

“But You Don’t Look Sick”

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## FIBROMYALGIA ILLNESS NARRATIVE

Elaine\* is a college student currently pursuing her undergraduate degree with the hopes of going to graduate school for epidemiology. She was born in Atlanta, Georgia in 1998. Her parents divorced just before she turned 5, and she has one older sister and four stepsiblings, all of whom are significantly older than she is. To the casual observer, she's a perfectly typical college student: she is involved in her campus community, is an active volunteer, and spends her weekends with her friends or preparing for the upcoming week's classes. However, Elaine is living with fibromyalgia, a chronic pain and fatigue syndrome that, according to the CDC, impacts up to 5 million adults in the United States.

### **Explanatory Model of Illness**

Elaine told me that her most obvious and persistent symptoms are musculoskeletal pain, attention issues that fibromyalgia sufferers often call "fibro fog", a lack of restful sleep, and depression. She shared that these symptoms began presenting themselves when she entered high school, but it took her four years to realize that what she was experiencing wasn't a normal part of being a high-school student. She was afflicted with chronic fatigue and pain localized in her back and shoulders. Right around the time these symptoms started emerging, she also started taking medication for her high thyroid levels, and she admitted she was unsure which conditions caused what. Elaine also shared that she's not sure what caused the illness to emerge in the first place. Her description of the proposed causes leaned toward personalistic as she explained that her rheumatologist said the symptoms normally appear for the first time following immense stress or abuse. During her first year of high school, which was already a stressful event in her life, her mother's live-in boyfriend starting showing emotionally abusive behaviors that lasted for the three following years. Her description of how her fibromyalgia impacts her body was very biomedical, as she described the cause of her pain through the application of anatomical and biological sciences, likening one category of her pain to that experienced by patients who live with diabetic neuropathy. She also explained that there has been research to suggest that the damaged muscle tissues of patients with fibromyalgia don't repair in the same way the muscles of a healthy person would.

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**Understanding Illness: Narrative and Metaphor**

“I’ve always liked fantastic stories,” Elaine told me as she took a sip of her coffee. “They’re all structured really similarly, no matter how creative the author thinks they are: Hero goes on an adventure to do something and, against all odds, will end up triumphing. My fibro’s probably not going to end like plague that’s befallen the village like it would in a book. Hell, I’m pretty sure I’m still fighting the first dragon.” This phrase sums up Elaine’s view of her life with fibromyalgia as a quest. She understands that fibromyalgia is a chronic condition without a cure, but she seeks to be able to live her life as a college sophomore in a way that appears almost normal to an outside observer. In Arthur Kleinman’s work *Suffering, Healing, and the Human Condition*, which we read part of while discussing illness narratives, he says that “the meanings of chronic illness are created by the sick person and his or her circle to make over a wild, disorganized natural occurrence into a more or less domesticated, mythologized, ritually controlled, and therefore cultural experience” (Kleinman 48). In the same work, Kleinman brings to light the idea that chronic illness is a game of self-deception in order to make life with it tolerable. Elaine laughed and nodded when she heard this, saying that she’s grown used to explaining both her illness and the Spoon Theory every time she makes a new friend. She’s also admitted to trivializing her pain, deluding herself into thinking that she’s actually healthy when she has a day with low pain. Occasionally, her narrative diverges from the neatly-structured progression that is associated with the quest narrative into a story that borders on chaotic as she describes the interplay of her mental and physical disorders.

Whenever Elaine discusses her illness, she alternates between phrases that make her illness seem like either a nemesis or a frustrating housecat. She describes feeling like an outsider in groups of both able-bodied and disabled people, an outlier in both healthy and ill folks, and like she is faking her disorder because there’s no real diagnostic test to prove that she has this condition. She also never calls it disease, because she’s a student of biology that was very firm in her belief that diseases are caused by the introduction of a parasite or pathogen to the body.

**Impact on Relationships**

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When we got to the series of questions that focused on how her fibromyalgia impacts her interpersonal relationships, I saw Elaine withdraw a little bit, so I didn't push her on this section. When I asked Elaine about the reactions she gets when people find out she has a chronic condition, she shrugged and told me that they were normally accepting. The only people she tells are people close to her, including her friends. Issues only arose when she came into contact with people who didn't understand that not all disabilities are visible. "I have to get used to the response "but you don't *look* sick" ... I get a lot of side-eye from folks if they see me take the elevator up only one floor because my hips hurt. They see no reason for me, a healthy-looking 19-year-old, to be doing that. It's really easy for people who don't know me to write it off as me being lazy due to the lack of mainstream knowledge surrounding the disorder." The normalization of people only taking the elevator if they're lazy or visibly disabled has proven harmful to people like Elaine, who must either take the stairs and put herself through more pain or face the shaming that comes with being labeled as lazy.

We then shifted to a discussion of how she discusses her illness with her family. She said that most of her extended family doesn't know, as she doesn't want them to worry about her. Her mother and sister both know, but her father is often less than supportive of her treatment. "He's not one for psychiatry, so he's not thrilled that I'm on antidepressants." She laughed bitterly at this and took another drink of her coffee. "He's got a degree in applied physics. 'Garbage in, garbage out' seems to be his general model of thinking when it comes to anything that can't be quantified with a test."

**Biomedicine as Culture, Medicalization, and Social Norms**

Elaine shared her course of treatment with me by explaining that she and her panel of doctors have just been cycling through medicines to see what will work to reduce her pain. They recommend pairing the medicine with low impact exercise and stretching. She believes that this is the best course of treatment for fibromyalgia, along with cognitive-behavioral therapy to combat the mental aspects of the disorder. This is a very naturalistic way of treating her issue, as her personal research has turned up that people who experience chronic pain syndromes outside of Western biomedical culture would treat pain through acupuncture and meditation.

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When she was first diagnosed with fibromyalgia, her doctor called it an emerging disease, so there was little that has been clinically accepted about it. In fact, there are still doctors who don't believe it exists. Amongst the ones who do, doctors have proposed multiple causes for the symptoms, including higher densities of nociceptors (leads to heightened perception of pain), higher densities of  $\mu$ -opioid receptors (more endorphins are required to reduce pain to the same level experienced by healthy people), build-up of ground substance in damaged muscles, random firings of pressure sensors that the brain interprets as pain... Elaine joked that we could spend an hour just talking about the ways that science has tried to explain what's wrong with her. All of these proposals focus on the applied understanding of physiology and biology that are characteristic of biomedicine. Elaine's view is very medicalized; her family's spent many generations immersed in the ethnocentrism that causes her to believe that all disorders are caused by a bodily malfunction of some kind, and she's a self-proclaimed member of that group.

**Conclusions and Discussion of Course Materials**

Talking with Elaine has helped me to understand the difference between naturalistic and personalistic models of understanding illness. I thought that personalistic explanatory models were only found in non-Western cultures, such as the Hmong culture described in *The Spirit Catches You and You Fall Down*, wherein Lia's epilepsy was caused by a dab leading her soul astray. When Elaine spoke of the stress and abuse that triggered the symptoms of her disorder, I realized that this wasn't the case at all. The emergent issues that came with this period in her life were not caused by some imbalance in her body, but by a person who caused a toxic environment which allowed her symptoms to manifest. Elaine's story also helped me understand the interplay of ethnomedical and biomedical culture in the treatment of her disease via the incorporation of pharmaceuticals and practices such as exercise and therapy.

\*Name has been changed