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Mary Boujaoude

Eastern Kentucky University, boujaoudemary@gmail.com

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Eastern Kentucky University

Relentless: The Social Identity of Chronic Illness and Disability

Honors Thesis

Submitted

In Partial Fulfillment

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Requirements of HON 420

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By

Mary Boujaoude

Faculty Mentor

Professor Stephanie Adams Saulnier, MSW

Department of Anthropology, Sociology, and Social Work

Relentless: The Social Identity of Chronic Illness and Disability

Mary Boujaoude

Professor Stephanie Adams Saulnier, MSW

Department of Anthropology, Sociology, and Social Work

Abstract

Despite the steady growth of rights and acceptance of people from other minority groups, the significance of the issues faced by people with chronic illnesses and disabilities has not enjoyed the same public endorsement. This population has experienced disproportionate disadvantages that have prohibited them from realizing their full potential as active members of society. Much of the scholarship in the area of Disability Studies and research into the social issues faced by people with chronic illnesses and disability is academic in nature, while most advocacy work is non-academic in nature. *Relentless* is a book of essays that blends personal narrative with research in order to highlight topics such as stereotypes and misconceptions about chronic illness and disability, invisible illness, the mind-body connection, fatphobia, ableism, and accessibility in higher education. The combination of peer-reviewed research, statistics, and personal narrative provides a well-rounded perspective on what it means to have a chronic illness or disability today. *Relentless* exemplifies the magnitude of the barriers people with chronic illnesses and disabilities experience while also emphasizing their incredible resilience and strength.

Keywords and phrases: disability, chronic illness, social identity, creative nonfiction, invisible illness, creative writing, ableism, accessibility, honors thesis, Disability Studies

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The Problem and the Purpose

People construct a social identity, or a sense of who they are, based on their membership to groups. Historically, people with chronic illnesses and disabilities are perceived through a medical lens as people that need to be “fixed”. Viewing people with disabilities and chronic illnesses from this perspective creates barriers to their active participation in society. This group has experienced harmful discrimination and persecution for centuries from nearly all societal institutions, including education, healthcare, government, religion, the workforce, and the family. In addition, many people with chronic illnesses and disabilities have been ostracized and isolated from the rest of the social world. The United States’ previous practices of institutionalization and sterilization of people with chronic illnesses and disabilities, among others, have contributed to a current culture of separation between this group and the able-bodied majority.

While other vulnerable populations, such as people of color and the LGBTQ community, are beginning to experience increased rates of acceptance, social justice, and political rights, the chronic illness and disability communities are often ignored. People with chronic illnesses and disabilities have made great strides gaining rights in the short time since the push for social justice began. However, the rights achieved are sometimes reluctantly enforced by institutions, and discriminatory attitudes and behaviors continue to proliferate America’s common culture. As one of the largest marginalized groups in the country, people with chronic illnesses and disabilities deserve the platform to advocate for opportunities and resources awarded to people who are able-bodied. This creative thesis, *Relentless*, seeks to showcase the social issues surrounding chronic illness

and disability through a collection of essays in order to give a voice to a group of people who have been repeatedly pushed aside and silenced. By highlighting these issues, *Relentless* will hopefully call attention to the injustices people with chronic illnesses and disabilities face and aid in creating lasting reform.

The Process

When writing chapters for *Relentless*, I typically followed a six-part process. First, I would decide what the overarching focus of the chapter would be. I outlined a table of contents drawn from a document of that I used to pitch my thesis to my mentor. This document contained ideas that I wanted to include in *Relentless*. I would oftentimes choose a topic from this table of contents; however, there were occasions where new ideas came to me and I ended up choosing to flesh them out into chapters. The topic for chapter ““No computers in class—*no exceptions*””, a chapter detailing ableism in higher education, was pulled from my table of contents.

Next, I would outline personal narratives that relate to the overarching focus on the chapter. I would sit and think of any memories of conversations, events, or other times in my life where I experienced something that related to the topic. Through these personal narratives, I remembered quotes said to me that fit within the scope of the chapter, and these quotes usually became the title of each chapter.

Outlining my personal narratives allowed me to think of different ideas that fell under the overarching focus of the chapter. I would create subsections where I could explore specific issues related to each topic on a more detailed level. By doing this, a general outline of the chapter as a whole developed naturally. I was able to visualize what the chapter would look like in its completion.

After outlining the chapter, I would conduct research related to its focus and subsections. I discovered the majority of my sources through Eastern Kentucky University's online academic journal database. I focused on finding peer-reviewed literature on my topic in order to ensure that my personal narratives were validated by reputable sources. In addition to peer-reviewed research, I sought out information from professional organizations, such as the Centers for Disease Control and Prevention, personal narratives from other people with chronic illnesses and disabilities, and articles written by journalists for organizations such as *BBC* and *Nature*. By including sources from a multitude of mediums, I was able to provide an insightful, comprehensive analysis of the issues at hand.

Once I gathered my personal narratives and research, I combined the two and wrote the chapter. I would typically write the beginning personal narrative first, placing it at the start of the chapter in order to draw the reader in. From there, I would write each subsection and a conclusion; usually, I would write the subsections in order, as dictated by my outline, but there were occasions where either writer's block or a sudden burst of inspiration led me to write subsections out of order. After writing each chapter, I would submit a rough draft to my mentor, who would give me feedback so I could revise and implement any changes as necessary.

The Product

My creative process has culminated as *Relentless*, a book of essays that details the social issues experienced by people with chronic illnesses and disabilities. *Relentless* currently stands at around fifty pages and six chapters. Summaries of each chapter written thus far can be found below.

“Before disability”

The first chapter, “Before disability”, is a short essay explaining how my chronic illnesses and disabilities have developed over time. This chapter is purely personal narrative that is meant to draw the reader in. An excerpt from this chapter follows.

“Disability snuck up on me slowly and then all at once. Like someone creeping up from behind to scare me, I felt an overwhelming sense of uneasiness as volleyball became harder and harder to play. This uneasiness made the hairs on the back of my neck stand up in an attempt to guard me from the enemy. The feeling of dread culminated in disability laying its hands on my shoulders and shaking me into a state of heart-pounding, ear-ringing hypervigilance. From then on out, the hairs on the back of my neck have grown weary from constantly fighting and preparing for another attack. Weary, but persistent (p. 3-4).

“How are *you* disabled?”: Explaining chronic illness and disability’

This chapter provides an overview of the definitions of chronic illness and disability. Particularly, these definitions offer the social perspective of these concepts, as many perceive chronic illness and disability as purely medical in nature. I then discuss the seven barriers commonly faced by people with chronic illnesses and disabilities as outlined by the Centers for Disease Control and Prevention (2020), including transportation, policy, programmatic, physical, communication, social, and attitudinal. Finally, I discuss common misconceptions about chronic illness and disability, informed by the work of Blahovec (2015). Personal narratives are weaved throughout this chapter, as shown below.

“Since people with disabilities are less likely to have the opportunity to pursue higher education (CDC, 2019), I experienced social barriers in that I was one of the only people on the trip who had a disability. This led to attitudinal barriers as the majority of the students and professors on the trip did not understand my conditions. My accommodation needs were announced publicly in front of other students during an excursion; afterwards, there were many people who I had never spoken to who asked, “What’s wrong with you?” (p. 8).

“But you don’t look sick!”: The stigma of invisible disability”

In this chapter, I discuss the stigma of invisible disability, which is where someone who passes as able-bodied actually has a chronic illness or disability. For example, if someone were to see me walking down the street, they may not necessarily realize that I have a chronic illness or disability. Kattari et al. (2018) conducted qualitative interviews with invisibly disabled people and found four common themes: policing of bodies, speaking out against microaggressions, desire for justice, and internalized ableism. I defined and expanded on each theme according to the researchers’ descriptions; for example, the quote below explains what it feels like as an invisibly disabled person to have someone police my body.

“Imagine that you’re a professional chef and someone who claims to know everything there is to know about cooking gallivants into your kitchen. As you’re preparing the daily special (a meal you’ve made hundreds of times before), the stranger says, “Oh! My cousin’s girlfriend’s uncle is a chef! Here, do this.” and pours enough salt on the dish to make the Morton salt girl proud. Before you can stop her, the stranger takes the plate and dashes to the dining room. The guest is

(obviously) upset, and now you're facing the chopping block because someone thought they could do your job better" (p.11-12).

“It’s all in your head!” Untangling the mind-body connection of chronic illness and disability’

This chapter seeks to clarify misconceptions related to the mind-body connection of chronic illness and disability. I reported on research explaining that people with chronic illnesses and disabilities are often dismissed by medical professionals due to preconceptions that their physical symptoms are caused by mental health issues (Dusenbery, 2018; Shefer et al., 2014). I then discuss, both through my own personal experiences and those of another chronically ill person (Quarry, 2018), how people with chronic illnesses and disabilities usually choose to downplay their mental health or prior mental illness diagnoses in order to receive better physical care. I end by calling for medical professionals to gain a greater understanding of the mind-body connection, especially because having a chronic illness and/or disability is a substantial risk factor for suicidal thoughts, plans, and actions (Lund et al., 2015). An example of how I included personal narratives follows.

“Especially when seeking my diagnoses, the decision to steer conversations away from my mental health was a double-edged sword. I started to find specialists who were willing to listen to my symptoms, run the tests needed to rule out other conditions, and refer me to other specialists who would eventually give me answers. However, doctors made me feel like I couldn’t safely discuss my mental health” (p. 27).

“Why don’t you try losing weight?” Fatphobia and issues with body positivity’

In this chapter, I analyze the connection between fatphobia and ableism. I first define fatphobia and describe how the negative correlation between weight and health evolved over time (Robinson et al., 1993; Ashbach, 2019). I then clear up misconceptions of fatphobia and argue that the health risks associated with weight stigma can be more harmful than being overweight or obese (Flegal et al., 2013; Association of Anorexia Nervosa and Associated Disorders, n.d.; Pearl et al., 2017). From there, I transition into discussing the relationship between fatphobia and ableism, highlighting how people with chronic illnesses and disabilities are often subject to both forms of discrimination (Dionne et al., 2013; McLaughlin et al., 2017). I conclude by explaining the difference between the body positivity and body neutrality movements and arguing that the adoption of a body-neutral mindset in place of a body-positive mindset can be a more disability-inclusive approach to combatting fatphobia (Broadwater, 2020; Kessel, 2018). Personal narratives were included throughout this essay; one example follows.

“I became trapped in a vicious cycle of unhealthy habits like a sailor is drawn to a siren. Internalized fatphobia led me to undereat and exercise in a way that hurt my chronically ill body. While being stuck in bed, nursing my aches with a cocktail of Advil and Gatorade, I would “overeate” (this perceived overeating was most likely the result of my body trying to gain back calories I lost). The reminder that my body was different than everyone else’s spoke loudly in a room with little distractions. I would then circle back to point A and start the process over again” (p. 33-34).

“No computers in class—no exceptions.” Ingrained ableism in the higher education system”

The final chapter written thus far seeks to highlight rampant ableism present in the American higher education system. I begin by explaining the barriers students with chronic illnesses and disabilities face before they even enter higher education (American Institutes for Research, 2013; Disability Statistics Compendium, 2019; National Disability Institute, 2020). I then write about times in my college career where I experienced ableism. From there, I present a variety of strategies experts offer for rethinking accessibility in higher education (Kattari, 2015; LoGiudice, 2019; Shew, 2020). I conclude with an analysis of accessibility during the COVID-19 pandemic, particularly focusing on how students with chronic illnesses and disabilities are suffering academically despite disability-inclusive technology being adopted by higher education institutions (Anderson, 2020; Shew, 2020). An excerpt from my personal narratives follows.

“I remember the first semester I gathered the courage to purchase a tape recorder, my professor told me that she wouldn’t allow me to record her classes or take notes on the computer, citing both pieces of technology as distractions to the other students. Instead, she would email me her PowerPoint lectures after class. It was incredibly embarrassing to be the only student in class not taking notes; I looked as if I didn’t care about the coursework. Also, the professor typically used her PowerPoint slides as a jumping-off point, discussing concepts in-depth that weren’t included on the PowerPoints she sent me. I ended up in the same place I was before— having to choose between less pain and greater comprehension.”

Limitations

Limitations exist in this creative thesis. Firstly, although I included solid research from peer-reviewed journals, experts in the field of Disability Studies, and disability advocates, my own personal narratives are limited in their scope. I am privileged in that I am a White woman with access to resources such as education and healthcare. Therefore, my personal narratives must be understood with my privilege in mind. I am also young. Although I have experienced a variety of the social issues people with chronic illnesses and disabilities face, I have not had the same amount of life experience as someone twenty years my senior. This could also limit the scope of my essays. In addition, *Relentless* only has six chapters thus far and there are a variety of other social issues that people with chronic illnesses and disabilities face that need to be addressed.

Implications and Future Research

In the future, I would like to write additional chapters so that *Relentless* can be as informative and influential as possible. For example, one chapter might include levels of privilege within chronic illness and disability. One's race, ethnicity, class, gender, sexuality, and geographic location can all interact both with one another and with one's disability status to create unique barriers to participation in society. Analyzing this phenomenon would be a way to speak on my own experiences as a disabled and chronically ill lesbian as well as bring in perspectives from people with different demographic characteristics. Other chapters could focus on access to medical care in the United States, barriers in obtaining and keeping gainful employment, and how to find hope and become your own advocate as a person with chronic illnesses or disabilities.

Once *Relentless* is finished, I plan to design a cover, print copies to send to friends and family members, and look into submitting it for publication.

Conclusion

The voices of people with chronic illnesses and disabilities are important and deserve to be listened to. By weaving in personal narratives with factual, scholarly information, *Relentless* has the potential to reach a wider audience. Personal experiences ground the scholarship, allowing the social issues surrounding chronic illness and disability to be digestible and relatable. In addition, the scholarship validates the personal experiences, allowing the general public to recognize the legitimacy of the arguments. Social change begins when society acknowledges that problems in the current culture exist. In order for lasting change to occur, the public needs to advocate for the rights of people with chronic illnesses and disabilities. *Relentless* seeks to bring the issues people with chronic illnesses and disabilities encounter to a wider audience in the hopes that this increased awareness will encourage others to share their stories and mobilize change.

Appendix: Example Chapter

“But you don’t look sick!”

The stigma of invisible disability

Picture someone with a disability. What does this person look like?

Many people conjure up similar images in their heads when they think of a person with a disability. Usually, their minds create a picture of a person utilizing a wheelchair, an elderly person, or a person with a moderate-to-severe developmental disability. All of these images have one thing in common: there are visible characteristics that lead an able-bodied person to come to the conclusion of disability. However, it isn’t that simple.

I am currently twenty years old and do not utilize assistive technology often. It’s very unlikely that someone like me is the image that pops in people’s heads when they think about what a disabled person looks like. People who do not possess any visual indicators of disability are referred to as having invisible disabilities.

For me, having an invisible disability comes with a complex set of issues when interacting with other people, society at large, and with myself. While the life experiences of people with invisible illnesses or disabilities are all unique to the specific person, there are common barriers to inclusion that the majority, if not all of us experience.

Kattari et al. (2018) interviewed fourteen adults with invisible illnesses and disabilities in order to gain a better understanding of how the invisibility of their conditions impacted their daily lives. The researchers found four major themes in the interviews, all of which also intimately affect my life.

Policing of bodies

As someone who has been living in my chronically ill and disabled body for years now, I am acutely aware of my body's signals. I can wake up in the morning, feel that my collar bone is slightly out of place, and figure out whether that's going to be a minor annoyance or a pain that commands most of my attention for the day. It's like I'm trapped in a Las Vegas casino and the house always wins somehow.

I also know my limits. My body is a run-down phone battery; I know that if I spend an hour cleaning, I'll probably need at least an hour's rest to recharge, and my battery life never reaches 100%. Stamina and endurance are elusive phenomena. Although I may have a solid understanding of my body's needs, some people believe that they know better. Kattari et al. refer to this as policing of bodies. People who police other's bodies assume a level of expertise on chronic illness and disability that they most likely don't have (2018).

Imagine that you're a professional chef and someone who claims to know everything there is to know about cooking gallivants into your kitchen. As you're preparing the daily special (a meal you've made hundreds of times before), the stranger says, "Oh! My cousin's girlfriend's uncle is a chef! Here, do this." and pours enough salt on the dish to make the Morton salt girl proud. Before you can stop her, the stranger takes the plate and dashes to the dining room. The guest is (obviously) upset, and now you're facing the chopping block because someone thought they could do your job better.

This is what it feels like when someone tries to police my body. Because I have an invisible disability, people are less likely to believe that my pain and fatigue are

legitimate. I've been called lazy, useless, hopeless and a killjoy for setting boundaries. If I relent and participate in an activity I don't feel up for, my body pays for it days after.

I also deal with people "prescribing" treatments to cure me. While I do appreciate that this is coming from a good place for the majority of people, it isn't always as easy as taking an herbal supplement not approved by the FDA. Many times, I've either already tried what people recommend or I know that it won't work due to complications with other chronic illnesses I have. Yoga would probably be great for the chronic nerve pain my Fibromyalgia brings, but the constant posture changes and pressure on my joints would have my POTS and EDS duking it out to see who could throw me out of commission first.

One of the most frustrating parts of having a disability is that a lot of people don't understand that my conditions are chronic. While my symptoms will change day-to-day, I most likely will never "get better". Invisibility only leads to more confusion and body-policing—people don't understand why I'm not getting better or being more positive or doing more because they couldn't tell that I was sick in the first place.

In people's attempts to motivate my laziness or cure my pain, they send me two messages: they know more about my own body than I do, and it's not okay to accept myself. This has led to distrust between myself and my body. If this many people take offense to what I need, then I must be wrong, right?

Making my lived experience more palatable to others isn't fair to myself. I deserve to be able tell others what's best for me and have them respect that. No matter how well-intentioned, if people with invisible disabilities didn't ask for your advice, please don't give any out. Validation and support can often be more helpful than yoga.

Speaking out against microaggressions

Kattari et al. (2018) describe microaggressions as “death by a thousand paper cuts”. Microaggressions are statements or actions that are discriminatory to a marginalized group. They vary from more active forms of discrimination in that they are subconscious, i.e., microaggressions are usually based on assumed knowledge about a minority group and many people who engage in microaggressions are unaware they are doing so.

The passive nature of microaggressions doesn't negate from their harmfulness. Microaggressions towards people with invisible illnesses and disabilities have a profound ability to wear people down. Like a sander, microaggressions remove all of the unwanted rough edges of a unique slab of wood until all that's left is the smooth surface, stripping that uniqueness to be indistinguishable from all others.

Microaggressions are the most common form of ableism I have experienced as someone with an invisible disability. Most often, these occur when I “show my disability”.

I had a bad flare last fall that made my hands swell and the joints in my fingers tender. I still needed to do homework, however, so I put on a pair of black compression gloves that left my fingertips exposed and able to type. For around a week, I wore these to work so I could be efficient. I heard a lot of comments from my co-workers and boss.

“What's with the gloves?”

“Interesting fashion statement.”

“I never pictured you wearing something like that.”

The comments felt like a cat scratch. They hurt, but they were manageable. Until one shift, when two of my co-workers stood on either side of my desk and had a conversation over me that broke skin.

“Oh! Is that the fingerless gloves girl?”

This may seem benign, but it hurt to know that my co-workers were talking about me behind my back without fully understanding my “fashion statement”. It hurt much more that they were talking about me while I was in the room and acted like I wasn’t there. They most likely didn’t mean any harm, but they caused it. Even though I’ve needed them, I haven’t worn my compression gloves to work since.

~

As the individuals interviewed by Kattari et al. (2018) mentioned, speaking out against microaggressions can be difficult to navigate when having an invisible disability. A considerable amount of pressure exists when microaggressions occur because people with invisible disabilities often appear to straddle the line between ability and disability. It’s not that they are less disabled, it’s the able-bodied appearance that can open people with invisible disabilities up to more harm.

I wanted to step in and say something to my co-workers, but I was scared. Firstly, their comments hurt. I didn’t want to speak out and share my medical history to educate them about why their comments were offensive because it made me vulnerable. I didn’t want them to continue talking about me behind (or in front of) my back.

Like the interviewees, I struggle with contemplating if I’m the best person to advocate for disabled people and educate others about ableist microaggressions. I recognize how important it is for able-bodied people to have an accurate understanding of

the disability experience, but sometimes the insecurity from the thousand paper cuts hijacks my self-confidence and makes me feel like my voice shouldn't be heard.

Desire for justice

People with invisible disabilities have different ideas about what justice looks like for the disability community. Some interviewees simply perceived justice as respect and acceptance— accommodations given with no pushback or questions asked. Others wanted more government regulations to protect the well-being of disabled people. They all agreed on one thing, however: that open conversation is key to justice (Kattari et al., 2018).

My idea of justice for the disability community encapsulates both of the opinions mentioned by the study participants. I would love to not have to worry about people assuming that I'm lazy for resting or if people will judge me for using assistive technology one day but not the next. But I would also love to be confident that I will always have adequate healthcare or a job that will truly accommodate my needs.

Societal change won't occur without individual change, and individual change won't occur without societal change. The attitudes of individuals influence the systematic and institutionalized ableism present in society, and vice versa. So, where do we start?

We start by creating a dialogue. Opening up the conversation about disability is invaluable to facilitating justice. If we don't listen to what people with disabilities need, nothing will ever get done. It is incredibly important for able-bodied people to understand the lives of people with disabilities and disabled people to understand the spectrum of complexities that exist within their own community. Understanding can lead to compassion, and compassion can lead to change.

Internalized ableism

Internalized ableism occurs when people with chronic illnesses or disabilities become inundated with ableist attitudes and beliefs from the world around them to the point that they adopt those ideas themselves (Kattari et al., 2018). This phenomenon is common among other marginalized groups (for example, internalized homophobia in the LGBTQ+ community and internalized racism among many people of color) and can have detrimental effects on people's lives.

Personally, internalized ableism is the most difficult aspect of being disabled. It's worse than any symptom that I've had because it's made me lose touch with myself. After I got sick, I slowly started losing parts of myself that were central to my identity. I stopped playing sports. I lost my friends. I couldn't enjoy the things I used to. I isolated myself from everyone else because I was grieving my old self and my old body.

Before getting sick, my self-worth was tied to my achievements. I wanted to be the best I could be in everything I did. Being a teenager and dealing with never-ending pain along with new symptoms that seemed to crop up daily was incredibly hard. Ableist attitudes that I had unknowingly internalized before getting sick seemed to amplify once I was the person these attitudes targeted.

My pre-existing tendency to be self-critical went from being a nagging voice in the back of my head to a voice that was the center of attention. Not being able to help with chores around the house meant that I was lazy and useless. Expensive appointments, tests, and medications meant that I was a burden on my parents. Letting myself rest meant that I was a failure.

Imposter syndrome also fueled my internalized ableism as someone with an invisible disability. Christine (2019) explains imposter syndrome as feeling as though she is misleading others with the severity of her chronic illness symptoms despite the fact that she is truly having these experiences. I know this feeling all too well.

There have been countless nights where I have laid awake contemplating the legitimacy of my disability. It would be three in the morning and I, unable to sleep from the aching pain in my joints, would tell myself to suck it up and snap out of it. People were telling me that it was all in my head and I believed them. They couldn't see my symptoms, so they assumed they weren't real. This constant message combined with my propensity to self-denigration created a bitter taste in my mouth that I couldn't get rid of.

I have spent years trying to learn to trust my body again. Self-love doesn't come naturally to me, so I am trying to take this one step at a time. Although I still deal with bouts of internalized ableism and imposter syndrome, I am starting to become more confident that my experiences are real and valid.

It's extremely challenging to feel secure in oneself when society and individuals feed messages that fuel negative self-talk. This is why it is incredibly important to work on erasing the stigma associated with invisible disability. Allow people with invisible disabilities to just live. We're all trying to do the best with what we have, so don't be the person that makes it harder for others to live their truth.

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