

Patient Narratives of Myalgic Encephalomyelitis:
Situated Knowledge for Re/Constructing Healthcare

by

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ABSTRACT

Medical policies, practices, and definitions do not exist solely in the clinical realm; they show up in the lived experiences of patients. This research examines how people with the chronic illness called myalgic encephalomyelitis (ME) define their own illness experiences. They have situated knowledge about their illness onset, search for care, and clinical encounters. Their knowledge complicates and challenges the existing norms in clinical practice and medical discourse, as the experience of searching for care with ME reveals weaknesses in a system that is focused on acute care. Patient narratives reveal institutional patterns that obstruct access to medical care, such as disbelief from clinicians and lack of training in chronic illness protocols. They also reveal patterns in physician behavior that indicate the likelihood of receiving effective care. These patient narratives serve as a basis for continued examination of ME as well as further reconstruction of medical practice and procedure.

DEDICATION

To Michelle and Pamela Cutler, for being my constant motivation and for making my own diagnosis possible. It is their work that led me to medical care and being well enough to enter graduate school in the first place.

To David Cramer, for maintaining this vision and seeing it through with me, day by day. And also, for planning our wedding while I did these interviews. I am daily grateful for you, love.

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CHAPTER 1

INTRODUCTION

Overview¹

*“Sickness doesn’t terrify me. Death doesn’t terrify me.
What terrifies me is that you can disappear because
someone is telling the wrong story about you.”*

Jennifer Brea (2017)

The social construction of illness crosses boundaries. It is constructed in and through history, politics, medicine, family relationships, education, and social movements. Collectively, language and institutions impact the experience of those with chronic illness, through the meanings that literature, popular media, and medical journals create about illness. This can provide common ground and common understanding. However, when misinformed definitions and narratives about illness dominate these institutions, in medical journals and in board meetings, it becomes a barrier to actual treatment, care, and quality of life. This is why Jennifer Brea (2017) and others with myalgic encephalomyelitis (ME)², a chronic neuroimmune condition, find it crucial to tell

¹ **Look for *tl;dr* footnotes.** I have provided a short summary of each section, listed as a footnote connected to the section heading. The acronym *tl;dr* stands for “too long; didn’t read”. It is used on social media platforms as a way to present information succinctly, and indicates the person is providing a short summary. Providing my own version of this facilitates communication with key communities outside academia. Including the *tl;dr* footnotes will also allow interview participants from this study to more readily scan, analyze, and provide feedback on this thesis. Their feedback has been vital to this thesis and continues to be is vital for future research. **Refer to Appendix A, which contains all the *tl;dr* summaries in one place.**

tl;dr - Overview - Beliefs and ideas about illness are created socially. This makes advocacy and patient narratives necessary in order to challenge harmful beliefs about illness held by dominant medical institutions. Disability studies offers analytical tools to reconstruct medical norms.

² For additional information on the diagnostic criteria for ME, see Appendix B.

their stories about how this chronic illness affects them. When her debilitating symptoms were classified by doctors as hysterical (a trend in medical institutions documented elsewhere by Hoffmann & Tarzian, 2001; Werner, Isaksen, & Malterud, 2004; Jäntti, 2010), Brea launched MEAction.net, a platform for advocacy and the #MillionsMissing³ social media campaign. This website highlights the lives and needs of millions of Americans who are homebound due to chronic untreatable illness, who have disappeared from society, and who are often told by medical practitioners to go home and wait for a cure (Brea, 2017). Her work with this community-based advocacy continues to gather support in cities across the globe, as people with ME demand to be seen and heard by physicians and funding agencies. They work to change harmful language and framing used by centers of medical power such as the CDC. They demand institutional attention through increased funding of clinical research that will lead to more effective diagnosis, stronger patient-physician collaboration, and the development of treatments for ME.

This fight for visibility and equal access to care mirrors similar conversations happening within the field of disability studies, where normative structures are critiqued and dismantled to create inclusive and accessible societies for people who do not match the ‘able-bodied’ societal norm. However, this field also marks clear boundaries that differentiate *illness* from *disability*, in order to keep disability conceptually distinct from illness (Couser, 2015), because of the history of harm on disability communities by medicalization and marginalization (Riessman, 1983; Dusenbery, 2018). *Illness* and *disability* are related, since chronic illness can lead to disability. However, disability is

³ For addition information about #MillionsMissing, see www.MEAction.net and my.meaction.net/calendars/MillionsMissing.

often impacted by the visible, and chronic illness is impacted by the invisible, which plays out in various ways across different communities at the intersections of ability, class, race, and gender. Feminist disability studies grew out of theories dedicated to centering the needs of those marginalized by these same domains of class, race, and gender (Garland-Thomson, 2014). The theoretical foundations within disability studies provide a workable framework that can accommodate two opposing demands:

1. Disability communities maintain that physical, mental, emotional, or behavioral differences do not need to be ‘cured’; insisting that all bodies meet the same standard of ability is erasure.
2. People living with ME, dysautonomia, and other complex chronic illnesses need options for medical treatment and are actively seeking them; insisting that people continue to live with debilitating symptoms while doing nothing about it is erasure.

Because of its commitment to exposing patterns of erasure, disability studies is uniquely equipped to handle these contradictory demands. The work of critiquing and dismantling the medical model can coincide with advocacy for medical research. By challenging the medical model’s dominance, this field can meet the needs of people demanding medical treatment as well as the needs of people seeking demedicalization. The parts of the medical model that concern this thesis are medical legitimacy (what type of knowledge is valid) and authority (whose knowledge is valid).

Definitions and diagnoses within the medical model are also embedded in contradiction, as people seek care as patients, yet are disadvantaged because they remain at the mercy of professed experts with preconceived standards of behavior. In this paper, I use the term ‘patient’ to refer to a person who is engaged in the role of seeking medical care. In the specific context of a doctor’s appointment, the patient and the physician both

engage in their respective roles as they interact with each other. The patient's role or responsibility is to communicate their symptoms, when feasible, and to receive care. The role of 'patient' can also extend further into a person's lived experience as people with chronic physical symptoms (such as debilitating fatigue, pain, motor/cognitive dysfunction, seizures, or organ system failure) lead them and their caregivers to operate day-to-day within the context of medical care, contacting physicians, and navigating hospitals, insurance codes, and treatment plans. This ongoing participation places them in the continuous role of 'patient', consuming their time and resources.

The term patient also appears in another context. Many people with misunderstood chronic illness feel immense pressure to be 'the ideal patient' (Edwards, 2008). One woman described her tenuous relationship with doctors in this way: "I have to be emotionally perfect in order to get help" (M. Cutler, personal communication, March 7, 2018). These standards of behavior come from social constructions of "normal behavior", "the ideal body", and who holds authority. It locates patients alongside disability studies scholars to the degree that they both recognize the harm done by these unrealistic standards and seek to deconstruct/reconstruct accepted norms surrounding behavior and the body.

I realize that using the medicalized term 'patient' is complicated within a disability studies framework that views the medical model as a source of oppression (Couser, 2015). Discussing dysfunctions of the body can be problematic as scholars within the field seek to dismantle the ideology of the atypical body as 'defective' or 'impaired' (Siebers, 2008). I use it strategically, because as long as the medical model

remains the dominant narrative, individuals are thrown into the medical industrial complex when they seek care as well as interpreting their lived experience from a medical perspective. People become lifelong patients within the medical industrial complex (Clare, 2017; Illich, 1976). Keeping these considerations in mind, I strive throughout my work to write in a way that recognizes the nonnegotiable, irrevocable personhood of everyone impacted by chronic illness while also recognizing the community of people their individual stories represent. I use the term patient to indicate the medical context the person is in and what actions are expected of them, just as the terms nurse or physician denote a medical context and set of responsibilities. Everywhere else, I will use the term ‘person with ME.’ This terminology highlights the value of each person’s experience while also turning attention to the expectations and norms of medical care.

Through my research, I seek to reveal contextualized aspects of the lived experience of ME. This project asserts that analysis of patient narratives will strengthen our understanding of lived ME experiences and can be used to challenge medical discourse regarding different aspects of chronic illness generally, such as patient-physician relationships, more effective collaboration techniques, removing barriers, and innovating clinical practices that meet patient needs. Hugo Campos, a Medicine X ePatient Advisor, captured the contribution of patient narratives to medical education curriculum in this way: “Patient stories will help us create a new generation of doctors who have more empathy and have a lot more joy for the profession of being a doctor” (Chu & Price, 2019, p. 8). This indicates that the knowledge chronic illness communities

already possess is key to addressing persistent inequities. As shown by Behl (2017), “knowledge itself is a product and productive of power” (p. 581). One of the key outcomes from examining patient narratives is the transformative influence they can have as medical practices and norms are reevaluated and recreated.

This paper explores and contextualizes the lived experience of ME in four sections. The first chapter is a combination of the literature review and methodology, which provides background on the history of ME, medical practices, and the theoretical framework employed in this thesis. The second chapter documents and explores the daily lives of people with ME as self-reported. The third chapter examines the experiences of people with ME as they navigate healthcare systems. These experiences shed light on some of the limitations of the healthcare system and possibly suggest ways the system needs to be transformed. The fourth chapter provides recommendations based on patient perspectives in order to guide medical and social constructions about ME toward effective and humane outcomes.

These patient narratives are located within current social and medical contexts maintained by institutions, processes, and systems. They provide perspectives that can contribute to the body of knowledge regarding invisible disabilities and chronic illness, while also pointing the way to important, practical changes.

Literature Review

Myalgic Encephalomyelitis

Myalgic encephalomyelitis (ME) is currently defined as a neuroimmune disease characterized by physical and cognitive exhaustion not improved by sleep, with an ongoing occurrence of symptoms over months and years. Although this disease has been on the books since 1956, research on this disease is still in its infancy. There are still no FDA approved treatments (Centers for Disease Control and Prevention, 2018B) and a continued lack of coverage in medical curriculum (Jason, et al, 2010). For this thesis and its accompanying research, I utilize the International Consensus Criteria (ICC) for ME⁴. These diagnostic criteria are outlined in Appendix B. Note the four symptom categories in the ICC that comprise the main elements of ME: post-exertional neuroimmune exhaustion (PENE); neurological impairments; immune, gastro-intestinal, and genitourinary impairments; and energy production/transportation impairments⁵. One of the key symptoms that differentiates ME from other chronic illnesses is PENE, which causes a drastic reduction in physical and cognitive activity. People with ME navigate

⁴ *Why I use the term ME instead of ME/CFS or CFS:* The name Chronic Fatigue Syndrome (CFS) is often confused with the symptom “chronic fatigue” (CF). CF as a symptom is present in many diseases, but CFS is a specific syndrome with neurologic and immunity components. The vague language and lack of understanding surrounding the term ‘fatigue’ has contributed to misinformation about the seriousness of the CFS and has led to patients being labeled chronic complainers or malingerers. ME and CFS are often used interchangeably, amplifying existing confusion. The term ME/CFS arose from patient-community requests to refer to ME first, to draw increased attention to the term myalgic encephalomyelitis; however, it still contains the reference to ‘fatigue’ as an overshadowing component of this disease, which can perpetuate misinformation. In this text, I use the term ME to refer to this illness, unless I am matching specific language used in cited publications, in which case I may use the terms CFS or ME/CFS (Dimmock & Lazell-Fairman, 2015, p. 4).

⁵ Appendix B provides specific examples of each of these.

these physical symptoms while simultaneously seeking medical care through a complex healthcare system.

History of ME⁶

The names used to describe ME reveal a lot about the views of the medical establishment and its influence on the general public. Tracing myalgic encephalomyelitis back through the last several decades shows the influence of the social conditions that surround this illness:

‘Chronic fatigue syndrome’. In 1984, there was an outbreak of viral infections in the resort town of Incline Village, Nevada. At the insistence of two local physicians, the Centers for Disease Control and Prevention (CDC) investigated the outbreak. Relying on an all-white, mostly female sample, the CDC determined that the Epstein-Barr virus could not be reliably linked to the outbreak; it was in this report that they used the term “syndrome of chronic fatigue” (Centers for Disease Control and Prevention, 1986). Beyond this, the men sent from the CDC to Incline Village did little more than encourage the two physicians to focus their energy on patients with conditions that are already medically understood (Newsweek, 1990). Many of the phrases from an article in Newsweek Magazine that reported on chronic fatigue syndrome still ring true to the current situation: “We’re desperate for care “, “treatment proceeds by trial and error”, “no one would take them seriously” (Newsweek, 1990). The cause of the outbreak remained largely a mystery, but the association of ‘fatigue’ with women was beginning to be established.

⁶ *tl;dr* - ME has gone by various names over the years. These names reflect social attitudes of the time period toward the disease, by their emphasis on fatigue/burnout OR on specific biological processes.

‘Yuppie flu’⁷. Time Magazine ran a piece in 1987 that listed many names for this condition, including epidemic neuromyasthenia, myalgic encephalitis, Iceland disease, Royal Free disease, postviral fatigue syndrome, chronic Epstein-Barr virus infection, chronic mononucleosis, and chronic fatigue syndrome (Boffey, 1987). The label that appealed the most at this time with mainstream information was the Yuppie flu. Yuppie was the derogatory term for middle-class women in the 1980’s who entered professions that had previously been overwhelmingly male. Using the term yuppie flu pulled on the misogynistic heartstrings of a changing society; the logic used at the time was that women had violated social norms by pursuing professional status and yuppie flu was the natural consequence. This terminology centered the issues and concerns of white, middle-class communities. The social perception of the disease supported the move toward predominantly psycho-social methods of treatment, including psychotherapy to remove patients’ beliefs about their illness, as the common trope from the medical establishment was that the disease was rooted in an innate desire to be sick (Dimmock & Lazell-Fairman, 2015).

‘Myalgic encephalomyelitis, International Consensus Criteria’. While the term myalgic encephalomyelitis appeared far back as 1956⁸, the name did not gain

⁷ In the cultural context of this time period, the ‘yuppies’ of the 1980s were the ‘hippies’ from the 1970s—whose belief system transformed from ostensibly anti-establishment to embracing the establishment and striving for greater economic, upward mobility. Thus, they were given the moniker, ‘yuppies’. This increase in socio-economic status caused a good deal of anxiety. While both men and women were in the ‘yuppie’ group, women were specifically targeted as more and more women entered the workforce in jobs that were traditionally male dominated.

⁸ Published in *The Lancet*; in an editorial in 1956, and in an article by Ramsey on the outbreak at Royal Free hospital in London in 1957. The term was subsequently overtaken by psychiatric terms throughout the 1970s.

traction until relatively recently. In 2011, a collaborative panel of clinicians, medical school faculty, researchers, and one patient advocate published the International Consensus Criteria (ICC)⁹, designed for the purpose of providing an accurate diagnostic tool for patients and clinicians. This criteria sets a higher bar for diagnosis with multiple symptom categories. The ICC purposefully removed language about ‘fatigue’ from the diagnosis, noting that other diseases that cause fatigue, such as cancer or multiple sclerosis, don’t have ‘fatigue’ as part of their name, and therefore, neither should CFS (Carruthers, et al., 2011). They promoted the use of myalgic encephalomyelitis over CFS, with particular care taken with each of the descriptive symptoms to remove or change language that diminished the seriousness or credibility of the disease. For example, they replaced post-exertional malaise (PEM) with post-exertional neuroimmune exhaustion (PENE). ‘Malaise’ suggests malingering or indistinct discomfort. This report changed the language so that it centered the impact of the neuroimmune system (Carruthers et al., 2011). The ICC definition and symptomatology are the criteria used for my thesis research.

ME/CFS. The official language from the Centers for Disease Control and Prevention (CDC) currently utilizes the term ‘ME/CFS’ and makes an effort to highlight that the disease is biological, not psychological (Centers for Disease Control and Prevention, 2018A). This term is widely used in academic and medical literature since it includes both ME and CFS.

⁹ See Appendix B.

Systemic Exertion Intolerance Disorder. In 2015, the National Academy of Sciences (NAS) released a report based on the input of ME specialists, patient advisors, and others. They examined the various criteria for ME and CFS, including areas of overlap as well as limitations of each criteria. They created a new diagnostic criterion¹⁰ and suggested a new term, Systemic Exertion Intolerance Disorder (SEID), to replace ME/CFS. One of their main goals was to give primary care providers practical tools for learning about, diagnosing, and treating people who meet the diagnostic criteria for SEID. This term has not yet taken hold in academic, medical, and conversational areas, and NAS recommends that this criterion be re-examined in 2020 (NAS, 2015).

ME in Context¹¹

In the United States, ME has a disease burden slightly higher than HIV/AIDS and multiple sclerosis (MS). However, in terms of funding for research and treatments, ME/CFS receives approximately \$5 per patient from the National Institutes of Health

¹⁰ “Proposed Diagnostic Criteria for ME/CFS. Diagnosis requires that the patient have the following three symptoms:

- 1) A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest,
- 2) Post-exertional malaise,* and Unrefreshing sleep*
- 3) At least one of the two following manifestations is also required: Cognitive impairment* or Orthostatic intolerance.

* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity” (NAS, 2015, p. 6).

¹¹ ***tl;dr - Funding*** - In the United States, the NIH does not fund ME research at a level appropriate to the disease burden.

tl;dr - Medical Model - The medical model claims that all life events are under the jurisdiction of medical institutions. Under this model, symptoms and illnesses are counted as ‘real’ when they are visible and thereby granted medical legitimacy by the institution.

(NIH), compared to \$2,482 for HIV/AIDS and \$255 for MS, according to data from 2014 (Dimmock, Mirin, & Jason, 2016). Both HIV/AIDS and MS as disease categories have gone through significant periods of patient activism and institutional change to get where they are now in terms of funding, public understanding, and professional understanding¹². Government agencies have known about ME for decades, but unlike the needed growth of research provided for HIV/AIDS and MS, the NIH has kept ME funding persistently low. This process of funding does not take only medical factors into consideration. Social beliefs and behaviors factor in to decisions about medical care. When examining the reasons for underfunding, Dimmock, Mirin, & Jason reported, “we tend to underfund things where we blame the victim” (2016, pp. 2). Issues of funding first require a shift in social perceptions, followed by a shift in legislative and bureaucratic prioritization of funds. To comprehend this issue of funding, we must explore the broader issues.

Decisions about medical funding occur within the broader framework of accepted beliefs about illness. Scholars in disability theory refer to our western dominant narrative as *the medical model*¹³. The medical model is a system of ideas and practices that bring all life events under the authority of medicine and healthcare, positioning physicians’ offices as sites of power (DasGupta, 2015). The term medicalization also refers to subsuming human behaviors into a medical context and using the medical field as a tool for controlling deviant behavior (Riessman, 1983). Because this model is the dominant

¹² Refer to the section on psychogenesis for further discussion of the history of MS.

¹³ For additional context about the academic critique of the medical model, refer to section of this literature review on Critical Disability Theory, which, in contrast to the medical model, views disability “as the product of social injustice” (Siebers, 2008, p. 3) as opposed to the bodily failings of an individual.

narrative in western cultures, conversations about illness¹⁴ and mainstream understandings of ME (plus other similar diagnoses¹⁵) center around medicalized ideas and practices. This is also referred to as the medical industrial complex (Clare, 2017), an assemblage of corporations that profit off medical systems, particularly the pharmaceutical industry, which is the direct beneficiary of creating higher demand for an increasing range of treatments. Pharmaceutical companies continue to fabricate medical needs and then provide the drugs. This plan has worked quite successfully, since “the public finds medicalization attractive because the notion of simple but scientific solutions fits in with a general cultural overinvestment in biological explanations and interventions” (Tiefer, 2006). In this way, the dominant model is self-sustaining.

People enter the medical industrial complex through their primary care provider and from there they run the course from clinician to clinician who specializes in one small area, not in whole-body understanding or interconnectedness. Because modern medical protocols largely developed from wartime needs and emergency-related medical care, focus on transportation and acute injury care remain in force (Rostker, 2013). The systems developed around this type of acute care prioritize focusing in on one aspect, such as the lungs or a leg injury, instead of considering how systems work together.

Acute care results in more and more specialized areas of medical practice. However, not

¹⁴ Conversations about illness occur through dialogues in medical journals, medical school curriculum and training, disability accommodations, and they also happen person-to-person.

¹⁵ For clarity, **diagnoses** is the plural form of diagnosis. The last syllable of **diagnosis** is pronounced “sis” like “sister”. The last syllable of **diagnoses** is pronounced “es” like “ease”. I use both the singular form and the plural form throughout this paper.

every condition can be addressed in that way, particularly chronic illness, which requires a robust knowledge of how organ systems relate to each other. Because of this, western medicine¹⁶ has fallen short¹⁷ regarding chronic illness care.

Within this model, empirical data and observable proof are highly valued which creates an over-emphasis on that which is visible and easily measured (Brea, 2017). The prevailing belief is that conditions that matter can be seen concretely in lab results, which disadvantages the experiential knowledge held by patients (Spandler & Allen, 2018). Medical institutions decide what is real, what is urgent, and what is not; those decisions are largely based on what the eye can see. The authority rests with medical professionals, who further codify beliefs about illness into the DSM, ICD-10, and other lists of official clinical diagnoses. When Brea (2017) says that the wrong story is being told about people with ME¹⁸, she is referring to this fraught history of the medical model.

The accepted narrative of the medical model says, *you don't look sick.*

It says, *if doctors don't know what's wrong, the patient is the problem.*

It says, *if science cannot explain your symptoms, your symptoms are not real.*

This results in erasure and harm. Health advocates and community organizations for health equality imagine an alternative narrative, in a system built around reciprocity instead of erasure, where this phrase could be flipped on its head: *if science cannot*

¹⁶ A deeper look into Eastern modalities of medicine is beyond the scope of this paper; however chronic illness patients may seek out this kind of care because of the limitations of Western medicine.

¹⁷ In addition, the medical model places responsibility on the individual through stigma (Oliver, 2008) but does not individualize the approach to meeting patient needs, which include the nuances of managing chronic illness, which cannot be met by examining discrete parts disconnected from the whole.

¹⁸ See quote at the beginning of the Overview section.

explain your symptoms, then it needs to be interrogated, not the patient (Adams, Reiss, & Serlin, 2015; Brea, 2017).

The medical field is not a neutral environment. The development of medicine as a distinct profession was rife with biopolitical struggles, as upper-class male physicians pushed out lower-class female healers in the ongoing struggle for authority and credibility (Ehrenreich & English, 1973). In her work, Riessman (1983) explains that “medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms” (p.48). This idea is supported Conrad and Schneider (1992) and also by Ehrenreich and English (1973) who investigate the centuries old tradition of erasing women from professional medical practice, and warn that “the stakes are even higher today, when total control of medicine means potential power to determine who will live and who will die, who is fertile and who is sterile, who is ‘mad’ and who is sane” (p. 28). Additionally, medical advancement has been borne on the backs of communities of color through unethical medical trials such as Tuskegee, profiting off the contribution of Henrietta Lacks, and testing on nonconsenting emergency room patients (Washington, 2006). Recognizing this violent history behind current medical practices is key to understanding their formation and the ways in which they operate today. Specifically, Riessman (1983) argued that women as a group have negotiated the risks involved in both rejecting and accepting the medicalization of human life for a long time. Rejecting the system distances women from potential life-saving advances, but accepting the system puts women in jeopardy of being (mis)treated for illnesses that were constructed

for the purpose of control (such as conversion disorder, the modern equivalent of hysteria, or treating pregnancy and menstruation as disease). Women have navigated these risks for generations, and people of all genders are susceptible to the negative impacts of living in a system built around these risks.

The relationship between women and chronic illness¹⁹. As an umbrella category, people who self-identify as women in the United States are more likely to experience chronic illness than fatal illness. Case and Paxson (2005) found that women are more likely to experience non-fatal-chronic illnesses that affect their quality of life and are also more likely to report and seek treatment for those conditions, compared to men who are more likely to experience fatal medical events. This phenomena of higher levels of morbidity (illness) in women contrasted with higher levels of mortality (death) in men is referred to as the sex health paradox. Case and Paxson (2005) conclude that the health risks associated with smoking contribute to a higher mortality rate in men (p. 209) even when the rate of hospitalization and self-reporting of symptoms is the same among women and men. The main takeaway here is women as a whole are more likely to experience, report, and seek treatment for chronic illnesses that affect their day to day quality of life.

These differences in the likelihood of chronic illness between women and men reveal the need for healthcare systems at an institutional level to be able to provide

¹⁹ *tl;dr* - Women are more likely to have chronic conditions. Men are more likely to have fatal conditions. An estimated 75% of people with ME are women.

adequate care for chronic illness²⁰. The lack of institutional attention to these issues allows the dominant norms (fixation on acute, fatal events) to remain in force. Dusenbery (2018) refers to this as a systemic emphasis “on preventing death over improving health” (p. 163).

Since ME is one of the chronic illnesses that is more likely to be found in women, with an estimated 75% of people with ME identifying as women (National Academy of Sciences, 2015), the question remains: how has our healthcare system traditionally handled issues relevant to women’s health? One prime example is the reaction of the medical establishment to the shifts that occurred during the last part of the twentieth century.

The changing position of women’s health within medical institutions²¹. The decade spanning from the mid-1990s to the early-2000s saw unprecedented scrutiny of medical norms, due to the action and scholarship stemming from feminist researchers (Dresser, 1992; Fourcroy, 1994; Riessman, 1983). During this time period, women made

²⁰ Jennifer Brea’s work in film and community advocacy addresses the harm of gender bias: “Our immune systems are just as much a battleground for equality as the rest of our bodies ... Bias against women in medicine operates at every stage from lab research to diagnosis to treatment. Women are significantly more likely than men to suffer from ME and autoimmune disorders. Yet, many of these diseases are significantly underfunded relative to their impact on human well-being and cost to the economy. Human males and male animals are still used more frequently as test subjects. At the diagnostic level, women’s symptoms are more likely to be perceived as exaggerated or psychosomatic, meaning women are often misdiagnosed, underdiagnosed, or, worse, blamed for their symptoms with invalidating diagnoses like ‘it’s all in your head.’ It wasn’t long ago that doctors were diagnosing women with “hysteria” for diseases they didn’t understand. The medical profession has moved on from the name but the bias lives on” (Brea, n.d).

²¹ *tl;dr* - Limited gains have been made in integrating women’s health concerns into medical curriculum and clinical practice. The FDA banned women from participating in drug trials from 1977 to 1993. Despite attempts to reverse this practice, drug companies still test drugs primarily on male samples, resulting in consumer risk for the broader public.

bold reclamations of autonomy over their bodies (Davis, 2007). Ineffective medical practices were called out like never before, particularly when it came to treating female bodies as a subset of male bodies: “Many of the problems associated with women today can be considered signs of mental illness only in comparison with a male standard of what is healthy and normal” (Tavris, 1994, p.101). Scholars and public citizens demanded recognition of the medical field’s failure to address women’s health from start to finish, in research and training and diagnosis (Dresser, 1992; Fourcroy, 1994; Tavris, 1994; Herz, 1997).

One area of particular importance is the exclusion of women from drug trials. Women have historically been barred from participation in medical research and clinical drug trials (Ibarra, et al., 2017; Uhl, Parekh, & Kweder, 2007; Herz, 1997; Mastroianni, Faden, & Federman, 1994; Fourcroy, 1994), resulting in little attention to the role of female biology on the usage and metabolization of prescription medication. Drugs were tested for safety and dosage on male laboratory rats (Dresser, 1992; Goodman, 1994). Subsequent testing on human populations followed patterns of erasure and violence: an overemphasis on sample populations comprised of white, single, middle-class men (Dresser, 1992); or unethical, nonconsensual experiments on minority groups (Washington, 2006). Marked with the FDA’s stamp of approval, these medications were then put on the market for consumption by all patients.

Centuries of social and political ideology were codified in the FDA’s 1977 policy that all women capable of reproduction must be excluded from drug trials (Carey, et al., 2017; Josefson, 1997) but by 1993 the persistent backlash over that decision prompted a

reversal by the FDA (Cotton, 1993, p. 2067). An FDA report on the ongoing inequalities in medical research listed reasons why male bodies were/are used as the model while female bodies were prohibited: “simplicity”, “homogeneity”, “lower costs”, “paternalism”, “fear of liability” and “concern about confounding effects of hormonal and reproductive issues” (Uhl, Parekh, & Kweder, 2007, p. 600). This had and continues to have consequences for women who take medication.

Because of this scholarship and activism, the tacit acceptance of male biological data as general human data fell into disrepute. A well-known study of aspirin at the time claimed the drug was successful in preventing migraines and reducing the chance of heart attack, but their data were collected from all male subjects²². One study went so far as to analyze the effects of obesity on breast cancer, which they “conducted—you guessed it—solely on men” (Dresser, 1992, p. 21). These two reports were not well met in the public. Researchers were attempting to carry out business as usual, which in their field meant male lab rats and male subjects; however, this institutional norm, long ignored, was repeatedly brought to light in an effort to replace it with an equitable standard.

These demands for procedural change, and the subsequent changes in policy by the FDA, represent an important step forward, but it was not sufficient to make lasting changes on the medical industrial complex. Pharmaceutical corporations continued to test drugs on male populations and then sell those medications to both women and men. Female patients continue to be misdiagnosed or mis-medicated because male norms are still universalized. A recent study shows that medications are metabolized in women

²² It also ignored the data that showed women experience 66% more migraines than men and also experience high rates of heart disease (Dresser, 1992).

differently than in men (Ibarra, et al., 2017), but clinical trials are still functioning under a rationale that claims the results found in men can be applied to female populations. A 2017 analysis of generic prescription drugs found that the results of clinical trials did not maintain their validity when tested in female populations²³. Drug companies do not want significant numbers of women included in clinical trials because it leads to “higher intrasubject variability” (Ibarra, et al., 2017, p. 31). Recommendations from the study urge pharmaceutical companies to redo the trials with specific attention given to sex differences in order to reduce consumer risk, but there is no indication that companies will do so voluntarily.

The scholarship and medical activism of the 1990s was an attempt to solve a twentieth century problem. In the two decades since, the problem has evolved but our healthcare institutions are no better equipped to solve it. Changes in law and policy have resulted in limited gains. In 1994, the US Congress pressed for an analysis of the curriculum used in medical schools, and over the next decade, from 1994 to 2004, even under pressure from Congress, medical schools in the United States have shown 0% growth in the number of courses and student rotations that focus specifically on women’s health, though they have incorporated more information into their existing courses (Henrich, 2004, p. 283). A study involving male professors in medical courses found that they consistently described gender-related issues as relevant, “but of low status” and exhibited reluctance to incorporate issues predominantly affecting women into their

²³ This also applies to male-centered theories in human and moral development. Theories generated through data gathered from women resulted in markedly different insights into moral development. cf. Gilligan, *In a Different Voice*, 1982

syllabus (Risberg, Johansson, & Hamberg, 2011, p. 613). This medical and cultural norm persists into the twenty-first century and continues to impact new generations of clinicians and patients—particularly patients with chronic illness.

Naming chronic conditions²⁴. While modern medicine has brought about significant advancements, there remain glaring omissions in medical understandings of the causes of certain diseases²⁵ such as ME, dysautonomia, lupus, and others with autoimmune and neurological components. These diagnoses are particularly chaotic for patients because the medical community has limited answers about causes or treatments. These chronic illnesses consist of multiple symptoms across multiple organ systems. Because of the war-time emergence of medical protocols, modern western medicine does not view the body holistically, thus missing the ways in which systems interact and affect each other, and also fixating on managing acute symptoms rather than understanding the underlying causes. Refer to Appendix C for a list of diagnoses that pose particular problems in medical categorization and understanding. The three main categories shown in Appendix C are: 1) diagnoses related to the immune system, 2) diagnoses related to the autonomic nervous system, and 3) conditions where diagnosis is currently elusive. These umbrella categories represent large groups of similar conditions, each of which contains its own body of research, debate, hegemonic understandings, resistance, and transformation. In addition, the specific diagnostic terms within the umbrella categories

²⁴ *tl;dr* - Conditions that fall in the neuroimmune and autoimmune category have similarities in patient experiences of stigma, dismissal, and lack of specialists.

²⁵ Appendix C shows an overview of definitions and distinctions between these chronic illness categories: diagnoses for the immune system, diagnoses for the autonomic nervous system (ANS), and terms for undiagnosed conditions.

often have multiple iterations. For example, there are eight different sets of diagnostic criteria for ME alone. There are also over seventy sub-types of dysautonomia. These categories and terms overlap, intersect, disrupt, and complicate each other.

It is important to note that the immune system (IS) and the autonomic nervous system (ANS) are connected to many other organ systems (for example, the circulatory system or the digestive system). Therefore, when the IS or ANS are not functioning, it can impact any number of different organs. This results in a difficult path for people seeking medical care. For example, if a person's ANS isn't running well and symptoms arise such as gastrointestinal dysfunction, a person might seek out care from a gastroenterologist. But the problem isn't rooted in the digestive system—it arises from problems in the ANS. Due to the current nature of medical education, and the symptom-specific approach of medicine, it is unlikely that a gastroenterologist will have specialized training about the ANS. The next logical step would be to seek care from someone who is accredited as an autonomic specialist. However, as of this year there are only 48 certified autonomic specialists in the United States (United Council for Neurologic Subspecialties, 2019). Due to lack of specialists, lack of research, and limited clinician time, patients with diagnosis listed in Appendix C present healthcare needs that are incompatible with the current healthcare system. Patients with these types of chronic illness face decreased access to treatment in addition to increased stigma and invalidation (Agency for Healthcare Research and Quality, 2014, p. ES-4). These experiences of erasure forge a sense of community around these illnesses. The terminology in Appendix C shows how far the medical field has come in understanding biophysical processes; each

diagnosis represents a condition that medical institutions recognize and treat. However, it also highlights vital areas where medical knowledge is lacking.

The processes involved in naming and categorizing chronic, multi-system illnesses have been influenced by two medical concepts worth discussing here: medically unexplained symptoms and psychogenesis²⁶. Both of these concepts are problematic and directly harmful for people with ME and other chronic illnesses. Many of the terms for undiagnosed illnesses highlight the absence of physical evidence that the medical model requires. The ‘unexplained’ part of medically unexplained symptoms (MUS) does not refer, as it should, to the limitations of our current scientific knowledge, but instead places the blame on the individual patient.

The physical symptoms of the chronic illnesses in Appendix C are often explained or dismissed using psychogenic terms. Language and assumptions from the field of psychiatry have caused particular harm to people with chronic illness. This field uses categories such as ‘functional’ and ‘somatoform’ disorders to indicate physical symptoms that cannot be medically explained, such as the psychiatric diagnosis conversion disorder, which claims that pain in the absence of biophysical markers originates from the brain converting emotions into physical complaints.

The historical assumption has been that symptoms with no physical explanation are psychologically based. Patients with chronic, multi-system illnesses navigate a

²⁶ psycho = of the mind
genesis = origin or cause
psychogenesis = the idea that a disease comes from the mind instead of from physical factors

minefield of medical attitudes and assumptions, as has been shown in studies of patients with ME/CFS:

“Seeking and receiving a diagnosis can be a frustrating process for several reasons, including skepticism of health care providers about the serious nature of ME/CFS and the misconception that it is a psychogenic illness or even a figment of the patient’s imagination” (National Academy of Sciences, 2015, p. 1).

People who deal with ME *and* people who deal with mental health issues are both underserved by the concept of psychogenesis (Spandler, 2018). When illness is framed in a psychiatric context, patients often bear the burden of unmet physical disorders. This issue has permeated psychiatric care for decades. Hoffman (1982) found that 63% of patients admitted to psychiatric in-patient centers for dementia were found to have treatable *physical* conditions which were ignored, and that 41% of patients admitted to one psychiatric hospital had neurological/physical disorders rather than psychiatric ones. For these patients, no one was looking for possible biological underlying causes until Hoffman’s team arrived. Even after these revelations, the passage of time did not yield systemic improvement. Fifteen years later, Klonoff and Landrine (1997) reported on the same issue:

“Many physical disorders suffered by women have psychiatric symptoms. For example, hyperthyroidism can result in depression and anxiety, and temporal lobe epilepsy can have the same symptoms as bipolar disorder. As a result, women are in danger of being misdiagnosed as having psychiatric problems and receiving completely inappropriate treatment” (p. xxii).

The process required to reach accurate diagnoses can contain high levels of uncertainty. Instead of dealing with that uncertainty, healthcare institutions fall into patterns of stereotyping, often gendered, that lead to quick and uninformed medical decisions. These

practices are unacceptable in a field that has sufficient technical and scientific resources to address this issue.

The leap from clinical uncertainty to psychogenesis can happen immediately, due to the formation and frequent use of psychogenic language in clinical settings—for example, one of the medical terms used synonymously with MUS is somatization (Smith & Dwamena, 2007). This language gives clinicians license to categorize puzzling symptoms as psychosis. This is the story told in medical journals and medical schools, a dominant narrative that ignores the profession’s own ugly history of erasure. For example, clinicians historically used the diagnosis ‘hysterical paralysis’—this diagnosis is no longer used because we are now able to administer CAT scans—the ‘hysterical paralysis’ patients showed physical evidence on their CAT scans of demyelination in the brain. We now refer to that same condition as multiple sclerosis (Brea, 2017). Now that clinicians have the technology to see the physical evidence that was always there, the condition is officially recognized and no longer labeled ‘hysterical’. This disease gained clout the moment it became visible on a CAT scan. A side-by-side comparison of funding from the National Institutes of Health shows the discrepancy between visible and invisible diseases. In 2016, the reported government spending on multiple sclerosis was \$97 million compared to \$8 million for ME/CFS (NIH Research Portfolio Online Reporting Tools [RePORT], 2017). This points to the ongoing pattern of medical funding for conditions with visible evidence.

The failure to medically explain ME symptoms is rooted in a collective misunderstanding of the human body due to gendered, racialized, ableist, sexualized gaps

in knowledge and the types of conditions that our medical institutions have refused to investigate.

The role of institutional betrayal²⁷. Institutional betrayal is the trauma experienced by an individual when an institution²⁸ they trust or depend on is a source of harm. This type of trauma emerges in varied ways—isolated or systemic, caused by direct action or omission, or a complex combination of all of these descriptors (Smith & Freyd, 2014). Patients with chronic illness depend on healthcare services for their continued well-being, while also experiencing the trauma of repeated dismissal, disbelief, and dehumanization from those same healthcare services. This is reflected in Smith’s (2017) findings: participants reported that healthcare professionals did not respond to their concerns and denied the accuracy of their negative reports. Smith and Freyd (2017) found that institutional betrayal came up as a barrier to healthcare services, since the participants who experienced institutional betrayal in healthcare settings were less likely to invest their trust in the medical institutions that were the source of both harm and care. There remains a paradox that systemic change often requires patients to first demand change but advocating within such a broken system destroys the trust that is fundamental

²⁷ *tl;dr* - When people are harmed by institutions they depend on for their well-being, this is called institutional betrayal. In healthcare, this occurs when patients’ reports of their conditions are dismissed and their reports of negative experiences are not believed.

²⁸ The institutions that are most frequently perpetrators of systemic trauma (such as higher education, the military, and healthcare) possess common characteristics, listed here with specific ways the healthcare system meets each description:

- 1) rigid standards for membership (medical certification and board exams),
- 2) prestige (valuing empirical data over contextualized experience; social capital of clinicians),
- 3) priorities (valuing reputation over individual member health, as in the treatment of medical students),
- 4) and institutional denial (continuous refusal to research certain conditions, shifting blame to patients).

(Smith & Freyd, 2014)

to effective healthcare relationships. Smith (2017) delineates the concept of trust—specifically in the context of betrayal in healthcare institutions—into fiduciary trust (which can be expressed as “They will help me”), confidence (expressed as “They are able to and qualified to help me”), and satisfaction (“They helped me”) (p. 134). Smith notes that fostering an environment of trust is self-serving for healthcare organizations, as it is linked to higher rates of recovery and lower cost (p.133). However, this study showed that 66% of participants reported institutional betrayal in their healthcare experiences (p. 138). These results provide empirical backing for populations who experience unalleviated betrayal in healthcare settings.

Drawing on the work of Smith and Freyd (2014), Tamaian, Klest, and Mutschler (2017) conducted a study to assess negative experiences patients with chronic illness experienced in the Canadian medical system. While this study had only 14 participants, making it difficult to generalize the findings, it was conducted outside the US healthcare system and remains relevant because it builds on and raises questions about Smith and Freyd’s original research regarding institutional betrayal. Most importantly, this study creates a link between betrayal trauma theory (usually reserved for victims of direct violence) and chronic illness, applying the framework of institutional betrayal to the experiences of patients with ongoing medical needs. The barriers to care that Tamaian, Klest, and Mutschler (2017) reported include shortages of doctors, no accountability for doctors who are perpetrators of trauma, and the regularity of negative experiences. They suggest changing institutional factors to create accountability for doctors and ensure that providers will report medical errors when they occur. As it stands currently, healthcare as

an institution continues to evade accountability. In 1999 and again in 2015 the Institute of Medicine found systemic errors in diagnosis (Smith, 2017, p. 135) that had not been addressed despite public attention. Smith and Freyd (2014) identify the barriers to addressing this continued betrayal, including a “lack of language around the issues” (p.581), as well as a pattern of knowing an issue exists but creating taboos about discussing it. Advocates can begin by using repeated language to frame the problem and make that language widely accessible. Repairing the damage of institutional betrayal requires institutional leaders to actively practice transparency and protect members at the expense of the institution; this practice of repair remains rare and elusive.

Feminisms and Disability Theories

The ongoing dismissal of people with ME and other chronic illnesses is a feminist issue because of the work feminism does in taking apart the ideas of positivism and how these operate to dominate the medical model’s approach to scientific research.

Multiple Feminisms.²⁹ Feminist movements are concerned with the lived experience of women and dismantling patriarchal structures (Murfin, 2016). In the academy, feminist theory has critiqued longstanding norms of Western philosophical tradition because of that tradition’s role in the marginalization of women and their work (Dhamoon, 2013; Mies, Bennholdt-Thomsen, & Von Werlhof, 1988). In Western tradition, positivist theory claims to create ‘neutral’ data because it is empirically based; the assumption that empirical observations are objective and neutral (and thereby

²⁹ *tl;dr* – Feminist theory encompasses the lived knowledge of multiple groups (queer theory, disability theory, Latinx theory, womanist theory) and makes ample room for the contradictions within and between these groups. Feminist research acknowledges that the scientific method and ‘objective’ research are impacted by human biases. It seeks to reveal hidden power imbalances.

meaningful) has long stood as the standard for creating the false dichotomy between legitimate (objective) and illegitimate (subjective) knowledge (Hawkesworth, 2006; Schwartz-Shea & Yanow, 2012). For example, in clinical encounters experiential reports of pain are taken less seriously than reports generated through medical imagery technology (Brea, 2017). This practice marginalizes patients, particularly women, and undermines the process of care. Understanding knowledge inequities such as this requires situated knowledge (Nagar & Geiger, 2007); feminist methodology provides the tools to excavate the deeply contextualized nuances and experiences that constitute relationships within medical care. The deployment of this experiential knowledge as opposed to the exclusive use of empirical knowledge (Hawkesworth, 2005) works within feminist methodology to make visible these power structures.

In a medical context, one form of oppression occurs in the hierarchical relationship between physicians and patients, where the subjectivity of the physician (their own implicit or learned biases) is hidden behind a facade of neutrality (Spandler, 2018). Feminist theory seeks to expose that subjectivity and feminist research methodology sits in tension with positivism as it “seeks to reveal concealed power dynamics” (Ackerly & True, 2013, p. 135). Positivist theory may also present categories as fixed points; categories that include binaries such as male/female, sick/healthy, and good patient/bad patient. These categories ignore the chaos, context, and fluidity of material realities (Dhamoon, 2013). Deploying meanings as fixed points is an effective way to hide the dynamic relationships and oppressions that underpin those definitions (Hawkesworth, 2006).

Feminist methodology replaces positivist assumptions with the context-rich norms of interpretivism; this creates a fluid construction of meaning that is constantly critiqued and simultaneously built and unbuilt (Behl, 2017). This process continues as ever-changing relationships and power dynamics unfold new social constructions. Feminist methodology claims plurality as a strength, in this way destabilizing the normative meanings found in positivist theory (Dhamoon, 2013). This plurality is also layered with additional tensions between multiple feminisms, drawing on scholarship that places a particular marginalized group at the center (queer theory, disability theory, Latinx theory, womanist theory). Dhamoon (2013) threads a single question through multiple feminisms by asking: how does this form of feminism disrupt conventional meanings and contribute to their continual reconstruction? For example, the field of poststructural feminism claims that “systems of meaning-making that produce and organize sex must also be deconstructed” (p. 99). No category or definition is taken for granted; all are questioned and examined.

In this way, the category of ‘woman’ serves as a departure point, not an end point. Categories of gender are socially and culturally negotiated; they do not arise from static categories of sameness. Notice the word choice in Dhamoon’s (2013) interpretation of the debate over the meaning of *woman*: “Ultimately this gender trouble is a challenge to the **naturalized coherency** of sex, gender, sexual desires, and woman—categories often presumed to be **stable** among feminists” (p. 102, emphasis added). This is further complicated by the backlash from those in power when the power structures they stand on are made clear. Feminist methodology matters because power is at stake. Conducting

feminist scholarship that utilizes fluid definitions and constant critique brings the benefit of being able to create meanings that reflect lived experience, as Dhamoon (2013)

explains:

“Rather than posing a problem for feminism, continuous critical questioning of concepts and categories that seem foundational (such as woman) opens up the possibilities of imagining and reimagining differences in alternative and new kinds of ways” (p. 104).

Using research that explores gender differences in no way implies that all people navigating the medical system fall into binary categories of sex or gender. Instead, these studies shed light on the ways in which society constructs expectations around masculinity/femininity or generates knowledge about male/female bodies, which have direct bearing on medical experiences for all patients.

Disability Theories.

*Feminist Disability Theory.*³⁰ A key component within feminist methodology is the critique of relationships of power. For Dhamoon (2013) power is at the center of feminist critique as “an organizing device” and a “site of transformation” (p. 89).

Feminist scholars recognize health, and women’s health in particular, as not only a personal concern but as a political concern (Ackerly & True, 2010, p. 465), because any field that deals in life and death must reckon with the concept of power.

Patients face a number of inequities as they seek access to healthcare. Navigating the US healthcare system is an embodied experience that is materially constructed by

³⁰ *tl;dr* – Feminist disability theory uses the tools within feminism and critical race theory in order to address the social inequalities experienced by people disabled by that society’s norms.

race, gender, sexual orientation, and class (Charlton, 1998). The experience of illness is affected by social, environmental, and biological factors; therefore, solutions, treatments, and diagnostic criteria cannot be developed in a vacuum that ignores these domains. Feminist disability studies is an intersectional framework that grew out of decades of work in queer studies, critical race theory, and feminist theory (Garland-Thomson, 2014). It focuses on ability/disability as a positionality that crosses over social positions of class, race, and gender. Addressing marginalization based on ability enhances and supports scholarship that addresses these other forms of marginalization.

Critical Disability Theory.³¹ This theory views disability as a function of power, instead of a function of health or medicine (Siebers, 2008). As a field of study, Critical Disability Theory (CDT) interrogates ableist norms with its methodological focus on fluid definitions, embodied experience, the human right to life, and local knowledge (Siebers, 2008). Approaching the issue of #MillionsMissing³² from this methodology uncovers the critical issue of whose knowledge matters and whose presence in society is valued. The current erasure of millions of people with under-researched chronic illness points to major problems with the social and medical models, both of which are key concepts that CDT interrogates (Adams, Reiss, & Serlin, 2015). As a field, disability studies provides an analytical path for interrogating these issues, particularly through CDT, which focuses on critique of the medical and social models of disability. The

³¹ *tl;dr* – Critical Disability Theory (CDT) examines medical and social systems that create disabling circumstances.

³² For more context on the #MillionsMissing campaign, refer to the Overview.

medical model, as described previously³³, is a way of thinking that revolves around granting medical institutions power over life and death. On the other hand, the *social model* is a way of thinking that reveals the role of society in health and well-being, because “disease is always generated, experienced, defined, and ameliorated within a social world” (Jones, Podolsky, & Greene, 2012, p. 2333). The social model was described in part by Wendell (1996), as the “social conditions that straightforwardly create illness, injuries, and poor physical functioning” in addition to the “subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies” (p. 36). This is also implied in Siebers’ (2008) commentary on the limits the medical model places on human capacity. Identifying the social constructs that exist within the medical profession can cast light on what needs to change. Women in particular stand as stakeholders in raising the general consciousness that medicine is a social business and not a purely scientific endeavor.

Even if the medical model claimed to have absolute clinical knowledge of the human body, it would not solve the power imbalance between physicians (perceived as educated, healthy, contributing members of society) and patients (perceived as unreliable, weak, burdens on society) (Adams, Reiss, & Serlin, 2015). Disability activism often centers on this shift in cultural values and perceptions (Charlton, 1998). In disability studies, the social model’s mission to depathologize the body is vital, even in the context of chronic illness, because patients are more than a body and live out their experiences in a social environment. Wendell (1996) defines the social model in terms of how social

³³ The medical model is discussed in depth later in this chapter.

factors damage bodies: lack of access to basic resources; injuries from assault or war; medical malpractice; increasing the standard expectations of pace and productivity; the ubiquitous assumption “everyone is healthy” (p. 39); the physical design of buildings made for strong bodies to navigate; and some forms of dependence being invisibilized for the able-bodied. Each of these considerations point to social systems of erasure and the marginalizing impact of patients striving to maintain a hectic pace of life based on social expectations of performance that are invisible to the non-disabled. Wendell (1996) notes that “any increase in the pace of work will decrease the energy available for other life activities” (p. 37); this concept is referred to in the chronic illness community as the spoon theory (BBC, 2013). Many of the conditions delineated in Appendix C are described as ‘invisible illnesses’ because they easily go unnoticed: some patients ‘pass’ as able-bodied, while others are homebound and out of sight.

Wendell (1996) also acknowledges the limits of the social model, in that not every disability arises from social factors alone (p. 42). For patients grappling with poorly understood chronic conditions, social and cultural issues are one part of their illness experience, added to their experience with physical pain. Viewing illness from a social standpoint alone does not address the underlying physical nature of the conditions these patients face.

Where the social model thrives is its capacity to take into consideration the personal and social costs of prolonged illness and its effect on the material conditions of life. For patients, every exertion is mediated through the filter of chronic illness; all decisions pass first through its hands. This impacts everything from employment to

relationships. In addition, there is a social cost that impacts our society at a national level. The economic burden of ME alone from lost income and medical expenses is between \$17 and \$24 billion annually in the United States (National Academy of Sciences, 2015, p. 2). Medical practice would benefit from incorporating the work of scholars in the social deconstruction of disability (Wendell, 1996, p. 45), which promotes addressing human needs with social solutions, because healthcare is both a human need and a social solution.

Multiple strategies.³⁴ Relying solely on the medical or the social model results in dead ends for those with complex chronic illnesses and their advocates. For example, adrenaline release (a physical response common in dysautonomia patients) can be connected to high stress environments (a social consideration). Looking at this symptom with purely medical eyes or purely social eyes does not address the experience holistically. Neither model offers the patient a complete solution.

When it comes to creating viable solutions for patients with chronic illness, disability studies is uniquely positioned to offer a methodological framework that incorporates both social and medical strategies in innovative ways, as well as offering modes of analysis from which activists can create a variety of strategies. Using the theoretical scholarship in this field, patient activists continue to pursue multiple modes of action, in securing funding for medical research as well as reconstructing social norms in ways that promote health equality. Even though the biological nature of chronic illness often places it in contrast to the groups that founded disability studies, the scholarship

³⁴ *tl;dr* – Solutions to health inequality require simultaneous work in *both* medical and social systems.

generated in this field can both support this set of patients as well as reciprocally benefit from their shared goals of social and medical change. The very complexity created by the urgent need for better medical understanding alongside the call to dismantle the medical model altogether positions disability studies as an appropriate field from which to analyze the treatment and erasure of complex illnesses.

Theory & Methods

Theoretical Framework & Methodology³⁵

This research engages qualitative feminist inquiry³⁶ in order to “render visible” (Ackerly & True, 2010) people with myalgic encephalomyelitis (ME) and the meanings they create in terms of their lived illness experiences and healthcare barriers. It values co-generated understandings of authority, credibility, access, and navigating complex relationships (mis)diagnosis and various clinician interactions. Feminist theory in relation to medicine operates as a critique of bias shown against women when they report pain. It operates as a rebuttal of the overreach of medicalization. It offers a method to reconstruct medical norms, practices, and expectations in effective and humane ways.

Using feminist methodology in the examination of data and knowledge production adds value to the construction of meaning from the patient’s point of view and increases the applicability of academic work to lived experience. This situated knowledge (Nagar & Geiger, 2007) from each participant reveals the material implications of healthcare policy and practice. While macro-level quantitative and statistical data are important, these methods are critically enriched by contextual knowledge, and they maintain meaning as they are supported by qualitative data containing rich descriptions and situated knowledge through lived experiences.

³⁵ For tl;dr summaries, refer to the footnotes throughout this section.

³⁶ *tl;dr - Qualitative feminist inquiry* - A method of study that critiques bias and power imbalances.

Throughout this thesis, I incorporate theoretical elements that support the production of knowledge with patients at the center. I draw on Feminist Disability Theory³⁷ to frame and challenge existing medical terminology with experience-near data, since terms like ‘treatment’ and ‘recovery’ cannot be abstracted for patients. They are lived in concrete ways. This type of knowledge production can push back on dominant claims from the medical model. I center patient narratives as a vital source of context-rich knowledge (Shwartz-Shea & Yanow, 2012).

The institutional, systemic power structures within medicine are materially significant because they dictate viable modes of knowledge production, select the beneficiaries of the work, and impact the agency and authority of vulnerable groups (Nagar & the Sangtin Writers, 2006). Viable modes of knowledge production rely on social validation, often from our institutions. When an institution values one form of knowledge over another, this is called epistemic injustice³⁸ (Spandler & Allen, 2018). For example, the medical institution values empirical knowledge over experiential knowledge, and visible evidence over lived experience. Scholars of epistemic injustice ask the question: how do you know what you know? How does society know what they collectively know? When considering medical practice, this idea leads us to ask: how do clinicians *know* when a person has an illness? With all the complexities that people with ME face, it is not that myalgic encephalomyelitis is so complex—the complexity arises

³⁷ *tl;dr - Feminist Disability Theory* - Used here to center the stories and perspectives of people with ME, in keeping with the disability rights motto ‘Nothing About Us Without Us’.

³⁸ *tl;dr - Epistemic injustice* - Certain types of knowledge (empirical) are privileged over others (experiential).

from the medical world that houses diagnoses like ME. The illness is not the source of confusion, nor is the patient. It emerges from the hierarchy of ways of knowing.

In keeping with my commitment of trustworthiness to the communities I research, I utilize techniques from the plain language movement³⁹, which seeks to address the outsized load put on marginalized communities by recognizing specific communication needs (Cheung, 2017). This is usually applied to legal documents about rights, policies, contracts, and consent; however, the same ideas apply to creating academic products that are accessible to the communities that made the production possible. Using tl;dr summaries (see Appendix A) is one way I incorporate plain language into this thesis.

My procedures are grounded in interpretivist processes⁴⁰ (Schwartz-Shea & Yanow, 2012) with epistemological commitment to local knowledge, awareness of speaking *with* rather than speaking *for*, member-checking, and prioritizing interconnectedness and empathy (Khan, 2005; Nagar & Geiger, 2007). When considering how power dynamics impact specific groups, Schatz (2009) highlights the value of “close, person-to-person contact that is attuned to the worldviews of the people we study” (p. 4). The tendency to hold conversations about disability without incorporating the input of the people who are most affected underscores the need for the disability rights movement’s slogan: *nothing about us without us* (Charlton, 1998; Carey, 2015). This is why I center the experiences and discourse of people with ME in this thesis.

³⁹ **tl;dr -Plain language movement** - Language and documents should be accessible to the people they are made for.

⁴⁰ **tl;dr - Interpretivist processes** - This method of research uses ethnography (close up study of communities) and awareness of positionality (intersections of social privileges and oppressions).

Starting from an *ethnographic sensibility* (Schatz, 2009) that recognizes the importance of context and co-generation of meaning, I approach my interview participants as co-equal members of the research team rather than subjects of study. As a researcher, I am also an active agent, visible in the work; not as an unattached ‘neutral’ observer, but as an invested participant. Within the context of his work on ethnography, Schatz (2009) introduces empathy as methodology, since ethnography “is an approach that cares—with the possible emotional engagement that implies—to glean the meanings that the people under study attribute to their social and political reality” (p. 5). Embeddedness produces situated knowledge. Designing research around an ethnographic sensibility involves emotional entanglements; it claims these without apology as a source of strength because they provide a richer, more complete picture of the social landscape. It is important to note that “for the interpretivist, we can only discern what is ‘real’ by taking people’s worldviews seriously; after all, such worldviews lie at the core of the social construction of reality” (Schatz, 2009, p. 13). This is empathy. The skills necessary for practicing empathy (such as listening, attending to the emotional state of others, and thinking through the impact of your actions on others) lend themselves to ethnographers as ways to understand relationships, power dynamics, and community experiences.

The positionality of both the researcher and the participants impacts the development and formation of knowledge in this thesis (Behl, 2017). In their work, Nagar and Geiger (2007) combine the concepts of identity and plurality in order to emphasize the fluid quality of identities which constantly shift as perceptions are formed, questioned, discarded, and reformed. My positionality as a patient, though part of a

somewhat different community, means that I have been embedded in patient communities for more than a decade and have formed relationships over time. Working with patients is an area where I can leverage my lived experience with chronic illness to speak to core concepts with authenticity, as well as have access to participants through my embeddedness in patient support communities. However, maintaining critical reflexivity (Behl, 2017) throughout the research process continuously revealed to me the ways in which my own experiences diverge from people with ME due to the differences in our physical symptoms. My understanding of the chronic illness experience on a general level does not provide insight into specific experiences of post-exertional neuroimmune exhaustion for each participant. I was mindful of this as I listened to participant narratives and endeavored to lead with their specific definitions rather than my own.

It is important to note the two salient categories that are crucial to my own positionality in relation to the medical field: standing at the axis of being female and having years of experience with chronic illness. My medical experiences include a series of disbelieving doctors (“You don’t look sick”) and twelve years of misdiagnosis. I saw a fundamental refusal within medical institutions to believe patients. I am also situated in various locations of privilege as a white, educated, cis, middle-class woman. My privileges provided a support system to fall back on while I navigated misdiagnosis and provided a network through which I found a doctor who would eventually listen with sensitivity and curiosity. This exploration required time, money, energy, and social connections. Chronic illnesses are further complicated for many patients by their embodied experiences of race, class, and sexual identity. Neither my personal

experiences nor this thesis have shed sufficient light onto racial and economic considerations, pointing me toward further opportunities to study and uncover the intersection of these categories with health equality.

As a researcher, I have to negotiate my own lived experience in the medical industrial complex, including medical professionals crossing boundaries of dehumanization. I have to manage anger toward individual doctors who categorized physical symptoms as psychological ones. I have to reckon with the systemic misogyny that operates at every level of medical practice, from lab research to diagnosis. These experiences continuously shape my perceptions when dealing with medical personnel. While I strive to mediate the effects my own anger, I also value the information it yields. It gives me a keener view to identify possible sites of inequality and inequity. It has the power to provide insight into patient perceptions that may differ from their provider's perceptions. It allows me to ask questions and explore responses that others may not bring to the situation. Scholars with more research experience have already marked a path, recognizing that "anger is loaded with information and energy" (Lorde, 1981, p. 8) and that love, guilt, and anger can motivate and underpin my writing so that it becomes a manifestation of the real in contrast to the abstract (Behl, 2019). Following their lead, I seek to harness that energy into qualitative, embedded methods and feminist theoretical orientations that have the potential to make visible the power struggles and structures within healthcare.

Methods⁴¹

⁴¹ *tl;dr* – In conducting this study, I used semi-structured interviews with seven participants with ME.

For this study, I recruited seven people with ME to participate in semi-structured interviews. To be eligible for this study, each participant needed to be over the age of 18, meet the diagnostic criteria outlined in the ICC (see Appendix B) via self-reporting, and be currently or formerly housebound. Approval for this study was granted by the Institutional Review Board at Arizona State University.

During recruitment, I communicated with existing contacts in patient support groups. These relationships with community gatekeepers were an important resource in locating individuals to interview. I used purposeful sampling⁴² to create interview environments that are most relevant to the research question at hand. Interviewing participants who are homebound or have previously been homebound offers a perspective of the lived experience of ME that is not often reflected in the medical literature. Current college students, clinic patient lists, or those who respond to a survey are often the main population utilized for patient studies. These populations tend to reflect the experiences of the healthier segment of patients, not the more afflicted group. Conducting in-home interviews that take a participant's physical endurance into account is one way to balance this oversight. Digging into theory-based considerations contributed to the way I approached participant recruitment. Home visits, personal interaction, and reflexivity are key considerations due to the lack of mobility many patients face. Interviewing participants from absent groups (for example, those who are housebound) has the potential to reveal dynamics of erasure, while participants from groups that *are* regularly represented have the potential to problematize and refine those representations through

⁴² Refer to Table 1 for participant demographics.

their own specific narratives. For these reasons, I focused on recruiting people with ME who are homebound and, whenever possible⁴³, from underrepresented cultural ethnoracial groups⁴⁴. These are the patients whose stories are most often erased and are therefore at the center of my work. Through the gatekeepers, members of the ME community who met these criteria were put in contact with me if they were able to participate.

I chose semi-structured interviews as a means of data collection in order to best meet the needs of the participants. I knew that “close, person-to-person contact” (Schatz, 2009), attuned to their individual needs for rest, would provide a beneficial environment for communication of patient narratives. This knowledge comes from my experiences being embedded in ME patient support communities through community work, an internship, and advocacy with them. The interviews lasted approximately one and a half hours and consisted of open-ended questions designed to explore context-specific meanings of ‘access’, ‘diagnosis’, and ‘recovery’. Each person's medical history contains insight into the way social constructions of illness, institutional narratives, and patterns of dismissal impact people every day.

⁴³ The demographics of the participants in this research still reflect a heavily European-descended female sample, despite efforts to mitigate this pattern.

⁴⁴ Jason, et al. (1999) indicate in their findings that, despite a common misperception that CFS occurs primarily in white populations, higher rates of CFS occur within Latino and African American populations. Jason, et al. use the diagnostic criteria for CFS here, instead of ME, because of the historical time period of their research.

Table 1 <i>Participant Demographics</i>					
	<u>Mobility¹</u>	<u>Gender</u>	<u>Age</u>	<u>Ethnoracial Group</u>	<u>Marital Status</u>
Adaline	Housebound Semi-bedbound	W	47	European-descended American	Married
Ashanti	Housebound Bedbound	W	38	African American	Single
Cheryl	Semi-housebound	W	53	Mixed race ²	Married
Elizabeth	Semi-housebound Semi-bedbound	W	41	European-descended American	Single
Karen	Employed, fulltime Semi-housebound	W	52	European-descended American	Divorced
Kelli	Semi-housebound	W	56	European-descended American	Married
Lena	Housebound Mostly bedbound	W	46	European-descended American	Divorced
<p>¹ Mobility terms and definitions Definitions of Housebound— <i>Fully-housebound:</i> Due to symptoms, spends essentially all their time within their home, leaving only for the most necessary activities, such as medical appointments.</p> <p><i>Housebound:</i> Due to symptoms, spends a clear majority of their time within their home. Leaves their home rarely (a couple times a month), for medical appointments, errands, or special occasions.</p> <p><i>Semi-housebound:</i> Able to spend part of the day out and about, while still having substantial periods of time within their home.</p> <p>Definitions of Bedbound— <i>Fully-bedbound:</i> Due to symptoms, spends all their time laying down.</p> <p><i>Bedbound:</i> Due to symptoms, spends most of their day-time hours laying down, leaving only for necessities.</p> <p><i>Semi-bedbound:</i> Able to spend part of the day upright within their home.</p>					
<p>² Latina/Sub-Saharan African/European-descended American</p>					

Each participant in this study is referred to by a self-selected pseudonym, as shown in Table 1. Each of the seven participants identify as women, therefore that is the term I use when describing them. The average age of this sample is 47, with the youngest being 38-years-old and the oldest being 56-years-old. The average age of onset nationally is 33 (NAS, 2015), indicating that this sample encompasses the experiences of people with ME who are older than the average time of onset and have more years of experience dealing with the illness.

The term ‘ethnoracial groups’ recognizes that race and ethnicity are socially constructed categories with material implications that affect everyday life. European-descended American is my term of choice over white or caucasian because of the latter terms’ rampant misuse in medical literature, which normalizes the categories of race as biologically determined, rather than socially constructed. This misuse also occurs in the form of categorizing populations as either white or non-white, a practice that centers and normalizes whiteness, and collapses all other distinctions.⁴⁵

Throughout the writing and revision process, I engage in ‘member-checking’ (Shwartz-Shea & Yanow, 2012). Each person I interview is a co-collaborator in the generation on the final thesis product (Galleta, 2013). Primarily via email, and less frequently via videoconference and phone calls, I brought my analysis and writing to the participant, listened to their feedback, asked clarifying or deepening questions, and

⁴⁵ I came to these conclusions about the use of ethnoracial terms after conducting a review of each article in volumes 3 - 5 (2016 - 2018) in *Lupus Science and Medicine*, a peer-reviewed medical journal, identifying how each published article handled ethnoracial terms and considerations.

incorporated all this into the formation of each chapter. This process of member-checking brings their own voice more fully to the project and insures that their situated viewpoint is reflected in the writing by using their nuances of understanding which may differ from my own. This reciprocity between researcher and participant is foundational to the construction of meaning in this thesis.

The stories⁴⁶ that these participants shared about their personal experiences contain key insights into what goes astray in medical policies, beliefs, and systems; they also contain insights that can lead to transformative actions to make medical encounters more of a partnership between patient and medical provider, and thus more effective and humane rather than condescending, dismissive and oppressive.

⁴⁶ A note on edits made to the original transcripts of each interview: When quoting participant interviews in the text, I removed the following extraneous phrases in order to maintain clarity: "I mean", "you know", "um", and "like". When "like" was used the same way as "for example", I kept it. When "like" was used in the same way as "um", I deleted it.

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CHAPTER 2

THE LIVED EXPERIENCE OF ME

“It was a lifesaver just to have somebody understand what I was going through”⁴⁷

Throughout this chapter I will explore the lived experiences of seven women with ME in order to understand their day-to-day lives, the changes ME brought to their lives, and the ways they balance rest and exertion. Knowledge about the lived experience of people with myalgic encephalomyelitis is key to creating more informed healthcare practices. People with ME already hold valuable knowledge about this disease. A crucial element of building from an interpretivist framework is centering the voices of the seven people with ME who participated in this project. Each participant shared the details of their day-to-day lives, which reveal both broad themes and subtle nuances integral to understanding the reality of living with this disease.

What does it mean to live with myalgic encephalomyelitis? Elizabeth, a biochemist, describes her symptoms in this way: “It's sort of that feeling that you have when you have a fever or the flu or something and your body just aches. That's how I feel most of the time.”

Adaline, a 47-year-old college instructor and marketing professional, categorizes her days in this way: “On a bad day, I'm pretty much in bed... no noise, no stimulation. On a decent day, I can do stuff at my desk. If I have a really, really good day, which is

⁴⁷ Quoted from Kelli's interview.

tl;dr - Direct quotes from each interview participant give an overview of life with ME

where we might actually go out and have dinner, that's maybe once a month, if I'm lucky.”

Ashanti, a 38-year-old registered nurse, shares what it's like to communicate with the people in her life about her illness:

I actually tell them that I know what I experience is incomprehensible to them and that it's incomprehensible to anyone who has never experienced uncontrollable body failure. Healthy people really struggle to wrap their brain around chronic illness and how it affects us ... they think, oh I'm tired today, and that that's the same as what I feel on the day-to-day.

Kelli, a 56-year-old journalist and grandmother, finds it similarly difficult to get others to understand what her experience is really like: “People don't realize that I'm in bed eleven hours a night generally, and another nine or ten hours either lying down, reclining, or sleeping. Takes a lot out of your day. I just don't have the kind of time that I used to, even when I'm awake.” In Kelli’s search for medical treatment she encountered physicians, nurses, family members, and others who had no knowledge of myalgic encephalomyelitis. Her symptoms became more and more disabling as her search for care continued to yield ineffective responses from her doctors. By chance her daughter heard a segment on NPR about ME; she called Kelli and said, “Mom, I think this is what you have.” That kernel of information helped Kelli find a doctor who was knowledgeable about ME. “It was a lifesaver just to have somebody understand what I was going through and not feel like a strange—a person with a bunch of strange symptoms.”

Many people with chronic illness experience isolation after the traumatic life event of illness onset, both of which are common risk factors for suicide. Suicide among chronic illness patients is an important discussion that was beyond the scope of this

study; however, research on this topic is urgently needed. Currently, recorded data about the rate of suicide in populations with ME is limited⁴⁸. The topic itself is fraught due to decades of work to destigmatize ME and distance it from being viewed as psychosomatic (Gilman, 2015; Spandler; 2018). Self-described observations by the ME community members indicate that patient support groups often deal with suicidal ideation, with limited resources at hand⁴⁹. Further research is needed; specific interventions need to be developed and implemented as part of chronic illness care. See Appendix D Suicide in Chronic Illness Communities for participant commentary on the topic of suicide.

The experience of living with ME changes over time, with periods of intense and/or debilitating symptoms (often referred to as ‘crashes⁵⁰’) and periods of less intense symptoms. Cheryl, a registered nurse who specialized in psychiatry, summarizes her life during particularly difficult crashes:

At my worst, I was homebound and nearly bed bound. I had only about four hours a day of being upright—sitting or standing—and could not shower daily, help with chores or cooking, or go out for anything but medical appointments. If I exceeded my limits, I could crash for two weeks and up to a month at a time.

For Lena, a 46-year-old health advocate and mother of three, the onset of ME was sudden and extreme: “I couldn’t even speak. I couldn’t do anything. I was basically in a

⁴⁸ See Devendorf, McManimen, & Jason, 2018 for some of the available data.

⁴⁹ In Adaline’s experience, “patient support groups have NO resources. The only resource we have is each other.”

⁵⁰ Elizabeth adds nuance to the usage of ‘crash’, extending the meaning to day-by-day highs and lows, not just the “longer-term low points in a person’s disease experience.” She further notes, “for me, a ‘crash’ can be what happens after I do too much in day or week ... I’d say I ‘crash’ regularly, sometimes even daily, whereas my worst [period of] disease was in the first year and perhaps a few periods of a few months each since then.”

coma, except I was alive and suffering enormously. I was just praying to get through hour to hour physically because I couldn't speak, I couldn't move, I couldn't do anything.”

Karen, a 52-year-old educational director, says that life with ME means being “always sick, always tired.” The pervasiveness of ME in their lives showed up in unexpected ways as well; not just in the stories shared with me, but imbedded in the conversations as we talked together:

... [clears throat, coughs] *excuse me—yeah, my voice struggles with ME; this is a part of life with ME, so you'll hear me clearing my voice and my voice will weaken and teeter...*

... *Now I lost my train of thought because—that's the brain fog...*

... *sorry, my brain is failing me again ...*⁵¹

These types of brain fog symptoms are just one facet of the daily experience of living with ME. Because of the physical symptoms these participants deal with, they have each developed ways to balance the demands of their illness with the demands of everyday life.

Exertion, Payback, & Rest: The Balancing Act⁵²

Kelli: I was already figuring parts of it out. I figured out that if I did anything on one day then I was useless the next. Not just the next, maybe for three weeks. I could already make a correlation between any activity or stress or anything and some sort of payback.

⁵¹ Quoted from Ashanti's interview.

⁵² *tl;dr - Exertion, Payback, & Rest: The Balancing Act* - People with ME are careful about overexertion in order to minimize crashes. Rest serves the purpose of counterbalancing physical or cognitive activity, to the degree it is possible. Restorative, scheduled, and pre-emptive rest are some of the types of rest that participants utilize.

Cheryl: If I exceeded my limits, I could crash for two weeks and up to a month at a time.

Elizabeth: I would say most days I had spent about 50, at least 50% of my day lying down, of my waking hours, lying down. And then the rest of it will be mostly just kind of getting basic stuff done around the house.

Part of the illness experience that ‘healthy’ people in the participants’ lives struggle to understand are the consequences of engaging in physical or cognitive exertion. The consequence for over-exerting is a ‘crash’: a state of neuroimmune exhaustion with a flare up of symptoms, often resulting in being bed-bound for stretches of time.

Woven through every decision about exertion is the unremitting need for rest. To be very clear, rest does not result in renewed strength and it does not neutralize post-exertional neuroimmune exhaustion. Rest serves solely to avoid overexertion. Once neuroimmune exhaustion kicks in it is a different story.

Kelli: Rest does not help me feel better. I don't rest and regroup, then rise with more energy, as I used to. Instead, ‘resting’ is what I'm doing when I'm not utilizing the tiny amount of energy I have. During a crash, there is less energy, so there is more ‘resting’. In other words, I rest because I can't do anything else, and because if I am foolish enough to push through my energy envelope, I'll need even more rest in the days and weeks that follow.

People with ME and other chronic illnesses utilize different modes of rest. Often, they will have routine-based *scheduled rest* at the same time each day no matter what else is going on. They may prepare for an activity beforehand by doing *pre-emptive rest* or they may compensate after a strenuous activity with *restorative rest*, as Cheryl describes:

I can also do restorative rest after an activity. If I have my hour rest this morning and then we do this interview and then I decide okay, I'm going to grab a walk before it gets dark, and I take a walk and then I come back and I'm like, wow, I

feel a little symptomatic, like have a little pain or feeling really tired or my brain feels a little foggy; I will rest.

Some periods of rest focus on limiting physical and/or cognitive activity; this may or may not include sleep. Other forms of rest focus on reducing or eliminating sensory stimuli.

Figuring out *how* to rest, and how important it is, plays a large role in the transition from pre-illness:

Cheryl: I realized every day—and it would happen usually by noon—I was hitting a wall ... If I got up and took a shower, which normally when I was healthy I could take two or three showers a day and it didn't bother me, but if I got up and took a shower I would have to lay back down.

Because of physical and cognitive exertion limitations, people with ME are mindful about the activities they give their energy to. They carefully choose which tasks are the most important.

Among the seven interviewees, everyone had different responses when it came to what types of activities they prioritized, revealing the diverse lives of people with ME.

Some of the top priorities that emerged are (not listed in order of importance):

- Physical activity, such as taking a walk every day
- Cognitive activity, such as reading and community advocacy
- Maintaining relationships with family and friends
- Career and continuing education
- Art and concerts
- Taking care of their children

Making space for things that specifically bring them joy, and supplementing with rest before and after, guides each person as they plan their days. While the specific priorities vary from person to person, the necessity of consciously planning for those activities

remains constant. Planning ahead often includes reserving an entire day, several days, or weeks in order to make their priorities achievable.

In addition to holding different priorities, each of the seven women have their own methods for balancing exertion with rest in order to avoid the most severe consequences of over-exertion. Scheduling in large chunks of time to rest is a major factor, but people with ME also use other techniques to make it through the tasks of the day.

Many people with chronic illness, including the interview participants in this study, use *activity-shifting*. This is a pacing strategy which consists of alternating short bursts of exertion with rest and also “switching between different activities that require different types of energy”; for example, “do a cognitive task, then do a physical task, rather than two physical tasks in a row.”⁵³ This requires the person to have an accurate awareness of their own crash patterns in order to calibrate this successfully.

Adaline: It took a while to find people like me who could teach me about pacing and planning. Because that's not something that is really shared or taught in disability world in general.

Participants reported using activity-shifting in two ways: short-term and long-term.

Short-term activity-shifting is used hourly; a few minutes of exertion followed by rest; or switching between varying levels of cognitive and physical exertion. Long-term activity-shifting is used at the daily or weekly level; an intensive day preceded or followed by a day of minimum exertion. Kelli describes her long-term use of activity shifting with this example:

⁵³ Quoted from Elizabeth.

Interviewer: On the days when you do things with your daughter do you take other activities out?

Kelli: Yes, I do balance it. I will have big rest spaces between ... I'm going to take my four-year-old granddaughter, pick her up from preschool, and do something with her and feed her lunch and take her back to her mom ... I will rest as much as I can before something like that. And then I will know I'm probably not going to get anything else done that day. I'll still pay, but I'm trying to get some life in.

On a short-term scale, Karen alternates work with “a 15-to-20-minute rest period; lights out, covered eyes, earplugs.” This pattern of alternating rest and exertion is key to these women’s management of ME symptoms.

Other techniques used to compensate for symptoms include:

- Making lists on their phone
- Taking notes to process small chunks of information
- Calling to get information about insurance instead of reading long descriptions
- Outsourcing household tasks like cleaning and cooking⁵⁴
- Documenting symptoms and events to make up for poor memory
- Using assistive devices: wheelchair, shower chair, walker, or spinal/wrist brace
- Resting in areas where their family members are near, for social engagement
- Laying down (rest) while talking (exertion)
- Scheduling showers

Even with a pattern of activity shifting, conserving energy is needed as well. This means refraining from certain activities or tasks, going slow, laying down while talking, and avoiding/missing social events. As Karen puts it: “I do those things to conserve energy.”

In addition to individualized techniques, all seven interviewees talked about their family support structure as a key element to their survival. Close family members stepped in to fulfil the tasks that ME made impossible for the participants to continue to do. One

⁵⁴ Hiring out household tasks requires a level of financial security that is not available to all people with ME. Systemic social issues of class and wealth inequality impact a person’s ability to utilize many of these compensating measures.

participant organizes her life so that she is able to take care of her own household tasks. The others shared how their family members they live with contribute by taking on the cooking, laundry, shopping, and cleaning. For this group of women, husbands and mothers were the ones who most often stepped into that caretaker role. They express gratitude to be fortunate enough to have these support systems already in place.

Support not only occurs through direct assistance with physical needs, but also through emotional support and understanding. Having family members who know about and truly see their lived reality is important.

Karen: My family sees about 75% of my life, now. They used to only see about 50%. But I've told my mom and dad recently, my brother recently, my son. So, in the last nine to twelve months, slowly, I've been explaining to people and they're getting it and they're supportive. Thank god they're supportive.

Sometimes it is involved family members who know the details of this illness who are able to open the door to getting a diagnosis:

Ashanti: My sisters actually had separately—they hadn't even spoken to each other about it—found information about ME and texted it to me. So, I ended up reading and I'm like, *oh wow*, these symptoms do sound like me.

Kelli: ...the Institute of Medicine's 2015 report on chronic fatigue syndrome came out. My daughter heard about it on NPR. And she called me and she said, "I think that's what you have."

Lack of family and community networks can result in increased stress and worry about meeting the basic necessities of life. After a divorce and a move to a new neighborhood, Lena wondered about what would happen: "I was kind of worried I would have nobody to take care of me." That worry extends to others they know through online communities. Both Adaline and Kelli expressed concern as they considered what might happen to people who don't have family members to fight for them.

Day-to-Day Life

Ashanti: A typical day, I would say, is primarily spent in my bed, the way you see me right now. I'm in my bed, I'm in my pajamas. That is pretty much a typical day for me. If I have a doctor's appointment then I have to get myself together for that, but the majority of my time is spent in my bed.

Early in the interviews, I asked participants to describe a typical day, including what kinds of activities they are able to do and what types of limitations arise. Their responses detailed what might occur in a usual day, what kinds of activities they do, and methods they've developed to balance basic life tasks with their symptoms and physical ability that day.

Routines⁵⁵

While some trends were fairly consistent across the interviews, there are two circumstances of note that only apply to a couple of the participants. First, Karen is the only participant who is currently employed, so many of her routines center on managing her energy on the job, including making time for rest in her office. Second, Ashanti and Lena have young/teenage children at home, so their experiences are impacted by daily tasks that relate to child care.

Two participants offered the exact same caveat before describing the day-to-day conditions of their lives: "every day is different".

Interviewer: "Will you walk me through a typical day for you?"

Adaline: "Quite honestly, there is no typical day for me. Every day is different. I never know how I'm going to feel."

Interviewer: "Would you walk me through a typical day for you?"

⁵⁵ *tl;dr - Routines* - While day-to-day routines differ between each person with ME, common concerns include managing energy output and symptoms. Large portions of the day are dedicated to rest.

Elizabeth: “Oh gosh ... every day is different.”

Morning routines. A typical morning consists of waking up, taking pills⁵⁶ and supplements, eating a light breakfast, resting, brief online activity, child care, and light exercise or stretching. The wake-up times among the participants varies widely. While their wake-up times differ, many report that they wake unrefreshed, in pain, and stiff. Unrefreshing and inconsistent sleep patterns are one of the hallmarks of ME⁵⁷ (Carruthers, et al., 2011) and this is reflected in the interviews, as participants note that falling and staying asleep can be a difficult aspect of their lives.

On better days, this morning routine could also include small chores (i.e. laundry, vacuum, dishes, pet care) and hygiene activities (i.e. showering, getting dressed). For the two participants with children at home, child care tasks were the focus and priority of the day. These activities are often done in brief chunks, such as fifteen minutes of work at a time, with rest between each chunk. Every participant brought up resting in some form (in bed or on a sofa, sitting quietly, reclining, meditating) especially after describing their engagement in household chores. Physical activity in the mornings is particularly gentle, with an emphasis on stretching and yoga.

The topic of rest came up in every interview as participants talked about their morning routines. Participants shared how difficult it was to adjust to the need for this level of physical and cognitive rest.

⁵⁶ One healthcare routine that impacts the entire day is taking medications at certain times. This requires physical and mental effort and may determine eating patterns too if the medication needs to be taken with food. This results in the day revolving around when medications need to be taken. [Noted by Adaline.]

⁵⁷ See Appendix B International Consensus Criteria.

Lena: So, in the meantime I go back to bed, because I need as much rest as possible. Sometimes I'll sleep, sometimes I won't, it depends, and I'll just lay in bed for a while, until probably 10 o'clock, sometimes later, sometimes 11, sometimes 12, depending on how sick I am that day.

Kelli: I head back to either my sofa or my bed and I lay on top of it reclining with my computer with very little getting up.

Karen: I always go back and lay in my bed.

Elizabeth: At that point, I'm generally pretty exhausted and I need to get back in bed or on the couch and just rest for a bit.

Adaline: On a bad day, I'm pretty much in bed . . . no noise, no stimulation. Being in bed or reclined on a sofa often created frustration at first, followed by a process of understanding that rest allows them to do everything else throughout the rest of the day.

Daytime routines. From approximately late morning to dinner time, daily activities frequently center on rest, basic chores, managing medical logistics, and limited online activity. Doctor's appointments and clinic visits also take up a significant amount of daytime energy, which participants plan for throughout the week. Again, rest plays the largest role throughout the day and most particularly during daytime routines, as will be discussed later. Any physical activity is counterbalanced with laying down on a bed, a yoga mat, or a sofa.

Basic chores done throughout the afternoon include changing laundry from the washer to the dryer (folding the clothes too, if it is a particularly good day), feeding pets, washing dishes, and general chores around the house. These are accomplished in short spurts with rest in between, as described by Cheryl:

... if I know I'm going to be home for the day, I might do some chores around the house. I typically will break things up into small chunks and maybe spend 15 to

30 minutes doing some kind of chore. Could be a load of laundry, could be clean one bathroom, or vacuum one area, or sweep the kitchen floor, you know, small tasks.

Cognitive activities were often brought up in the context of daytime priorities.

Some participants indicated involvement in volunteer work with patient advocacy groups or other online activity during the afternoons. They may play word games or other cognitive exercises, make phone calls, answer emails, or manage medical appointments and insurance issues. This work requires cognitive exertion which, like physical exertion, must be counterbalanced with rest.

Evening routines. When talking about their end-of-day routines, participants brought up dinner, going out (or *not* going out), low-key activities, and bedtime. Dinnertime looks different for all of the participants, depending on who is in their household. Some eat with their families, some have a very light dinner before bed, some use their allotted energy on meal prep, and some do not, but dinner remains a daily activity that requires some degree of attention.

Participants commented on their ability to go out in the evenings with friends or family once a week, once a month, or almost never, depending on their symptoms. Elizabeth, who leaves the house approximately two - five times a week, reserves energy for restorative service and exercise: "One night a week I often go to [do volunteer work]." Ashanti shared that being "sick and trapped in your house, it's hard to get out. I'm not saying I'm never able to leave my house besides doctor appointments but it's very rare." For these participants, evenings commonly consist of a little food, a little television, and settling into bed by 8 or 9pm, although actual sleep may occur much later.

These morning, daytime, and evening routines reveal a group of people doing what they can with what they have. This requires razor-sharp attention to their current energy levels to calibrate an appropriate balance of exertion and rest. They are likely to overdo it, push themselves further than their bodies allow, and pay for it with symptom flares. Over time their expertise about their own bodies has become a well-honed craft.

These routines also hold undercurrents of grief and joy, frustration and satisfaction, over the difficulty of tasks that used to be mundane and the accomplishment of small victories. Cheryl described it this way:

I've got[ten] a little bit better about that, like now it sort of gives me a sense of accomplishment when I—when I mopped all the floors the other day I was like, *oh the floors look really nice!* And I feel like I've done something productive. So, it's helpful to sort of reframe stuff that you used to not enjoy to be more enjoyable now, just like, *oh my gosh, remember three years ago I could never mop a floor.* I had to—I remember having to sit down to fold laundry, like sit down next to the dryer and pull the clothes out and put them on hangers and fold them right there. I couldn't stand and do laundry.

Many participants communicated the importance of recognizing their own progress within the context of learning to live with their illness.

Boundaries Around Exertion⁵⁸

Cheryl: The most benign activity is taxing to your energy.

Lena: In terms of like physical activity and stuff, I can't really do anything. You know, the only thing I can really do is talk a little bit to people sometimes but even that really wears me out. I can't do it too much.

⁵⁸ *tl;dr - Boundaries Around Exertion* - Living with Post-exertional Neuroimmune Exhaustion (PENE) means that physical and cognitive activities (such as hygiene, online tasks, advocacy, emotional labor, and sensory input) take a serious toll and must be accounted for.

Kelli: ... everything used to be easy, you know, like cleaning the bathroom. Everything was easy ... Now I'm generally lying down twenty hours or more a day.

For people with ME, exertion of any type requires careful planning and awareness because of the consequences of overdoing it. This is the reality of living with post-exertional neuroimmune exhaustion. Even basic fine motor skills, like lifting light objects, can be affected. As Adaline notes: "I have trouble with my grip and I drop things. We like antique stuff and I've broken our vintage glasses because it's just fallen out of my hand." Any exertion (physical, cognitive, emotional, sensory) must be accounted for.

Pain. Interrelated with exertion is physical pain. In one of the interviews the word 'pain' did not come up at all, and in another it was used twenty-three times. In one, the word 'pain' was used solely to describe chest pain, and in another it only came up when the participant described the pain of swallowing. Pain often came up in descriptions of symptom flares, such as:

Adaline: I'm generally too weak to stand at a stove or it just causes such a pain flare that it's really impossible.

Elizabeth: I don't know if I have brain fog. All I know is sometimes I'm so tired that that kind of activity causes my pain and other symptoms to get worse.

Seeing doctors for pain often pre-dated their ME diagnosis. They sought out pain-specific treatments, often with no success, as their symptoms worsened.

Hygiene. One of the most commented-on physical activities throughout the interviews was the topic of showering. The physical energy required to take a shower

makes this hygiene task an important topic of conversation that reveals the boundaries of physical exertion that each participant lives with.

Adaline: Showers. I really only shower every once—once every week or two. It's just, it's one of those activities that is so exhausting. And I have to plan for it. I have to go, okay, so on this day, I'm going to see a doctor, so I probably don't want to be completely stinky, so let's keep the day before clear so that I can shower ... and that's my day, is showering.

Interviewer: Just the one thing.

Adaline: Yeah. Which sucks, but that's, you know, kind of the way it is.

The topic of showering came up over and over again. It is a task that most took for granted and it now looms as a major activity. Showering becomes a gauge or a benchmark of well-being, as Cheryl expressed in her sum up about her most difficult crashes, by including the inability to shower regularly as the indicator of her mobility level. The inability to perform this personal act of bodily care sat heavily on the minds and hearts of many of the participants. Even during periods of physical improvement Cheryl found that, “one of the issues that was really clear to me was any time I took a shower it wiped me out.” She turned to her online community of people with ME and drew on their shared knowledge. (“It’s POTS⁵⁹!). They told her lovingly, “... *get a shower stool dum-dum*. I was like, oh you can get one on Amazon for 20 bucks. I got a shower stool and that really made a huge difference.” Sitting often helps people with ME to complete hygiene tasks. Ashanti sits on her walker at her vanity to do her hair and also

⁵⁹ Postural Orthostatic Tachycardia Syndrome (POTS) is commonly co-morbid with ME. People with POTS have trouble standing because the nervous system fails to send the appropriate signals to the cardiovascular system to counteract gravity, causing blood to pool in the legs instead of carrying needed oxygen to the rest of the body including the brain.

uses a chair for showering, as she notes here: “Occasionally I am able to shower. I do use a shower chair, and even with the shower chair, while sitting, my heart rate is usually in the 140s to the 150s.”

Karen manages getting ready in the morning “basically through stages, through my makeup and dressing. Some days, I wear more makeup than others, some days I don't wash my hair, I'll use a dry shampoo, you know, I do those things to conserve energy”. And alternating activity with rest is key. Karen has had to adapt to this and notes that after showering, “I always go back and lay in my bed”. Planning ahead and putting showers on the calendar helps too. For Elizabeth, “to shower and wash my hair is a big twice weekly event that I kind of plan into my schedule.”

Cognition. The ability to remember, the ability to read, and the ability to retrieve words are issues that arise daily for these seven women. Cognitive tasks, like physical activity, must be planned for.

Elizabeth: ... cognitive work, particularly anything that I'm doing with my activism with MEAction and anything related to ME, puts me into ... reading the literature or thinking about the science in some way. **And that will definitely crash me way faster than any other effort.** And I think it's a combination of ... just being on a screen ... it's just the cognitive effort of doing science or reading science and thinking about science is harder. And I've had a few times in the last few months where I didn't think I did that much, I was lying down, just reading a science paper, but then it took me a week to recover from it. So I had a really bad crash and then took a week or two to get back to baseline and—and just realize, *oh!* And then after that happened a few times, it was like, *right, I need to be really careful about cognitive because I think that I'm just lying down but it turns out that I really am—yeah—exerting!*

Throughout their daily routines, most participants included descriptions of their cognitive tasks, such as online activity, processing the sensory input from television or music, calling doctor's offices, and communicating with others by email or phone.

Rationing cognitive activities helps to mitigate the negative effects of overdoing it, but there are some aspects of cognition that participants have lost and often grieve that loss.

Cheryl: I don't have creativity. I can't generate ideas about what to get for people—what my nieces and nephew might want for Christmas ... it's probably going to be gift cards for everyone and that makes me sad. I used to have a brain that I could think of something and I just—I don't have it anymore. It's gone.

Not only is the loss of creativity and memory an issue, so is the ability to negotiate healthcare decisions, as highlighted in this conversation with Ashanti:

Interviewer: How has that been, navigating that whole web of decisions and signing on and paperwork [for insurance plans], while also navigating your physical symptoms?

Ashanti: Very difficult. Extremely difficult. Sometimes I just don't have the brain capacity to even absorb ... like, okay this plan does this, and this one does this, this, and this. Like what? What are you saying? It's too much. I can't ... The thing is this, I was very smart before I became sick. Although to those people who don't know me, I still appear smart, I know that my brain is not functioning anywhere near the level of function that it was pre-illness. Nowhere near ... I used to have a photographic memory. That's all gone. My ability to focus, concentrate, my ability to read—I used to love to read. Literally, I cannot read anymore. I cannot absorb what's on the paper. Like, I can say the words. The words I can actually read, if I have to read out loud. If you ask me what I just read, I don't know.

Elizabeth also notes: “I would say emotional effort also counts as exertion ... life is challenging for all humans and doubly so for having cognitive—for having chronic illness ... and stigmatized misunderstood chronic illness.” People with chronic illness

have to deal with the physical symptoms of the disease but there is also an emotional element of grief and loss when things that were once easy become huge obstacles.

Lena: Yes. Yeah, even just the other day I had my one of my friends who has ME message me about how tough of a time she's having and she's dealing with other things too, like everybody does, and it's a really hard time for her—but also the disease compounds everything.

Elizabeth shares how stressful the process of applying for disability status and social services is; just thinking about that process represents an emotional load. She tries not to let it take too much of her energy.

Elizabeth: For me—it's always about just figuring out how to fill those most important niches. And I think, yeah, having a cognitive life—I'm very grateful that I'm able to. There have been times ... when I'm particularly unwell, where word-finding is a little bit of a problem or short-term memory. Like I'll open a web browser and then literally from the second that I was like, *oh I should look up X*, and then I open the browser, and I'm literally on my computer, so it's a second that I've clicked a button and the browser comes up and I can't remember what it was I was going to look up. And then it'll take me five or ten minutes to come back and realize, *oh it was X* ... that never happened to me before ... I would say I don't always have that problem, I think it's more when I'm particularly unwell or pushing myself or—I don't know. I mean, there's so many variables.

The terminology around these symptoms is used differently among people with ME, who may gravitate toward some terms and reject others.

Elizabeth: I don't know what this term brain fog means—still means nothing to me. I don't know if I have brain fog. All I know is sometimes I'm so tired that that kind of activity causes my pain and other symptoms to get worse. And sometimes I just can't do it. I can't make myself do it, because I'm so tired. But it feels more like the pain and the fatigue are what limit me cognitively, both in terms of reading or listening to music or those kinds of things, ... it was hard for me to kind of relate my symptoms to what I was hearing from other people. Just because of the way that it looks so different in different people.

Cognitive exhaustion affects each person differently, and so do environmental sensory factors.

Sensory Stimuli. Some have found that limiting stimuli from light, noise, and scents helps to maintain their well-being. Too much stimuli from any of those sources can exacerbate symptoms. For example, Cheryl related an experience of encountering strong scents and perfumes at work that made her pain worse. She also notes that playing music in the background makes it difficult to have a conversation because it means doing two cognitive activities at once (processing the musical sound *and* attending to the conversation). She's learned to do just one thing at a time. The same can be true for light and visual stimulation, as Cheryl wears blue blockers when using devices with screens to cut out the extra sensory stimuli. However, not all experiences around light and sound are consistent. During periods of post-exertional neuroimmune exhaustion, light sensitivity is particularly problematic for Elizabeth. She says "... if I'm doing well then sound and light don't bother me" and in regard to stimuli from sound, "it's mostly just the effort that it takes to process the sound, like somehow that's actually the problem ...it's like it's asking energy of me that I just don't have." The process of taking in sensory stimuli is often thought of (or not thought of) as unconscious, but it does require exertion and therefore becomes a topic of importance for people with ME.

Changes

When the women I interviewed described their lives before their illness began, they talked about being active, busy, hard-working, and fit. They worked as nurses pulling 12-hour overnight shifts, as entrepreneurs keeping their small businesses running,

as university faculty and staff mentoring students and researching. A high-activity lifestyle⁶⁰ functioned as part of their self-formation. And then everything changed.

Onset⁶¹

‘Onset’ refers to the period of time that marks the transition from pre-illness to illness. Some people with ME experience sudden onset and some experience gradual onset. Some have adolescent onset and some develop symptoms later in life. Of the seven participants in this study, six commented on viral infections at the time of onset or just previous.

Six women who participated in this research talked about the onset of their illness in the context of work. They spoke about their employment, their experiences on the job, the tasks they suddenly struggled to complete, and the logistics of remaining at work versus leaving. Here are three of their onset stories in their own words.

Ashanti. "Some people I know get sick gradually. For me, it was like an instant ... My last night shift was August 10th, 2016 and my symptoms began a few days after that ... *Interviewer:* And you weren't able to return to work after that? *Ashanti:* Yup. That's why I say, for me it was like getting run over by a train, because once I was hit, that was it. I never recovered. I never went back to work for one day, for one hour, nothing. That was it. That was my last night shift ever."

⁶⁰ When reports of viral outbreaks and chronic fatigue syndrome hit the news in the 1980s (see ‘Yuppie flu’ in the Literature Review), the rebuttal from medical institutions was: *this is what you get for upending social norms and gender roles in order to pursue careers; you wanted it all and you burned out; that's what you get* (see Dusenbery, 2018, pp. 259-262). This response, while sounding wildly out of place today, continues to have harmful implications and continues to reverberate through clinician beliefs. One participant in this study indicated that she still encounters this idea.

⁶¹ *tl;dr - Onset* - Participants share their personal stories about when their symptoms started.

Elizabeth. "I had a gradual onset ... at that time I was a postdoctoral fellow [in biochemistry] ... I took five days right after I finished my postdoc and I rested ... I just rested for five days straight. I slept a lot of the day. I didn't even read that much. I was just so, so tired. But I got better and went back to my very active life ... I would every once and awhile dip into this deep tiredness. But I would rest and I would come back out and be able to be totally physically active. So, it wasn't until 2014 that rest didn't seem to make a difference anymore ... I started thinking, I need to do another deep resting, because I'm feeling really tired. And I did that over ... the summer after I started as a tenure-track faculty member ... I was at a small undergraduate institution, so—but they had very high standards for research and publications and all that. So, yes, I had students in my lab but I wasn't teaching and that was a huge shift ... so then I try to rest over the summer. I felt like I had rested a bit but I started the fall feeling tired. And then I started getting lots of infections ... I knew something was wrong ... feeling just so exhausted all the time. And in a way that felt different from just normal tired, like everybody's tired and everybody's overworked but this just felt like a whole other dimension of tired.

And then I started prepping ... and I was trying to help a friend, a colleague friend who—we were going to co-teach a class together—and I was trying to—he was the main one and I was assisting—and I just kept finding I ... physically couldn't move. And I realized I was just dropping the ball so badly and I was like, I can't do this, I'm barely able to get out of bed. So, I went on medical leave. And I ended up being on medical leave for a year ... I had a lot of friends who were junior faculty with me ... I had some people bring me food, mostly because they offered, but some because I asked, I think. So

that was the main thing, was just people bringing me food. And I had a friend who took me to at least one doctor's appointment that was kind of far away and that was most of it ... I was somehow getting by. I don't really know how ... the whole time is sort of a blur.”

Cheryl. “One of the problems I had was just chronic pain and I was having terrible pain in my tailbone and my hips and both my arms. I had tennis elbow in both arms. And I worked in a psychiatric emergency room, which was a very busy place anyway, and a lot of what I did was running around, but I also sat a lot for documentation purposes and to interview patients. And so, I decided that standing would be better for my pain. So I ... asked for a stand-up desk. They actually installed one that folded out from the wall where I could stand and do my charting ... so I tried just standing through my shift thinking that was better for me. And then I literally became disabled at work during a shift where cognitively I could not function. I could not fax a document and that's something that I would do hundreds of times during a shift, it was so second nature. And I tried like ten times to fax this document and finally the clerk that was sitting in front of me turned around and she's like, ‘Cheryl what's—what's going on? What's the problem?’ She's hearing the fax machine make these rejection noises or whatever. She's like, ‘What's going on with you?’

And I'm like, ‘I'm not—you know—call the supervisor, I'm not doing well.’

Because here I am, I'm the charge nurse. I'm supposed to not only be supervising staff but make sure that the milieu of the unit is safe, and dealing with the police that are coming in, the ambulances that are coming in, all the stuff that's going on. And I can't even fax a simple document. Something was really wrong. And that's the last shift I ever

worked. I didn't know it at the time, but I never went back. The supervisor came and relieved me so that I could leave. And I went to the doctor the next day and that was the beginning of all the nightmare."

These women were involved in high-intensity jobs. When the symptoms of ME first started appearing, those jobs became unfeasible, no matter how much they fought it. Two participants used the same phrasing to emphasize the toll that their jobs took as they continued to work through their increasingly debilitating symptoms: "I broke." They worked until they physically couldn't anymore.

Transitions⁶²

Lena: All the ripple effects ... obviously it was incredibly difficult emotionally, psychologically, mentally, financially, socially, pretty much any way possible. It was very, very difficult. I just had to struggle to adapt.

The onset of debilitating illness brings a host of changes and shifts that people with ME navigate as they adapt to unfamiliar conditions. They have to get used to a new kind of body that is frequently bedbound, quite different from the active one that traveled and cross-trained and worked. Tasks that were once easy, like showering or cooking, become difficult. It takes time to accept the realities of a paced, measured lifestyle; a lifestyle they did not choose but now have to navigate.

The shift from independence to dependence on caregivers is a particularly difficult one. Losing the ability to be self-sufficient weighed heavily in many of the stories from the interviewees.

⁶² *tl;dr - Transitions* - People with ME navigate many changes, such as the transition from an independent lifestyle to dependence on caretakers and reframing their beliefs about health and personal worth.

Ashanti: You know, this illness [took] away my independence which has been, for me, one of the biggest challenges. I've always been independent ... I've never asked for help ... When you're chronically ill, that thought process goes out the window. I desperately need help. And I've gotten better at asking for help. I still really struggle, because for my whole life I didn't live like that. I would handle all of my business all on my own, being a single mom while going to nursing school, etc etc, I've always done it. So, to have my independence taken away has really, really, really been difficult.

Adaline: I was a writer and editor. Well, guess what? Cognitive issues. Brain fog. I was an artist and photographer. My hands don't work anymore. I can't paint. I can't hold my camera because it hurts so bad. I did marketing. I did events. I can't do an event now, like, there's no way in hell.

Their physical bodies react differently to exertion than they are used to. Ashanti compares her level of exhaustion as a nurse working twelve-hour shifts, sometimes being awake well over twenty-four hours at a time, to her exhaustion levels now with ME:

I was tired then [working as a nurse] and it was exhausting but the level of exhaustion that comes with chronic illness makes that so-called exhaustion look like energy. There [were] nights where I wasn't even able to get a break because I'm chasing my tail the whole night trying to save a baby's life. So that level of exhaustion that I experienced [sometimes being awake well over 24-hours to meet the demands of nursing and motherhood], it really looks like energy compared to the level of exhaustion that comes with this illness.

The shift away from being able to be physically independent not only brings material changes, such as being homebound or having a caretaker, it also impacts internal beliefs.

Participants spoke with me about how living with ME has reframed their beliefs and changed the way they think about the world and themselves.

Adaline: I really had to rewire my whole worldview because of getting sick ... The whole thing is already stacked against sick people ... People act like it's a moral failing that you're sick. And it's been really hard for me to divest myself of

that view. I'm not a bad person because I got sick. It's not my fault I got sick. I'm worth fighting [for] to get the care that I need.

Up until her own illness onset, Cheryl believed that diet, exercise, and stress management would protect her health.

Interviewer: And how would you describe your belief now?

Cheryl: Shit happens [*laughs*]. I mean, I don't know, it's—did I choose this? Hell no. Would I wish it on my worst enemy? Hell no. But did I cause it? Hell no.

Changes in physical ability can result in changes in personality and self-formation. These participants have had to reframe their thinking, create new ways of making decisions, and shift their worldview in order to incorporate what they've learned about living with chronic illness.

“This disease obviously caused a lot of problems⁶³”: Dealing with loss.⁶⁴ With chronic illnesses, including ME, life after onset is drastically different than before. As a life event, it brings with it a period of grief. People with ME often lose their jobs, social contacts, and financial security after the onset of this disease (National Academy of Sciences, 2015). Time is needed to reconstruct their sense of self in the absence of previous activities that contributed to their identity formation.

Cheryl: Grief is a huge part of the illness, right? You lose everything in a very short period of time. It's not like a death. It's like *the* death, you know what I mean?

Interviewer: But you're still alive to watch yourself go through it.

Cheryl: Yeah ... I was grieving hard and I went through all the stages of grief.

⁶³ Quoted from Lena's interview.

⁶⁴ *tl;dr - Dealing with Loss* - Participants share the losses that ME has caused and the period of grief that goes along with that.

On a similar note about going through the stages of grief, Kelli shared her experience of dealing with grief over a long period of time and not being prepared for this particular type of loss in her life.

Kelli: It has been, definitely been, five years of grieving. It has. I think one of the things about this disease is that nobody, nobody, prepared me for this. Because it's not in the news. I knew that I could get a cancer diagnosis or MS or ALS or a stroke or—nobody told me there was a disease that's not going to kill you, but that will take so much away from you, and you will have to fight through illness, possibly every day of your life. Nobody ever said that. So ... it's been kind of a grieving process.

These are just some of the losses that participants reported due to their illness:

- loss of hobbies (hiking, baking, biking, writing, reading)
- loss of professional skills (analysis, writing, photography, teaching)
- loss of ability to walk their dog
- loss of ability to drive a car
- loss of time (having a limited number of active hours in a day)
- loss of job and financial security
- loss of home
- loss of fitness
- loss of relationships (divorce, isolation, missing out on social events)
- loss of memory-function
- loss of self-sufficiency

Participants describe these losses in individual, personal ways.

Kelli: I really miss baking. Just baking ... If I do it, I do it in steps ... I look at the Great British Baking show and I think, I can't do that anymore. I couldn't do something like that. And then you get a little jealous because you're like, they could do that all day, and I can't do anything like that anymore.

Cheryl: I learned the hard way. I kept pushing, I kept trying, I didn't want to lose my fitness. Oh my god, I was a fanatic and yeah, I've lost my fitness and that's okay. It's worth the gains. And I think I'll get it back at some point. I have that optimism.

Lena: [The physician] saw me, diagnosed me with ME/CFS, and sent a letter to [profession] letting them know what was happening, and pronto (snaps fingers)

within hours they dismissed me from work. I was severed and let go ... We lost our housing, my husband lost his job because he had a spousal job, it was dependent on mine, so now that I no longer had a job, he no longer had a job, so we lost both of our jobs, we lost our home, my kids got kicked out of their school.

As Kelli put it simply, “it's a reduced life.” And the loss of employment has the compounding effect of financial insecurity.

Ashanti: It's really a nightmare to say the least. It's really scary for me because I never envisioned not having financial security and stability for myself and for my family. And good health care.

Elizabeth: Right now, even though I do have long-term disability coverage, like benefits, there's ... just the fear that at some point the insurance company will find some dumb excuse that, won't be legitimate, but will be hard to fight and then will kick me off. So, I just feel financially insecure in various ways and I have some personal long-term goals that make the most sense to be in a place with more support.

These losses and the onset of ME also have an impact on family members of the person with ME, particularly their caregivers and their children.

Lena: It was really hard for my kids too. I mean, obviously it's really hard for me, but it's also really hard for my kids because they lost their mom. I could not even speak or do anything at that point. They lost their dad. He was out of their life at that point ... They lost their friends. They lost their community. They lost their school.

The effects of illness radiate out into the lives of their family and community.

“Society is a huge barrier against sick people⁶⁵”: Expectations Around Work and Worth.⁶⁶ During the interviews, some participants acknowledged the idea that it is

⁶⁵ Quoted from Adaline's interview.

⁶⁶ *tl;dr - Expectations Around Work and Worth* - Social norms of productivity cause disruptions to self-worth for people experiencing the physical limitations of chronic illness.

embarrassing to admit their limitations. Admitting the realities of what they can and cannot do is tough, and even saying the words could be a struggle. For example, admitting that all they could fix themselves for breakfast was a cup of yogurt carried substantial levels of embarrassment. There was an underlying fear of social judgement, based on past experiences. Cheryl shared a simple example of trying to check out at the grocery store when she was still relatively mobile. She was having memory issues as she tried to put in her pin number and was nervous about what the people behind her thought, knowing that she probably looked healthy to them.

In a society where productivity and personal responsibility are highly valued, admitting personal limitations can chip away at a person's sense of worth, particularly when that message is reinforced by medical professionals.⁶⁷

The internalized belief that worth is linked to work stands as a barrier for people with ME. In regard to her employment status, Elizabeth “wanted to be working and there was a lot of guilt and shame around my having been ill and still not really having any answer to why.” Adaline shared that before the onset of ME, she used her ambition and hard work to prove her worth. When she got sick, she felt like the universe was playing a cruel joke—she felt worthless before, when she could do so much more, and here was this illness saying, *“Now you don't get to do any of it. I'm taking away everything that makes you, you. I'm taking away everything that you consider makes you worthwhile.*

⁶⁷ For examples of dehumanizing language from clinicians, see Chapter 3 Navigating Healthcare.

Now how do you feel?" She emphasized that she would rather be working because so much of her life had centered on her ability to work.

Adaline: I've been working since I was 10 years old, and paying my own way since I was 14, so having to quit a job because it crippled me was so embarrassing. It's been five or six years now, so I can talk about it without bursting into tears. But, you know, society is a huge barrier against sick people ...

Standards of productivity serve as social norms, and when illness becomes a part of everyday life, those norms are often weaponized against those with chronic illness.

Despite this social pressure to be productive, participants also shared ways that they shifted their perspective in order to identify ways in which they continued to have worth as a chronically ill person.

Adaline: I can be kind. I can be on my support group and someone says, *I'm having a really shitty day*, and I could say, *okay talk to me*. I can listen. And I feel like what's missing a lot in our society is the feeling that bearing witness is worthwhile. So, when I'm talking to someone ... I'm bearing witness and I'm helping them carry that burden. And so that kind of helps me feel like I do have worth.

Kelli: I know I'm a middle-aged woman with vague complaints but my life matters to me ... my possibilities are worth looking at.

Part of living long-term with any chronic illness is persisting in the knowledge of their own worth. See Chapter 3 Navigating Healthcare for more about self-advocacy.

Relationships⁶⁸

As previously discussed, family relationships emerged in the data as core support systems; however, ME also puts a strain on those relationships. As Ashanti said, "Of course, you're unable to attend many things and people get upset." Because of ME, she

⁶⁸ *tl;dr - Relationships* - Despite the difficulties of losing relationships, maintaining connections with family and online networks remains a key aspect of quality of life for people with ME.

was unable to attend her sister's wedding in Mexico. International air travel was not feasible with her severe symptoms and the wedding venue was not wheelchair accessible. The risks associated with traveling out of the country, to an unfamiliar location with limited medical resources for her if an emergency were to arise, were too much to be expected, particularly in light of her multiple hospitalizations. Even though these circumstances were out of her control, Ashanti's two sisters are no longer speaking to her. Missing family events due to symptoms and physical considerations can be interpreted as lack of care or effort, which impacts family relationships.

Another theme that emerged was having family members (extended and immediate) who did not believe their ME diagnosis. Some family members came around eventually and some did not. Adaline received clear messages from her family when she first started trying to get medical treatment for her illness: "Even my husband didn't believe I was sick at first. He just kept saying, you need to find a job, you're just depressed, you need to try harder." They pressured her to stop going to doctors, but she didn't, "even with my mother and other people telling me: Just don't, you don't need to know what's wrong with you, just give it up." With Kelli's extended family, they recognize her symptoms through a limited and psychological frame: "I know that the narrative out there is that *Kelli's sick, but it's probably in her mind. There's something wrong with her.*" Having just one or two family members shift their perspective made a positive impact on participants' family relationships, such as Adaline's husband growing into a supportive stance over time as he learned about ME.

Living with a chronic illness like ME affects intimate relationships, whether past, present, or potential. Looking back on her past relationships, Karen says, “I do think this illness has contributed to two divorces. I didn't understand it and my husbands at the time didn't understand the fatigue, the brain fog, the inability, my communication, my understanding of things.” In partnerships that do continue through the onset of ME, the physical symptoms impact everything. Cheryl describes the relational cost on her marriage: “I mean sex—nobody wants to have sex with this illness.” Even for potential future relationships, going out and dating is particularly problematic.

Ashanti: Being chronically ill and primarily house-and-bed-bound and single, that makes it basically impossible—not impossible but near impossible—to date or try to have any sort of romantic [relationship]. I can't meet anyone ... I'm not on any of the dating apps. I don't do any of that because again with that comes, you need to be able to leave your home, to meet the stranger. I don't want strangers coming in my house ... So, it makes it very difficult. And I'm a human, so I would like to have a life partner, especially to navigate chronic illness, but the fact that I didn't already have one at the time that I became ill, it makes it seem less likely that that's going to happen, unless, you know, I see somebody at a doctor's appointment or something. *[laughs]*... these are things that when you're healthy you just, oh, meet someone, no big deal, but when you're sick ... it's hard to get out. I'm not saying I'm never able to leave my house besides doctor appointments but it's very rare. It's hard to meet people.

The continuous isolation emerged as a theme in the interviews, connected with the importance of creating new friendships via online support groups.

Cheryl: ... and then isolation. The online support thing was huge for me. And then advocacy work has given me a huge connection of friends, which helps, but I'm definitely isolated from my colleagues and my tennis friends and my gym friends and my yoga friends because I disappeared basically from all those activities and eventually people just stopped asking when you're still sick and it is isolating. So luckily, I like my own company and the wild animals [around her home].

Kelli indicated that almost all her relationships are online now, with the exception of her husband, daughters, and granddaughters. Having access to an online network of people with ME has had a significant impact on her quality of life.

Kelli: ... one of the things that's helped me through this as much as anything else has been a social network of other patients. I do not know how people survived before social network. I just—hearing other people and knowing that they're going through the same thing or that they have gone through the same thing for 34 years is lifesaving. It's eased the isolation quite a bit.

Online groups and social media provide the platform, as a tool for connection and advocacy, which is accessible even for those who are homebound. Nepveux (2015) refers to this in her writing about the purposeful use of technology by health advocates: “social media has enabled geographically disparate disability groups to organize” and increase their “communicative and coalition-building capacities” (p.24). These online tools create opportunities for personal connections and a network of support.

Despite outside messages to the contrary and periods of grief, these seven women have been able to stay clear on a key truth: people who live with ME matter. Their stories matter and their experiences are valid. Based on the impact of social expectations about ability and productivity on self-perception, those who live with ME are a valuable source of knowledge to view those expectations through a new lens. Within their community, they hold the knowledge that can re-pioneer social norms, with all the multi-faceted dynamics and various experiences they bring. They matter.

The elements of day-to-day life described in this chapter focused on the inner lives of people with ME, their experiences at home, and with loved ones. Another element remains which needs its own chapter: navigating healthcare. The cognitive and

physical labor required to get care is interwoven into the routines and balancing techniques of everyday life. Navigating healthcare emerged as a prioritized activity, not through choice, but by necessity.

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CHAPTER 3

NAVIGATING HEALTHCARE

“All I wanted was to figure out what was wrong with me”^{69 70}

The energy it takes to navigate healthcare systems is one part of the lived experience of ME that needs further scrutiny. For people with ME, every day includes different elements of accessing healthcare that require exertion and planning. In her work, Riessman (1983) highlights the levels at which medicalization happens: conceptually, institutionally, and between doctors and patients (p. 48). Even though her work was published more than thirty years ago, the ideas she raised are still crucial to understanding disease in its social context. In this chapter, I will 1) address the conceptual formation of disease names and terminology related to ME, 2) examine the institutional barriers to care for people with ME, and 3) analyze the behavior of individual physicians toward study participants.

During the onset of ME, each participant sought out medical care. Their searches include a great deal of trial, error, and iterative stories of both finding care and encountering harm. This period of searching for a diagnosis occurred for participants when their symptoms overtook their ability to work and function. When describing the period of time spent seeking healthcare after the onset of their symptoms, both Cheryl

⁶⁹ Quoted from Elizabeth’s interview.

⁷⁰ *tl;dr* - This chapter focuses on the conceptual, institutional, and interpersonal barriers that participants encountered during their search for medical care. Some participants utilized their prior medical training to help them access care, with mixed results, and all participants expressed the desire to improve even in the face of stereotypes about malingering.

and Adaline characterize it as a “blur”. Others summarize this process as well, based on their personal experiences:

Karen: Other than that, all those years I was just going to doctors trying to figure out what was going on. Everything was inconclusive. Or they would diagnose me with IBS or diagnose me with chronic bronchitis, asthma, just those standard type of things.

Elizabeth: I was just so unwell, it was hard for me to keep up with what was going on. And then if I had a negative experience it just sort of got filed into ‘that-was-BS-it's-not-going-to-help’. And then just trying to function again ... I remember [a doctor] telling me that ... a lot of people have really bad reactions to amantadine. So she was making it sound like I might not want to take it. I think that was part of why didn't take it. Now I look back and I'm like, oh, I wonder what would have happened if I had taken it, **but I was doing the best I could at the time.** (emphasis added)

Cheryl: I just wanted to see a general practitioner and find out what the hell is wrong with me. Why am I having these bizarre horrible symptoms that are unrelenting and that don't respond to normal treatments?

Lena: It took me a while to come across a good doctor. And at first, I was too sick to even do research to find a good doctor.

The process of seeking out medical care was fraught with complications for these interview participants due to the macro- and micro-level barriers discussed throughout this chapter.

Of the seven participants, Ashanti and Cheryl have prior medical training as registered nurses. This training both helped and harmed them.

Ashanti: I start[ed] requesting all kinds of specialists because I'm a nurse. I'm not working anymore. I'm disabled but I will always be a nurse. So I still refer to myself as a nurse. I'm a nurse, so I knew what specialists to ask for. I knew how to navigate the medical system.

Because of her medical training, Ashanti knew what to ask for, and requested a referral to an allergist, and later to a rheumatologist who specializes in autoimmune diseases, as

well as referrals to a neurologist, gastroenterologist, and an infectious disease specialist. She also knew it would be beneficial to get her medical records, to see for herself what physicians had written⁷¹. Cheryl noticed that some clinicians continued to respect her medical training; for example, a neurologist who respected her standing as a recently working nurse, and believed her symptom reports right away. On the other hand, some clinicians were outright dismissive once they saw her diagnosis list. Cheryl's training as a nurse is reflected in her use of the word 'we' when talking about medical professionals, grouping herself with her clinician colleagues. This training, however, resulted in her initially not believing CFS and CFIDS were 'real' when her doctor first diagnosed her.

Overall, in discussing their search for care, participants emphasized that they want to get better. This stance is often challenged by medical professionals who characterize them as noncompliant (Dimmock & Lazell-Fairman, 2015). For Adaline, like many others with ME, her drive to find treatments was frequently derailed by clinicians: "I [had] to find out what I could do to get my energy back and deal with this fatigue. So I went to a doctor who basically said, there's nothing wrong with you." Elizabeth emphasized that her main priority was to figure out what was wrong, even during the worst of her symptoms when she was unable to do much. Ashanti expressed this as well: "I'm grasping for straws at this point, because I want to figure it out, I want to get back to my life, working out, working, and being an active mom." From hospitalization to hospitalization, doctor to doctor, and one diagnosis to another, she paved her own way and advocated strongly for herself. This was necessary because of the conceptual,

⁷¹ As shown later in this chapter, this choice to pull her medical records allowed Ashanti to challenge inaccurate statements about her symptoms.

institutional, and interpersonal dynamics that create barriers to care for people with ME. These conceptual complexities are discussed in the following section.

Concepts & Diagnostic Terms

What's in a Name⁷²

Myalgic encephalomyelitis does not exist in a vacuum. It is interrelated with a host of other diagnoses that have grown out of the medical model (see Appendix C for a constellation of other conditions that interrelate with ME).⁷³ Language plays a role in how patients, physicians, and the public conceptualize illness. As previously discussed⁷⁴, a multitude of different names fall in, around, and near the term myalgic encephalomyelitis. Each name carries its own connotations, usages, and history which intersect with the connotations, usages, and history of all the others. Each name is an attempt to capture a certain aspect of the illness. For example, CFS emphasizes the fatigue element, and ME emphasizes the neurological element.

The terminology that each participant uses to describe their diagnosis reveals the ways in which language constructs illness conceptually:

Ashanti: I hate the term chronic fatigue syndrome because it trivializes the illness and doesn't really convey all the multiple systems that this illness actually affects and impacts. It's not just about being fatigued. I wish it was that simple.

⁷² *tl;dr* - The names and terms used to describe illness reflect and impact the conceptual formation of illness. People with ME use different medical terms, even amongst each other.

⁷³ See the History of ME section of the Literature Review for a discussion of different names that have been used to describe ME.

⁷⁴ See History of ME in the Literature Review.

The connotations around ‘fatigue’ have made life difficult for people with ME, when their fatigue symptoms differ significantly from the common usage of the word.

Elizabeth describes her exhaustion as ever-present, “in a way that felt different from just normal tired, like everybody's tired and everybody's overworked, but this just felt like a whole ‘nother dimension of tired.” This type of fatigue is not improved by rest, in contrast to the experiences of people without chronic illness. Cheryl describes her approach to the concept of ‘fatigue’ in this way:

An important thing that I want to make sure that I convey: for both of those two doctors that suspected the chronic fatigue syndrome, I never ever used the word fatigue. I never ever complained about being exhausted. I complained about sleep problems. But I did not recognize fatigue in myself. It was not a symptom that I identified with at all, which was part of why the diagnosis seemed so bizarre to me ... But, yeah, for being fatigued or not having energy, that didn't click for me. All the other symptoms would happen because I was over extending my energy but I didn't understand they were consequences of that. I just—I felt like I should be able to do all the things that I normally did even with these weird symptoms. It didn't occur to me that I was pushing my body too hard.

Each person with ME has their own relationship with their diagnosis and the terminology that accompanies it (see Table 2 for each participants’ preferred term).

Terminology for individual symptoms is subject to these same issues. For example, the International Consensus Criteria (ICC) refers to post-exertional neuroimmune exhaustion (PENE) as the hallmark symptom of ME (Carruthers, et al., 2011). This same symptom is also referred to as post-exertional malaise (PEM) or post-exertional fatigue. All these terms refer to the same phenomenon, and they all have baggage. ‘Malaise’ possesses the negative connotations associated with ‘malingering’, and fatigue is a symptom routinely dismissed by clinicians, particularly for women, as

evidenced by medical practices in the context of hysteria (Dusenbery, 2018). Historically, PEM was used in diagnostic criteria up until 2011 (NAS, 2015), at which point the team that created the ICC replaced it with PENE. They view the word ‘malaise’ as “inaccurate and inadequate” (Carruthers, et al., 2011, p. 331) to describe these biophysical processes. However, the term ‘neuroimmune exhaustion’ can also be problematic. ‘Neuroimmune’ narrows the scope down to neurological and immunological processes which may preclude exploration into other causes for symptom flare ups. ‘Exhaustion’ has connotations in the general public as being a condition improved by rest, which neuroimmune exhaustion is not.⁷⁵ This means that, along with the nuances of meaning and usage within medical literature, individual patients also differ in their choices of which term they personally use as they describe their symptoms to others. This array of words and meanings makes the diagnostic process complex for people with chronic illnesses such as ME.

⁷⁵ Paraphrased from discussions with Adaline.

Table 2
Diagnostic Terms within the Participant Interviews

	<u>Distractor Diagnoses</u> ¹	<u>Comorbid Diagnoses</u> ²	<u>Diagnosis</u> ³	<u>Term of Choice</u>
Adaline	hormone imbalance endocrine disorder^ pain amplification syndrome^ thyroid dysfunction chronic lyme disease toxic mold syndrome	hyper mobility (EDS) fibromyalgia insomnia Epstein-Barr virus radiculopathy nerve damage migraines TMJD depression osteoarthritis	ME/CFS [2017]	ME
Ashanti	none	asthma* HAE* ⁴ autoimmune autonomic neuropathy	ME [2017]	ME
Cheryl	anxiety^ depression^ thyroid nodules tonsillar cysts arthritis asthma sleep apnea mild cognitive impairment	POTS MCAS	CFIDS & CFS [2015]	ME ⁵
Elizabeth	iron anemia stress (somaticized)	uterine fibroids* insomnia* sleep apnea*	SEID [2015]	ME ⁶
Karen	asthma	scoliosis chronic bronchitis* Epstein-Barr virus MCAS fibromyalgia* IBSC* orthostatic intolerance	CFS [1986] ME [2018]	ME/CFS

Kelli	stress deconditioning lupus ⁷	valley fever* MCAS POTS Epstein-Barr virus	CFS [2015]	ME ⁸
Lena	none ⁹	mono ¹⁰	ME/CFS [2012]	ME/CFS

Note: acronyms

CFIDS = chronic fatigue and immune dysfunction syndrome

CFS = chronic fatigue syndrome

MCAS = mast cell activation syndrome

ME = myalgic encephalomyelitis

SEID = systemic exertion intolerance disease

* Indicates a comorbid diagnosis that participants currently (or formerly) receive treatments for, **however**, it was **also** used by clinicians as a distractor diagnosis, an inaccurate explanation for ME symptoms, which deterred them from finding answers about ME.

¹ **Distractor diagnoses** are guesses that clinicians made based on the participant's symptomology; these turned out to be inaccurate explanations. These diagnoses were given when the participant started seeking medical care at the onset of ME symptoms. Participants **do not** have these conditions. Some distractor diagnoses were made in good faith but ultimately reflected a lack of knowledge. Distractor diagnoses that were made in bad faith, as evidenced by participant experiences, are marked with an ^ symbol. These are often due to physicians' failure to engage best practice.

² **Comorbid diagnoses** indicate accurate diagnoses that participants have in addition to ME or are conditions that link back to the symptomology of ME, like insomnia.

³ **Diagnosis** refers to the variation of ME the participant was first diagnosed with (usually CFS, CFIDS, ME/CFS, or ME, depending on what year they were diagnosed and what information their doctor had been exposed to). This does not include previous illnesses or diagnoses that were treated before onset.

⁴ HAE = hereditary angioedema. This diagnosis is still inconclusive.

⁵ Cheryl notes: "I prefer ME but will often use ME/CFS because that is what most agencies are using now. Depends on who I am talking to. Among friends or family, it is ME. When communicating to educate others, it is ME/CFS."

⁶ Elizabeth notes: “I prefer ME, but I think SEID is ok, too. Anything that more accurately reflects the nature of the illness and my experience than CFS (e.g., it's not just fatigue).”

⁷ This diagnosis was seriously investigated as a possible explanation; however, after recent tests it has been ruled out.

⁸ Kelli notes: “I tell people ME, and when they don't know what that is, I tell them ME/CFS, and when they don't know what that is, I blush and tell them I have Chronic Fatigue Syndrome.”

⁹ Because Lena was able to get an ME diagnosis quickly, she did not have distractor diagnoses.

¹⁰ Lena notes: “Mono was a preceding diagnosis. Mono is what triggered the MECFS, so they did not occur at the same time.”

Diagnoses of Trial and Error⁷⁶

Many diagnostic terms that came up in the interviews represent a category of conditions that people with ME *do* experience but were *not* the explanation for their ME symptoms (see Table 2 for comorbid diagnoses). For example, doctors told Ashanti her symptoms were due to her continuing asthma, and Karen’s doctors kept treating her for chronic bronchitis. For Elizabeth, her “main doctor decided that my uterine fibroids, which I've had for over a decade, were suddenly the problem and that I should have them removed and then I would feel fine. So I went to [another city] to have them removed.” This was not effective, nor were the dietary supplements they previously offered.

In other cases, participants were given new possible diagnoses. For example, doctors told Kelli her symptoms were due to a new onset of valley fever, or ‘stress’, or possibly lupus. A few months after fibroid surgery proved to be an insufficient answer for

⁷⁶ *tl;dr* - Before receiving an ME diagnosis, participants navigated a series of other diagnoses that were ultimately inaccurate, comorbid, or unclear.

Elizabeth's symptoms, she was diagnosed with sleep apnea; the treatment for this resulted in just enough improvement for Elizabeth to return (briefly) to work; however, under that work load, her symptoms resurfaced in force. Similarly, Ashanti received a diagnosis that brought some measure of relief, but was only loosely linked to her symptoms, explaining some but not all of her symptoms:

[The allergist] ran extensive blood work. What he *did* find was a possibility that I had something called hereditary angioedema (HAE). Now at that time I had not had any symptoms of it, that I knew of ... But then right after that I ended up presenting with these digestive system symptoms, which are a symptom of HAE ... They ran multiple tests. It was decided that it was the HAE. I was given fresh frozen plasma. And my symptoms actually seemed to improve.

... if it is HAE, which is possible ... it still didn't explain everything. HAE doesn't explain muscle weakness. HAE wouldn't explain the voice hoarseness that I have. HAE wouldn't explain the profound fatigue that I have.

These diagnoses were painstaking stepping stones on the way to understanding what was happening to them.

Other diagnostic terms that came up in the interviews represent a category of conditions that participants experience simultaneously with ME. These comorbid conditions (see Table 2) may be linked to ME, as with insomnia or pain conditions, or they may exist independently from it. For example, Adaline considers ME her primary, overarching diagnosis, with other diagnoses underneath it which describe different aspects of ME: "Nutritional deficiencies point back to ME, with the mitochondrial dysfunction and causing malabsorption ... Adrenal fatigue? ME. Insomnia? Goes back to adrenal fatigue, goes back to ME." One diagnosis that comes up frequently in discussions of ME is the Epstein-Barr virus (EBV). Adaline notes that she "always tested positive for Epstein-Barr as if I have [an] active infection." The CDC reports that 90% of adults test

positive for EVB, but this statistic does not differentiate between those who currently have the viral infection and those who have previously had the infection; in either case, antibodies are present, which is what clinicians look for in a blood test before making an EVB diagnosis (Centers for Disease Control and Prevention 2018C). Because this virus is so prevalent among the general population, its specific role in the onset of ME has been difficult for researchers to determine.

Some diagnoses do not describe the ME symptoms that participants experience. These are conditions that people have in addition to ME. Often, lifelong mental health issues that are under successful treatment are conflated with chronic illness symptoms.

Adaline: Now the [diagnoses] that don't go back to ME—which it makes me really mad—when people say, oh you're just depressed. My mental illnesses, those I believe are separate from ME. I've had them all my life because of my childhood and they also run in my family. So those are the only ones I say don't go back to ME, but everything else I think [does].

Participants reported that even when they were actively treating their mental health issues with a professional clinician, doctors in other specialties would still place the blame on anxiety or depression. This messiness with negative stigma about mental health conditions made it important to participants to highlight the need for therapy and emotional support to get through the life-altering impact of chronic illness, since others in their patient support networks exhibit trepidation about bringing up mental health care:

Lena: I have a therapist who I see once a week or every couple of weeks and so that's been really helpful ... This is just a very difficult life ... I think that it's really important for people with these kinds of diseases, that are so tough emotionally and have so much stigma, to have therapy or some kind of emotional support structure.

Kelli: I have been seeing a counselor since long before I got ill. I was seeing her for childhood issues ... we'd made some serious progress and I was getting ready to quit when I got ill and then I thought, I better keep it going. So I still see her every six weeks or so and it's been really helpful. I find actually that most of the doctors I've seen, when I mention that I'm seeing a counselor, have been respectful of that. They've said, good, you probably need to, it's probably important to do that. So most of them have been pretty good.

Not every diagnosis from clinicians falls cleanly into the categories of comorbid conditions or misdiagnoses. There is a grey area of unconfirmed diagnoses that may or may not be answers for participant symptoms. Some diagnoses remain inconclusive, such as HAE for Ashanti, meaning that their doctors take it heavily into consideration when pursuing treatment options or adding diagnoses to their list, but opinions between doctors may differ on whether it is the best explanation of the symptoms. Additionally, participants mentioned specific diagnoses that they were not diagnosed with, but were tested for, in order to rule out other options before arriving at the ME diagnosis.

Experiences with Institutions

On a macro-level, medical institutions play an important role in the experiences of individual patients as they are seeking care. The term 'medical institutions' as used here refers to conceptual centers of medical knowledge (medical journals, research facilities, government health organizations, and professional organizations for clinicians) as well as medical locations (hospitals, clinics, and doctor's offices). These are sites where institutional betrayal occurs. This is the landscape people with ME have to navigate. In the following sections, I will address the institutional-level hurdles that participants face, including, 1) harmful narratives of disbelief, psychogenesis, and recovery, and 2) the ways medical systems and procedures produce systemic barriers for people with ME.

Harmful Narratives⁷⁷

Disbelief as a medical narrative. The lack of credibility given to patients starts at the institutional level, and subsequently seeps down into clinician attitudes and behaviors. According to dominant medical norms, physicians hold the knowledge and dispense it to the patient (Conrad & Schneider, 1980). This social narrative about credibility dictates whose report is valid, valued, and listened to. It dictates whose knowledge is perpetuated and acted on. Having socially sanctioned legitimacy in addition to knowledge (whether experiential or academic) is power; currently that power is imbalanced in patient-physician interactions (Dusenbery, 2018).

When asked what barriers she encountered during her search for treatment, Adaline pointed immediately to the norm of physicians not believing their patients: “Obviously a lot of barriers are disbelief. Doctors not believing you.” Other participants spoke about the harms of disbelief as well:

Elizabeth: [My doctor] told me that she couldn't find anything wrong with me and therefore there was nothing wrong with me. And she wouldn't support me continuing to have medical leave even though I was no better than when I first started seeing her, and in fact may be a little bit worse ... at that point even just having people who believe that there was something wrong with me was important, I think.

Kelli: I feel like I have to convince them. I don't know how to convince them. They don't understand that even sitting in their office is a difficult thing for me.

⁷⁷ *tl;dr* - For people with ME, access to care is obstructed by assumptions that permeate the medical field: disbelief (the patient is not treated as a credible source of knowledge), psychosomatic cause (unexplainable symptoms are dismissed as psychological and not given treatment), and recovery (assumption that chronic illness will eventually go away).

Disbelief also falls into patterns of gender bias, which plays a significant role in patients' experiences when they enter a doctor's office, particularly in relation to having their symptom reports believed (Dusenbery, 2018; Newton, Southall, Raphael, Ashford, & Lemarchand, 2013). A study of medical interns showed that they responded to two identical cases of neck pain with different treatment recommendations. When given the case labeled with a male name, the interns suggested lab testing. When given the case labeled with a female name, the interns recommended psychoactive drugs or referred the case to a different doctor (Leresche, 2011). O'Leary (2018) claims that, due to the history of hysteria, "psychogenic diagnosis is entangled with an assumed lack of autonomy in women" (p. 9). Ashanti experienced this with her pulmonologist: "[He] didn't listen early on, he just kept saying that it was a severe asthma exacerbation. And maybe if I had been a male patient, maybe it would have been different, because doctors tend to not believe women." Kelli said that sometimes she would resort to taking her husband with her to appointments, for the express purpose of creating a situation where her physician would pay more attention:

I know a lot of this [harmful medical treatment] was because I'm a woman. I know that I was getting less attention than I was when my husband was there. There were doctors who would literally turn and talk to him. I know I'm a middle-aged woman with vague complaints, you know, but my life matters to me just as much as their professional, highly-paid lives matter to them.

This environment of disbelief is a barrier for patients with ME as they seek medical care. As Adaline put it, "A lot of doctors don't believe that their patient is a subject matter expert in their own illness."

This narrative is powerful enough that some people with ME struggled to believe it was a real thing when they were first diagnosed. After a considerable search, Cheryl met with an infectious disease doctor who told her she had chronic fatigue syndrome:

Cheryl: I'm like, I don't believe in that. That was my response. I don't believe in that. And that kind of took her [the infectious disease doctor] back for a minute and she said, "Well, I hate to be the one to tell you, but everything—all these symptoms you're describing—fit into that diagnostic category perfectly."

And I said, they do? And she said, "Absolutely."

And I thought, there is no way I have what I perceive as a psychosomatic illness because I'm a medical professional and I work in psychiatry and we have those kinds of patients. We refer to them as somatic and histrionic and we believe that their physical illnesses are not real ... And in my brain I said, I'm going to figure out what this is and then I'm going to make sure I let this woman know she was wrong. She misdiagnosed me. That was literally my decision.

But my husband and I walked out of there and we talked about it. He was a med-surg nurse, so his experience was much like mine, where nobody really believes people who say that they have these sorts of illnesses, but he said, "Let's look at the paperwork."

... and we went down the list. And I had like twenty-one out of the twenty-three [symptoms]. And so my husband and I looked at each other and it was like, holy shit, she's right. This well-respected, from a world-class institution, doctor is saying this is not in your head. This is a real thing. This is physical, even though we don't know exactly why ... My husband's like, "Look, there's treatments, maybe this is something." So, I was like, okay. I still don't buy it. I still think I'm going to figure it out. But it's pretty hard to be in denial at this point.

Cheryl indicated her medical training as the source of her initial disbelief and indicated that her husband had to overcome the same ideas due to his training as well. But this belief is not limited to medical personnel. The narrative of disbelief radiates out into public consciousness, as evidenced by the responses of people with ME who are not former nurses or clinicians.

Kelli: In the spring the Institute of Medicine's 2015 report on chronic fatigue syndrome came out. My daughter heard about it on NPR and she called me, and she said, "I think that's what you have." And I said, I think that's in people's heads. I'm so embarrassed that I said that now, but I just—to tell you where my head was with it—I don't think that really exists.

She said, "But it sounds right."

I went home and I looked at the thing and I was like, wow, I have all of this.

Even in the absence of direct disbelief, participants knew that this diagnosis was undesirable. They responded to this diagnosis, at first, from a place of denial:

Elizabeth: So [the Institute of Medicine] came out with the SEID term and the new standards for diagnostic criteria, and I fit this criteria to a T.

Interviewer: And your primary care knew about it?

Elizabeth: Yeah. And she told me, "This is what I think you have." And I was just like, no, I don't want to have this.

At one point, Elizabeth thought sleep apnea was the full answer. However, the treatment for sleep apnea did not fully restore her health; it could not be the whole story. It was only after she delved into the medical literature that she realized ME "isn't a wastebasket diagnosis, it's just been treated like one."

Participants in this study reported their experiences encountering disbelief from clinicians. This trend is supported by Smith's (2017) findings, where patients reported that healthcare professionals did not respond to their concerns and denied the accuracy of their negative reports. Smith's work creates a robust discourse surrounding institutional betrayal, which she defines as the trauma experienced by an individual when an institution they trust or depend on becomes a source of harm (Smith & Freyd, 2014). Medical institutions fit this description. Smith (2017) found that 66% of participants

reported institutional betrayal in their healthcare experiences. The widespread nature of these findings underscores the need for change at the macro-level, not just at the micro-level between patients and providers. As previously discussed⁷⁸, patient trust can be categorized as fiduciary trust (“They will help me”), confidence (“They are able to and qualified to help me”), or satisfaction (“They helped me”); fostering an environment of trust is beneficial for healthcare organizations, as it is linked to higher rates of recuperation and lower cost (Smith, 2017). However, the medical narrative of disbelief persists, supporting harmful macro-level norms that result in harmful micro-level relationships between physicians and patients.

It should be noted that medical curriculum *is* moving closer to patient-centered practices, as evidenced by the recent rise of medical humanities programs within schools of medicine as well as the increasing presence of patient advisory boards (Graham, et al. 2016; Chu & Price, 2018). However, it remains widely documented that patients are routinely treated as non-credible, non-authoritative sources of information about their own bodies (Spandler, 2009; Edwards, 2008). Because of this persistent dynamic, the knowledge offered by this study’s participants exists as documentation of patient autonomy, authority, and credibility.

Psychosomatic cause as a medical narrative. Medical institutions have nurtured the prevalent belief that medically unexplainable symptoms originate from the mind, while simultaneously failing to build robust mental health care protocols (Spandler, 2018). This belief protects the institution at the cost of the patient (O’Leary, 2018).

⁷⁸ See Literature Review.

Clinical conceptions of ME and other chronic illnesses that depend on harmful psychosomatic narratives were previously discussed in the Literature Review. Specific participant experiences with individual physicians who used the psychosomatic narrative are included later in this chapter. According to O’Leary (2018), the medical norm of frequent assumptions of psychological causes for patient symptoms raises two issues about informed consent: 1) “When a patient consents to medical care from her doctor for specific bodily symptoms, does that include consent to evaluations and recommendations for psychosocial cause if the patient has never imagined such causes might be possible?” and 2) “How could a physician successfully explain, and support, [the] conceptual leap [from MUS to psychogenic diagnosis]?” (p. 8). For question one, many physicians operate as if the answer is automatically yes. Question two calls for physician accountability, in the form of justifying their direct leap from uncertainty to psychogenic explanations without the sort of deliberative steps that are generally expected to support a diagnostic conclusion.

This psychosomatic narrative exists alongside a coinciding lack of mental healthcare resources, as referenced in Cheryl’s interview in the context of suicide interventions:

Interviewer: What do you imagine that avenue being, if there was a robust medical response to suicidal ideation in chronic illness communities?

Cheryl: Well, I think, you know, it's unfortunate because there just isn't adequate resources in mental health training to manage schizophrenia, the chronically mentally ill, and the people with chronic physical illnesses, but if specialty providers for ME/CFS ... could provide some kind of psychological intervention that would be useful. Part of it is just getting people to reframe their perception of the illness, for example, and then part of it is actually providing help with things like insomnia, which is definitely a suicide risk.

People *with* chronic illness and people *without* chronic illness may need mental health services at some point in their lives. As it stands now, the psychosomatic narrative reinforces stigma without addressing large-scale improvements for mental health treatment (Spandler, 2018).

‘Recovery’ as a medical narrative. Since the medical model is limited by protocols that only have the bandwidth to deal with acute illnesses, many clinicians and community members assume that people with chronic illnesses like ME will eventually ‘get better’ or be ‘cured’⁷⁹ by treatments. Interview participants in this study do not identify with the word recovery; it does not mesh with their illness experiences.

⁷⁹ *Problematizing the concept of a ‘cure’.* Conceptualizing physical difference in terms of a ‘cure’ is one aspect of the medical model that is detrimental for communities who value their identities of disability (the deaf community, as well as cerebral palsy, autism, and others). The continued refrain is that mental, emotional, or physical difference is not disease. The medical model, along with the concept of a normative body, is widely rejected among scholars and advocates in disability studies (Adams, Reiss, & Serlin, 2015), which uncovers the violence done in the name of ‘treatment’ and ‘rehabilitation’. They reject hegemonic claims that health is the result of a ‘normal’ body. As a field, disability studies interrogates normative standards of ability. At the same time, the idea of cure is essential for communities who grapple with ME and other chronic illnesses, particularly if the chronic illness is debilitating and painful. Advocacy groups such as MEAction and Dysautonomia International focus their efforts on funding and medical research in order to work toward better treatments, medical care, and if possible, a cure. Health equality movements led by ME patients align with the disability studies goal to promote the message that marginalized voices matter in policy, government, and community. Both groups seek to disrupt systems of biopolitics that create disability in the first place. Oliver (2012) argues that modern society, built on a capitalist ideology of individualism, places value on a narrow range of abilities (work and production) and does not provide space for communal considerations or people who cannot produce. In his view, medicalization continuously replaces social action and doctors are in charge of the disability experience instead of an interactive coalition of community members. Applying Siebers’ (2008) work to this conversation creates nuance, as he writes that disability identity must address and embrace both the negative and the positive in order to be a critical, effective category that crosses the boundaries of all other human categories, while also stating that his field is not interested in treatment, and instead frames human experience within social structures, both physical and otherwise. Critical disability studies is focused on this process of deconstructing both the social and medical models.

In practical terms, communities that eschew the ideology of cure and those that seek cure would benefit from joining forces against ableist policies. Dysautonomia International and other advocacy groups primarily use medical terminology to spread awareness about dysautonomic conditions; however, they do so in a patient-centric manner (Dysautonomia International, n.d). This complicates the narrative by relying on diagnostic measures (empirical, medical knowledge) to describe patient experiences (qualitative, local knowledge). Within the literature of disability studies, chronic illness patients play a role, as Nepveux notes

Ashanti: With a chronic illness, even if you reach a point where your symptoms are very minimal, it's a *chronic* illness. So, it's lifelong. The illness is always lurking. And so, I think 'recovery' is misleading ... I've read [about] a lot of ME warriors who have been sick for many years, have experienced periods where they feel pretty good, almost but not quite back to normal, and then that went away ... So, I think recovery is a little misleading and not really accurate and it's more, I would say, like remission, relapse; those type of words, I think are more accurate.

Karen: I never use [the word recovery]. That's why I'm laughing, because honestly, all these years the word recovery has never been in my vocabulary. I don't use that word. And when you say recovery to me, I laugh because there's no recovery. I've been ill since I was sixteen ... so I've never been well. I can't relate to the word recovery at all.

Adaline: I don't know that any of my doctors have used recovery as a—well, maybe the first primary who actually started to take me seriously, they might have thought that they could give me the right hormones, and I'd recover. But I don't really blame [them] so much, since it was at the beginning of my process of figuring out what was wrong with me, and I wish it had been it.

... Society in general doesn't understand the idea of not recovering from an illness.

... It's not really a term that's been used by a lot of doctors, I don't think, in my case. But it's been more—it's not necessarily that term specifically, but the idea of "Are you better?", and "Are you well?" That has come up a lot.

... no, I'm sick, I'm still sick, I'm not going to get better ... it just doesn't compute. Because all the illnesses that are given attention, like cancer, there's a path, there's a treatment regimen, and then you either recover or you don't. You don't ever see anybody who's in between.

in her scholarship about patient-driven advocacy: "Activists with chronic fatigue and immune dysfunction syndrome . . . for whom in-person activism is largely inaccessible, engage from home via the Internet" (2015, p. 24). Consider the example of Jennifer Brea's #MillionsMissing campaign, which gained traction via online collaboration. The goals of this campaign are centered on the needs of people with ME: "1) Research commensurate to the disease burden; 2) clinical trials to secure medical treatments for ME; 3) accurate medical education and improved clinical care; 4) commitment by our governments that is serious and urgent" (MEAction, 2016A). The influence of the medical model runs strong in these demands; however, they do so by drawing on the most beneficial aspects of the medical model—solid research, innovative treatments, and improvement of quality of life.

People with chronic illnesses who have improved over time live in that middle space where their condition isn't fatal, but recovery is out of the question. In conversations with their friends, family, and community members, recovery isn't a useful concept. Social expectations constructed around recovery place undue pressure on people with ME. In our current system, the entire responsibility for getting better falls on patient, and cultural beliefs reinforce the idea that a sick person is a bad person (Conrad and Schneider, 1980). These social beliefs make the concept of recovery difficult for people with chronic illnesses.

When asked about their own definitions for the term 'recovery', participants emphasized the ability to return to 'normal' life:

Cheryl: Fully recovered, to me, means able to work full time, able to travel, able to engage in your previous level of activities, which includes sports and fitness type activities, with maybe a little decline due to the natural aging process...

I'm still okay, but okay is different than recovered ... Okay means that my quality of life is sufficient that I choose to live. Recovered is—my quality of life exceeds—if I ever was fully recovered, I imagine just being this happy grateful person after the suffering that led me there and how I see my peers suffer.

... [recovery] includes my ability to work and make money again.

Lena: Recovery is different than remission. Right? Recovery would mean I don't have the disease anymore and I don't have any symptoms. That would be a full recovery. I don't know anyone who's had that situation.

In terms of remission, I think remission is basically the same, except your symptoms have gone away but you still have the disease in your body and you still know that and so you still take preventive steps to keep it from coming back. Like they say with cancer, you never recover from cancer, you always have remission, because it can always come back. And so, I think that's probably at this point where we are with the science, more realistically.

These definitions sometimes clash with how clinicians conceptualize recovery in abstract ways. For example, Elizabeth met with a physician whose definition of recovery had no bearing on her lived reality:

Elizabeth: His experience is like, if you rest enough, you'll get a little bit better.

And I was like, okay, but would I ever be able to work?

And he's like, well probably not, but you can recover.

And I was like, but can I work?

Probably not.

So, I mean, his idea of recovery is different.

Living with the day-to-day realities of ME changes these conceptual terms into concrete terms. For some participants, this results in a combination of optimism and realism about recovery:

Ashanti: We don't even have any treatments, so we're so far from a cure it's not even funny. I don't even think in terms of those. Of course, I'm hopeful, I hope for a miracle. But realistically—I mean, there's illnesses that have actually been adequately studied for a number of years and there are still no cures for those, so it would be naive to believe that my illness, which is very poorly studied and poorly understood, is going to be the one that suddenly, miraculously has a cure in a short period of time. Science just doesn't work like that.

Kelli: I think I used to swing more wildly from crashes so even though I rarely felt good, sometimes I would have a half a day or a day and a half and I would start planning for my recovery ... I would have a little bit of a break and I would start planning.

Cheryl: I have fantasies about what I'd like to do. I have difficulty really believing that my brain function will come back and that I'll have enough energy to be able to have a career again or play sports again. It's hard to imagine being that much better, but I've gotten this much better. So, I'd like to keep those fantasies going ... I think it's super important to believe in the possibility of recovery ...

Asking the interview participants about recovery proved to be a highly emotional and difficult topic. During Cheryl's interview, her narrative about recovery was marked by starts and stops, as it was hard to construct thoughts around the idea: "You know, it's hard to plan anything with an illness like this." For Elizabeth, the word recovery is painful, and she shared her struggle to even think in those terms:

Interviewer: What does the word recovery mean for you? And do you even use it?

Elizabeth: No. It feels impossible. *[pause]* Wow, that brings up a lot of emotions. I don't know. I know that people have gone into remission and been able to live fully active lives, but they're pretty few and far between. And I think even then, if they're fairly knowledgeable about the disease, which having been completely ignorant about my own disease for so long, I recognize that many people are aware of the possibility of both relapse and also that maybe they aren't quite back to what they had been before.

... it's a funny thing because there are people who say they've recovered. They tend to do a lot of weird stuff, right? Like they don't live fully normal lives. They eat weird diets, they take tons of pills, they sleep and eat at weird times of day, whatever it is. To me, I guess, recovery means that you would be totally back to the way you had been before. And maybe that's not ever really true because you never go back to the way things were before anything. But just in terms of that you would have all of the capacity that you had before. I guess if you still had to be on medications for that recovery to persist—that seems reasonable—that still seems like recovery, I guess ... I don't allow myself to think that much about, or dwell that much on, remission or recovery. I do things and I make plans to do things that I hope will help me get into at least some kind of temporary remission, ... I think because of the Fukuda definition and so many questions around, *well, if they recovered do they even have my disease?* You know, that's such a big question in the field, among the patient community. And then I think there are a lot of questions about it in the medical community. And it's just hard because I don't feel like we have enough information to know what recovery can look like, how often it really does happen, or doesn't.

I have a lot of fear around recovery too, because I know I don't want to go back to the job that felt like it caused my—I mean, I know that it didn't cause it—but I don't plan to go back into teaching science or doing research.

Interviewer: It's a really high pace of life.

Elizabeth: Yeah... I think even if I recovered to a considerable degree, I have trouble imagining—I think I just—I can't even wrap my head around it. I have trouble imagining a time where I would have energy enough to live a normal life and do that job, and still feel like I wasn't dying.

And then there's a lot of fear around, *well, what if I get just enough better that I can work some—what kind of job could I do?* And, I don't know, maybe I have less confidence than I used to. I used to just be like, well, I'll figure it out, I'm smart, I have a PhD, I can make this work, but it feels like everything is difficult and maybe that's partly just because of my illness but it's just so hard to point at ... the whole idea of what I would do for work and what I'd be capable of physically—it is just such a big question. Yeah, makes it hard to think about. Those are my musings on recovery ... I won't pretend that there aren't a lot more complex emotions going on underneath it all but ... I want to speak cogently rather than break down in tears.

Elizabeth's narrative shows how abstract medical terms are very real to people with ME, who live the everyday experiences that these terms are supposed to describe, but often fall short as meanings are separated from their context.

Systemic Barriers⁸⁰

In addition to, and intertwined with, the harmful conceptual narratives in the medical model, people with ME also face systemic and procedural barriers as they navigate healthcare systems.

The system is not designed for chronic illness. At an institutional level, the medical systems that dictate physician training, medical record keeping, insurance coverage, cost of healthcare, and disability benefits create sizable barriers for people with ME.

⁸⁰ *tl;dr* - Large-scale issues such as inadequate physician training, the cost of healthcare, lack of information about ME, and lack of ME specialists create barriers to care.

Elizabeth: If we're just thinking about what the medical community does with respect to chronic illness, I think that there's just a general problem with the medical community not being set up to engage with people who have higher medical needs, right, and that starts with a general dismissal of anybody who has multiple complaints...

I don't think anybody has illusions that this system works well. You know? It doesn't work well for preventive care, it doesn't work well for complex patients.

Certain procedures in our current healthcare system, discussed below, stood as roadblocks to the people with ME that I interviewed.

Physician training. The communication methods and norms of behavior that physicians leave medical school with have a direct impact on patient experiences.

Interviewer: In those times, in those moments in clinics when the physician is dismissing whatever it is you're reporting, what changes do you think could happen in those patient-physician relationships?

Lena: Well, I mean, not much I can do from my end because I'm so sick, I can't even speak ... I'm not the one who has the problem in this interaction, right? It's them being rude, dismissive, uncompassionate. They're really not trying to connect and support their patient and relate to their patient, they're reacting from a place of ego and closed-mindedness. So, I think you just have to do a better job training physicians.

In addition to explicit training, Adaline points out the cyclical nature of discrimination in medical schools:

Adaline: Logically, it seems probable that medical students are also being poorly treated if they have a disability, which likely has the two-fold result of disabled people not pursuing a medical career, and those people who do stay in medical programs are taught that it's okay to treat those with disabilities as less than/other. They likely aren't even taught explicitly how to work with people who have illnesses that aren't easily solved and/or cause disability. Those lessons then stay with them as they go into their medical practices, which leads to a lot of the abuse [of] patients in general— and those with ME/CFS, a difficult to diagnose illness—experience from doctors.

Not only does current training leave clinicians unprepared to address chronic illness, the pressures placed on them to run a lucrative practice place them in a tough spot. The financial incentive structure of medical practice causes direct harm to patients with chronic illnesses.

Elizabeth: A fifteen-minute exam is just never going to be enough. And the system doesn't reward the deep kind of work that certainly ME and probably a lot of other more complex multi system diseases need...

My impression is that at least an MS doctor knows how much time they need to spend with a [patient], and I would say our very expert clinicians do, but the rest of the clinical world isn't set up for that. If you go in complaining of chronic fatigue syndrome, they may or may not even write it in your chart, and they may or may not even know that it leaves you at risk for certain other diseases or issues.

As expressed by Elizabeth in her interview, clinicians often do not have the training to know approximately how long they should be sitting with a chronic illness patient during an appointment. On top of that, physicians are under pressure to streamline appointments to maximize profit. Studies have shown that physicians will prioritize the things they are paid for, even at the expense of accurate treatment. In one medical network in St. Louis, the number of cataract surgeries dropped by 45% when physician reimbursement changed from per-surgery to salary (Shrank, Ettner, Slavin, & Kaplan, 2005). This shows that when other influencing factors are controlled for, the method of physician reimbursement dictates the number of surgeries performed in that medical network. This kind of decision-making is incentivized by the medical system and is dangerous to patients.

Insurance coverage. Insurance is a topic that came up frequently in the interviews as an example of a systemic barrier to care.

Adaline: Insurance obviously needs a huge overhaul. They'll send you these educational leaflets on things to help with pain and those things will include acupuncture, but they won't pay for acupuncture ... insomnia is a huge issue and [I have] horrible sleep, just horrible sleep, and [my insurance] refuses to cover a sleep study. My psychiatrist sent a letter, my primary sent a letter, I sent them data off of my watch showing that in the previous twelve months before that date, I had not slept at all 51 days, and they still denied it.

For people with ME, their unique symptoms make navigating insurance plans even more fraught, due to the effects of cognitive limitations and brain fog.

Ashanti: That's very frustrating for me because you often have to read. You have to know what you're signing up for. So, I find myself doing phone calls instead of trying to read the stuff online. And I try to let the people tell me and then I try to take notes that are abbreviated so that I can actually understand them, instead of [in] paragraph form, because there's no way that's going to stick. So, it's hard. And my ability to focus, concentrate—I become very frustrated when I try to read stuff and I can't figure out what I'm supposed to do. Especially if it's something I need to fill out ... that is so stressful. And I was never like that before. I was always an excellent writer ... so to be unable to formulate my thoughts onto paper for short answers is extremely frustrating and I often end up with things that were past due ... but I can't meet the deadline because every time I sit down to look at them, my brain is like, *no, we can't do this, no.*

These issues with navigating health insurance, while common across various illness categories, are particularly difficult for people with ME due to the effects of post-exertional neuroimmune exhaustion.

Notably, one participant reported that insurance does not pose a barrier to her: "I have insurance and insurance has done okay. So that, for me, has not been a huge barrier." Another participant couched their description of insurance coverage with the caveat that they feel fortunate to even have insurance and others have it far worse.

Cost of healthcare. Participants reported the burden of medical care costs on themselves and their families. Lena characterized the cost of treatments and medical

devices like heart rate monitors as “incredibly expensive.” Elizabeth faces the decision between buying supplements that are cheaper or buying ones that work well for her but are “very expensive.” Cheryl reported that she “spent \$8,000 getting these injections in my hip and my neck and my arms. And it did not make me well ... we have depleted our savings, believe me, through all of this, all of these treatments paying out of pocket for specialists \$500 an hour.” The cost of insurance without employment takes a toll as well. After she was unable to continue working as a nurse, Ashanti “had to go on COBRA which costs a fortune.” These costs for treatments, traveling to specialists, and paying for insurance plans create financial instability for these participants.⁸¹

Disability benefits. The system in place to provide financial help for those who are unable to work for medical reasons ends up creating more barriers for many people with ME:

Kelli: I finally was able to apply for disability benefits ... I have a hearing in February and so I was finally able to apply for that because without a diagnosis I couldn't even get started, and again I'd been out of work for nearly two years by that time ... the disability system is terrible for things like that. To make you wait so long is to make you stay sick so long. It's so counteractive. They want you to get better, you want to get better, but they put you in limbo for all this time ... something needs to be done with it because it's such a ridiculous, compassionless system.

Adaline: Applying for disability has been a complete nightmare. I've been denied three times. The judge didn't believe me; my primary didn't submit the prescription for my rollator, the judge acted like I was making up needing it ... disability says I should be able to work, and I tried until I broke myself.

Elizabeth: I moved from [city] because my initial application for long-term disability was denied and I was running out of money. So, I moved to my mom's

⁸¹ For more about the financial impacts of this illness, see *Chapter 2, “This disease obviously caused a lot of problems”*: *Dealing with loss*.

house ... But right now, even though I now have long-term disability coverage, there's just the fear that at some point the insurance company will find some dumb excuse, that won't be legitimate but will be hard to fight, and then will kick me off. So, I just feel financially insecure in various ways ...

Between the cost of medical care and the precariousness of disability benefit eligibility, financial security goes by the wayside.

Lack of options. Harmful narratives and a system that was not designed to handle chronic illness contribute to a continuing lack of options for people with ME. This topic emerged in the interviews, as participants returned frequently to the theme of not having options available to move their medical care forward. Their experiences fell into three broad categories: lack of general clinical knowledge, lack of specialists, and lack of research.

General clinical knowledge. When participants met with both specialists and primary care providers, they encountered a general lack of information about ME. Many clinicians had not received medical training about ME or other neuroimmune diseases, and therefore were not able to identify it. A study of medical curriculum found that CFS represented only .09% of medical textbook content, a lower percentage than other conditions that are less prevalent (Jason, Paavola, Porter, & Morello, 2010). This results in clinicians moving in inaccurate directions with their subsequent diagnoses and treatment plans.⁸² Adaline commented that it “took a while to find—obviously—to find out what I actually had.” This can prove dangerous when patients cannot rely on medical providers to be proficient in possible complicating factors, as Elizabeth indicates:

⁸² Refer to the earlier section in this chapter, *Diagnoses of Trial and Error*.

Because I know myself and I know what things I think I'm at risk for, I can go into surgery and not worry that anesthesia will be a problem. But many other people with ME shouldn't be that cavalier about it. But I know that if I told an anesthesiologist, I have chronic ME, they won't know what it means. And if I say, chronic fatigue syndrome, they won't think it's something that they need to consider.

She later notes, “That's why I work hard to try to get us into more medical school curriculum.”

Specialists. Gaining access to ME specialists is particularly difficult when medical institutions are failing to educate clinicians in this area. A recent study with ME and CFS patients found that 52.2% of participants had never seen a specialist, with geographic distance being the number one barrier, followed by cost and insurance coverage (Sunnquist, Nicholson, Jason, and Friedman, 2017; see Figure 1 in this article which maps the percentage of patients who see a specialist by region, ranging from 0% in middle America to 17% in Middle Atlantic states). Adaline notes the significant burden of finding a doctor who knows about ME in her own experience searching for care: “I started trying to figure out what is wrong with me. Initially, they just said, oh it's hormones, you're out of hormones. Nope. Oh, well, maybe it's your thyroid. Nope. So, I went to all kinds of specialists and I did not get my ME diagnosis until November of last year.” She saw 41 doctors over the course of three years.

I saw an endocrinologist. I saw a rheumatologist. I saw a general practitioner. I went to physical therapy, orthopedic, pain specialist, neurologist, another orthopedic, and other pain specialist—he refused to treat me—mental therapists, physical therapy, endocrinologist, psychologist, rheumatologist, gastroenterologist, acupuncturist, chiropractor, allergy, dental, eye.

Seeking out care from these specialists makes sense when looking at individual ME symptoms; however, none of these clinicians were looking at the whole picture and none possessed specialized training in ME specifically.

Due to the lack of specialists, the wait lists for existing specialists are prohibitively long, with no guarantees that the appointment will offer any substantive treatments.

Adaline: The rheumatologist I saw ... I waited months for an appointment. I was supposed to have one in August, but then he canceled it and I had to wait another month. So, it ended up being like four or five months' wait to see this rheumatologist, who then said, "Eh, you have terrible fibromyalgia, try this antidepressant, I can't help you."

These wait times for specialists are a significant barrier for people with ME.

Research. Decades of institutional neglect have resulted in sparse treatment options, even for people who do manage to find a doctor who knows about ME (Dimmock, & Lazell-Fairman, 2015). There are currently no FDA-approved treatment options for ME. This presents a problem to patients who are trying to find answers, often on their own.

Elizabeth: I feel like between the fact that there were so many just conflicting pieces of information around it, like doctors telling me like SEID is real, and this new report says you have this, but *still not having any treatment protocol* and therefore not really being—to me—a useful diagnosis.

... I started seeing [doctor] who was—is still—one of the thirteen or so doctors who know anything about ME. So, she was very helpful in many different ways. She also has a *pretty narrow arsenal of medical approaches*—like medications and treatments—that she uses regularly. So, I still wasn't getting treatments. (emphasis added)

Karen was initially diagnosed with CFS in 1986. In the more than thirty years since then, relatively little progress has been made in the clinical understanding of the disease, particularly compared with other diseases over the same time period (NAS, 2015).

Karen: I did not even look at the internet regarding my health until 2017 really. And I was shocked to find out that really there had been no research really until like 2010 on chronic fatigue syndrome that really made any difference. And I thought, *oh my gosh, I wasn't missing out on anything*. Here I thought it was going to jump in and find all these cures and medicines and then I looked at it and I thought, *wow*. That was an absolute shock ... just unbelievable that there hadn't been any additional research.

She assumed that since CFS impacts so many people, there would be some sort of progress. These assumptions were based on what she knew about other diseases such as cancer or diabetes.

Even with this litany of systemic problems and barriers to care, patients still bear the burden of responsibility when things go wrong.

Adaline: The pharmacy would say, oh we didn't get the script ... then I'd have to call the doctor and say that they didn't get the script. They say, we sent it. I'm like, can you send it again, and then call [the pharmacy again] ... [this is a] bullshit process around just getting the care that you need. Nobody wanted to take responsibility for who was supposed to be doing what. They all act like it was your fault if something didn't happen. Even if you had done everything that had been requested of you.

This responsibility to keep all the plates spinning is placed on patients in addition to their cognitive and physical symptoms. These barriers at the institutional level persistently get in the way of medical care. They also influence the ways in which individual physicians approach their medical practice.

Experiences with Individual Physicians

Interview participants shared their in-office experiences with individual physicians, which revealed patterns of physician behavior. Behaviors that support effective medical care will be discussed in Chapter 4; these behaviors resulted in participants receiving accurate diagnoses and working out treatments collaboratively with their medical team. Physician behaviors that create barriers to care for the participants are detailed in the following sections.

Barriers⁸³

Half of participant responses regarding barriers to care fall under the category of physician behavior. When directly asked, “*What barriers to care did you encounter?*”, five of the interviewees brought up physicians’ responses as the very first thing, indicating its importance in their process of gaining care. In one interview, the participant first gave the caveat that others have it worse than her, and then immediately talked about physician response and sexism. And the last participant talked about insurance coverage being the primary barrier, followed by how much energy it takes to navigate the system, and then she talked about physicians’ responses. These responses are characterized by disbelief, dismissal, psychosomatic assumptions, and expectations about patient behavior and appearance. Disbelief can be summarized as “I don’t believe you”—an issue of credibility. Dismissal can be summarized as “I don’t care”—an issue of physician empathy. The narratives in each section illustrate the specific one-on-one experiences that

⁸³ *tl;dr* - On an interpersonal level, between physicians and patients, physician behaviors can create barriers to receiving effective care. These behaviors include approaching patients with disbelief, telling patients ‘you’re fine’, using dismissive and dehumanizing language, assuming psychogenic cause, and giving bad faith diagnoses.

participants had with physicians, influenced by macro-level beliefs and norms reproduced in medical institutions.

Disbelief from physicians. Narratives of disbelief can occur in the form of physicians telling patients “you’re fine” even when they clearly are not. This scenario repeated across the interviews, and carried this theme: in clinical encounters, the physician assumed that their own opinion was valid, and the patient’s experience received little to no validation. For example, doctors told Cheryl, “No, your brain scan was fine. You don’t need any other testing.” Another physician told her that her case of foot drop means nothing, that she was fine, and that it would resolve itself in six weeks. It did not. Adaline got blood work back from a physician who said everything looked fine on the labs, so she must be okay. Lena had one experience with physician disbelief that flipped the usual narrative but still had the same negative results:

Lena: The doctor was like, “There’s no way you have chronic fatigue syndrome; you walked in here. Chronic fatigue syndrome is a really serious disease.” Nobody ever thinks that, right? He’s like, “There’s no way you have chronic fatigue syndrome. I just did your check, you have all the antibodies to mono now, so it looks like what happened is you had a bad case of mono, and it’s gone, and you should start getting better soon. So, don’t worry about this chronic fatigue syndrome.”

On the one hand, he thought it was a serious disease, on the other hand he was completely uninformed, had no clue that it’s a spectrum illness and that I in fact had it. And by telling me I’m perfectly fine, he was really putting the nail in the coffin because he was basically saying, act normal and do your normal thing, you’re fine. So, the exact opposite of “it’s not a disease, you’re fine”, no, “it’s a serious disease, you’re fine.”

These physicians were comfortable telling patients that they are ‘fine’ in the same moment that patients experience extreme drop offs in physical and cognitive ability.

Physician authority can be so inflated that it crosses over into gaslighting:

Adaline: The ENT doctor didn't [say *I think this is in your head*] but he also didn't listen to me. He would say, “Oh, you have X symptom.”

“No, I don't.”

But he put it in my chart anyway.

This physician assumed complete authority over his patient’s symptoms. He was not influenced or informed by the direct words and testimony of the patient in front of him. If he said a symptom was real, it was real, and he made it real by writing in her medical record, meaning that she would have to deal with the real effects of that recorded symptom over and over, even though that specific symptom was in no way part of her physical experience.

Dismissal by physicians. In contrast to disbelief, which engages physicians’ internal belief systems and training about credibility, dismissal operates in terms of concern. How attentive is the physician to patient needs? How does the physician treat the patient? Does the physician use the cognitive skills needed for empathy?⁸⁴ Different kinds of dismissive behaviors emerged in the interviews: 1) overt dismissal, including dehumanizing language, and 2) subtle dismissal, including delay and inaction. Both result in harm to the patient because they obstruct access to medical care.

⁸⁴ Chapter 4 contains more information on empathetic behavior, which is centered on three cognitive strategies:

1) understanding the patients’ point of view, 2) successful communication of that understanding, and 3) taking action to help (Frankel, Hojat, DeSantis, & Gonnella, 2017).

Overt dismissal occurs when physicians communicate outright disdain toward their patients. They laugh at the patient, or repeatedly fail to listen to the patient, or refuse to incorporate new knowledge provided by the patient. In participant examples, it often reads as being brushed aside.

Lena: They laughed. They literally laughed when I asked for a Lyme test. They rolled their eyes and started laughing like it was the most ridiculous funny thing they'd ever heard.

Kelli: So, they finally said, "Well, we've done as much as we can for you there." The pulmonologist said, "You know what, come back, if you're not feeling better in a year come back." He was kind of laughing as he said it. So, after that I was on my own.

Cheryl: These people are treating me like I'm crazy and all I'm trying to do is get a diagnosis ... [The doctor responded with a loud noise] "Ppuuhh!" [*the sound of a dismissive burst of air*]. Literally, he's like, "Ppuuhh!" And I'm like, sorry?

And he's like, "People get foot drop all the time, drunks get it when they pass out in bad positions. You're fine, that foot drop's going to resolve in six weeks."

That's how he talks to me. So, I'm like, okay. I said, well, why would I have gotten it, and isn't it strange that it kind of coincides with all these other symptoms that I've been having?

And he's like, "Pfft. Listen. It'll resolve in six weeks."

Elizabeth: I feel like there are different levels of engagement and all of them are appropriate and the only one that's inappropriate is dismissal, for whatever reason. Either because you don't believe it's a disease, because you haven't thought about it, or read about it, or learned about it, since you were in medical school and back then they didn't know anything, or were actively trying not to know anything, or for whatever reason you're not interested.

This is an iterative experience. Participants reported encountering this behavior from multiple physicians as a matter of course, not just from one or two bad actors. When

asked, Adaline recounted three physicians who exhibited dismissive behavior, off the top of her head:

The last rheumatologist I saw diagnosed me in the top one percent of most severe fibro cases ever, but suggested an antidepressant. He also denied some of my other diagnosis that I have, and said they weren't real.

You know, the first doctor I saw, to try to get better, basically looked at the blood work and said, "you're fine."

The pain doctor, she just refused to treat me at all.

People with ME also experience overt dismissal in the form of dehumanizing language from physicians.

Lena: The doctor said basically, "She'd be better off dead, because she's a drain. Not only is she so sick and can't do anything and there's no cure no treatment, but she's a drain on her family as well. And so she'd be better off dead." And I was lying there, not particularly thrilled.

This physician told a mother with three children that they would be better off without her. Basic standards of professionalism were not present at that appointment for Lena and her family. Kelli also shared an experience with outright dismissal that was a flashpoint for her as she sought medical care. The way the physician treated her is an example of this pattern of dehumanizing dismissal.

Kelli: When there was a question about lupus and I thought that the rheumatologist was the one to go to, for ME, for CFS, I had my GP at the time recommend someone. So, I went to this rheumatologist. I liked the office staff, they were real nice and things. I went in there and told him what I had, told him that I was there with a question about lupus. And he took blood tests and things and I came back for the results and I didn't have lupus, it was a negative test. And I thought he was going to be watching my CFS. I just thought he was—and he wasn't. I don't know if he just wasn't good with patients or what. He started basically kicking me out of his office, he told me, "Rheumatologist have enough patients with rheumatoid arthritis, we don't need other people with other things, we don't want patients that have those."

And I was shocked. It was so not what I expected, that he was like, "I don't want to see you anymore."

... I didn't understand that he was just looking into the lupus and if I didn't have lupus I was out ... the other rheumatologist had offered to see me like once a year and watch me, so I just didn't know. And I finally was trying again to be proactive and I said, tell me you do believe in chronic fatigue syndrome. And he said, "Oh, I believe chronic fatigue syndrome exists. I just have no idea if you have it." And there was something about that in that moment—and I'd had the disease three and a half years—just knocked me off my center ... That was the worst that ever got for me. That was the moment when I was like, I just can't do this anymore. I don't know what it was about the dismissal, but it was just ... it was a stinger.

This experience is more than a bad day at the doctor's office. This is a potentially life-altering, meaningful event. Kelli shared the desperate feeling that forms after several of these dismissive interactions with professionals who are tasked with providing medical care:

Kelli: How do I get you to care? Because I need someone to care. It's a very orphan feeling to go home almost bedbound, almost homebound, and have nobody, no physician, no medical provider, even care. They're not asking about you. They're not thinking about you. They're not concerned about you. You're not dying. All your tests look good. That's the way it is. So, you just really feel like a medical problem with the ME. You really do.

In addition to the examples above, physicians may also exhibit subtle dismissive behaviors. In these instances, physicians are polite on the surface but ultimately disinterested. There is no patient-blaming or confrontation, but there is a lack of engagement, no effort to research possibilities, and no feeling of responsibility from the physician. It comes from a simple foundation of "I can't/won't help you." This less overt form of dismissal often emerges as delay or inaction, meaning that physicians fail to follow up on tests, labs, treatment, and appointments. These behaviors are less abrupt than dehumanizing language, but they also pose significant barriers to accessing medical

care. It was dismissal from a physician that caused Lena to stop seeking treatment for a time:

Lena: The problem was that Dr. ___ told me that this disease is basically hopeless; I will be totally and permanently disabled for life. I was still at the point where I could barely talk, I couldn't sit up, and he said this is how my life would be for the rest of my life, and in five, ten years I might get a little bit better but there's nothing I can do. People are doing all kinds of research but they don't know what they're doing, and so what I would suggest is don't even waste your time trying different treatments because there's nothing that works and there's no hope, and this is the kind of disease that just—it's not solvable.

Interviewer: And how did you respond to that?

Lena: Well, I wasn't happy about it, but I kind of believed him that he knew what he was talking about, and so for several years I never sought out treatment or doctors or anything because he was a very respected doctor ... so I kind of believed him that he knew what he was talking about.

Dismissal from physicians is also expressed through non-verbal communication:

Kelli: When I say chronic fatigue syndrome—I try to say ME, but nobody knows what ME is—but if I say chronic fatigue syndrome, I have seen their eyes just glaze over.

Following these interactions, participants experience delay and inaction from these medical providers, further obstructing their access to medical care.

When physicians tell patients, “it's probably stress”, they are enacting a form of dismissal, because this response from a medical professional is often followed by no action; no further testing and no investigation into causes or treatments. It serves as a polite stand-in for “I can't/won't help you.”

From an ethical standpoint (O'Leary, 2018), institutions that are responsible for medical training must ask themselves why a person's diagnosis is an acceptable reason

for medical professionals to treat them with disdain. And they must then ask what they are doing to reconstruct their own norms in order to address this existing problem.

Psychosomatic assumptions by physicians. The way physicians think about ME is formed over time by exposure to medical curriculum that routinely advantages visible illness and protects clinician authority. Assuming psychogenic cause leads down a treatment path that ignores biological treatments and leaves patients at dead ends, as Adaline experienced:

The pain doctor who refused to treat me never said specifically, didn't spell out, *I think this is in your head*, but kind of acted like it. Same thing with the endocrinologist ... Now one of the psychiatrists I saw did tell me that I should be able to imagine my pain away. So, that was great.

The rheumatologist suggested an antidepressant. The orthopedic doctor just sent me to the neurologist who sent me to another orthopedic doctor. So, I wouldn't say—it wasn't as overt as some of the stories I've heard. But I would say that it was there and sometimes it was implied.

When physicians spend limited time with patients, without doing any examinations, they tend to fill in the gaps with assumptions. For example, Ashanti met with an infectious disease specialist who spoke with her briefly, ordered a cursory blood test, and sent her on her way. He did not communicate what he wrote in her medical records.

Ashanti: I ended up requesting my consultation note from him ... and he had the audacity to put on there that I might be ill from a psychological illness ... I sent him a very not-so-nice email—it was very professional, but it was not so nice—and he apologized profusely.

[He] didn't even examine me physically. [He] talked to me for five minutes and had the audacity to put in my consult note that I might be sick due to something psychological ... I told him off, in a professional way, and he did change what he wrote on the note. He apologized profusely, he agreed that I was correct, and changed it. So that was nice, but not everyone knows that they can do that and not everyone gets that kind of response. But what I wrote in the email was right and I

called him on it and I used my medical knowledge to be able to convey to him how wrong that was ... I was glad that I had requested the records and actually read and saw that and was like, *oh no, excuse me sir, you're not going to have this on my record, because it's not accurate*. And you can't draw those conclusions on a patient that you spend five minutes with, that's just asinine. You're not a psychiatrist. You're not a psychologist. You're an infectious disease specialist. So please stay in your lane.

These psychosomatic assumptions impact the level of trust that patients have with clinicians; they can't be sure if the clinician will act in their best interest.

Interviewer: Have you found that people with CFS themselves are hesitant to embrace their own anxiety and depression symptoms or even recognize or talk about it because there's a fear of being dismissed? And that their whole treatment process is at risk? Like, if I admit that I am depressed, will I suddenly not be able to get treatment for my POTS?

Cheryl: Right. Or will they say you don't really have POTS⁸⁵, you just have depression and you somaticize the POTS. It's hard to somaticize a heart rate that increases. I mean, that's pretty objective.

Chronic illness patients who repeatedly experience these types of reactions from physicians are less trusting of practitioners in general (Smith, 2017) and it takes longer to find adequate care (Dusenbery, 2018).

Care and Harm from the Same Hand⁸⁶

Not surprisingly, the interactions with physicians did not cleanly divide into binaries of good/bad, effective/harmful. What did arise from my data was a pattern of three-steps-forward, two-steps-back. For example, when talking about specific physicians sometimes participants had infrequent negative experiences in the context of an office

⁸⁵ Postural Orthostatic Tachycardia Syndrome (POTS). See footnote in the hygiene section of Chapter 2.

⁸⁶ *tl;dr* - Interactions with individual physicians often contain positive *and* negative elements, and do not sort cleanly into a binary of effective/ineffective.

environment that is supportive overall. This is feasible to maintain, as progress happens iteratively over many appointments and trying different tactics. However, they also reported instances of gaining one positive piece of information from a physician despite the wider context of a degrading and inept office environment.

The physician that finally provided answers for Adaline by diagnosing her with ME/CFS was an example of this sort of mixed-bag experience. She did get a diagnosis there, which moved her in a productive direction, but there were also problems with delay, disbelief, lack of insurance coverage, and unprofessional organization of medical records.

Elizabeth described one appointment she had with a “scatterbrained” doctor who had wildly disorganized records, lost Elizabeth’s payments, and was two hours late for the appointment while Elizabeth struggled to sit upright in the waiting room. She recalled, “The whole experience was too physically taxing to be sustainable.” The positive take away? This physician *did* know about ME/CFS. On another occasion, Elizabeth had a mixed positive/negative experience with a clinician with good bedside behavior, but nothing real to offer:

Elizabeth: [My primary care doctor] sent me to this mind/body clinic... and that doctor there had a resident with him that day when I saw him, and he was asking me all these questions. And every time I'd answer, he'd turn to the resident and say, *that's so typical of this disease*, and it was really nice to have, like this is something people see and it's normal, I'm normal, within the same group of people.

But also, the only real things that he offered me were yoga and meditation, which I already did and was pretty deeply trained in for a long time. So, it just didn't make sense—I was like, I know these things aren't going to help me.

Elizabeth's experience at this clinic illustrates the nuanced ways in which care comes about. This clinic provided the validation of a medical professional recognizing the disease, while also falling into the trope of offering yoga as treatment, when Elizabeth was already extensively trained in it.

It can be tempting to categorize clinical encounters as either effective care or ineffective care, but for the most part doctor's appointments contain both. Successful care and negative experiences can co-occur. Physician engagement exists on a spectrum, ranging from full dismissal to cooperative care. Somewhere in the messy middle of that spectrum are the physicians who acknowledge that they are unable to help with ME (they may even hold questionable underlying beliefs about recovery or the nature of illness); however, they do step up for specific needs, such as letters to insurance companies or getting assistive devices. These physicians are problematic *and* helpful.

Conclusion

These responses from participants echo the broader global problems that women with ME experience, as quantified by Hansen and Lian (2016), which reports that quality of care was rated as 'poor' by women with ME and CFS 60.6% of the time for primary care, 47.7% of the time for specialist care, and 71.2% of the time for coordination of care. The limitations in current medical policies and practices need to be changed. Despite the difficulties that they have faced while seeking medical care, the participants in this study made a point of saying that others with ME have it worse. For example, Ashanti's illness narrative covers multiple years, hospitalizations, unclear diagnoses, disbelief, confronting inaccurate records, and still she frames her experiences as far smoother than average.

With this in mind, participants offer collaborative solutions to many of the systemic barriers, which are discussed in the following chapter.

References for Chapter 3

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CHAPTER 4

RECOMMENDATIONS⁸⁷

Everybody in our community knows, but few people outside of our community know, that there needs to be a sea change in terms of education, increased clinical care, destigmatization, and increased urgency for the research and drug trials.

There's so much that needs to be done on this disease. - Lena

The lived experiences of people with ME reveal key domains within medical practice, structure, and belief systems that need to be reconstructed so that medical care is accessible to those with chronic illnesses such as ME. Participant experiences provide insight into these medical norms at both the institutional and interpersonal levels.

<u>Level</u>	<u>Recommendations</u>
Institutions	<ol style="list-style-type: none">1. Include ME in the U.S. Medical Licensing Examination.2. Implement feedback systems for medical students and patient groups.3. Strengthen the role of communication skills in medical curriculum.4. Incentivize the use of telemedicine.5. Coordinate professional medical care through a case manager.
Individual Physicians	<ol style="list-style-type: none">1. Believe the patient.2. Express statements of willingness.3. Engage meaningfully in collaborative care.
Patients	<ol style="list-style-type: none">1. Find and stick with physicians who advocate for you.2. Self-advocate by asking questions and requesting medical records.

⁸⁷ *tl;dr* - see Table 3.

Recommendations for Institutions

Throughout the interviews, participants in this study suggest institution-level solutions to address the barriers discussed in the previous chapter. Their comments focus primarily on medical training and telemedicine.

In order to receive effective care, people with ME need clinicians to be better trained in two key areas: 1) content knowledge about ME and 2) communication skills. In the interviews, Lena mentions that we “have to do a better job training physicians”, in reference to the harmful behavior physicians exhibit with no accountability. Cheryl indicates that while training alone “won’t entirely solve the problems in this field” it remains a key component of systemic change, because “educating physicians is essential and will make a difference.” People with ME frequently encounter a knowledge gap (Dusenbery, 2018) with their physicians because these medical practitioners were not exposed to the diagnostic criteria for ME or CFS in medical school (Jason, Paavola, Porter, & Morello, 2010). In one health advocate’s investigation of this lack of coverage in medical curriculum, she reached out to the directors of a few top ranked medical schools in the United States. They each displayed a lack of knowledge about ME. When asked why their medical curriculum did not include ME/CFS, the director for the Office of Medical Education at The University of Nebraska Medical Center responded that medical students will be exposed to ME while they are in rotations. ME advocates noticed a striking oversight by the director: “This presumes, however, that the students in clinic will have a chance encounter with a patient who has ME/CFS – likely – but that the individual will have the diagnosis of ME/CFS – far less likely” (MEAction, 2016). It also assumes that the attending physician in the rotation would know how to work with people

with ME or what to teach medical students about the illness⁸⁸. This circular fallacy highlights a persistent problem: for many patients, getting a diagnosis takes years because their physician received no training, and those in charge of training are relying on chance encounters with diagnosed patients in rotations. This knowledge gap can begin to be addressed by adding the diagnostic criteria for ME, as well as key considerations for differential diagnosis, to the U.S. Medical Licensing Examination. This would incentivize medical schools to include it in their curriculum. Additionally, this gap can be addressed through the development and wide dissemination of continuing medical education courses specifically about ME for physicians already in the field.

Another knowledge gap that needs to be addressed at an institutional level is the incorporation of student feedback and patient collaboration in subject areas that have historically been marginalized; namely, chronic illness and women's health. In their work, Henrich, Viscoli, and Abraham (2010) document the perceptions of medical students about the level of preparedness their medical training offered in the area of women's health. They found that students were engaged in only 'brief to moderate' coverage of sex and gender information pertaining to mental health disorders, reproductive function, preventative health, interpersonal violence, and common medical conditions. The ratings were lower among female medical students, indicating a possible difference in expectations. Henrich, et al. suggest further study to implement student feedback into teaching protocols. Using this suggestion to integrate feedback from medical students—and adding to it the need to incorporate consistent, integral feedback

⁸⁸ From a discussion with Elizabeth.

from patient committees into medical teaching—would act as one possible tool to resolve barriers to care for the women with ME.

Another element of medical training that emerged from the interviews is the issue of physician communication:

Kelli: A barrier was lack of communication from the doctors. [The primary care and the rheumatologist] were not sharing information with me. So I can't help them because they're acting like it's a secret and I don't get to be in on the secret. That's how it feels, like this is a secret language— “*we need to know, but you don't need to know.*”

Including more robust communication skills and professional expectations in medical training would help to address this issue, especially in regard to preparing physicians to conference with patients about complex medical conditions. As noted by a key scholar in bioethics, “in medical education there exist few guidelines for communicating with patients about diagnostic uncertainty—and given the incredible prevalence of MUS [medically unexplained symptoms], this seems both surprising and worrisome” (O’Leary, 2018, p. 8). Training physicians with better communication skills should not be employed solely for the purpose of increasing patient compliance, as this runs the risk of reinforcing hierarchical and paternalistic models of communication. It also fails to account for patient credibility and agency. Rather, physicians should be equipped with the skills necessary to engage meaningfully with patients with the goal of mutual understanding and effective care. The way forward for improving physician training can be found in patients’ experiences and descriptions of collaborative solutions. Participants in this study reinforce the need for change, to create expectations of collaborative clinical encounters where the knowledge of both the patient and the physician is valued.

A recent study on clinician behaviors tracks the importance of empathy in a clinical setting (Frankel, Hojat, DeSantis, & Gonnella, 2017). The researchers define empathy in this setting as a *cognitive* characteristic founded on three main behaviors:

- understanding the patients' point of view
- successful communication of that understanding
- taking action to help

Patients' perceptions of empathy are more highly correlated to clinical outcomes than the perceptions of third-party observers, and both of those are better indicators of correlation than the doctors' self-reported perceptions (Frankel, et al., 2017, p. 79). Barriers to care arise when clinicians lack any of these three behaviors. Frankel, et al. suggest implementing better training for doctors to verbalize and communicate their understanding of patient experiences and needs. Their recommendation is supported by the experiences documented by participants in this thesis research.

In addition to medical training, medical institutions can implement the practice of telemedicine. This includes following up with patients via email, telephone, or video conferencing. The need for telemedicine and the reasons it is necessary are expressed by participants in the context of their own geographic location and physical needs:

Karen: [My most recent doctor] is the first one that's ever suggested [telemedicine] and been able to do that as an option. And if she had not, I wouldn't be getting the care I am right now ... I don't know where I would be right now without having those ongoing virtual appointments.

And especially having [a traumatic setback], because when that happened I was able to contact her immediately and she recognized the set back and she understood what was going on with that.

Interviewer: And in the middle of that set back with heightened symptoms, you didn't have to drive to [city].

Karen: Yeah, and there's no way I could have. There's just no way I could have. I barely made it up there for the first appointment because I knew how critical it was. I even spent the night up there. So even spending the night and making the drive back ... I barely made it. She saw how ill I was when I was up there. It's dangerous... I explained how unsafe and unacceptable it is for a single woman who is very ill, driving across the barren desert, to get to quality healthcare, and how thankful I am that she would meet with me subsequently via virtual.

Similarly, when Elizabeth was too unwell to travel three to four hours away to see her doctor, she attempted to coordinate her care via email and phone conversations, with little success. Clinicians currently have little motivation to engage remotely because it is not part of their billing system and payment method; incentivizing the practice of telemedicine would open the door to patients for whom distance is an obstacle.

These main themes of physician training and telemedicine are accompanied in the participant interviews by two smaller themes: perception and coordination of care. Public perceptions about ME create barriers, as Cheryl indicates, “part of it is just getting people to reframe their perception of the illness.” Kelli has personally seen how increased news coverage, new research papers, and the conversations about new research affect individual people in positive ways. Her path to diagnosis depended on hearing about ME through news coverage and then learning more through conversations about new emerging research.

Participants also report that the responsibility to coordinate care falls on them, which is unfeasible during the worst of their symptoms when they need effective care the most. They were responsible for coordinating communication between specialists, primary care physicians, pharmacists, and insurance representatives. Having a team of professionals working in collaboration, with an assigned case manager, would help to

address this barrier. Currently, this type of collaboration does not happen for participants unless they coordinate it themselves.

As it is set up currently, the healthcare system has implicit prerequisites for care that are unacceptable moving forward. These prerequisites are never explicitly stated, nor do they appear in policy. They are created by the material implications of current and past priorities and biases in medical institutions, such as the second-class role of women's health⁸⁹ and the lack of specialists for chronic illnesses that primarily impact women. These prerequisites, as described throughout patient narratives, include the ability to fly to another state to see a specialist (including the exertion required to do this and the financial burden of travel), the necessity of convincing clinicians to do their job (based on gendered norms of credibility), and the frequent requirement to be more educated on ME than their clinicians (due to knowledge gaps in medical curriculum). Elizabeth's narrative of seeking medical care includes many different but interrelated barriers along these lines: doctors believing she was fine; having difficulty sorting through theories online; not finding helpful information about ME from the Mayo Clinic or the CDC; and cognitive limits making researching it all on her own unfeasible. This experiential knowledge from participants is key to guiding changes within medical systems at an institutional level, which will create systems and contexts in which individual physicians will be equipped to provide effective care.

⁸⁹ See Literature Review, 'The changing position of women's health within medical institutions.'

Recommendations for Physicians

Across the interviews in this research project, participants describe the characteristics of effective physicians. This topic is heavily represented in the interview data; when asked about barriers to care, more than half of participant responses related to physician behavior. The characteristics of effective physicians come from three vital traits that emerge from the data:

1. **Belief:** Effective physicians believe their patients.
2. **Willingness:** Effective physicians make statements of willingness.
3. **Engagement:** Effective physicians actively work with patients as collaborators.

These three traits differentiated effective experiences from harmful and obstructive experiences for the participants in this study.

As a counter-action to the harmful narratives of disbelief, effective physicians are characterized by the way they believe their patients. They take patient reports seriously and respect the patient's knowledge about their own body. Effective physicians believe that ME is a physical disease, not caused psychologically. The way they treat patients reflects these beliefs.

Participants reported that effective physicians also made statements of willingness, such as:

- I will treat you.
- I will refer you to a specialist.
- I will read up on ME research.
- We can follow-up over phone or email.

These statements indicate that the physician is, at a minimum, willing to meet with the person with ME and consider different treatment options. A physician may not know

about ME, but expresses willingness to pursue the available options, such as identifying a specialist to refer the patient to, or providing documentation for mobility devices, insurance, and/or disability hearings. Whether or not this willingness translates into effective care is revealed over time by the level of follow-through exhibited by the physician and their staff.

Last of all, participants reported that effective physicians actually do the things they said they were willing to do. They actively listen to patients, ask questions, perform examinations, and follow through with a well-communicated plan of action. This sounds like a basic job description of what physicians should be expected to do. But participants interacted with numerous physicians who do *not* exhibit these traits, on the way to painstakingly finding physicians who do. Engagement is distinct from willingness in the interviews, as shown in this example from Adaline:

My former primary was actually kind of a big barrier because anytime I needed something I would have to fight for it. I'd have to call and email, or they'd only send me part of what I requested. They were supposed to be on my side, and when I was in the office in front of them they acted like they were on my side, but then they wouldn't do what they said they were going to do.

Expressing willingness while a patient is in the office is not enough. In order to provide effective care, physicians need to follow through in a collaborative manner with patients.

When it comes to physicians lending a listening ear, participants have a lot of non-examples at hand, of what *not* to do:

Adaline: Again, my biggest gripes are the doctors not listening. And they also have blinders on. If you don't fit in what they think you should fit in, they either ignore what you say, or they don't want to help you at all.

Kelli: He really just was a horrible doctor. He was always an hour and a half late to appointments. And the last time I saw him, I was his first appointment of the

day and he was an hour and a half late into the office. So, there [was] a whole office full of people waiting for him. So of course, he was in kind of a hurry. So, he walks in and ... he didn't even ask, he said, "You're feeling better."

And I said, no, no, I'm not. I'm not feeling any better.

He said, "But that's because there's a lot of viruses going around right now" and he left within a couple of minutes. And he said, "So I'm glad to hear you're feeling better. Well, you will be once you get rid of that virus."

And at least I was like, I've got to get rid of this guy. This guy's just not listening at all.

Through careful listening, effective physicians know their patients well enough to know what is helpful for them on an individual basis:

Elizabeth: Having a doctor who gave me scientific papers, for me that was helpful. I think for most patients it wouldn't be. But I think that's part of treating a patient, based on who they are, not just what disease they have.

Physicians can get to know patients during face-to-face interactions and also by engaging meaningfully with the documentation that patients provide:

Interviewer: If you could imagine better clinical care, what would those interactions look like for you in your doctor's appointments? What kind of tone or behaviors would you expect in those clinical meetings?

Adaline: First of all, it would be nice if they actually read my effing medical information document. I think I have had two doctors, in all of [the forty-one], actually read them. One was my allergist. And the second one was the geneticist I saw on Monday. Nobody else reads it.

Adaline took the initiative and spent energy to track her heart rate, pain symptoms, and activity levels in an app, as well as documenting her medical history (a list of her allergies, prescriptions, diagnoses, doctors she has seen, and medications she has previously tried or is currently taking), which her doctors refused to look at, with the notable exception of her allergist and geneticist. Patients are taking the time and attention to

gather data and there is not a reciprocated level of time and attention given by their physician. Patients have more incentive to return to clinicians that respect their work and input.

In addition, physicians who initially received medical training that is ineffective for their patients can personally implement the institutional recommendations listed at the beginning of this chapter. For example, instead of waiting for systemic changes to be enacted from the top down, Karen's doctor implemented telemedicine protocols into her own practice because it meets the needs of her patients. These recommendations can prepare physicians to meet the needs of people with ME and improve patient outcomes.

Recommendations for Patients

Health advocates are working to address systemic issues that make healthcare inaccessible to people with ME. However, systemic changes take time. In the meantime, people with ME need practical actions to implement when they face barriers to care. In the interviews, participants commented on the necessity of holding out for effective physicians and of advocating for themselves.

Participants in this study were persistent in trying again and again to find doctors who are willing and able to help them, despite the difficulty of receiving dismissive and dehumanizing feedback from many of their clinicians. Descriptions in medical articles, and physician attitudes, sometimes rely on caricatures of ME patients as lazy. The data in this study indicates that these women with ME are active, involved participants in their own well-being. Ashanti summed up the reasoning for this persistence in the face of barriers:

For me, when you're dealing with an illness like this that is so poorly understood and difficult to navigate, you need to stick with the doctors that are familiar, the doctors that believe you, the doctors that advocate for you, the doctors that are in your corner.

Weeding out ineffective physicians from one's team of medical providers is a labor-intensive process, but one that participants engaged in with ultimately positive outcomes.

In the absence of adequate physician training, for example, Lena takes her own precautions before meeting with a new physician:

I have this really good technique now for finding doctors ... I first go on Yelp and check all the reviews. And then I go on Google and check all the reviews. And if I can find anybody who's in my vicinity who has all great reviews, then I see if they take my insurance and then I call them up. And pretty much I've done that for all my doctors and it's been great. And then once I find somebody good, I ask them for recommendations. That works really well, and I have a great doctor. My kids' doctor is great. Our dentist is great. My therapist is great. I have wonderful, wonderful people helping me. ... I've been pretty well informed enough to be able to research and seek out good doctors. And so that's been really wonderful.

Implementing this system helps Lena find effective care and avoid repeats of the dismissive experiences she had previously.

Self-advocacy also plays a major role. People with ME are often in situations where they have to develop a clear knowledge of what is in their own best interest and what is not, even in the face of medical uncertainties. During appointments, the participants take on a proactive role, asking questions, requesting referrals, requesting to see their own medical records, and calling out reckless or biased actions by clinicians. Both before and after appointments, these participants search online for scientific articles and reports about treatment options. They learn what they can and use that knowledge to move their medical care forward. Researching on their own is not easy given the

symptoms of ME, but participants share their experiences of doing what they can, whenever they can.

Adaline: I don't know where I got the wherewithal to keep fighting, but obviously I did. And a lot of it was me researching and me going, okay, I have these symptoms, what causes these symptoms?

Interviewer: Where did you go to do your research?

Adaline: Google. Scientific journals. A little bit WebMD, but I don't really trust them so much. I try to go to the source ... I go back to the primary source.

Cheryl sometimes uses a combination of asking for insight from her online patient groups and using her professional knowledge as a nurse. This is how she arrived at her POTS diagnosis; she navigated the information with her community, not through doctors.

Ashanti indicates the benefits and limitations of entering an appointment with prior preparation: "I think me being a nurse and knowing what to ask for and how to ask for it definitely helps tremendously. But even still I encountered the infectious disease specialist who writes in my medical record that this was in my head." Patients who are not medically trained often seek out friends or family members who are trained, to support them and teach them. Some people with ME use apps to track biophysical feedback like heart rate and sleep patterns. Each strategy may not work in all instances; however, the combination of a variety of actions, including these strategies, help participants access a greater degree of medical care.

Throughout all of this, participants held on to the underlying truth of their own worth as people. Kelli repeated this theme throughout her interview: My life matters. Over the course of her search for medical care, she had to continuously assert the value of her own life in the face of procedures and people who do not value it.

Recommendations for Future Research

As a chronic illness community, people with ME require research that is commensurate with the disease burden. This means a twenty-seven-fold increase in funding from the NIH, according to the NIH's own algorithms for calculating the burden of a disease (Dimmock, Mirin, & Jason, 2016). This funding would support biomedical research to isolate biomarkers and treatments for ME, and studies to clearly capture the current prevalence of ME⁹⁰.

In addition to biomedical and prevalence studies, researchers can build on the original data from this study to continue to expand our understanding of the lived experience of ME. This expansion is particularly needed across categories of gender identity and race. Additional interviews with women of color need to be prioritized to reveal the particular nuances of navigating healthcare that result from the intersectional domains of race, health, and gender. Previous ME research has been unable to address these specific issues because of the consistent focus on primarily white populations in research samples, compounded with under-representation in patient advocacy leadership positions.

To conclude, the lives of the seven women with ME in this study reveal that medical policies and definitions do not exist solely in the clinical realm; they show up in the lived experiences of patients. As health inequality continues to be a pressing issue in U.S. healthcare, creating responsive medical protocols for chronic illness communities is increasingly important. Research that centers patient narratives can help disrupt the cycle

⁹⁰ Elizabeth notes that “prevalence studies are currently being proposed under the auspices of the CDC but require additional funding to that agency.”

of underfunding, stigma, and dismissal from medical institutions and physicians that people with ME have experienced for decades.

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APPENDIX A

TL;DR

This thesis includes summaries of each section to make this piece as accessible as possible to all communities impacted by chronic illness. Each heading, or group of sub-headings, has a footnote containing “*tl;dr*” and a brief sum-up the main ideas of that section.

The acronym *tl;dr* stands for “*too long; didn’t read*”. It is used on social media platforms to sum up a long post. Providing my own version of this within an academic paper supports my commitment to plain language (see Theoretical Framework & Methodology) and facilitates communication with key communities outside academia. Including the *tl;dr* footnotes will also allow interview participants from this study to more readily scan, analyze, and provide feedback on this thesis. Their feedback is vital to the formation of this work.

Below is a collection of all the *tl;dr* footnotes, which condenses each chapter down to a page or two.

Chapter I INTRODUCTION

Overview

Beliefs and ideas about illness are created socially. This makes advocacy and patient narratives necessary in order to challenge harmful beliefs about illness held by dominant medical institutions. Disability studies offers analytical tools to reconstruct medical norms.

Literature Review

Myalgic Encephalomyelitis: ME has gone by various names over the years. These names reflect social attitudes of the time period toward the disease, by their emphasis on fatigue/burnout OR on specific biological processes.

ME in Context

Funding: In the United States, the NIH does not fund ME research at a level appropriate to the disease burden.

Medical model: The medical model claims that all life events are under the jurisdiction of medical institutions. Under this model, symptoms and illnesses are counted as ‘real’ when they are visible and thereby granted medical legitimacy by the institution.

The relationship between women and chronic illness: Women are more likely to have chronic conditions. Men are more likely to have fatal conditions. An estimated 75% of people with ME are women.

The changing position of women's health within medical institutions: Limited gains have been made in integrating women's health concerns into medical curriculum and clinical practice. The FDA banned women from participating in drug trials from 1977 to 1993. Despite attempts to reverse this practice, drug companies still test drugs primarily on male subjects, resulting in consumer risk for the broader public.

Naming chronic conditions: Conditions that fall in the neuroimmune and autoimmune category have similarities in patient experiences of stigma, dismissal, and lack of specialists.

The role of institutional betrayal: When people are harmed by institutions they depend on for their well-being, this is called institutional betrayal. In healthcare, this occurs when patients' reports of their conditions are dismissed and their reports of negative experiences are not believed.

Feminisms and Disability Theories

Multiple feminisms: Feminist theory encompasses the lived knowledge of multiple groups (queer theory, disability theory, Latinx theory, womanist theory) and makes ample room for the contradictions within and between these groups. Feminist research acknowledges that the scientific method and 'objective' research are impacted by human biases. It seeks to reveal hidden power imbalances.

Disability Theories

Feminist Disability Theory: Feminist disability theory uses the tools within feminism and critical race theory in order to address the social inequalities experienced by people disabled by that society's norms.

Critical Disability Theory: Critical Disability Theory (CDT) examines medical and social systems that create disabling circumstances.

Multiple strategies: Solutions to health inequality require simultaneous work in *both* medical and social systems.

Theoretical Framework & Methods

Qualitative feminist inquiry: A method of study that critiques bias and power imbalances.

Feminist Disability Theory: Used here to center the stories and perspectives of people with ME, in keeping with the disability rights motto ‘Nothing About Us Without Us’.

Epistemic injustice: Certain types of knowledge (empirical) are privileged over others (experiential).

Plain language movement: Language and documents should be accessible to the people they are made for.

Interpretivist processes: This method of research uses ethnography (close up study of communities) and awareness of positionality (intersections of social privileges and oppressions).

Methods: In conducting this study, I used semi-structured interviews with seven participants with ME.

Chapter 2

THE LIVED EXPERIENCE OF ME

“It was a lifesaver just to have somebody understand”: Direct quotes from each interview participant give an overview of life with ME.

Exertion, Payback, & Rest: The Balancing Act: People with ME are careful about overexertion in order to minimize crashes. Rest serves the purpose of counterbalancing physical or cognitive activity, to the degree it is possible. Restorative, scheduled, and pre-emptive rest are some of the types of rest that participants utilize.

Day-to-Day-Life

Routines: While day-to-day routines differ between each person with ME, common concerns include managing energy output and symptoms. Large portions of the day are dedicated to rest.

“The most benign activity is taxing to your energy”: **Boundaries Around Exertion:** Living with post-exertional neuroimmune exhaustion (PENE) means that physical and cognitive activities (such as hygiene, online tasks, advocacy, emotional labor, and sensory input) take a serious toll and must be accounted for.

Changes

Onset: Participants share their personal stories about when their symptoms started.

Transitions: People with ME navigate many changes, such as the transition from an independent lifestyle to dependence on caretakers and reframing their beliefs about health and personal worth.

“This disease obviously caused a lot of problems”: **Dealing with Loss:** Participants share the losses that ME has caused and the period of grief that goes along with that.

“Society is a huge barrier against sick people”: **Expectations Around Work and Worth:** Social norms of productivity cause disruptions to self-worth for people experiencing the physical limitations of chronic illness.

Relationships: Despite the difficulties of losing relationships, maintaining connections with family and online networks remains a key aspect of quality of life for people with ME.

Chapter 3 NAVIGATING HEALTHCARE

“All I wanted was to figure out what was wrong with me”: This chapter focuses on the conceptual, institutional, and interpersonal barriers that participants encountered during their search for medical care. Some participants utilized their prior medical training to help them access care, with mixed results, and all participants expressed the desire to improve even in the face of stereotypes about malingering.

Specific Diagnostic Terms

What’s in a Name: The names and terms used to describe illness reflect and impact the conceptual formation of illness. People with ME use different medical terms, even amongst each other.

Diagnoses of Trial and Error: Before receiving an ME diagnosis, participants navigated a series of other diagnoses that were ultimately inaccurate, comorbid, or unclear.

Experiences with Institutions

Harmful Narratives: For people with ME, access to care is obstructed by assumptions that permeate the medical field: disbelief (the patient is not treated as a credible source of knowledge), psychosomatic cause (unexplainable symptoms are dismissed as psychological and not given treatment), and recovery (assumption that chronic illness will eventually go away).

Systemic Barriers: Large-scale issues such as inadequate physician training, the cost of healthcare, lack of information about ME, and lack of ME specialists create barriers to care.

Experiences with Individual Physicians

Barriers: On an interpersonal level, between physicians and patients, physician behaviors can create barriers to receiving effective care. These behaviors include approaching patients with disbelief, telling patients ‘you’re fine’, using dismissive and dehumanizing language, assuming psychogenic cause, and giving bad faith diagnoses.

Care and Harm from the Same Hand: Interactions with individual physicians often contain positive *and* negative elements, and do not sort cleanly into a binary of effective/ineffective.

Chapter 4 RECOMMENDATIONS

Refer to Table 4 for a summary of institutional, interpersonal, and patient recommendations.

APPENDIX B

INTERNATIONAL CONSENSUS CRITERIA (ICC)

As found in Table 1 in: Carruthers, B., van de Sande, M., De Meirleir, K., et al. (2011). Myalgic encephalomyelitis: International Consensus Criteria. *Journal of Internal Medicine*, 270(4):327-338.

Also referred to as the ICC for myalgic encephalomyelitis.

The following four categories constitute the criteria for ME according to the ICC:

Category 1: Postexertional neuroimmune exhaustion (PENE)

Patient must exhibit this symptom.

Marked, rapid physical and/or cognitive fatigability in response to exertion, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse. Postexertional symptom exacerbation: e.g. acute flu-like symptoms, pain and worsening of other symptoms. Postexertional exhaustion may occur immediately after activity or be delayed by hours or days. Recovery period is prolonged, usually taking 24h or longer. A relapse can last days, weeks or longer. Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level.

Category 2: Neurological Impairments

Patient must exhibit at least three of the four symptom categories.

1. *Neurocognitive impairments*

For example, difficulty processing information: slowed thought, impaired concentration e.g. confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, acquired or exertional dyslexia

OR

Short-term memory loss: e.g. difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory

2. *Pain*

For example, headaches: e.g. chronic, generalized headaches often involve aching of the eyes, behind the eyes or back of the head that may be associated with cervical muscle tension; migraine; tension headaches

OR

Significant pain can be experienced in muscles, muscle-tendon junctions, joints, abdomen or chest. It is noninflammatory in nature and often migrates. e.g. generalized hyperalgesia, widespread pain (may meet fibromyalgia criteria), myofascial or radiating pain

3. *Sleep disturbance*

For example, disturbed sleep patterns: e.g. insomnia, prolonged sleep including naps, sleeping most of the day and being awake most of the night, frequent awakenings, awaking much earlier than before illness onset, vivid dreams/nightmares

OR

Unrefreshed sleep: e.g. awoken feeling exhausted regardless of duration of sleep, day-time sleepiness

4. *Neurosensory, perceptual, and motor disturbances*

For example, neurosensory and perceptual: e.g. inability to focus vision, sensitivity to light, noise, vibration, odor, taste and touch; impaired depth perception

OR

Motor: e.g. muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia

Category 3: Immune, Gastro-intestinal, and Genitourinary Impairments

Patient must exhibit at least three of the five symptom categories.

1. Flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion. e.g. sore throat, sinusitis, cervical and/or axillary lymph nodes may enlarge or be tender on palpitation
2. Susceptibility to viral infections with prolonged recovery periods
3. Gastro-intestinal tract: e.g. nausea, abdominal pain, bloating, irritable bowel syndrome
4. Genitourinary: e.g. urinary urgency or frequency, waking in the night to urinate
5. Sensitivities to food, medications, odors, or chemicals

Category 4: Energy Production/Transportation Impairments

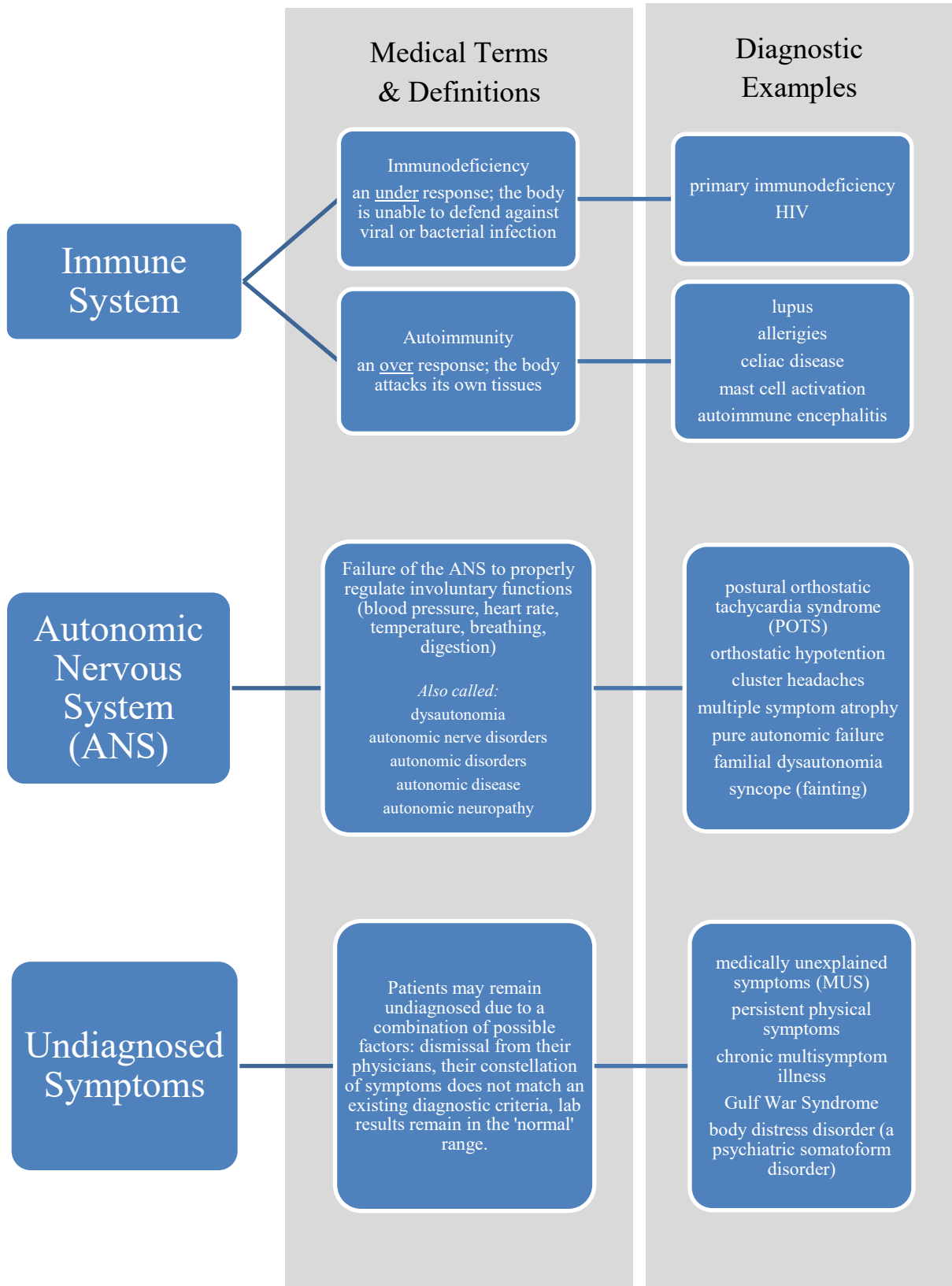
Patient must exhibit at least one of the four symptom categories.

1. *Cardiovascular*: e.g. inability to tolerate an upright position - orthostatic intolerance, neurally mediated hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, light-headedness/dizziness
2. *Respiratory*: e.g. air hunger, labored breathing, fatigue of chest wall muscles

3. *Loss of thermostatic stability*: e.g. subnormal body temperature, marked diurnal fluctuations; sweating episodes, recurrent feelings of feverishness with or without low grade fever, cold extremities
4. *Intolerance of extremes of temperature*

APPENDIX C

NAMING MULTI-SYSTEM CONDITIONS



Note: ME is classified as a neurological disease by the World Health Organization. It is related to the above classifications due to the neurological elements of the autonomic nervous system, as well as symptoms of ME that involve the immune system.

References for Appendix C
(alphabetized by diagnosis)

Autoimmune encephalitis:

Graus, Titulaer, Balu, Benseler, Bien, Cellucci, . . . Dalmau. (2016). A clinical approach to diagnosis of autoimmune encephalitis. *The Lancet Neurology*, 15(4), 391-404.

Bodily distress disorder:

Gureje, O., & Reed, G. M. (2016). Bodily distress disorder in ICD-11: problems and prospects. *World psychiatry: official journal of the World Psychiatric Association (WPA)*, 15(3), 291-292.

Dysautonomia:

Dysautonomia International. (n.d). *What is Dysautonomia?* Retrieved from www.dysautonomiainternational.org.

Gulf War Syndrome:

U.S. Department of Veteran Affairs. (2017). Public Health: Gulf War veterans' medically unexplained illnesses. Retrieved from

www.publichealth.va.gov/exposures/gulfwar/medically-unexplained-illness.asp

Note: The VA avoids the term Gulf War Syndrome.

Medically unexplained symptoms (MUS):

Marks, E. M., & Hunter, M. S. (2015). Medically Unexplained Symptoms: An acceptable term? *British Journal of Pain*, 9(2), 109-114.

Smith, R. C., & Dwamena, F. C. (2007). Classification and Diagnosis of Patients with Medically Unexplained Symptoms. *Journal of General Internal Medicine*, 22(5), 685–691.

Myalgic encephalomyelitis:

ICD-10-CM - International Classification of Diseases, Tenth Revision, Clinical Modification, July 26, 2018. Retrieved from

<https://www.cdc.gov/nchs/icd/icd10cm.htm#FY%202019%20release%20of%20ICD-10-CM>.

The ICD-10 categorizes ME under the name *benign myalgic encephalomyelitis*, as follows:

- | Diseases of the nervous system
- | Other disorders of the nervous system
 - | Other disorders of brain
 - | Postviral fatigue syndrome

APPENDIX D
SUICIDE IN CHRONIC ILLNESS COMMUNITIES

Participant commentary on the topic of suicide, from various interviews, presented in six segments (bold emphasis added).

I.

Participant: I get why suicide is one of the top three causes of death with this illness. And it's not necessarily just to end suffering but to avoid being a burden to people who give up everything for you, which my husband thank god is that kind of supportive partner ...

Interviewer: Is there anything you want to add about the suicide rates?

Participant: Just that first of all, they don't even track the disease, much less the suicide, so it's really tricky. But I see it on social media all over the place, people from all over the world killing themselves with this illness at all ages because of the just devastation of it. **And I really believe it should be researched, studied, and we should be looking for specific interventions that we can provide to people with chronic invisible illness to help them cope.**

Which is— I thought that maybe I could do something. I doubt that I can— I can't. I just can't. You know, I'm not a researcher. That's not my thing. But I have definitely— I've got my sort of hypothesis and ideas about research that could be done using some interventional stuff that might help— not medication but other types of interventions.

But it's a really taboo subject. What I found in reaching out to other advocates nationally is that people don't want to really address it.

Interviewer: Specifically with ME/CFS?

Participant: Yeah. Well, part of it is **they worked so hard at destigmatizing** and clarifying that it's not psychological or psychosomatic or a psychiatric problem that they don't want to be seen as depressed, anxious, or suicidal people. But they are, because they're killing themselves. You know what I mean? And so it's tricky and if you bring it up— I brought it up to, as I said, some top advocates and nobody wanted to form a committee or work on it. I've asked a couple researchers. I've asked even my specialist if she would reach out to some people. And just people aren't— people are afraid to touch it. I don't blame them.

But I just know psychiatric emergency rooms. I know how people deal with crises. And I know what happens when people call suicide hotlines and things like that. And I've had plenty of patients brought in handcuffs and having their— losing their civil rights and being treated—taking— we take their clothing. We take their cell phones. We isolate them. We put them in areas that might have violent people, or loud agitated people, people high on meth, they're all thrown in a room, no matter what their stuff is, in psychiatric emergency rooms. And sometimes they're held for days and days, sometimes

even weeks in [location]. It happens for weeks. I've worked in there and it's horrifying to me and anybody with a chronic illness that's triggered by stimulation like that; lights, not being able to have control over temperatures, and scents, and things that trigger them. It's just not a good option.

II.

Participant: I have actually a friend in [location] who has been suicidal recently, who reaches out when she feels that way, and she actually asked me at one point: What's the best psych hospital in [location] and I told her go to [hospital name] because they'll at least treat you and they'll try to keep you with depressed people instead of violent people ... it's a nicer facility and there's activities and art therapy and there's things to do. It's not just a holding tank. But I said, it's still— they still take your cell phone away, they're going to take your belts and your shoelaces and anything that you could use to harm yourself. And it's still not—you're not going to have internet access and you're not going to have any— She was like, *I'm gonna choose to stay home and just ask my husband to come home from work and sit with me.* And I feel bad for her. **I wish there was better resources for her, but there aren't.**

III.

Interviewer: Have you found that people with CFS themselves are hesitant to embrace their own anxiety and depression symptoms or even recognize or talk about it because there's a fear of being dismissed? And that their whole— if I admit that I am depressed, will I suddenly not be able to get treatment for my POTS?

Participant: Right. Or will they say, you don't really have POTS, you just have depression and you somaticize the POTS— it's hard to somaticize a heart rate that increases, I mean that's pretty objective.

But yeah, I do believe that people avoid it.

Some do and then others just— I can't tell you how many Facebook posts that I see or is like, *oh I can't take it anymore.* You know, and I just think this is so inappropriate, like **this should not be the only avenue for these people to ask for help.** It's frightening to me and as somebody who was a psychiatric nurse who could involuntarily commit people to mandatory evaluation or treatment, I don't feel comfortable really because I'm still licensed and just in case, and I just, I don't feel comfortable with advising people or intervening and neither should anybody be doing that on social media, but they do so I just— I try not to look at a lot of that. But it is it is really tragic to me how many people have died by suicide.

Interviewer: What do you imagine that avenue being, if there was a robust medical response to suicidal ideation in chronic illness communities?

Participant: Well, I think it's unfortunate because there just isn't adequate resources in Mental Health Training to manage the schizophrenia, the chronically mentally ill, and the people with chronic physical illnesses. But if specialty providers for ME/CFS, like Bateman Horne has done now, could provide some kind of psychological intervention that would be useful. Part of it is just getting people to reframe their sort of perception of the illness ... and then part of it is actually providing help with things like insomnia, which is definitely a suicide risk.

... there's three I's ... of suicide, and the three I's were **perceiving your situation as interminable, intolerable, and inescapable**. Which anybody who gets the diagnosis, once they start researching it, starts to see that *oh my god, that's so characteristic*. You don't know when it's going to end. You don't know if you can ever get better. The symptoms can be so severe that you don't know if you can suffer that pain one more day or that insomnia one more night or whatever it is.

IV.

Participant: But the worst [physician interaction] that hit me hardest was two years ago. I went to another rheumatologist, the first one that diagnosed me ... he took blood tests and things and I came back for the results and I didn't have lupus. It was a negative test. And I thought I was going—I thought he was going to be watching my CFS. I just thought he was ... and he wasn't. I don't know if he just wasn't good with patients or what. He started basically kicking me out of his office saying ... "Rheumatologist have enough patients with rheumatoid arthritis, we don't need other people with other things, we don't want patients that have those." And I was shocked. It was so not what I expected ... he was like, "I don't want to see you anymore."

Interviewer: How many appointments had you made with him?

Participant: This was a second. So, this was the blood test. I didn't understand that he was just looking into the lupus and if I didn't have lupus I was out. I thought he was maybe going to— because the other rheumatologist had offered to see me like once a year and watch me, so I just didn't know.

And I finally was trying again to be proactive and I said, tell me you do believe in chronic fatigue syndrome. And he said, "Oh, I believe chronic fatigue syndrome exists. I just have no idea if you have it." And there was something about that in that moment—and I'd had the disease three and a half years— just knocked me off my center.

If I had had the means at that moment, I think I would have ended it. It hurt that bad and it was that shocking ... And I walked out, almost in a daze, and I remember the receptionist saying, "When are we going to see you again?" And I said, he doesn't want to see me. She's like, "What?" and she confirmed it with him ... And I kind of just reeled out into the light and then after about five minutes, because I am 56-years-old and have been through a certain amount in my life, I remembered that he hadn't given me the disease and he had no answers for me and I'd be okay. Yeah, I didn't need him ... I just laughed it off and things. But it stung. That was the worst that ever got for me. **That was the moment when I was like, I just can't do this anymore.** And I, like I said, I don't know what it was about the dismissal ... I think I don't even know his name. I would have to really do some research to even remember his name. But it was it was a stinger. So.

Interviewer: Yeah, those stand out.

Participant: Yeah. And I think to myself, **had I not had the support system—what happens to people?** [pause] It actually still upsets me.

Interviewer: It's upsetting.

Participant: ... I've had worse, but that was the most upsetting one.

V.

Interviewer: Is there anything I haven't touched on that you would like to include?

Participant: Let me think real quick.

Interviewer: Take your time.

Participant: Probably one last thing, and that was probably one of the things that's helped me through this as much as anything else, has been a social network of other patients. I do not know how people survived before social network. I just— hearing other people and knowing that they're going through the same thing or that they have gone through the same thing for 34 years or what— **is lifesaving.** It's **eased the isolation** quite a bit. So that's just one—you know, that's just been really important. Even if I get no information on the disease, it's not— it's aside from that. It's just knowing, recognizing, that when someone's talking about their life it sounds a lot like mine. That's been good because otherwise I would literally not know one other person who's experiencing what I have. We all in our bedrooms.

VI.

Participant: But you know if it wasn't— to be completely honest, if it wasn't for my husband taking care of me, **I would probably have killed myself**. Because it's just— I have no one else. And I— I'm in— disability says I should be able to work and I tried until I broke myself.

So, instead of— I really believe that when I had first gotten sick, to the extent that I got sick that I felt like I needed help for it, if someone had said, "This is what you have. Learn how to pace, you know, do these things," I would be a hundred times better. Because I wouldn't have run myself ragged. But there was nobody to say those things. There was— you know back to society saying your worth is based on you working and what you contribute. So, sorry I just got a little soap box there.

Interviewer: That was very articulate and such a beautiful way to put it. Yeah, all of the ways that medical systems are working or **not working** for people who can't work.

APPENDIX E

IRB APPROVAL DOCUMENTS

EXEMPTION GRANTED

Annika Mann
 Humanities, Arts and Cultural Studies, School of (SHARCS)

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Annika.Mann@asu.edu

Dear Annika Mann:

On 10/26/2018 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Patient Narratives of Myalgic Encephalomyelitis: Context-rich descriptions of access, diagnosis, and recovery
Investigator:	Annika Mann
IRB ID:	STUDY00008992
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • IRB Application Protocol for Patient Narratives of ME, Category: IRB Protocol; • Recruitment Scripts for Patient Narratives of ME, Category: Recruitment Materials; • CITI Completion Report for Annamaria Oliverio Lauderdale, Category: Other (to reflect anything not captured above); • CITI Completion Report for Annika Mann, Category: Other (to reflect anything not captured above); • ICC Checklist, Category: Screening forms; • Consent Form for Patient Narratives of ME, Category: Consent Form; • Contribution Matrix and Selection Process, Category: Screening forms;

	<ul style="list-style-type: none">• Interview Instrument, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);
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The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 10/26/2018.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Carmen Cutler
Annika Mann
Carmen Cutler
Annamaria Oliverio Lauderdale

BIOGRAPHICAL SKETCH

Carmen Cutler is graduating from Arizona State University with a master's degree in Social Justice and Human Rights, a program embedded in interdisciplinary collaboration and community action. Her research centers on the experiences of people with chronic illness and how their knowledge can transform healthcare processes. Drawing from her professional background as an educator and curriculum designer, her academic work focuses on strengthening patient/physician collaboration, reimagining clinician training, and signal boosting the voices of the chronic illness community.