are literally life or death. With misdiagnosis, often doctors will never know they've misdiagnosed and in all likelihood, the patient will never know either. *Washington Post* writer reflects that sometimes misdiagnosis is only discovered "after autopsies, or as a result of medical malpractice suits."<sup>114</sup> Patients who do discover their misdiagnosis, typically by getting another opinion, will likely not return to the first doctor. Thus, doctors have little way of knowing about how often they might accidentally misdiagnose a patient. There needs to be more communication between doctors about this and more empathy in the community about mistakes. As Christine Cassel, president of the National Quality Forum, says, "doctors shouldn't feel embarrassed if they hear from a colleague who has diagnosed their patient with X instead of Y. Every physician should be open to getting that kind of feedback."<sup>115</sup> That kind of feedback saves lives. The medical

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<sup>114</sup> Lena Sun, "Most Americans Will Get a Wrong or Late Diagnosis at Least Once in Their Lives," *The Washington Post* (WP Company, September 22, 2015), <https://www.washingtonpost.com/news/to-your-health/wp/2015/09/22/most-americans-who-go-to-the-doctor-or-will-get-a-wrong-or-late-diagnosis-at-least-once-in-their-lives-study-says/>

<sup>115</sup> Sun, "Most Americans"

community needs that feedback immediately if chronic pain in America will ever be fixed.

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Today, I take my body back in the hair salon. Today, I burn away the pain, the silence, and the fear. I prepare to be reborn, stepping out of the ashes like a phoenix.

I rage against the pain with fire in shades of purple, red, blue, and green. This is my body and I don't want it stolen ever again. It is mine to take back from the invisible hand that twists it into something I do not recognize. My body may hate me, but it is time for me to offer it love.

I let the bleach soak into my skin, feeling the colors bleed into my soul and give my life color again. This pain that I feel burning through my skull can set me on fire because I *allow* it to. It burns the test results, the pills, the echoing footsteps in hollow hospital hallways. I created this pain for myself and I want to feel the burn, knowing this is how it feels to come into myself at last. I didn't want those files to be my entire story. I want *this*.

My stylist uses an aloe spray on my roots before painting the canvas she and I create. Her gentle brushstrokes are a welcome reminder that painful endings can become something beautiful. I keep my head down as she paints the pieces different shades of purple. My eyes avoid the mirror as she styles it. My nerves jump into my neck and hands, fluttering my fingers.

“What do you think?” she says, turning my chair to face the mirror, fluffing my hair, triumphant smile on her face

“I love it.”

I hate it. This...these purple waves around my face...it’s too much. I wanted to explode with that *je ne sais quoi* kind of confidence, but instead, I feel like nothing more than the bruises IV needles left in my arms. I feel like an imposter. *This isn’t me.* I sacrificed the mangled remnants of my body and instead of stepping out of the flames like Khaleesi, Mother of Dragons after she emerges from the pyre,<sup>116</sup> I feel like the dragon resting at her feet. My stylist threw gas on our fire and I burned way, way, too bright. I force a smile.

“Thank you so much. It’s amazing...just so *bright*,” I say, avoiding the mirror.

She smiles and nods. She’s proud of herself. The chemical burns all over my scalp ache as I walk towards the door. This was the thing, the thing that was supposed to give me back what doctors had taken from me. I didn’t get my body back. I selfishly destroyed it, mutilating it. I wanted so badly to breathe again I forced a breath despite being on the moon. *There’s no oxygen here. What are you doing?!* I leave the salon and cross the street, jogging in the direction of my car. People glance at me as I pass. My back straightens as one woman nudges her friend and points at me.

My hair feels soft on my shoulders. I give it a flip. Passing a storefront window, I catch my reflection. *That’s kind of...jaunty.* I run my fingers gently through it. Out of the

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<sup>116</sup> “Fire and Blood,” *Game of Thrones* (HBO, June 19, 2011)

sides of my vision are lavender streaks, coloring my day and taking my burnt sepia-toned dreams into technicolor. It's bright. It is way too bright. But maybe if I was a different girl, this wouldn't be bright at all. If I was that girl I've always wanted to be, maybe hair like this would be normal.

The pain hasn't disappeared. I don't think it ever will. I live with pain and as far as I can tell, I will always be a sick girl. Being sick, though, doesn't mean this body belongs to medicine. This body, in all its failures, deserves better than what American healthcare provides. I thought to myself after blacking out in the St. Louis Science Center that I can't do this anymore. At that moment, I thought I meant being sick. I realize now that I can't escape my sickness. It lives in me as I live in this body. What I can't do anymore is stand by, complicit, as American healthcare takes people like me and destroys them. I can't wallow in my misery and complain while doing nothing to solve the problem. Today, I can tell this story and speak a truth that belongs to me and many others. Today, I can be an agent of my own pain and burn away the ice around my heart. My ocean still stirs, threatening to pull me under, but this body of work I've written demolishes the walls hiding it. Today, people can see my ocean and they can see the fire engulfing my body.

I lift my head a little higher. I don't need to be strong and poised like Khaleesi rising from the ashes. I can be Michelle, growing from the dirt in full bloom. I can learn to love these purple flames. For the first time, in a long time, I control this body and have agency over it. This is my new beginning and I rise like a phoenix, ready to soar.



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