Spring 2023

Rate Your Pain on a Scale of 1-10: A Look Into a Life with Fibromyalgia

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Recommended Citation

Martinez Barrios, Anais, "Rate Your Pain on a Scale of 1-10: A Look Into a Life with Fibromyalgia" (2023). *Regis University Student Publications (comprehensive collection)*. 1069.
https://epublications.regis.edu/theses/1069

RATE YOUR PAIN ON A SCALE OF 1-10: A LOOK INTO A LIFE WITH FIBROMYALGIA

A thesis submitted to

Regis College

The Honors Program

in partial fulfillment of the requirements

for Graduation with Honors

by

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April 2023

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Acknowledgements

To Dr. Lucas, Dr. Campisi, Dr. Narcisi & Dr. Schreier, they helped turn my idea into a full honors thesis. Their guidance both inside and outside the classroom changed the trajectory of my life for the better.

To my aunt Cathriene who also battles Fibromyalgia. She has always understood my experiences in a way no one else has.

To Trinity who is my best friend. She has taught me the value of friendship and I am eternally grateful for her support throughout these last four years.

To my partner Saream who has shown me that I am worthy of love. She has given me a future I thought I would never have.

To my brother Issac who makes me laugh even on my bad days. He is my lifelong best friend and without him life would be dull.

Finally, to my parents. Without them I wouldn't be half the woman I am today. They have supported me through every step of my journey and made healing possible.

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RATE YOUR PAIN ON A SCALE OF 1-10: A LOOK INTO A LIFE WITH FIBROMYALGIA

Thesis Advisor (Dr. B. Lucas):________________________________

Thesis Reader (Dr. J. Campisi):________________________________

Around twenty-six percent of US adults have a disability. It can impair their physical and mental health forcing many to adjust their everyday life. Fibromyalgia is a chronic pain disorder that is considered a disability. As someone who has been living with Fibromyalgia for three years, I have a first-hand account of how this condition affects one's outlook on life. By speaking with professionals, we become aware of both the physical and mental effects of Fibromyalgia. A side of the medical world also begins to appear, one where those with invisible disabilities, like Fibromyalgia, lack access to proper care and providers. They face geographical and financial barriers as well as lack of understanding from doctors, friends, and family. This creates an environment that prevents proper healing and long term management of Fibromyalgia symptoms. I argue that by sharing my story able-bodied individuals can get a better understanding of the day-to-day life with chronic pain and how having providers focused on co-production aids in the process of healing. I then propose that by creating a health system focused on co-production we can provide the necessary resources to help those with Fibromyalgia manage their symptoms and even live a fulfilling life.

Introduction: Death

When you think of someone in their late teens/early twenties what do you see? Maybe you see a person who stays out late, dancing the night away. Or someone who is active, hitting the gym every week, working on their physique. What about someone who is living carefree, not worrying about their future, and only focusing on having fun? Usually, someone at this age is at peak physical health, and they feel almost invincible, like nothing can bring them down. They have the rest of their lives ahead of them and they may not put much thought into their lives five years from now. But what happens when at 18, the life someone thought they had was ripped away all in one day? How does one continue when they've been diagnosed with a life changing condition?

A disability is a condition of the mind or body that makes certain activities more difficult and affects the way an individual interacts with the world. Twenty-six percent of US adults have a disability (Centers for Disease Control and Prevention, 2020). Disabilities can range from physical impairments to mental health and all are considered chronic (Centers for Disease Control and Prevention, 2020). There is a wide range of disabilities, which means that no two disabilities look the same. One subcategory of disabilities is invisible or hidden disabilities. An invisible disability is a physical, mental, or neurological condition that is not visible but still impacts the way an individual interacts with their world (Invisible Disabilities® Association, 2022).

The image that most commonly represents a person with a disability is a person in a wheelchair, and while those individuals may have a disability, not everyone who has one uses a wheelchair. Many individuals with a disability look seemingly healthy to those around them causing confusion, misjudgment, and discrimination (Invisible Disabilities® Association, 2022). This leads to a lack of support and care for those battling hidden disabilities. All individuals with disabilities deserve proper care and support. I continue to be surrounded by friends, family, and providers. However, there are people around me who do not have people to assist them on this long and arduous road, and they deserve the same support that I have been given.

Hello, my name is Anais, and I have fibromyalgia, a hidden disability. On the outside, I look able-bodied, but I struggle daily with my disability. Growing up I imagined my late teens/early twenties to be filled with joy, laughter, and fun. I thought I was going to be dancing into the night with some handsome boy or beautiful girl. I wanted to be the girl who never failed, the one who always had her life together, and could conquer any challenge thrown her way. However, that is just not the case. When I was diagnosed with Fibromyalgia, the future I once wanted faded from my view, and I will be battling with this condition for the remainder of my life.

My story begins on November 17th, 2019. This is when I first began showing signs of abnormal pain. At the time, I wasn’t sure what the cause could be. However, at this point in my life I had been dealing with non-stop anxiety attacks for about a year. I had been diagnosed with generalized anxiety at 16. For two years, I struggled to manage my worries, fears, and panic attacks. During my senior year of high school, I went through a friendship break-up with my best friend of six years. I was so heartbroken that I was unable to process the loss at the time. Due to this, my anxiety worsened and caused me to become very isolated. Instead of processing the loss of this friendship, I pretended like it didn’t happen.

I distracted myself with finishing school, applying to college, and seeing my boyfriend at the time. However, I noticed the toll it was taking on my mental health. My anxiety ruled my life causing daily panic attacks, loss of appetite, lack of motivation, and isolation from those around me. I lost 10 pounds, weighing in at a mere 75 pounds at 17 years old. The only person I spoke to was my boyfriend at the time. I thought that once I started college, I could invent a new me and leave my anxiety and unprocessed trauma behind. In my mind leaving high school meant leaving childhood behind and stepping into adulthood. I know now that ignoring the past only harmed my future.

I started college in August of 2019. I was excited to move on campus, meet new people, and start becoming an adult. Due to my overpacked schedule in high school I assumed that 18 credits would not be a problem, and so I packed my schedule and even decided on an 8 am philosophy class. However, my anxiety didn't go away like I thought. I had a hard time making friends as I was always worried that people wouldn't like me, or they secretly didn't want to be my friend. I was scared they were going to cut me off without any explanation. I continued to isolate myself and became resentful of who I was.

My boyfriend was still in high school at this time, and it made it very difficult for us to adjust. Since I spent a majority of my senior year with him, we became codependent which caused a rift between us when I started college, ultimately leading to the end of the relationship two years later. Not only was I away from family and having difficulty making friends, but my boyfriend and I were bickering daily. I felt alone, lost, and jealous of those around me. I didn't know who I was or what I wanted to do with my life. Days, weeks, and months melded together. It was as if I was an outsider watching my life unfold.

After years of reflection, I realized that at 18 I was scared that if I learned how to cope with my anxiety it would change who I was. My anxiety is what drove me to be the best, it was a motivator, and I was scared that without my anxiety I would fail, disappointing everyone around me. So, instead of working through my mental health, I distracted myself. As a freshman in college, I was taking 18 credit hours, working a work study job 10+ hours a week, and worked 7-hour shifts as a caregiver every Saturday and Sunday. To adjust to my busy schedule, I cut out sleep and meals, eating only a couple bites of food a day and sleeping 6 or less hours a night. I knew this wasn't sustainable, but I refused to change. I kept pushing my body to its limits on a daily basis. I knew my body was angry at me for not nourishing it or letting it recharge but time doing nothing meant processing my failing relationship, loneliness, and anxiety.

My life was falling apart, and I felt like there was no way out. I woke up on November 17th and began to get ready for work. I felt under the weather and thought I may be getting a cold, so I called out of work. I hadn't had a day off in months and so I decided to actually rest for once. However, the cold never came and I was only left with body aches and pains. The next morning, I woke up and immediately knew that something was wrong. My legs felt like they were being weighed down with bricks. Every time I lifted them, they would shake uncontrollably. I could barely get out of bed and needed to stop and breathe after every step. Walking to class was nearly impossible and I needed support when sitting and standing. I took over-the-counter pain medicine to try and reduce the pain, but nothing helped. I emailed my doctor asking if I could get an appointment as soon as possible. She told me she would schedule me for the next week but suggested I go to the emergency room in case of an infection in my legs. My mom and I went to the ER, and I was hoping they could do something to at least make my pain bearable. My mom was hesitant, insisting that it was just a cold, but I knew that something else was wrong.

However, the ER doctor did not seem to believe my symptoms. She insisted that everything seemed normal, and it was probably normal aches and pains. She recommended over-the-counter pain medication, pain cream, and a heating pad. I had insisted that I tried all those remedies with no results, but she had nothing else to say. I left that visit with a $1400 bill and second guessing my own feelings.

As the days went on, my symptoms only got worse. Climbing down from my bed became so difficult that I would sleep on the floor with my pillows and blankets. It would take me twice as long to walk to class because I couldn’t lift my feet to take a normal step. I had to grab onto anything I could to stand straight, and I avoided stairs everywhere I went. The pain also moved from my legs into my lower back. I could only sit or lay down for 10 minutes at a time, so there was a constant back and forth between the two positions. This made sleep impossible. I began to cramp in my legs and lower back due to laying in the same position while I slept. I became increasingly exhausted; no matter how much I slept I never felt rested. I also noticed difficulty staying focused in class. I remembered nothing from class and my grades started to slip from A’s to B’s and even some C’s. It seemed like everyone around me was speaking gibberish and my mind would constantly go blank. I began to document these symptoms on my phone. My symptoms included tingling in my legs, numbness in my legs, joint pain, difficulty with mobility, inability to sleep, difficulty with concentration, shaking/weak legs, inability to lift legs, and lower back pain. My life was at a standstill. All that existed was my inability to move properly. I wanted answers so I could finally be pain-free again.

The first of many appointments was with my primary care doctor. I explained all of my symptoms and demonstrated how difficult it was for me to move. She suspected that I possibly had an autoimmune disorder, probably lupus, so I gave a urine and blood sample to test. They also tested for an indication of cancer or infection. Three days went by until I got back my results. During those three days I was coming to terms with the fact that I may have lupus. I knew that having lupus meant a lifelong battle with my body. At 18 this was a daunting thought. I had my whole life ahead of me but if I had lupus, all of that could change.

Three days later and the test came back negative. I was relieved to know that I didn't have an autoimmune disorder, infection, or cancer. I thought these tests were going to answer all my questions, but I was wrong. I still was in pain and my mobility wasn't increasing. Something was wrong and no one knew why my body was in constant pain. So, the next step was to get an MRI. Due to my lower back pain, it was possible that I had a slipped disk or pinched nerve. I scheduled my MRI and was confident that this would answer my questions. I laid in a metal tube completely still for an hour. I remember looking down at my feet and hoping that my pain was simply caused by a slipped disk. I thought that it would be an easy fix and I could go back to normal life.

A couple weeks later, the MRI showed nothing. My spine looked completely normal, other than a small bit of scoliosis by my tailbone. I was disappointed to learn that all my imaging and blood tests were normal. When I got these results, I was in my car and I was so angry that my body was shutting down and no one knew why. I wanted to be able to fix what was wrong so I could walk again and sleep in bed rather than on the floor. I was angry at myself for being in pain and I was angry with the doctors because, surely, they read the test results wrong.

Another visit to my primary care doctor and she said she would like me to see a neurologist. I called the number on the referral and scheduled my appointment for a month out in January of 2020. This meant I had to wait another month before I maybe had answers. It was another month of living off Aleve, a heating pad, and sheer willpower. I was desperate to figure out a solution. I had to continue to go to class and work as if my body wasn't shutting down. My condition became the talk of both my dorm floor and honors class. Every class period my classmates would ask what the results of my test was or if I had polio. In the communal bathroom on the third floor of Desmet Hall, everyone would ask if I had a diagnosis while we brushed our teeth.

Finally, the day had come for me to see the neurologist. I described my symptoms just as I had many times before. He ordered a couple of blood tests and sent me on my way. As I sat in the chair, the nurse poked me with a needle to draw more blood. A couple weeks later, I was back at the neurologist. Nothing. My blood work was completely normal and showed no signs of neurological disorders. He then wanted to look at my muscles to see if he could find anything. I changed into a hospital gown, and he stuck needles with microphones into my legs. I was hoping with each prick that he would find something. Nothing.

How could every single test come back perfectly normal? I broke down frustrated that I still didn't know what was wrong with me. I wish I was told that I had cancer or an autoimmune disorder or an infection surging through my bloodstream. I wanted answers. My body was tired, and the pain was only getting worse. My mental health was declining because my body was shutting down and no one knew why. I felt so alone because no one could understand the pain I had felt every day since November. My family and friends could see the toll this was taking on me. I remember one night at my parents' house, we just finished dinner and I was talking about how hard everything had been. I broke down in my mom's arms, yelling because my life was crumbling underneath me.

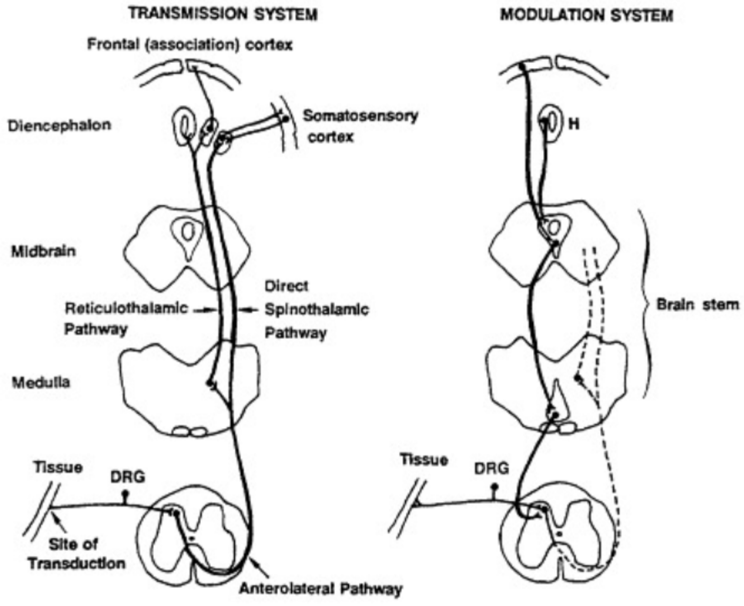
A couple weeks later I was back in my doctor's office. She referred me to a rheumatologist in hopes I would get a diagnosis. The next week, I was on my way and the car ride seemed to take hours. What if they also found nothing wrong? This was my third doctor in three months, and I wasn't sure if there were any more options after this. I explained my symptoms for what seemed like the hundredth time. She looked over every test I took since November. She said everything looked normal and so, after three months, in February 2020 I was told I have Fibromyalgia, a condition that causes chronic pain. There is no cure, and the physiological cause of the condition was and still is unknown. For the rest of my life my only treatment is pain management.

Fibromyalgia has taken many things from me, including control over my own body. For three years I have been battling with accepting this new life and in turn accepting that I am disabled and no longer able bodied. To a stranger I look like a normal 21-year-old, but what they don't see is a dull pain radiating from every inch of my body every second. Fibromyalgia changed my life in an instant, and the last three years I have been learning how to move forward with my life. Unfortunately, there are many barriers both from a medical point of view and systematic point of view that prevent myself and others from receiving the tools needed to move forward. Those with disabilities deserve to have access to trained providers and accommodations that allow them to live a life they wish. All individuals deserve to have the resources that allow them to not be defined by their disability. The only way to provide access to these resources is to reevaluate our healthcare system and provide new ways to make care more accessible and dependable. My life will never be the same as it was before November 17th, 2019, but within these pages is the death of who I was at 18 and my rebirth into something I never could have imagined.

Chapter 1: Fibromyalgia, a Mystery

The clinical definition of Fibromyalgia is a chronic condition categorized by widespread pain for at least 3 months before diagnosis as well as tenderness of 11 or more of the 18 specific tender points. These tender points include the base of the neck both front and back, upper breast, elbow area, knees, hips, buttocks, back of the neck, and shoulders (Levey, 2021). Sleep disturbance, fatigue, stiffness, anxiety, and depression are also reported with Fibromyalgia (Cuesta-Vargas et al., 2013). Fibromyalgia symptoms can be broken into 5 categories: somatic (swelling, restless legs, muscle spasms, abdominal pain, and bladder issues), distress (anxiety and depression), Fibromyalgia core (stiffness, pain, and fatigue), dyscognition (dizziness, inability to concentrate, and forgetfulness), and finally sleep problems (difficulty falling asleep and staying asleep) (Cuesta-Vargas et al., 2013). A common comorbidity with Fibromyalgia is Chronic Fatigue Syndrome. Chronic Fatigue Syndrome is persistent and relapsing fatigue (Friedberg, 2010). Both Fibromyalgia and Chronic Fatigue Syndrome cause a variety of symptoms and impairments such as severe fatigue and pain, cognitive difficulties, and sleep disturbances which can be debilitating (Friedberg, 2010).

The largest symptom of Fibromyalgia is widespread pain. Pain is subjective, meaning every individual feels it differently. The feeling of pain begins when an outside stimulus, like stubbing your toe, activates nerve endings. These nerve endings then send a message to the brain that activates sensory signals producing the feeling of pain (Osterwise, Kleinman, & Mechanic, 1987). More specifically, the nerve endings in the tissue and the attached nerve create a primary afferent nociceptor (Fig 2).



After my diagnosis I was ecstatic. I finally knew what was wrong with me. I started to do research on possible pain management and realized that in order to manage my Fibromyalgia, I needed to start with my mental health. That day, I made a promise to myself to focus on healing and growing and to always put myself first. I was ready to work on my mental health in hopes of combating Fibromyalgia.

A month later, the COVID-19 pandemic began. I was optimistic about managing my pain because all of life was at a standstill. Everything was virtual which meant that I was at home sitting at my desk all day. Due to quarantine restrictions, I did very limited physical activity which created the illusion that my pain was manageable. For five months, my Fibromyalgia hardly bothered me. I felt a dull pain every day, but I rarely had any flare ups. I was optimistic that my Fibromyalgia wouldn't affect my life too much and that I could possibly even get to a point where I felt no pain. Unfortunately, that was not the case.

In August of 2020, I moved back on campus and started sophomore year. Classes were hybrid, which meant I had to walk around campus for part of the week. This also meant that schoolwork and my caregiver job would pick back up. I was confident in my current pain management skill of Aleve when needed, therapy, yoga, and mediation. However, October of that year was when I realized how much my life would be impacted by my Fibromyalgia. I began having more flare ups, ranging around 2-3 times a month. These flares lasted anywhere from one day to a whole week. These flare ups caused me to become immobile. I needed help getting out of bed, walking, serving myself, even sometimes bathing and feeding myself. Holding something as light as a pencil felt like I was holding a brick. My arms and legs would tire easily. I also became extremely exhausted and going to class seemed pointless because I wouldn't be able to take notes or remember lecture material anyway. I became more and more angry that my body would not work. About a year and a half into my diagnosis I questioned whether it would be worth it to continue living in a body that was never going to work.

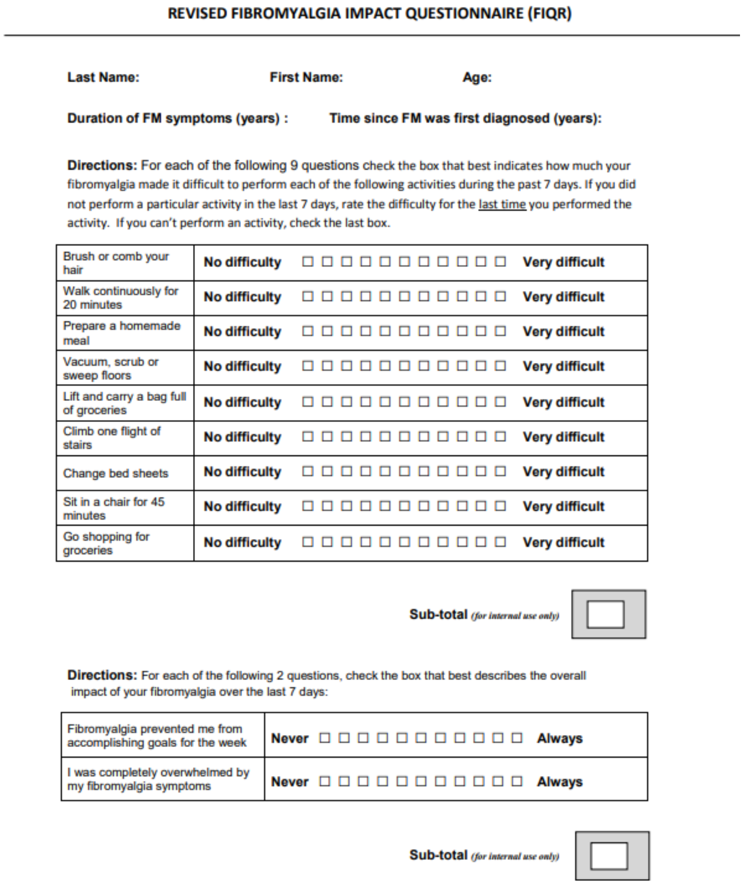
There is no answer to what causes Fibromyalgia. Researchers have not discovered a pathology, pathophysiology, or psychopathology pathway that explains its origins (Cohen & Quintner, 1993). The current theory is that abnormal levels of chemicals in the brain change the way your central nervous system processes pain (NHS, 2022). It's as if your nervous system only had a gas and no brake, your body is always sending pain signals to your brain. When going through the process to reach a diagnosis, many tests for autoimmune disorders, cancers, infections, neurological and musculoskeletal diseases continue to come back as negative. There is no test that diagnoses one with Fibromyalgia; instead, Fibromyalgia is known as a diagnosis of exclusion (American College of Rheumatology, 2021). One can be diagnosed if all other options have been exhausted and pain in either the upper or lower body continues for more than 3 months. One also must be diagnosed by a rheumatologist. This is because this condition can mimic many rheumatic diseases, thus the rheumatologist will rule out any of these diseases and make the Fibromyalgia diagnosis (American College of Rheumatology, 2021).

However, there seems to be an issue within the medical field that the pain itself is ignored and instead the focus shifts to just making a diagnosis (Cohen & Quintner, 1993). Unfortunately, there is constant debate over the legitimacy of Fibromyalgia (Häuser & Fitzcharles, 2018). This leads to physicians claiming that Fibromyalgia does not exist. There is no definitive answer to the etiology and pathophysiology which means that Fibromyalgia is classified as a disorder rather than a disease. However, the term disorder is used when describing mental illness, causing many to believe Fibromyalgia is a mental disorder with no real physiological effects (Häuser & Fitzcharles, 2018). This also causes a debate if Fibromyalgia is actually a psychosomatic disorder and some specialists believe it should be diagnosed as a persistent somatoform pain disorder (Häuser & Fitzcharles, 2018). This erroneous thinking by professionals leads to a lack of support and causes many individuals to believe that their pain is invalid and leads to numerous misdiagnoses. The consequence of getting a misdiagnosis is not getting the treatment needed for a specific condition. The diagnosis of Fibromyalgia lacks both an explanation of the causes as well as the therapeutic implications especially due to the lack of a defined disease (Cohen & Quintner, 1993).

There is currently no cure for Fibromyalgia. There is only treatment which comes in a variety of forms. Many patients have coping strategies that can include pacing/planning, distraction, coping with touch sensitivity, medications, and social support which plays a very important role in coping with Fibromyalgia (Kengen et al., 2012). Treatment for Fibromyalgia can also include lifestyle changes (getting restful sleep and staying active), medical therapy (antidepressants), physical therapy (aerobic activities and yoga), and other alternative therapies (Song, 2005).

One form of treatment is managing stress. Stress plays a large role in the cause, maintenance, and exacerbation of Fibromyalgia (Malin & Littlejohn, 2016). Having Fibromyalgia may also increase stress which then increases Fibromyalgia, so it is important to understand the complexity of stress and Fibromyalgia when determining treatment (Malin & Littlejohn, 2016). To understand how stress may affect Fibromyalgia, we first need to look at our body's physiological response to stress. The HPA axis is the body's primary stress response. Stress signals the hypothalamus to release corticotrophin-releasing hormone or CRH. CRH then signals the anterior pituitary to release adrenocorticotrophic hormone or ACTH. ACTH signals the release of cortisol, our stress response hormone (Gupta & Silman, 2004). In Fibromyalgia patients, there is an elevated level of ACTH, which suggests high levels of stress; however, there are low levels of cortisol. This may be due to an under secretion of cortisol. Low cortisol levels can cause fatigue and muscle and joint pain which may explain the pain felt by Fibromyalgia patients (Gupta & Silman, 2004).

The Fibromyalgia Impact Questionnaire was developed to "capture the total spectrum of problems related to fibromyalgia and the responses to therapy" (Bennet, 2005, S-154). The questions ask about the ability to perform everyday tasks. For example, it asks if one is able to drive a car or do laundry. It then asks how much Fibromyalgia has influenced one's life (Fig. 1a-1b). This can range from level of pain to quality of sleep (Bennet, 2005). The higher your score the greater the impact. On average Fibromyalgia patients score a 50 out of 100. More severe patients score a 70 (Bennet, 2005).



REVISED FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQR)

Last Name: **First Name:** **Age:**

Duration of FM symptoms (years) : **Time since FM was first diagnosed (years):**

Directions: For each of the following 9 questions check the box that best indicates how much your fibromyalgia made it difficult to perform each of the following activities during the past 7 days. If you did not perform a particular activity in the last 7 days, rate the difficulty for the last time you performed the activity. If you can't perform an activity, check the last box.

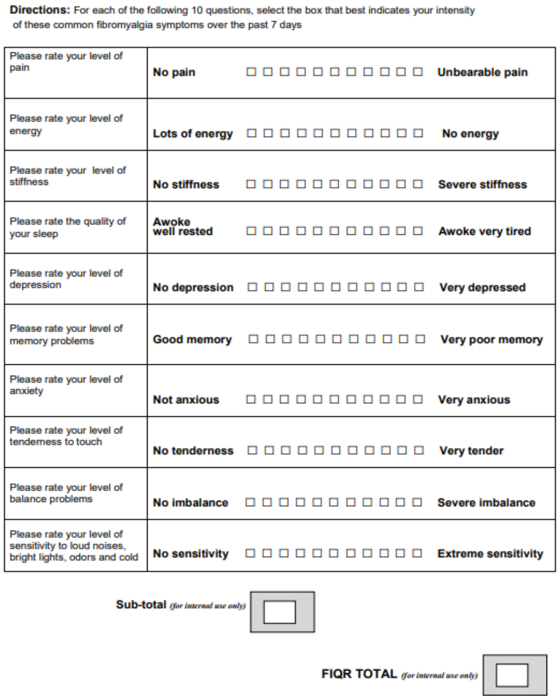
Brush or comb your hair	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Walk continuously for 20 minutes	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Prepare a homemade meal	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Vacuum, scrub or sweep floors	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Lift and carry a bag full of groceries	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Climb one flight of stairs	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Change bed sheets	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Sit in a chair for 45 minutes	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**
Go shopping for groceries	**No difficulty** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Very difficult**

Sub-total *(for internal use only)* ☐

Directions: For each of the following 2 questions, check the box that best describes the overall impact of your fibromyalgia over the last 7 days:

Fibromyalgia prevented me from accomplishing goals for the week	**Never** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Always**
I was completely overwhelmed by my fibromyalgia symptoms	**Never** ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Always**

Sub-total *(for internal use only)* ☐



Directions: For each of the following 10 questions, select the box that best indicates your intensity of these common fibromyalgia symptoms over the past 7 days

Please rate your level of pain	**No pain**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Unbearable pain**
Please rate your level of energy	**Lots of energy**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**No energy**
Please rate your level of stiffness	**No stiffness**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Severe stiffness**
Please rate the quality of your sleep	**Awoke well rested**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Awoke very tired**
Please rate your level of depression	**No depression**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very depressed**
Please rate your level of memory problems	**Good memory**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very poor memory**
Please rate your level of anxiety	**Not anxious**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very anxious**
Please rate your level of tenderness to touch	**No tenderness**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very tender**
Please rate your level of balance problems	**No imbalance**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Severe imbalance**
Please rate your level of sensitivity to loud noises, bright lights, odors and cold	**No sensitivity**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Extreme sensitivity**

Sub-total *(for internal use only)* ☐

FIQR TOTAL *(for internal use only)* ☐

Fibromyalgia also seems to have a large burden on those diagnosed (Zitko et al., 2021). Those with chronic musculoskeletal pain have deficient mental health and are largely affected by stress, lack of restful sleep, and depression symptoms (Björnsdóttir & Jónsson, 2014). In fact, some research suggests that those with Fibromyalgia have lower serotonin levels (Gupta and Silman, 2004). Lower serotonin levels are also associated with mental illness like depression. They also report dissatisfaction with life (Björnsdóttir & Jónsson, 2014). Those with Fibromyalgia also use pain to determine when they have too much stress and many drastically adapt their lifestyle in response (Bennet, 2004). Some patients may get diagnosed with

Fibromyalgia as juveniles. Those with Juvenile-onset Fibromyalgia need ongoing support to help with the symptoms and mental health impact of Fibromyalgia (Daffin et al., 2021).

The physiological cause of Fibromyalgia is still unknown, but research suggests it may be hormonal or autoimmune (Personal communication, October 8, 2022). Fibromyalgia causes both physical and mental/emotional symptoms. Many individuals with Fibromyalgia must adjust their lifestyle to accommodate this condition. In the medical field, there are some who believe that Fibromyalgia is “not real,” causing many to become discouraged from seeking treatment (Personal communication, October 8, 2022). The pain felt by Fibromyalgia patients is real and should be treated as such. Those with Fibromyalgia need support and mental health assistance from those around them and their providers.

For two years I have felt every symptom mentioned. Flares happen anywhere from once a week to 2-3 times a month and they can last anywhere from a couple of hours to a couple of days. Recovery after a flare can take about a week. My flares are usually caused by stress, high anxiety, lots of physical activity, dramatic changes in weather, cold temperatures, and long travel. My mobility decreases once flares begin and can take days to return to normal. I no longer remember what it is like to not be in pain as I have felt the sensation of pain every day since November 17th of 2019. When my flares are at their worst, I need assistance for anything that requires the physical use of my body including walking, bathing, and eating.

There are many ways that I currently treat my Fibromyalgia. The biggest is working on my mental health. I see a therapist once every two weeks and am constantly trying to adjust my way of thinking to be more positive. For my physical pain I perform low impact exercises. These include yoga and walking which I try to do five days a week. The most helpful work has been seeing a chiropractor once a month. During these appointments I receive a realignment as well as a massage. These appointments have been crucial to helping lessen the frequency and intensity of my flares. These providers have aided in my physical healing which has made a tremendous impact on my outlook on life. The providers that I see have years of experience with working with Fibromyalgia patients. By gaining insight into Fibromyalgia, these providers have been better able to help improve the symptoms of their patients.

CHAPTER 2: My Chiropractor Has My Back

My Fibromyalgia was caused by my lack of care for my physical and mental health. I felt miserable every day leading up to the diagnosis, but after my diagnosis I began the journey of healing. I have learned to set boundaries, listen to my body's needs, and most importantly I have learned to rest. I have never been happier, and my mental health has never been better. I am on medication to help with my anxiety which has improved not only my Fibromyalgia symptoms but my overall happiness. I continue to go to therapy and practice mindfulness. By doing so I have more good days than bad, and when I have bad days, I can keep moving forward. I've learned that I am not letting anyone down if I choose to take care of myself. Allowing myself space to rest and recharge has been freeing.

I have taken steps to care for my mental health, but I have also taken steps to care for my physical health. I am currently receiving treatment at the Colorado Fibromyalgia Center. Once a month, I see a chiropractor who specializes in chronic pain. I also see a massage therapist to assist in pain management. These treatments have decreased my flare up frequency and intensity. I also practice yoga every day for around 10 minutes. By doing so I stretch my body, decreasing my daily pain. My Fibromyalgia management is a holistic approach to care for both my mental and physical health.

My healing would not be nearly as easy if I didn't have providers who want me to get better. In order to show what treating a patient with Fibromyalgia can look like, I interviewed a board-certified chiropractor who works specifically with patients who have Fibromyalgia and chronic pain. By doing so, I hope to show the variability and severity of Fibromyalgia. This chiropractor has spent years learning how Fibromyalgia affects not only a person's physical wellbeing but their mental and emotional wellbeing as well. According to them, “twenty years ago Fibromyalgia was considered a psychosomatic disorder” (Personal communication, October 8, 2022). This thinking is harmful to their patients and their ability to receive treatment. However, research has shown that there is a possible autoimmune cause for Fibromyalgia, ruling out the idea that “Fibromyalgia is not a real condition” (Personal communication, October 8, 2022). It is vital that we understand that Fibromyalgia is a physiological condition that has lasting effects on a person’s mental and physical health.

The chiropractor defines Fibromyalgia as a chronic pain disorder that is characterized as widespread pain, sensitivity, fatigue, and brain fog (Personal communication, October 8, 2022). They often see the onset of Fibromyalgia caused by some traumatic event. This can be physical trauma like a major car accident or broken bones. Another cause is emotional trauma, and many patients have depression, anxiety, PTSD, and events of high stress like a death in the family (Personal communication, October 8, 2022). However, some patients do not recall any traumatic event that may have triggered their onset of Fibromyalgia. Many are diagnosed between their late 30’s into their 50’s and it is more common in women than men (Personal communication, October 8, 2022). They do, however, treat some younger patients who have been diagnosed.

They most commonly see widespread pain, sleep difficulties, and “fibro fog” (cognitive difficulties due to Fibromyalgia) with their Fibromyalgia patients (Personal communication, October 8, 2022). There are many things that can trigger a Fibromyalgia flare and the etiologies of Fibromyalgia vary from patient to patient. Some common flare triggers are temperature (some individuals may be triggered by hot temperatures while others by cold temperatures), elevation changes, humidity, stress, inflammatory foods, and movement and exercise (Personal communication, October 8, 2022). There are many other triggers than the ones listed above, but they are the most common triggers that the chiropractor sees.

There are many avenues of treatment for those with Fibromyalgia. Body work (hands on manipulation of the body), chiropractic work, physical therapy, and mental health therapy are all treatments that can help a person manage their Fibromyalgia symptoms (Personal communication, October 8, 2022; https://www.spine-health.com/glossary/bodywork). While movement, exercise and any other body work can be difficult for Fibromyalgia patients due to their pain, it can help immensely once started. The chiropractor spoke about how pain management can be achieved through use of medications, injections, and ablations, a procedure where nerve endings are destroyed preventing pain signaling (Anonymous, personal communication, October 8, 2022). They have also seen some patients partake in ketamine therapy, especially those suffering from PTSD and depression (Anonymous, personal communication, October 8, 2022). They also have their patients partake in physical therapy, specifically aquatic therapy, as it is easier to move in water. Acupuncture, dry needling (needles placed on or by trigger points), cupping, Meyers IV (an IV drip with magnesium, calcium, B vitamins, and vitamin C), and antidepressants are also other forms of treatment (Personal communication, October 8, 2022; https://my.clevelandclinic.org/health/treatments/16542-dry-needling; https://pubmed.ncbi.nlm.nih.gov/12410623/). They touched on how not just one of these therapies or treatments will help one manage Fibromyalgia. It is important to have a holistic approach to treatment, as it allows a patient to work through all aspects and challenges that come along with having Fibromyalgia (Personal communication, October 8, 2022).

One difficulty with treating patients with Fibromyalgia is the possibility of misdiagnosis. For example, the chiropractor spoke about a common misdiagnosis between Fibromyalgia and Ehlers Danlos syndrome (Personal communication, October 8, 2022). This latter condition attacks the connective tissue in your body causing joint and body pain (Personal communication, October 8, 2022). However, there is a genetic test to determine if one has Ehlers Danlos Syndrome and without getting tested, it can be misdiagnosed as Fibromyalgia. Another example is small fiber neuropathy, an autoimmune disorder. This condition causes your autoimmune system to attack the smallest nerve endings in your body causing pain (Personal communication, October 8, 2022). This condition can also be misdiagnosed as Fibromyalgia.

Due to the nature of Fibromyalgia, there is also a common comorbidity with mental health. When intaking patients, the chiropractor covers mental health and encourages all their patients to seek counseling (Personal communication, October 8, 2022). Fibromyalgia causes an added layer of stress that needs to be processed, and seeking counseling can help navigate life with this condition. They also noted that their patients who lack a support system have a harder time accepting and adjusting to their condition (Personal communication, October 8, 2022). It is vital for Fibromyalgia patients to have support from their medical providers as well as friends and family.

Having practitioners that believe you and your pain makes treatment accessible. Having doctors who understand how Fibromyalgia works and what can be done to treat it is crucial to healing from Fibromyalgia. I have been working with this chiropractor for a year and half at the Colorado Fibromyalgia Center. The work that they have done has helped me recover from flare ups quicker and has even reduced the number of flares up I experience each month. They have taken the time to understand how Fibromyalgia affects my body and what techniques work the best for me. By having this treatment option, my Fibromyalgia has become even more manageable. For me, the work that my providers have done for me has changed my outlook on life.

Unfortunately, not everyone has access to these services. Chiropractic work and any medical care for that matter can be costly. Personally, after insurance I pay around $150 a month to receive chiropractic work. This may not be possible for some individuals, especially those who do not have access to medical insurance. There are also some communities that may not have access to a chiropractor. The current healthcare system places many obstacles in front of those trying to receive long term, preventive care including cost, insurance coverage, and accessibility of healthcare settings.

Chapter 3: The Pain Is All in Your Head

Pain is relative. Everyone feels pain differently and there is no one way to measure pain. Usually, when you feel pain you go to the doctor, they do a couple tests, and you're sent home with a way to treat your pain. But what if the doctor has no idea why you're in pain? What if there is no medical explanation for your sensation of pain? This is what typically happens with Fibromyalgia. There is no medical explanation for a patient's pain. If you're lucky, like me, you get doctors who are determined to figure out what's wrong, you receive a diagnosis, and you find providers who help you physically and mentally. Unfortunately, in many cases pain is ignored. People's pain is dismissed and they are sent home with no answers or treatment for their condition. They are expected to continue their daily lives as if they aren't in constant, debilitating pain.

In our current healthcare system, individuals with chronic disorders or disabilities face numerous barriers when trying to receive equal treatment. They may lack access to quality care as well as transportation, housing, and employment just to name a few (Mitra et. al, 2022). All of these factors, as well as socioeconomic barriers faced by women, people of color, and the LGBTQIA+ community , contribute to low health outcomes of those with disabilities (Mitra et al., 2022). The word disability alone brings on different challenges depending on how it is defined. How one chooses to define disability can affect eligibility to services, social stigma, and rights protection (Mitra et al., 2022). There currently are sixty-seven federally used definitions of disability. The most commonly used definition follows a medical model and defines disability as "an impairment or problem existing within the body or mind that can be identified by objective scientific or expert observations and ameliorated with the guidance or treatment of experts to help the person adapt and conform to the “normal” environment” (Mitra et al., 2022, p.1380). Our current healthcare system does not account for all these obstacles faced by individuals, making it extremely difficult for them to receive much needed medical care.

Individuals with invisible disabilities, such as Fibromyalgia, face another obstacle. On the outside, they look perfectly healthy. Their tests come back clean and there seems to be no medical reason for the pain. So, not only do they have to face many systemic barriers they also have to prove the legitimacy of their illness. One aspect of Fibromyalgia that is intertwined with the physical symptoms of Fibromyalgia is social pain. Social pain can be described as a painful feeling caused by the lack of understanding about an illness and can lead to social rejection or loss (Ghavidel-Parsa & Bidari, 2021). Social pain is seen more in patients with an invisible disability since there is no medical explanation of the condition (Ghavidel-Parsa & Bidari, 2021).

Lack of understanding and support from others and their judgment can lead to higher levels of mental illness as well as higher levels of pain (Ghavidel-Parsa & Bidari, 2021). Current research shows that the same neural pathways that contribute to the physical pain of patients are activated by social pain, thus causing higher levels of physical pain (Ghavidel-Parsa & Bidari, 2021). Many individuals with Fibromyalgia also have a wide range of somatic symptoms like chronic headaches or sensory hyperresponsiveness (Ghavidel-Parsa & Bidari, 2021). Patients with Fibromyalgia see significantly higher levels of invalidation than those with other rheumatic diseases like rheumatoid arthritis, which have visible manifestations and clinical explanations (Ghavidel-Parsa & Bidari, 2021). Due to the wide range of symptoms, patients seeming relatively normal, and the lack of medical evidence many patients with Fibromyalgia commonly face invalidation from medical providers. Consequently, this leads to more pain due to the lack of understanding and support (Ghavidel-Parsa & Bidari, 2021).

Unfortunately, the current climate surrounding not just Fibromyalgia, but any disability, makes it difficult to receive proper care, accommodations, and benefits. It is extremely disheartening to see how frequently those with Fibromyalgia experience invalidation. I wish that I was making up my pain. I wish that I could just say it was all a joke and get control of my life back. Unfortunately, that's not the truth. My pain feels like someone has tied weights to every physical part of my body or that my body is made of cement. I feel weak in my legs and some days they can't even hold me up. My arms shake when I try to pick up something as light as a fork. On my flare days, I try to convince myself that I am making it all up, that I actually don't feel pain. I hope that if I try hard enough, I can make the pain go away. I have to live through all of this, I have to put those closest to me through all of this, just for people to say I am lying or it's all in my head.

Our healthcare system needs to be reevaluated and adjusted to make it easier for those with disabilities to access care and accommodations. Currently, those with Fibromyalgia are able to receive disability benefits through social security. However, in order to do so one must prove they have a medically determinable impairment, or MDI, of Fibromyalgia (Social Security Administration, 2012). To prove that you have a MDI you need a medical diagnosis of Fibromyalgia by a medical provider and that diagnosis needs to be approved by the social security office. In order to meet the criteria of MDI of Fibromyalgia, there must be a history of widespread pain in both the left and right sides of the body as well as in the upper and lower halves of the body for at least 3 months, 11 tender points must be identified, and be on the right, left, upper, and lowers areas of the body, 6 or more Fibromyalgia symptoms must be shown: fatigue, fibro fog, depression, anxiety, etc., and all other possible explanations for these symptoms must be excluded (Social Security Administration, 2012). After all of this, one can apply for disability and once they apply, the social security office will determine if the level of impairment is high enough to be considered a disability (Social Security Administration, 2012). This includes seeing how a person's work life and other daily functions are affected. If it is declared that a person with Fibromaylgia meets the above criteria, then they can receive disability benefits (Social Security Administration, 2012).

Now, it is great that individuals with Fibromyalgia can receive disability benefits. It is also understandable as to why there are so many strict rules in order to qualify for benefits. However, if one's Fibromyalgia is not taken seriously by providers, then they can't even attempt to apply for benefits. The variability of Fibromyalgia can make it difficult to meet all the requirements, even if one's pain can become debilitating. There are also requirements that are needed for social security but are not needed in the medical world to be diagnosed. For example, I was never given the tender points test by any of my providers. In fact, according to the chiropractor I interviewed, most providers are moving away from the tender points exam because it does not always help with a diagnosis. Due to this, if I wanted to receive disability benefits I would have to redo my Fibromyalgia exam. Those with Fibromyalgia deserve to receive a proper diagnosis and proper accommodations and benefits.

Now the question becomes how do we create a system that allows those with Fibromyalgia, or any disability, to receive proper and humane treatment, thus allowing them to lead fulfilling lives? We have to start with the very first step, receiving a diagnosis. Many individuals with Fibromyalgia struggle to receive a diagnosis. This can be due to both the numerous amounts of tests to exclude other conditions and the invalidation of pain from providers. It took me three months to receive a diagnosis because of the amount of testing that needed to be conducted. As stated above, those with Fibromyalgia are most frequently invalidated by medical providers compared to those with other disabilities, further lengthening the process of getting a diagnosis (Ghavidel-Parsa & Bidari, 2021).

Many patients with chronic pain are turned away by clinicians due to the fact that nothing can be found during a physical exam or imaging tests, so no diagnosis is given (Sullivan, 2019). However, it is the job of a provider to do everything they can to diagnose a patient, not turn them away because their cause isn’t easily found (Sullivan, 2019). The current healthcare system is focused on production (Batalden, 2018). In order to maximize production, productivity had to be at an all time high. This means numerous actions had to be completed during the day and would be measured by how many patients a provider sees in a day for example (Batalden, 2018). With this mindset the system is focused on the process, actions, and outputs of their service. However, this neglects relationships and individual preferences (Batalden, 2018). In order to improve the current system and shift from the production mindset, Elinor and Vincent Ostrom suggested that a public service should be coproduced (Batalden, 2018). Paul Batalden describes health coproduction as “interdependent work of users and professionals who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of individuals and populations” (Batalden, 2018, p.2). This allows for a relationship to be formed between patients and providers. By creating this relationship both parties can bring their own knowledge and skills into the conversation (Batalden, 2018). My current providers always start off the appointment with asking how my pain has been. We then have a conversation about what would serve me best and we go from there. This is the idea of coproduction, listening to my needs and combining them with their medical knowledge to provide the best care. Providers can then receive better insight into the patient's daily habits and environments which can be valuable in understanding their health needs and treatment options (Batalden, 2018).

The ultimate goal for caring for those with chronic pain should be improving their function (Sullivan, 2019). Improving function can mean various things like improving physical or emotional function. However, the purpose for improving function and what function needs to be improved is different for every individual, so it is important for providers to understand how a person's individual purpose influenced their pain treatment (Sullivan, 2019). The main goal for providers should be to improve the life of those with chronic pain by giving patients the tools they need in order to move their lives forward (Sullivan, 2019). The tools that a patient would need vary from person to person. For example, I personally work with my chiropractor and massage therapist to target my pain. After each appointment my chiropractor gives me exercises I can try as well as suggestions on lifestyle changes that can help minimize my pain long term. I know some individuals who use different therapy methods and medications to help with their pain. We both have the same condition and similar symptoms, however we each respond differently to therapies. We have worked with our individual providers to discover what works best for our pain.

Throughout my Fibromyalgia journey, my providers have been essential to my understanding and management of pain. Both my primary care physician and chiropractors have created a meaningful relationship with me. They understand how my stress and anxiety influence my health. For example, they understand that I may need more intense work during the school year because this is when my stress is at its highest, and the more stressed I am the more likely I am to go into a flare. By intensifying my treatment during this time, we can prevent both the intensity and frequency of my pain. They also understand how the environment around me and systemic issues influence my health needs. This relationship has allowed me to feel safe and be vulnerable around my providers. I feel like they genuinely care about my individual needs and they understand how my Fibromyalgia is different from their other patients. Because of this, my ability to manage pain from a physical point of view has been easier. Since they understand my needs, they can suggest ways to treat my body and mind on flare days as well as suggesting ways to improve my physical and mental health in the long term. However, my case is not very common. Unfortunately, many patients do not have doctors who take their individual needs into consideration or even believe that their pain is real. All individuals with Fibromyalgia deserve to have the same care across the board. Living with chronic pain is difficult enough and we shouldn’t have to prove our illness to anyone.

Those with disabilities deserve to live a fulfilling life and they deserve the care that allows them to enjoy their life. Outside of medical care, individuals with disabilities face many challenges systemically. Many individuals with disabilities have difficulty accessing healthcare due to physical barriers. This limits their ability to receive care and in turn accommodations as many services require a diagnosis by a medical professional. There are currently two laws in place that are meant to increase access to healthcare, the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973. Both require that healthcare settings are accessible to those with disabilities (Lagu, Griffin, & Lindenauer, 2015). However, little is done to enforce these laws. Policies and laws are useless if they are not reinforced and so it is imperative that the government perform checks to ensure healthcare systems are accessible. In the US 34% of individuals with disabilities also lack access to transportation, so many can not even make it to important appointments (Krahn, Walker, & Correa-De-Araujo, 2015). It is vital that we address these physical barriers so those with disabilities can access much needed care.

One of the biggest barriers individuals face is the cost of care. I have spent around $3,000 on chiropractic work and around $3,000 on diagnostic care. That is a total of $6,000 after insurance to get diagnosed with Fibromyalgia and participate in long term care. Around 75% of individuals are insured through private insurance. Despite this, around 16% of individuals do not seek out care because of cost (Krahn, Walker, & Correa-De-Araujo, 2015). There are some laws in place to help alleviate the financial burden of those with disabilities. Recently, the Affordable Care Act (ACA) expanded Medicaid eligibility while also increasing regulation on private insurance (Mitra et al., 2022). It also made it illegal for insurance companies to deny coverage to those with disabilities (Krahn, Walker, & Correa-De-Araujo, 2015). This addressed a large barrier that people faced when trying to receive coverage. Creating more policies similar to the ACA can help lower the cost of care for individuals with disabilities. Going one step further, we could even introduce universal health care which will also limit costs and expand services that are available for persons with disabilities.

Those with disabilities are overlooked in the healthcare system. There are many barriers that prevent people from receiving needed care. Lack of knowledgeable providers, access to healthcare, insurance coverage, and cost are only a portion of these barriers. It is important that we create a system focused on reducing the cost of care as well as creating accessible healthcare settings. Creating a system based on coproduction allows patients and providers to work together to create the best treatment plan. Increasing coverage to different services, reducing the costs of care, and increasing access to coverage can allow for people with disabilities to receive better care and in turn live better lives.

Conclusion: Rebirth

The future I pictured as a little girl can no longer be mine. I can no longer experience life with the same innocence and wide-eyed wonder. For a long time I had lost hope in ever being able to enjoy all that life had to offer. There were and are many days where I am stuck up in bed, unable to walk, and cursing the body I was given. On those days, it feels like there is no light at the end of the tunnel, only darkness and heartbreak and unbearable suffering. For three years I struggled to accept my new reality and to see any future for myself. I felt like a burden to myself and others. Like I didn't belong on this Earth because I was only causing more money, work, and worry for those I loved. Why would any life where all I feel is pain be worth living?

But then, there are these moments of peace and innocent pure joy. Like the warmth of sunshine on my skin or the feeling when my cat rubs against me because he is so excited I am home. The feeling of laying next to my girlfriend as she sleepily pulls me in closer like I am the center of her universe. The way the sun shines in beams during the sunset, making my room glow a deep orange hue. Or the thought of holding my child's hand as we venture out into the world. There are these moments throughout my life where I feel unconditional love and peace. This human experience is the reason I keep fighting.

The journey I have ventured on over the last three years has been the hardest thing I have done in my entire life. It has been extremely saddening and extremely exciting all at the same time. It is a struggle to understand why this happened to me and how to live with it. I am still angry that my body does not work and at times, I wish that I was born in a different body. I still feel like a burden to those around me and feel guilty about what I have put them through. However, I have also realized that the people in my life need me as much as I need them. They want to see me succeed and thrive. They love me for everything I am and I am learning to love myself for everything I am. I am learning to not let my Fibromyalgia control my life. By adapting my life to better manage my pain I have been able to enjoy all the big and small moments my life has to offer. Even on my bad days I still look for one reason to be grateful that I am still here fighting.

Now at 21, my goal is to continue healing. I want to enjoy the human experience and all it has to offer because it is finite. I have accepted that my life is a balancing act where I must always weigh the effect that my decision has on my Fibromyalgia but that is okay. I can still pursue my education and career. I can still become a wife and mother. I can still be a person, I will just be a person who has Fibromyalgia. My Fibromyalgia just adds another dimension to who I am, another brush stroke in my painting of life. I am still working on accepting that my Fibromyalgia is not just a condition but a disability. I have a preconceived notion of what someone with a disability looks like and I do not fit that picture. There is a lot of internal work to be done before I can fully accept that I am disabled, but I have learned that even though I have able-bodied days, my Fibromyalgia still prevents me from doing normal tasks without assistance, and I deserve accommodations so I can enjoy the life I have been given.

Of course there are still days where my Fibromyalgia causes me anger, sadness, and guilt. There have been days where I saw no way out and at times, I did question whether life was worth living. Ever since my diagnosis my life has changed drastically in a very short amount of time. The life I imagined at 18 is no longer possible. Accepting that the future I once wanted is no longer attainable was devastating and I had to mourn the loss of who I was. I imagined a funeral, where I buried an able-bodied me in a nice coffin with nice flowers, knowing I will never be that girl again. Now it has been a three-year journey of discovering who I am. Fibromyalgia has taken many things from me, including my future, but it has also given me so much. I have learned to love myself and have compassion for myself. I have learned to take care of my whole person, both physically and mentally. As of today, I have a job I love, an amazing girlfriend, a loving best friend, and a family who will always be by my side. But, most importantly I have myself and I know that I will keep fighting and I have learned that no matter what, I deserve love from others and myself.

Having a support system has a positive effect on a person's journey. My chiropractor once told me that the patients they see who don't have a support system have a difficult time healing and progressing. Luckily, I have had nothing but support from my family, best friend, and partner. They have unknowingly saved my life. It can be difficult at times because I do feel guilt for putting them through this. My parents should not have to worry about caring for their adult daughter like she's a toddler. They shouldn't have to feed or bathe or carry me. My best friend shouldn't have to help me out of bed or down the stairs or even worry about me when the weather gets bad. My partner shouldn't have to think about how to change their future to accommodate my disability.

Despite all this guilt, I realize now that having a support system has allowed me to get to where I am now. My support system has loved me back to life. They have supported me through every roadblock and congratulated me on every achievement. I am living proof that having providers who form relationships with their patients and having a support system can dramatically change the outlook of someone's life. I believe it is important to include them because they are the reason I am here today.

My mom and dad have done nothing but encourage me to keep fighting. They have shown me unconditional love and not once have they shamed me for needing extra help. It is because of them that I continue to achieve my goals. My brother who carried me down the strip in Las Vegas because my legs gave out. He never fails to make me laugh, even on my worst days. He is my lifelong best friend who still shows me how to have fun, even if my body stops working. My best friend, Trinity, has done nothing but support me. She has continued to show me true friendship and I know without a doubt that she will always care for me. She has agreed to live with me twice, meaning she has helped me on my worst days, and never once have I felt like a burden. I know that I will always have someone who cares about me. My girlfriend, within the short time we have been together, has shown me I am enough. She has taught me that I am worthy of love and that my Fibromyalgia does not take away my worth.

It has been essential for my journey to have community. Not many people in my life understand what I am going through. Yes they support me unconditionally but they will never understand what goes on in my mind. I am lucky enough to have someone close to me who understands; my aunt, who has helped me process my Fibromyalgia in ways no one else has. She is like my older sister, and she has done nothing but guide me through this journey with compassion and understanding. Not only does she offer new ways to help with my pain but she has helped those around me understand my needs. I am able to talk to her on my flare days and she understands exactly what I mean. Knowing that at any moment I can call her and rant about life with Fibromyalgia has allowed me to process what I am feeling and why. She has helped me see a new future that is filled with joy and love, and for that I will be eternally grateful.

My story has such a positive outlook because I have providers who believe me, people who support me, and the privilege of having health insurance that allows me to receive the medical care I need. Unfortunately, many people aren't so lucky. They don't have people who understand them, they don't have providers who believe them, and time and time again their pain is dismissed. Those struggling with Fibromyalgia or any disability deserve the same care and love I have received. They have been failed by the system, and it is vital that we continue to bring awareness to Fibromyalgia. Changes need to occur both systemically and socially. Those with Fibromyalgia need access to providers who are trained in this condition and know how to treat the numerous symptoms. They need providers who understand the importance of validating our pain. It is essential for providers and patients to be vulnerable and open thus creating a system of co-production. By doing so, the patient can receive individualistic care for their specific needs which will improve not only their physical health but their ability to manage pain and move forward through life.

We need to reimagine our systems to dismantle the current barriers faced by those with disabilities. By creating policies similar to the ACA we can provide quality care for those with disabilities. We can remove economic barriers as well as physical barriers that prevent many from affording care and/or accessing appropriate providers. We can also rethink our current insurance policies in order to lower costs for those with disabilities. Every individual deserves to enjoy the human experience. They deserve to be able to do what they love. Every person should be able to go through life without worrying about how their disability is going to affect their prospects for the future. This can only be possible if we give individuals the opportunity to heal and recover. We need to fix our system so that those with disabilities do not have to worry as much about how their disability is going to influence their ability to live the life they want to live. You may not have a disability, but there are millions who do, including me. We should all want to improve the lives of those around us, whether we are close to them or not. There is power in numbers and we need to fight for those who have struggled in our system for far too long.

I understand that my journey is ongoing. I know that there will be numerous ups and downs. The system may fail me at times, but I won’t stop fighting for not only myself, but others with Fibromyalgia. My disability does not define me. I may have to take it into consideration, but it does not get to decide who I want to be or how I want to live. My disability is a part of me, but it is not me. I am a smart, caring, outgoing, and hardworking person who at times can’t walk but that’s okay. It has taken me a couple years to accept that the future I planned at 18 years old is no longer possible, but that doesn’t mean it has to be any less amazing. I am still me and on days that I hate my body I remind myself that it has gotten me this far. Fibromyalgia does not get to define who Anais is or what her life gets to be.

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