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The Chronically Undiagnosed: How American Society and Health Care System Lets Ambiguously-Ill Patients Fall Through the Cracks

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Preface

This thesis will investigate diagnostic journeys and chaos narratives, the barriers to diagnosis and the repercussions of being sick without one. From the moment that I started experiencing the hallmark symptoms of autoimmune disease (intense fatigue, brain fog, depression), this was going to be the subject of my senior thesis, the topic I would dedicate my heart, soul, and final year of college to.

My symptoms began stealthily, as they are prone to do, becoming barely visible my senior year of high school. I had newfound difficulty focusing, lost weight, and felt more exhausted than ever before, regardless of how much I slept. My parents and doctors thought it was what it looked like— a teenager with depression and a disordered relationship with food. I met with a nutritionist, was put on medication, and went off to Vassar. My freshman year, symptoms worsened; I was too nauseous to eat anything other than saltines and vitamin water, incredibly fatigued, and went down to 105 lbs. One day, confused and defeated, I wandered into Vassar's Health Services office on campus. I repeated my symptoms to the nurse, who urged me to drink ginger ale and eat saltines. I cried of frustration, begging her to take my blood, to tell me something was wrong, that there was something they could do. That summer, at a routine GP appointment, I mentioned my symptoms and my conscientious physician took vials of blood. "I don't think anything will come up, but it's good just to be sure," I remember her saying. My labs came up positive for celiac disease, and after an endoscopy to confirm, I stopped eating gluten. One month later, all my symptoms had subsided, I stopped taking my anxiety and depression meds, and felt as though I had been given a new lease on life. With that small adjustment, I felt reborn.

As a white, upper middle class, highly educated woman who has been medically literate since a very young age, I had every opportunity to be diagnosed quickly. My father is a physician turned hospital administrator, and both my parents have always been receptive and responsive to my health concerns. And yet, it took two years for me to find my way towards diagnosis and relief. For celiac disease patients, every gluten exposure increases a patient's chances of developing further autoimmune disease or bowel cancer in the future. With my self-medication diet of saltines and ginger ale, I succeeded only in making myself sicker. In researching for this thesis, I found that my diagnostic journey, which once felt long, was in fact comparatively short, and I realize I'm very fortunate to have received a diagnosis at all. Originally my topic focused on diagnostic delay and autoimmune disease, but as I researched it grew to include patients who are in "diagnostic limbo," patients who, for years on end, never reach the "endpoint" of their diagnostic journey, and patients with diseases that aren't fully recognized by the medical establishment (contested illness).

With this thesis, I investigate our society's obsession with diagnosis, where it came from, and how it excludes patients without identifiable biomarkers. I examine the social, political, and medical consequences to being ill without a diagnosis, and imagine a more supportive system for patients with medically unexplained symptoms. As demonstrated by this paper, my story is one of many, and one of the more lucky ones. I hope you enjoy reading this thesis as much as I enjoyed writing it.

Ava Boal

Introduction: Medical Mysteries

New York Times Magazine has a section dedicated to diagnoses with the subtitle, "Dr. Lisa Sanders on hard-to-solve medical mysteries"; the author writes a subsection called "Diagnosis: Unsolved Cases: Help Dr. Lisa Sanders Get to the Bottom of Unsolved Medical Mysteries." In the column, she calls for readers' help, listing various symptom profiles and ending with pleas for aid.[1] Numerous "doctor shows," or television series about medicine, place diagnosis at the end of an episode. It is presented as the key to curing a patient; along the way they collect medical "clues." For example, a quote from an article titled "He Kept Seeing Sparkly Dots on the Edge of His Vision. What Was It?" reads, "a worrying smudge on a photo of his retina became an important clue."[2] The television show *House*, which aired for eight seasons, even had a main character that emulated Sherlock Holmes, with a house number of 221 B, just like Holmes; "Like Holmes, House's stock in trade is not simply superior knowledge and logic, but an acuity that perceives symptoms others ignore."[3] This column and genre of TV shows serve to reflect the nature of medicine today; diagnosis as the be-all end-all, end of an episode, murderer in the last page of an Agatha Christie novel— the key to treating patients. Dr. House "is the doctor of uncertainty, his diagnostics an old medicine rethought and repackaged for a new age of advancing disease."[4] The New England Journal of Medicine publishes a weekly "Image challenge," that presents readers with an anatomical picture and asks readers to identify the diagnosis, giving a few words of background next to the image. Readers are invited to select the correct diagnosis and see if they are right, once again underpinning the idea that accurate

[1] Sanders, "Diagnosis: Unsolved Cases"
[2] Sanders, "He Kept Seeing Sparkly Dots on the Edge of His Vision. What Was It?"
[3] Koch, "The Doctor in This House."
[4] ibid

diagnosis is the form by which medicine functions and doctors treat.[5] Diagnosis is meant to combat uncertainty, leaving our system ill-equipped to handle those patients for which "clues" do not help solve the "mystery," or for which solving the mystery diagnosis does not lead to a clear conclusion of treatment.

There is no denial that diagnosis-based medical practice has innumerable benefits. With no name to a disorder, we are left with no connection to its pathophysiology, or its treatments; with no name for what happens when plaque builds up in an individual's arteries, it would be difficult to organize our thinking and work out how to treat the patient. The ideal medical model functions in this way: an individual begins to feel sick, sees a physician, receives a diagnosis, receives treatment, and then recovers. Alternatively, a patient may receive a diagnosis for which there is no treatment, and therefore must adjust their lifestyle accordingly, knowing the path their disease will take and having information about how to manage their symptoms. However, diagnosis is only a model, one with utility, but a construct nonetheless. A map is not the territory; a medical model based around diagnosis does not function for the entirety of human experiences and conditions, and works better in some patient populations than others. Our diagnostic model does not function well with patients that have symptoms that do not have an identifiable pathological cause (or, biomarker), nor does it function as well with contested illness. Women are more likely to be underdiagnosed than men in almost every condition, as are other patient populations that have been shown to receive less thoughtful care (patients of color, for example). The mechanism of diagnosis has also been historically exploited as a form of social or political control— think of the medicalization of homosexuality, and psychiatric diagnoses given to institutionalize the politically deviant in the old Soviet Union.[6] The diagnosis model is imperfect,

[5] "April 2, 2009 | NEJM."
[6] Moncrieff, "Psychiatric Diagnosis as a Political Device."

as useful as it is and will continue to be. In this thesis, I will explore the history of the diagnostic taxonomical model, how technological innovation "creates" disease, and where diagnosis leaves individuals with contested illnesses, medically unexplained symptoms, and chronic illnesses behind. By looking at Thomas Kuhn's paradigm shift theory, I will analyze how diseases that were once contested went from being seen as "normal wear and tear" or whines by hysterical women to being accepted into mainstream medicine. In doing so, the path for diseases that are now contested to become accepted, understood, and that patient experience validated, will become clear. I will also examine the role of patient advocacy and embodied health movements on paradigm shifts, using the combined example of myalgic encephalomyelitis/chronic fatigue syndrome and long covid to elucidate this point. I will examine why patients are undiagnosed when they can be, how illnesses become recognized, and suggest avenues to mitigate the social, functional, and medical consequences to being ill without a diagnosis.

I. History and Taxonomy of Diagnosis and What it Leaves Behind

A Brief History of Diagnosis

The term diagnosis was first coined posthumously, by an English physician, Thomas Willis, in his notes in 1681; he defined it as "dilucidation, or knowledg."[7] In 1701, Reverend George William Lemon defined diagnosis as:

> "a knowledge or judgment of the apparent signs of a distemper, or a skill by which the present condition of a distemper is perceived, and thus three-fold 1. A right judgement of the part affected. 2. of the disease itself. 3. Of its case."[8]

Diagnosis, which can also be described as taxonomy in medicine, followed the movement of the natural sciences in the beginning of the eighteenth century, the notion that "taxonomy would provide a mechanism for understanding the world and for understanding and celebrating God's presence here on Earth."[9] Identified diseases were (and continue to be) grouped by similarity of symptoms, pathology, and identifiable cause, just as naturalists conquered and categorized the plants and animals of the New World. However, as Annemarie Goldstein Jutel writes in her book *Putting a Name to it: Diagnosis in Contemporary Society*, a pioneer text on diagnosis theory, classification is not value free.[10] Once taxonomical labels are laid out, it appears as though they are empirical, unbiased, when in fact they were written by people all with their own flaws and can only cover the breadth of medical knowledge accrued at the time they are written. Jutel quotes Thomas Arnold: "Various branches of human knowledge are capable of the most different arrangements according to the light in which we wish to regard them."[11] Essentially, all

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[7] Jutel, *Putting a Name to It: Diagnosis in Contemporary Society*. 6
[8] Jutel 6
[9] ibid
[10] Jutel 37
[11] Jutel 16

"empirical" knowledge is not only constructed from the taxonomer's vantage point, but is viewed that way as well.

The advent and narrowing of specific diagnoses drove great strides towards modern medicine as we know it today. Standardized diagnostic terms allowed doctors to communicate, collect statistics about prevalence, and share information about diseases. Disease research can take place when "like can systematically be described as like."[12] Phil Brown, in "Naming and Framing: The Social Construction of Diagnosis and Illness" describes how diagnosis in-and-of itself transforms unorganized illness into organized illness. He sees it as "a matter of the politics of definitions whereby illness designations are created from social conflict."[13] It is only in the past two centuries, however, that diagnosis as we know it today has become such an important part of medical treatment. As late as the 1880's many cause-of-death hospital records listed vague diagnoses such as "old age" or "marasmus"[14] (undernourishment), if anything at all. However, this shifted in the 20th century with the development of diagnostic methods such as chemical cytology and imaging. A new emphasis on physical diagnosis, studying normal and abnormal human functioning, and germ theory changed the way physicians thought about the body, creating strict notions of what constitutes a legitimate disease and, in doing so, what does not.

Technology and Disease

In "The Tyranny of Diagnosis: Specific Entities and Individual Experience," Charles E. Rosenberg explains how the advent of "instruments of precisions" such as the thermometer, blood tests, microscopes, and EKGs in the late nineteenth century were influential in the shift to

[12] Jutel, *Putting a Name to It: Diagnosis in Contemporary Society*.
[13] Brown, "Naming and Framing."
[14] Rosenberg, "The Tyranny of Diagnosis."

disease categories becoming "tight, seemingly objective pictures."[15] Disease could now be measured in units, with an agreed upon vocabulary and newly invented sound, measurable standards. This development placed patients on a spectrum, with therapeutic practice based increasingly on the results of these tests. By the end of the nineteenth century, standardized forms for case records in hospitals were widely used, leaving blank spots for diagnosis and little space for the patient's own description of their symptoms and perception of illness, though room was left for results of blood tests and urine tests: "the findings of physical diagnosis."[16] This new era of diagnostic technology, the switch from physicians treating patients based on self-reported symptoms to basing diagnoses on physical examination coupled with imaging and cytological procedures, led to a separation of the disease entity from the ontological self. Diagnosis has been important in medicine since its advent, but with these tools medicine has become increasingly "technical, specialized, and bureaucratized."[17] As a result of the increase in sensitivity of these tools and therefore "disease specificity," the idea that diseases "can and should" be seen as separate from their manifestations in the individual developed.[18] This distinction of care for the disease instead of care for the individual is upsettingly clear in the example of an unhoused individual becoming visible to the system when they have an "acute ailment," who then "returns to invisibility once that episode has been managed" and they are released from the hospital.[19] Rosenberg summarizes: "It is almost as though the disease, not the victim, justifies treatment."[20] Once again, this creates a culture that leaves sick individuals with no diagnostic labels effectively left out in the cold, with no space to occupy within a siloed and divided medical system.

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[15] Rosenberg, "The Tyranny of Diagnosis."
[16] ibid
[17] ibid
[18] ibid
[19] ibid
[20] ibid

Advancements in technology not only allow for more specific naming of the conditions that ail symptomatic patients, but also allow physicians to uncover disease in patients who feel well. In this way, technology works to reveal the invisible illness, even to create it out of thin air. Of course, in many cases this is life-saving, offering vital information that allow patient-doctor teams to tackle issues before symptoms arise or worsen and damage is irreversible. This technological invention of disease, though, also can have an immense psychological impact on patients who may feel perfectly fine. Take, for example, a routine blood test taken at a GP appointment that uncovers dangerously high levels of cholesterol. This requires a severe lifestyle change to amend, a burden on an individual who didn't expect anything to be wrong, who does not feel as though they are anything but healthy. In "Patients-in-Waiting or Chronically Healthy Individuals?", Mikko Jauho provides an example of the 'technoscientific illness identity' of individuals with high cholesterol. They feel well, receive a diagnosis and are told they must change their lifestyle habits. Many of these patients feel as though they are being seen as morally culpable, or betrayed by bodies that they thought were healthy.[21] Rosenberg describes diagnoses of this type (high blood pressure, for an additional example) as "proto-diseases." Once articulated, proto-diseases become both "emotional and clinical realities."[22] In many cases, "proto-diseases" of this sort are immensely beneficial, allowing for early intervention and treatment of disease in very early stages. However, the use of technology to identify and treat diseases before symptoms appear, as juxtaposed with a system that offers little care for symptoms that cannot be explained by diagnostic tests, becomes yet another example of the modes with which technological innovation perpetuates the medical community's priority of biological objectivity over trusting the patient's embodied experience and testimony.

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[21] Jauho, "Patients-in-Waiting or Chronically Healthy Individuals?"
[22] Rosenberg, "The Tyranny of Diagnosis."

Genetic testing also "creates" disease in this way, enabling diagnosis and therefore care, when available. One example similar to proto-disease is the identification of "carrier states," such as for Huntingtion's chorea or cystic fibrosis, yet another category of diagnosed but not diseased individuals, identified only by the development of a new technological insight. With increased screening spurred by national screening programs such as routine pap-smears for cervical cancer, monitoring of cholesterol levels and cardiovascular health, and recommended colonoscopies for colon cancer, the population of individuals with proto-diseases is ever-expanding; people who are considered to be at-risk for certain diseases, revising their health status from healthy to not, but, lacking symptoms, also struggle to consider themselves ill.[23] Symptoms have historically played a fundamental role in conceptualizing disease, but as medicine and its technological tools have developed, the focus has shifted to seeing "symptoms [as] mere placeholders for the diseases they represent."[24] With screening identifying disease or, often, the future possibility of disease, before symptoms become noticeable, the need for symptoms as signs becomes unnecessary. Thus, a culture emerges that cultivates a prioritization of the presence of biomarkers over patients' complaints, leading to a delegitimation of chronically ill patients for whom biomarkers cannot be found.

Diagnostic Social and Bureaucratic Power

Rosenberg goes on to place diagnosis within a social context as well as a conceptual one. He describes receiving a diagnosis as a "ritual of disclosure," pulling back the curtain to replace uncertainty with a structured, strict narrative.[25] Because of diagnoses' importance in today's

[23] Gillespie, "The Risk Experience."
[24] ibid
[25] Rosenberg, "The Tyranny of Diagnosis."

structure of medicine, it is both a "bureaucratic and an emotional necessity."[26] Emotional, in that it addresses the patient's desire for understanding their symptoms, the need to legitimize their illness in the eyes of others, as well as contend with resulting self doubt. Diagnoses are a bureaucratic necessity "for records, for reimbursements, and for the coordination of complex intraprofessional and institutional relationships."[27] Medical education revolves around diagnosis, which serves as "both objective and as heuristic."[28] As physicians are the only ones with the power to diagnose disease, "medical custodianship of diagnosis reinforces medical authority."[29] In 1980, Conrad and Schneider agreed that authority in medicine comes from physicians' unique ability to define and then treat illness, leading to high public esteem and "a prominent role in both the health and general social hierarchy."[30]

The process of diagnostic taxonomy, or categorization of an individual as sick or well, itself is limited by its construction by human beings who naturally have their own biases and notions of what it means to be ill. Not uncommonly, diagnoses are informed by outdated information and preconceived notions. These tendencies can lead to biased interpretation of symptoms and to labeling them as, for example, "run-of-the-mill" or psychosomatic when in fact they are much more than that. Jutel quotes an uncited writer in the *British Medical Journal* from 1886 to elucidate this point: "the imperfection of our medical vocabulary is not a matter for surprise. It is the measure and gauge of the imperfection of our medical knowledge and only imperfect knowledge admits of a perfect nomenclature."[31] Though this was written centuries ago, it holds true today; physicians can only judge their patients' symptoms on the body of medical knowledge available in that examining room, attempting to match symptoms and test results to

[26] Rosenberg, "The Tyranny of Diagnosis."
[27] ibid
[28] Jutel 8
[29] ibid
[30] ibid
[31] Jutel 12

previously-defined specific conditions. M Blaxter calls diagnosis a "museum of past and present concepts of disease."[32] Science and medicine are constantly evolving, but as Jutel and Blaxter point out, these changes lead to "remodeling rather than reconstruction." This is often clear in disease naming, as well as in the remaining presence of outdated ideas of which patient populations are more likely to have certain diseases in our physicians and our own social consciousness.

No classification system is constructed as an objective entity entirely separate from the social context. This is especially evident in the process of medicalization of conditions once seen as entirely needless of medical intervention, and in the demedicalization of once strictly defined disorders. Before the advent of instruments of precision in the nineteenth century, medical focus could be more loosely tilted towards social undesirability, such as the labeling of witchcraft and drapetomania (a diagnosis given to runaway enslaved persons) as physiological diseases. Female hypoactive sexual desire disorder was a diagnosis created for women who complained of a low sex drive, a diagnosistic existence that is predicated on unsubstantiated but pervasive societal "beliefs about what constitutes 'normal' sexuality."[33] Homosexuality was medicalized and "medicated," and other behaviors were brought into the realm of medicine that never before were considered in its purview. Jutel uses the taxonomical shift of homosexuality from being labled as a crime, to disease, and then nondisease to illustrate that "diagnoses are not prior, ontological entities but social categories that organize, direct, explain, and sometimes control our experience of health and illness."[34]

Jutel points to three necessary identifiers for disease classification; "some human recognition of its undesirability," a collective will to have it inhabit the medical realm (as

[32] Blaxter, "Diagnosis as Category and Process."
[33] Jutel 4
[34] Jutel 34

opposed to the moral, spiritual, or idiosyncratic), and the presence of technical capacity to discern it.[35] To summarize, undesirability, belief it belongs in medicine, and technological discernment are all necessary for disease classification. This brings us back to the central question this thesis will be examining: what are the social, functional, and medical consequences for an ill individual for whom these three conditions are not met?

[35] Jutel 35

II. Where Theory Leaves Contested illness, Medically Unexplained Symptoms, and Chronic Illness Behind

As discussed in the preceding chapter, receiving a diagnosis is integral to receiving medical care and developing an understanding of one's illness. However, there are many patients who go to the doctor because they feel ill and do not receive a diagnosis; this has consequences beyond not receiving treatment, also affecting their self perception and embodiment of illness. In this chapter, I will examine medically unexplained symptoms/MUS (symptoms for which there is no identifiable pathological cause), contested illness (conditions for which there is no consensus as to their existence as discrete diagnoses), and illnesses with long diagnostic delay to understand how patients suffering from these conditions do not fit into the expected "sick role" and the subsequent effects. The current medical model and social conception of disease does not allow individuals with unnamed or contested conditions to be "successfully ill."

"Achievement" of Disease and the Sick Role

A diagnosis, and the knowledge that comes with it (the why, the how, the cure or way to ease the symptoms) gives an individual the opportunity to "conceptualize the disease as separate from the individual's self."[36] As M. Bury discusses in "Chronic Illness as Biographical Disruption," this separation can be unavailable to those suffering from contested disease. A clear diagnosis allows for objectivity of disease, as a separable entity from the well body and therefore free of moral implications / fault of the diagnosed individual. A label puts the fault somewhere: a malfunctioning gene, a viral infection, pollution; to "be able to hold the disease 'at a distance', as it were, assists the claim that one is a victim of external forces."[37] Without it, the ability to hold

[36] Bury, "Chronic Illness as Biographical Disruption."
[37] ibid

the disease far away, is to "accept fully the burden of responsibility."[38] As has been stated, individuals with symptoms but no diagnoses fear being seen as hypochondriacs, attempting to benefit from social security benefits they don't need, and psychologically ill instead of physically. A diagnosis, or "achievement of disease" as it is described by Bury, is one of the sick role expectations, and can be experienced as "medical 'absolution' from individual responsibility."[39] While those receiving a diagnosis of incurable or painful disease may meet it with alarm and disbelief, patient groups such as those with medically unexplained symptoms or unspecific pain "often welcome and encourage positive diagnostic tests and diagnoses, describing them in terms of relief, as vindication and as 'proof' of their suffering."[40]

In a study conducted in Norway amongst chronic back pain sufferers, Claire Genton examined interviews and data from an online discussion board hosting discussions about patients' experiences living with chronic pain without a hard biomedical diagnosis. Her study affirmed that without "proof" that they are sick, patients fear being seen as malingerers, or having their symptoms discounted as psychosomatic or as rooted in mental illness. One sufferer of chronic back pain stated that she was glad when she had to go to the hospital because "then you've got a paper saying 'you are sick.'"[41] Many of those interviewed felt similarly, saying that a big topic of concern was social networks and health officials not accepting their pain as illness, and consistently reported being afraid of "the reality of [their] pain being questioned."[42] Explanations make people feel "relieved and vindicated."[43] Without them, individuals who know they are ill but live with unrecognized pain experience "profound feelings of de-legitimation."[44]

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[38] Bury, "Chronic Illness as Biographical Disruption."
[39] ibid
[40] Glenton, "Chronic Back Pain Sufferers—Striving for the Sick Role."
[41] ibid
[42] ibid
[43] Nettleton, "'I Just Want Permission to Be Ill.'"
[44] ibid

Essentially, without a label to legitimize their symptoms patients can feel shameful and guilty, which in turn threatens "their sense of self and social identity."[45] Nettleton summarizes: "The motivation for finding a diagnosis may therefore be both practical and psychosocial."[46]

Denton examines the socio-technological concept of "the sick role" as it applies (or more accurately, does not apply) to the illness experience of chronic disease. Chronic back pain sufferers cannot present the "proof" that those who are viewed as "sick" can, including but not limited to mobility issues, firm medical diagnoses, and clear courses of treatment.[47] One mother interviewed, whose two sons suffer from chronic back pain, stated that it was easier for her son who had a confirmed slipped disc. She described the experience of her other son, John, differently: "when it doesn't show up on the pictures, that's when it becomes difficult because you feel like nobody believes you, and that hurts a lot."[48]

While healthcare and diagnoses are integral to "the achievement of the sick role," being visibly ill may also be necessary to social acceptance and acknowledgement; this assumption or fear that their doctors do not believe they are ill can have social ramifications as well. One chronic back pain sufferer stated: "It would have been easier to have lost a leg because 'Wow, look at him. He's lost a leg and he's out mowing his lawn! He really works hard!.'"[49] There is no such commendation for chronic back pain sufferers going through the activities of daily life, nor for sufferers of chronic fatigue syndrome (ME/CFS), individuals with MUS, or those with fibromyalgia. In fact, seeing these individuals perform daily tasks may serve to further delegitimize their sickness in the eyes of those around them. In another interview, a woman describes not knowing if physicians and social security officers believe her because "who can

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[45] Nettleton, "'I Just Want Permission to Be Ill.'"
[46] ibid
[47] Glenton, "Chronic Back Pain Sufferers—Striving for the Sick Role."
[48] ibid
[49] ibid

see? You wear nice clothes and you get in and out of cars and you walk up [the] stairs…."[50] Dr. Hadler notes patients experience the defense of their illnesses as "battles" against the physician "gatekeeper."[51]

In 1951, Talcott Parsons defined four aspects of the "institutionalized expectation system" as it applies to the "sick role": two rights and two duties. According to Parsons, the sick individual is excused from both responsibility and social obligations, and "definition of the incapacity as illness provides a legitimate basis for the sick individual's exemption."[52] He goes on to argue that this legitimation is partial and conditional, however, and demands "recognition that to be ill is inherently undesirable and hence there is an obligation to try and get well."[53] This obligation includes going to the doctor, and "to cooperate in the process of getting well."[54] Clearly, this pervasive framework is inherently incompatible both with the conditions of chronic disease as well as those with undiagnosed illness, medically unexplained symptoms, and/or illnesses that are not fully accepted by the medical establishment. Illness, in this framework, is only legitimized and therefore supported with social services (paid time off, for example) as a transient state (not applicable to chronic disease) and with a diagnosis (unavailable to individuals suffering from contested illness and/or MUS).

Also, as Segall (1976) offers in "The Sick Role Concept: Understanding Illness Behavior," this Pasonian framework embeds the "sick role" in physical illness and does not account for psychological illness, thus creating an environment in which a psychological diagnosis may "weaken the claim to the sick role."[55] With a psychological diagnosis also comes an implication of personal responsibility. As a result, individuals in the chronic back pain study

[50] Glenton, "Chronic Back Pain Sufferers—Striving for the Sick Role."
[51] ibid
[52] Segall, "The Sick Role Concept."
[53] ibid
[54] ibid
[55] Glenton, "Chronic Back Pain Sufferers—Striving for the Sick Role."

were unwilling to admit the psychological effects of their pain, both due to perceived threat of stigma placed on mental illness and fear that a psychological diagnosis would "lead to a delegitimation of their physical pain."[56]

Again, without the presence of "a pathological abnormality,"[57] the common explanation today is that the cause is psychological. Not having an answer or even recognition of the legitimacy of their symptoms can lead patients to doubt themselves and their embodied experience of disease. As Bury emphasizes in "Chronic Illness as Biographical Disruption," realizing that their physicians have no answers, and that medical knowledge as a whole is incomplete and therefore their treatment plan is constructed based on trial and error, "throws individuals back on their own stock of knowledge and biographical experience."[58] In Nettleton's interview based study, she reported that every participant mentioned that they had at some point questioned their own pain, with questions such as: "'Am I imagining it?' 'Am I just being lazy?' 'Is it something I have manifested?.'"[59] Not only does the medical community tend to label individuals with undiagnosed illness and medically unexplained symptoms and pain as "malingering, hypochondria, and/or mental illness," but their dismissiveness can be internalized by those in pain. One woman in Nettleton's study described it as "a lurking fear in the dark out there that I may be faking it. It's an awful moment, a really nasty moment, a total put down when the tests don't show anything. Despair."[60] With a diagnosis comes "a socially legitimate basis both for deviant behaviour and clinical intervention."[61] Without it, ill individuals do not feel accepted into the sick role nor comfortable within it.

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[56] Glenton, "Chronic Back Pain Sufferers—Striving for the Sick Role."
[57] Nettleton, "'I Just Want Permission to Be Ill.'"
[58] Bury, "Chronic Illness as Biographical Disruption."
[59] Nettleton, "'I Just Want Permission to Be Ill.'"
[60] ibid
[61] Bury, "Chronic Illness as Biographical Disruption."

Contested Illness

Contested illnesses arise generally from an incongruity between lay and medical perceptions of a condition.[62] They can have nonspecific, transient, or atypical symptoms and are, by definition, difficult to diagnose.[63] Joseph Dumit, an anthropologist and science, technology, and society professor identified five key characteristics of contested illness, or, as he put it, "illnesses you have to fight to get." Firstly, they are chronic and therefore do not fit into the sick role theory discussed above, nor the acute disease model of treatment and calculation of costs.[64] They are "biomental;" their nature and etiology is unclear and causes may be credited to mental, physical, or psychiatric origin. Third, they are "therapeutically diverse"; no set treatment is agreed upon and therefore treatment is "wide open."[65] Contested illnesses also always have "fuzzy boundaries" — they may easily be misdiagnosed, have overlap with other illnesses, or comorbidity with defined conditions. Finally, Dumit describes contested illnesses as "legally explosive"; since there are not agreed upon diagnoses for these conditions, patients are often denied both legal and financial benefits as well as social recognition for their suffering. Clearly, individuals with chronic contested illness have immense barriers to achieving Parsons' two rights owed to those in the sick role; with no label to their illness they cannot be excused from responsibilities and social obligation, much less gain access to government services and even appropriate medical care. Though these individuals go to the doctor, with no treatment or explanation offered it is difficult to "cooperate in the process of getting well."

Contested illnesses, or illnesses not recognized by the entirety of the medical community, share several characteristics that make them incongruous with the system of diagnosis, treatment,

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[62] Jutel, *Putting a Name to It: Diagnosis in Contemporary Society*.
[63] Nettleton, "'I Just Want Permission to Be Ill.'"
[64] Dumit, "Illnesses You Have to Fight to Get."
[65] ibid

and wider understanding of disease. For one, they are often described as lacking a strong base of evidence for their existence. However, Maya Dusenbery in *Doing Harm* suggests this may in fact be because they are under-researched and under-reported precisely *because* the symptoms of these conditions are not taken as seriously as other symptoms and other conditions. For some diseases, rarity may contribute to the small information base, but many of the contested illnesses in this paper, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), are much too common for that to account for the lack of research and treatment. In other words, the absence of evidence is being conflated with evidence of absence. Not only does this lack of knowledge impact the traditional relationship between patient and physician, as physicians do not know what course of treatment to prescribe, but they also do not know the course this illness will take. Individuals with a diagnosis struggle without knowing the trajectory of their disease, and not having the published experience of others.

Many contested illnesses (such as ME/CFS, multiple chemical sensitivity, and fibromyalgia) do not have reliable diagnostic tests for them, making attaining the precise "objective" diagnosis impossible. Also, symptoms can often be nonspecific and transient, further allowing doctors to claim they are psychosomatic or just everyday "wear and tear." Rosenberg describes medicine as a system, with diagnoses as the key to the passwords that make the system accessible, that make the personal illness "experience machine readable."[66] The difficulty that comes along with undiagnosed illness and contested illness occurs because to live in a "state of limbo" is fundamentally incompatible with the Western medical model of treatment. As Dusenbery points out, the concept of "evidence-based medicine" that rose in the 1980s and 1990s has limits: "if a disease hasn't been sufficiently studied yet, the evidence base simply isn't

[66] Rosenberg, "The Tyranny of Diagnosis."

there."[67] This is core to the discussion of contested illness and diseases with extremely low diagnosis rates; often, patients desperate to feel better turn to physicians who simply do not have the answers. The dichotomy that exists between lay people and physicians when it comes to contested illnesses accentuates the unequal power dynamic between medical authority and patient, and the need for a physician-given diagnosis in order to access services. Jutel analogizes that this barrier for both legitimacy and resource allocation "[transforms] the doctor into gatekeeper (rather than explainer), with diagnosis as [their] key."[68]

Medically Unexplained Symptoms

"Medically unexplained symptoms" or MUS, is a term used among the health community as an almost catchall phrase for "unifying a diverse group of health problems where no joint cause or biomarker have been identified."[69] It is less of a clinical diagnosis than it is an analytical concept, and, as Malterud and Aamland discuss in "Medically Unexplained Symptoms: Are We Making Progress?," MUS contradicts the idea that objectivity in results is vital to confirm subjective symptoms (such as fatigue, chronic pain, etc) as a disease. Almost paradoxically, the use of the term "MUS" to group these "unclassifiable" conditions that cannot be grouped under existing diagnostic umbrellas implies homogeneity, "that all physical complaints without explanation can be viewed in the same way."[70] Individuals with symptoms and no diagnosis must consistently justify their right to be in the sick role, not only to friends and family and colleagues, but to medical authority figures as well. Living with constantly doubted health-related stressors causes immense feelings of self-doubt for afflicted individuals, as well as

[67] Dusenbury, *Doing Harm*. 264
[68] Jutel 77
[69] Malterud and Aamland, "Medically Unexplained Symptoms."
[70] Jutel 83

frustration, depression, and often necessitates learning to cope with chronic symptoms on their own.

Since antiquity psychiatric diagnoses have been doled out in attempts to explain what biomedicine was not yet equipped to. Labeling symptoms physicians cannot explain as inherently psychiatric not only shifts responsibility to cure the patient in front of them off of the physician to the field of psychiatry, but also ascribes moral blame, stigma, doubt, and shame unto the already suffering individual. Psychiatry is a legitimate field, with diagnostic tools just as physical medicine, but as Jutel asserts, "considering medically unexplained symptoms a psychiatric disorder is a diagnosis by exclusion,"[71] formed on the basis of an absence of physical explanation. The psychiatric fallback diagnosis is also problematic because it does not allow space for a recognition of the limitations of medical knowledge; referring a patient for psychiatry because a physician cannot identify a pathological cause for symptoms "presumes the infallibility of the doctor and of the field."[72] As no taxonomic system is perfect, just as no scientist is altogether unbiased, the diagnosis of psychiatric instability contributes to a refusal to improve the medical system or admit its potential shortcomings.

"Diagnostic limbo" and the Creation of Chaos Narratives

CB Drauker discusses the four coping challenges for individuals with difficult to diagnose diseases that have a physiological cause. These include situational ambiguity, characterological attributions, blocked information-seeking, and limited opportunities for downward social comparison. The first, situational ambiguity, poses a challenge because individuals who do not have a definitive diagnosis cannot adequately "assess harm and therefore

[71] Jutel 106
[72] Jutel 104

plan action to combat or avoid the harm."[73] Not having a diagnosis also causes patients to believe that their symptoms are their own fault (characterological attributions), resulting in lowered self-esteem and a lack of control. Because their disease is undiagnosed, they have little research to look at and cannot join traditional support groups for specific, named illnesses or read information on the course of their disease (blocked information seeking). Finally, without a diagnosis, there is no defined group of others with illness to compare oneself against, making it impossible for the individual to "enhance [their] self-esteem by downward social comparisons."[74] These coping challenges also apply to individuals with medically unexplained symptoms. In sum, individuals without diagnoses do not have the same pathways to cope as those with named illnesses do, creating harm aside from a lack of medical care to help with the physical realities of their illnesses.

In a 2006 article entitled "I Just Want Permission to be Ill: Towards the Sociology of Medically Unexplained Symptoms," Sarah Nettleton describes patients with medically unexplained symptoms journeys to diagnosis and paths through the medical system as "chaos narratives." They have no clear beginning, as a symptom onset timeline is often unclear, and the journey to diagnosis if patients ever reach one is long and complicated; it often spans years and many doctors and treatments with no answers and limited, if any, relief. The years are steeped in situational ambiguity and confusion. Nettleton identifies another feature of chaos narratives: that others do not acknowledge the reality of the illness. Arthur W. Frank, in "The Wounded Storyteller: Body, Illness, and Ethics," states that chaos illness narratives "[represent] the triumph of all that modernity seeks to surpass. In these stories the modernist bulwark of remedy, progress, and professionalism cracks to reveal vulnerability, futility and impotence."[75] As

[73] Draucker, "Coping with a Difficult-to-Diagnose Illness."
[74] ibid
[75] Nettleton, "'I Just Want Permission to Be Ill.'"

Rosenberg emphasizes, defined disease profiles are meant to be "objective narratives that provide meaning as well as underline social hierarchies." It is assumed that diagnostic conclusions are core to the interactions between physicians and patients; "even its absence [diagnosis] shapes our expectations and becomes part of a necessarily altered narrative."[76]

As Chris Shilling points out in *The Body and Social Theory*, we live in a time when we know more, and have more control over the biological body than ever before, but this presents a paradox, as we are also living during a time "which has thrown radical doubt about our knowledge of what bodies are and how we should control them."[77] He calls this "embodied doubt." The biological body and its subsequent state (of illness, of health, of age) is both absolutely inextricable from one's sense of self (embodiment of illness, related to characterological attributions), and from society's view of its condition. In an interview Nettleman conducted, one woman stated, "I just want permission to be ill."[78] This permission, as defined from the outside (physicians, friends, family, employers doling out sick leave) is at the crux of the difficulty with undiagnosed illnesses and modernist thought:

> "the modernist discourses of solutions, restitution and certainty can be constraining for those who must endure uncertainty and chaos. Searching for solutions and 'closure' can, in and of itself, form a further tyranny that people find they have to negotiate. Thus the problem as it were is one of life under a condition of uncertainty which is permanent and irreducible.'"[79]

In 1970, Eliot Freidson wrote *Profession of Medicine: A Study of the Sociology of Applied Knowledge*, in which he discusses autonomy of doctors over patients.[80] He states:

> "[w]hen a physician diagnoses a human's condition as illness, he changes the man's behavior by diagnosis; a social state is added to a biophysical state by assigning the

[76] Rosenberg, "The Tyranny of Diagnosis."
[77] Nettleton, "'I Just Want Permission to Be Ill.'"
[78] ibid
[79] ibid
[80] Glaser, "Review of Profession of Medicine."

> meaning of illness to disease. It is in this sense that the physician creates [illness]...and that illness is... analytically and empirically distinct from mere disease."[81]

Of course, this labeling can have far-reaching and negative effects when it comes to the embodiment of disease, but when that diagnosis is unavailable, a sick or chronically-ill individual exists in a sort of gray area, unwell but often unrecognized. Sarah Nettleton uses a term coined by Corbin and Strauss to describe this time as a 'diagnostic limbo' leading to existential uncertainty for both patients and their physicians. Diagnosis itself, as has been stated, is a loaded word with meaning that expands far beyond a simple categorical label. Having, or carrying, a diagnosis has social implications, implications for how one is treated on admittance to the emergency room (usually, quicker), and importantly has implications for the way in which diagnosed individuals view themselves (characterological attribution). Many of the accounts documenting when people receive diagnoses describe immense relief, even when treatment is nonexistent. This begs the question, what happens when a diagnosis is never found?

[81] Freidson *Profession of Medicine*

III. Factors Leading to Underdiagnosis

Clearly, our current medical and social conceptions of disease allow for people without diagnoses to fall through the gaps and therefore experience harm. In this chapter, I will explore the mechanisms through which that happens— why diagnosable diseases sometimes take years to pin down, why patients with medically unexplained symptoms do not receive adequate support, and the fallacies of relying too heavily on technology to identify what is wrong with a patient.

Autoimmune diseases encompass over eighty known diseases in which an individual's immune system malfunctions, attacking healthy parts of the body. Several autoimmune diseases are well known, such as rheumatoid arthritis and multiple sclerosis, but many are less well documented and are more difficult to identify, which, combined with common symptoms and comorbidities, leads to long diagnostic delay. The many factors leading to autoimmune diagnostic delay and how patients are treated before diagnosis also illuminate barriers to care for individuals with contested illness and medically unexplained symptoms. Many patients, particularly women, inhabit the same role as patients with medically unexplained symptoms for years before receiving a diagnosis, and many never get diagnosed due to various factors. For example, the average diagnostic delay for celiac disease is three and a half years and for lupus just under seven years.[82] Before patients are diagnosed, they are often misdiagnosed, seen as having medically unexplained symptoms, or their symptoms are perceived as the result of stress or the hazards of everyday life. As such, examining diagnostic delay for autoimmune disease sheds light on barriers to diagnosis in general.

[82] "Diagnostic Delays for People with Lupus Described in New Study."

The Legacy of Hysteria

Diagnostic delay, or time between symptom onset and receiving a diagnosis, can generally be split into two sections: patient delay (time between symptom onset and a patient going to the doctor) and physician delay (time between a patient being seen by a physician and receiving a diagnosis). Notably, the very concept of diagnostic delay framed in this way confers again the authority of physicians as gatekeepers in a diagnostic-based medical model. A patient's gender can impact both patient delay (women believing their pain is normal due to societal conditioning) and physician delay (physicians failing to recognize women's pain as valid). One glaring example of difference in doctor treatment and attention by gender is Ehlers-Danlos syndrome, a hereditary disorder that affects an individual's connective tissue, for which the average diagnostic delay for women is a staggering sixteen years compared to just four years for men.[83]

As discussed in Chapter Two, undiagnosed disease leads patients to suffer psychologically as well as physically, which introduces another barrier to diagnosis, especially for women: having their symptoms overlooked as pleas from overly-emotional, attention-seeking, hypochondriac patients. Drucker summarizes: "the resources of these individuals are called upon to cope with these debilitating symptoms at the same time as the symptoms are often being attributed, incorrectly, to poor mental health."[84]

For centuries women's pain has been ignored and neglected, misdiagnosed and written off. Think of the legacy of hysteria, "rest-cures," and nervous disorders. The tradition of women's health being dismissed as hysteria continues to pervade the doctor's office. In 1883,

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[83] Dusenbury, *Doing Harm*. 153
[84] Draucker, "Coping with a Difficult-to-Diagnose Illness."

August Fabre wrote, “Every woman carries with her the seeds of hysteria.”[85] Of course, this is no longer so explicitly believed, but the writing off of female symptoms as psychosomatic persists. Because hysteria was thought to “mimic all the physical diseases to which man is heir,” it is congruous to the many symptoms of nonfatal autoimmune diseases (“fatigue, muscle and joint pain, fevers, weight loss, weakness, neurological symptoms, rashes”) that would once have fallen under the umbrella of hysteria.[86] A study conducted in Israel in 2003 found that while men and women are equally likely to be misdiagnosed with multiple sclerosis, “women were more likely to get psychiatric referrals, while the men received orthopedic workups.”[87] This is compounded by a subversive view that “a woman's normal state is to be sick” that guided medical practice until the late 19th to early 20th centuries. There is no clearer example of this phenomena bleeding into every-day medical practice than that of endometriosis. Endometriosis occurs when the tissue that lines the inside of the uterus grows outside it. It is often immensely painful, causing intense cramping, pain during intercourse, and often infertility. Originally considered “the career women’s disease,” the condition was thought to be caused because “that type of [woman] who simply has to clean out the ashtrays all the time” was postponing childbirth in favor of a career, a notion that persisted into the 1990s.[88] Physicians recommended the treatment they favored for hysteria 4,000 years earlier[89] -- pregnancy.

Today, endometriosis is thought to affect 2-10 percent of women in the United States,[90] but was found in a 2020 study to have an average diagnostic delay of almost seven years.[91] This diagnostic delay is heavily influenced by the normalization of menstrual pain, with both patients

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[85] Dusenbury 214
[86] Dusenbury 140
[87] Dusenbury 142
[88] ibid
[89] Dusenbury 222
[90] “Endometriosis.” Hopkins Medicine
[91] Nnoaham et al., “Impact of Endometriosis on Quality of Life and Work Productivity.”

and physicians dismissing immense menstrual pain as a function of biology; "the inescapable fate of being a woman."[92] As Dusenbery writes, teenagers reporting debilitating pain are told it is normal and they have simply not yet become used to it, though "studies suggest that about 70 percent of teens who complain of dysmenorrhea [painful menstrual cycles] are eventually diagnosed with endometriosis."[93] Maya Dusenbury names "menstrual etiquette" as another factor, suggesting that stigma around periods and painful sex also contribute to silence and therefore less care. As the founder of The Endometriosis Association Mary Lou Ballweg put it, "It's bigger than just the physicians, it's our society which teaches girls that being female means to suffer."[94] This normalization of women's pain is another restructuring of the idea of women existing as "always sick" and, paradoxically, therefore not needing treatment. As Maya Dusenbery states in a discussion of why heart attacks are so often overlooked in women, "men have heart attacks and women have stress."[95]

As stated above, many symptoms of autoimmune disease overlap with those of hysteria, which likely contributes to physicians often missing autoimmune disease in women. Likely, after diagnostic testing became available many women who had been diagnosed with hysteria could now be diagnosed with autoimmune disease. Autoimmune diseases are much more prevalent in women— roughly 80% of patients diagnosed with an autoimmune disease are female[96]— but it is important to note that this is a physiological difference rather than a psychological one. The higher rates of autoimmune disease in those assigned female at birth are believed to possibly result from having two X chromosomes. Hormone level changes in females are also believed to increase risk of developing an autoimmune disease; autoimmune diseases seem to become more

[92] Dusenbury 214
[93] Dusenbury 224
[94] Dusenbury 218
[95] Dusenbury 121
[96] Angum et al., "The Prevalence of Autoimmune Disorders in Women."

or less prevalent/active depending on a woman's levels of estrogen and progesterone, such as during puberty, pregnancy, and menopause.[97]

Racialized Disease

Similar to how the legacy of hysteria has led to underdiagnosis and repudiation of women in the doctor's office, race is also an elemental factor in underdiagnosis of patients of color (POC). Due to limited research available, this section will predominantly focus on Black patients, specifically Black women. Racial and gender demographic characteristics intersect, creating disparity "more than the sum of being Black or being a woman."[98] Black women have higher rates of various health conditions, such as heart disease, diabetes, obesity, certain cancers, and maternal mortality.[99] While there is little data available on underdiagnosis along racial lines for the conditions that make up much of this paper (contested illness, medically unexplained symptoms, autoimmune disease, etcetera), it does stand to reason that underdiagnosis of other conditions and inferior medical treatment in general would lend itself to worsening the "chaos narratives" of undiagnosed patients of color. In *The Death Gap: How Inequality Kills*, David A Ansell discusses the impact of biologic definitions of race in "our racially stratified society."[100] In a chapter entitled "The Three B's: Beliefs, Behavior, Biology," Ansell states, "biologic definitions of race have served to justify the naturalization of the social order."[101] In other words, the perpetuation of the belief that people of color are more prone to certain diseases because of their race overlooks the very real issue of structural racism impacting people of color. Through

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[97] Angum et al., "The Prevalence of Autoimmune Disorders in Women."
[98] Chinn, Martin, and Redmond, "Health Equity Among Black Women in the United States."
[99] ibid
[100] Ansell, *The Death Gap: How Inequality Kills*. 57
[101] ibid

avenues such as environmental racism, scientific racism, and poverty, the health of people of color is impacted through social and political mechanisms, not biological ones. Ansel writes:

> it would be biologically and evolutionarily preposterous to attribute diseases as wide ranging as breast cancer, hypertension, diabetes, renal failure, and tuberculosis to the genes that program melanin deposition in the skin.[102]

However, this is a bias that does pervade the doctors office, leading to dangerous oversight as certain diseases or categories of disease are to some degree associated with certain populations. To give one example, in "Celiac Disease and the Forgotten 10 %: The 'Silent Minority,'" Researcher Lebwhol set out to investigate the possibility that POC are under diagnosed with celiac due to the fact it is often considered to be a condition that only affects Caucasian people. The study found that while the prevalence of celiac disease is still lower in minority patients than it is in Caucasian patients, it is higher than previously estimated: 1% in non-Hispanic whites, 0.4% in Hispanics, 0.22% in non-Hispanic Black patients. However, a duodenum biopsy, the test that confirms celiac, is statistically much "less likely to be performed in black or Hispanic patients" as celiac is considered "the European disease."[103] These are not zero numbers; it is still a real condition within communities of color, and because diagnosis delay leads to an increased risk of serious chronic conditions with real consequences, it is important that people of color are screened at higher rates.

Not only can deeply ingrained ideas about what demographics are prone to certain diseases lead to physicians missing "clues" they are not looking for, but race and gender also can impact the level of trust between physician and patient. "Under the Shadow of Tuskegee: African Americans and Health Care" by Vanessa Northington Gamble enumerates the long history of Black Americans' mistreatment at the hands of the American healthcare system, preceding and

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[102] Gamble, "Under the Shadow of Tuskegee."
[103] Lebwohl, "Celiac Disease and the Forgotten 10%."

beyond the Tuskegee syphilis study. She discusses a "collective memory" held by Blacks of the ways they have been exploited by physicians and researchers in the past, emphasizing that those fears should not be "cavalierly dismissed as bizarre and paranoid."[104] This historical legacy of exploitation and indifference leads to less trust in physicians, as well as less trust in the doctor's office. A 2019 *American Economic Review* study conducted in Oakland, California found that Black patients who had Black physicians were more likely to talk to their doctors about health issues, and more likely to agree to preventative testing such as cholesterol and diabetes screening.[105] This suggests that Black patients trust Black physicians to a higher degree than white physicians, and resultantly receive better, more comprehensive care. This article was published a mere three years ago, highlighting that the imprint of Tuskegee and medical experimentation has not faded from the collective memory of Black Americans.

A study published in 2016, aimed at examining why Black Americans are "systematically undertreated for pain relative to white Americans,"[106] found that Black patients are much more likely to have their pain underestimated and undertreated in the doctor's office.[107] Black patients are statistically significantly less likely to be prescribed pain medications and, when they are, are more likely to receive them at lower doses compared to white patients. Even in pediatrics, Black children with appendicitis are less likely to receive the recommended treatment of opioids for severe pain than white children are.[108] The study raised two possibilities for these disparities: that Black patients' pain is observed by physicians but they do not treat it, or physicians do not recognize Black patients' pain as legitimate. Researchers Hoffman et al found that, from a pool of 222 medical students and residents, 50% of them endorsed at least one of the false beliefs

[104] Gamble, "Under the Shadow of Tuskegee."
[105] Alsan, Garrick, and Graziani, "Does Diversity Matter for Health? Experimental Evidence from Oakland."
[106] Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites."
[107] ibid
[108] ibid

given about biological differences between Black patients and white patients.[109] They found that these false beliefs correlate to racial bias in pain perception and "participants who endorsed more of these beliefs reported that a black (vs. white) target patient would feel less pain and they were less accurate in their treatment recommendations for the black (vs. white) patient."[110]

Resultantly, there are many factors leading to disparate treatment for Black and white patients in the doctor's office; false opinions about biological differences can push physicians to not take Black patients' complaints seriously, leading to a lack of treatment and/or underdiagnosis. As Williams et. al emphasize in their 2019 article "Racism and Health: Evidence and Needed Research," when you look systematically at both diagnostic and treatment measures variation by race, POC "receive fewer procedures and poorer-quality medical care than do whites."[111] Less diagnostic tests and a poorer quality of care go hand-in-hand with underdiagnosis, and, as discussed earlier in this thesis, physicians not taking their patients seriously contributes to feelings that their pain is not legitimate and therefore would be less likely to voice symptoms and concerns honestly and fully. The intersections between race and underdiagnosis are highly relevant in synthesizing chaos narratives of diagnosis but are under researched, and as a result are not fully explored in this thesis. For decades, ME/CFS was believed only to affect white women,[112] and even though the CDC now states it is at least as common in Black women and Hispanic women as it is in white women,[113] this belief continues to pervade the doctors office, leading to underdiagnosis of the contested illness within communities of color. As contested illnesses and medically unexplained symptoms are by definition under

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[109] Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites."
[110] ibid
[111] Williams, Lawrence, and Davis, "Racism and Health."
[112] Darius, "When POC Can't Get a Diagnosis, Go Unseen."
[113] "Epidemiology | Presentation and Clinical Course | Healthcare Providers | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) | CDC."

researched and poorly understood, this dearth of information is compounded when it comes to how they affect Black women and communities of color as a whole.

Ambiguous Disease Profiles

Contested illness and many autoimmune diseases can be hard to identify due to the nature of their symptoms; they can be transient, common across disorders, or cause non-specific pain. One of the most common symptoms that often falls into the category of the medically unexplained, and is also common in contested illness and autoimmune disease, is fatigue (defined as exhaustion not resulting from lack of sleep that interferes with daily activity and quality of life). Fatigue often impacts quality of life and functioning, but is easy for physicians to write off as a consequence of lifestyle. Donna Jackson Nakazawa, author of *The Autoimmune Epidemic: Bodies Gone Haywire in a World out of Balance and the Cutting Edge Science that Promises Hope*, writes that clinical fatigue is so common that if it "were a sound made manifest by the 23.5 million people with autoimmune disease in America, the roar across this country would be more deafening than that of the return of the seventeen-year locust."[114] Patients, especially women, find it difficult to convince their physicians that their fatigue "is not the fatigue of depression or the drowsiness of sleep deprivation and that their other subjective, often transient symptoms are not just those of a somaticizer."[115] In fact, Dr. Abid Khan goes so far as to tell patients not to "describe their fatigue as fatigue" for fear of physician dismissal hampering their chance at a diagnosis.[116]

In an article ironically titled "The Detective Work of Autoimmune Disease," Dr. Angela Crowley explores several other factors that lead to diagnostic delay in autoimmune disease. She

[114] Nakazawa, *The Autoimmune Epidemic*. 162
[115] Dusenbury 147
[116] Dusenbury 147

touches on how the commonality of symptoms, such as fatigue or joint pain, make diagnosis difficult because they could stem from so many conditions, both autoimmune-related and not. As such, autoimmune diseases can "mimic" each other, leading to a longer path to diagnosis and subsequent care and pathways to coping strategies.[117] Autoimmune diseases often operate in conjunction; individuals with one are more likely to develop another. As a result, multiple conditions can complicate diagnosis. A study conducted in 2008 on multiple sclerosis found that having a comorbid condition increased patients' diagnostic delay.[118] Additionally, some individuals with autoimmune disease can be completely asymptomatic at first; this is true with celiac disease, as well as with ankylosing spondylitis, an autoimmune inflammatory disease with a diagnostic delay of approximately eight to ten years,[119] as it can take that long for the condition to show up on x-rays.[120]

Core to the topic of ambiguous disease profiles, and relevant to autoimmune disease, is a discussion of subjective versus objective indicators of disease. It can also be divided into symptoms and signs, with symptoms being subjective, only accessible through patient testimony (examples being joint pain, fatigue, headache) and signs being objective and measurable, such as a fever or a positive test result.[121] As discussed in chapter one, since the advent of instruments of precision and the move towards "evidence-based" medicine, signs, or objective, measurable symptoms, are prioritized over patient-described symptoms. As Foucault put it, physician questioning shifted along with the technological advancements, from "What is the matter with you?" to a more concrete "where does it hurt?."[122] Since ambiguous disease profiles majorly

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[117] Marshall, "The Detective Work of Autoimmune Disease."
[118] Marrie et al., "Comorbidity Delays Diagnosis and Increases Disability at Diagnosis in MS."
[119] Sykes et al., "Delay to Diagnosis in Axial Spondyloarthritis."
[120] Marshall, "The Detective Work of Autoimmune Disease."
[121] Dumes, "What Long Covid Shows Us About the Limits of Medicine."
[122] ibid

consist of subjective symptoms, they are harder to diagnose and require more trust between patient and physician.

Limitations of Medical Authority

Medically-unexplained symptoms with no known pathological basis force physicians to "base clinical judgements on something other than biomedical evidence."[123] Because there is no existing standardized framework for treating such patients, doctors' practices vary and patients fall through the cracks. A study conducted in Norway in 2015 to examine how patients presenting with medically unexplained symptoms are treated in the doctor's office found that although medically unexplained symptoms are a fairly common complaint in the country (a Danish study found one third of patients could be put in this category), physicians find these cases "tremendously difficult."[124] The GPs in the study reported feeling "powerless" when confronted with MUs, and "don't like conditions where you have zero objective findings."[125] This seems to indicate that physicians feel as though they have less medical authority in guiding their patients, and without definitive test results are at a loss for how to provide care. However, this stems not just from the physician's own beliefs about their role as care providers, but also from institutional insistence on the diagnostic model of disease.[126] As "health related benefits are contingent on a biomedical account" (work exemptions for illness and other benefits necessitate an illness be recorded for justification), physicians "bear a burden of evidence" that, in the case of MUs, requires them to base their recommendation solely off of patient testimony.[127] For

[123] Rasmussen and Rø, "How General Practitioners Understand and Handle Medically Unexplained Symptoms."
[124] ibid
[125] ibid
[126] ibid
[127] ibid

physicians, this forces an uncomfortable confrontation with the lack of medical authority and, therefore, their own individual authority, in treating their undiagnosed patients.

Once again, physicians act as the gatekeepers not only to knowledge (for with medically unexplained symptoms there is a dearth), but to resources. Connecting back to *Doing Harm* and the importance of trust in the physician-patient relationship, a lack of belief in the doctor's office is a huge barrier to diagnosis for those who can be diagnosed, and care for those who cannot. Many of the physicians in the study conducted in Norway stated that they feared "being misinformed or even deceived"[128] by their patients, thus indicating their view of patient testimony as unreliable. Medically unexplained symptoms necessitate patients' physicians relying solely on their testimony, which is impossible if physicians take the "lack of objective [by which they mean biomedical, and separate from patient testimony] evidence" as a problem.[129] One GP in the study, when discussing patient testimony about their symptoms with no discernable biomedical cause, reported that what their patients say in the examination room could be "entirely correct, or it could be entirely wrong."[130] Clearly, in the face of a patient with symptoms but no positive tests, or findings during physical examination, physicians doubt the individual "rather than doubt in medical knowledge."[131] Due to their need to be taken seriously, people who have visited many doctors to no relief change their behavior in an attempt to access care. For example, for women who have had their symptoms attributed to their mental health before, and subsequently dismissed, their fear of being considered "hysterical" causes them to be "anti-hysterical" to such a degree "of actually being dishonest about how much pain they are in."[132]

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[128] Rasmussen and Rø, "How General Practitioners Understand and Handle Medically Unexplained Symptoms."
[129] ibid
[130] ibid
[131] ibid
[132] Dusenbury 189

Lack of Lay and Medical Awareness

The "biomedical evidence" is often not present not because these symptoms aren't real, nor because we do not have the technological capacity to uncover the cause, but often simply because *no one has tried*. No research can happen without funding, but funding is not doled out unbiasedly, nor by prevalence, impact, or severity, nor necessarily to the diseases discussed in this thesis (for the most part chronic and debilitating but non-fatal). Despite its prevalence, endometriosis only received ten million dollars in NIH funding in 2016, equivalent to a mere $1.50 per patient.[133] As such, there is no absolute cure and a dearth of universal effective treatments. This results, as Dusenbury puts it, simply from a lack of effort to deeply investigate: "for hundreds of years, pain in menstruating women has not qualified as a medical mystery worthy of actually solving."[134] Autoimmune diseases, a category that encompasses around 80 conditions in which the body recognizes its own cells as foriegn and attacks them, are more common in women than in men, and in women under 30 particularly.[135] While the mechanisms of some of these conditions are known, many are not and almost all autoimmune diseases are lifelong. According to a report the National Institutes of Health gave to Congress, as of 2005 autoimmune diseases were believed to impact 14.7 to 23.5 million people in the United States, and these numbers are rising.[136] It is difficult to find more current accurate statistics, revealing a dearth of research efforts and information availability. Autoimmune disease is the second leading cause of chronic illness, and yet, the average autoimmune disease patient "sees six doctors before attaining a correct diagnosis."[137] Surveys conducted in 2008 found that 45% of patients with

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[133] Dusenbury 226
[134] Dusenbury 229
[135] Dusenbury 162
[136] National Institutes of Health, "Progress in Autoimmune Diseases Research."
[137] Nakazawa 30

autoimmune disease "had been labeled as hypochondriacs in the earliest stage of their illness."[138] The average patient with an autoimmune disorder navigates the "chaos narrative" of diagnostic limbo for four years and six doctors.[139]

Why might this be? Why is there such a long diagnostic journey for illnesses that are really quite common? The concept of autoimmune disease is not an exceptionally recent understanding, it was discovered in 1957, though was not fully accepted into the profession until the 1970s.[140] It took until the 90s for autoimmune disease to be seen as a major health threat, and its acceptance was plagued by a "lingering disbelief that the immune system could mess up so badly."[141] Though research is ongoing, for many of the diseases in this category cause and prevention is yet unknown, and treatments not completely successful. The mechanisms of autoimmune diseases are complicated, but are also historically under researched and lack both medical and lay awareness. Autoimmune disease is the second leading cause of chronic illness but nine out of ten Americans cannot name a single one.[142]

One explanation is Western medicine's focus on mortality versus morbidity, and on longevity over quality of life. While autoimmune diseases can be chronic and debilitating, often reshaping the lives of those afflicted and their families, they usually are not the causes of death. The same can be said for fibromyalgia and chronic fatigue syndrome; though they may increase patients' risk of dying from related conditions, they are not usually the cause of death themselves. However, it is important to note that the fibromyalgia patient population has a suicide rate more than ten times that of the general population,[143] and those with ME/CFS were found to have a

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[138] Nakazawa 30
[139] ibid
[140] Nakazawa *The Autoimmune Epidemic* 35
[141] Dusenbury 142
[142] Dusenbury 24
[143] "Fibromyalgia Comes with a Suicide Risk." Reuters

sucicide rate seven times higher than that of the general population.[144] Unfortunately, the lack of an information base and lack of awareness of these conditions likely results from, at least partially, the fact that they are not explicitly fatal. The average person cannot name the color of the ribbon for fibromyalgia (purple) or celiac awareness (green), but everyone knows breast cancer's signature pink. The NIH spends around six times as much money on cancer research as it does on autoimmune disease.[145] These diseases are chronic, lifelong, and frequently incurable. "Solving" the repercussions of these illnesses, despite their immense suffering, is simply less glamorous than finding the "cure" to fatal illness, highlighting medicine's focus on "on preventing death over improving health."[146] This lack of flashiness not only impacts what researchers choose to apply for grants to research, but also affects what diseases policy makers choose to back. For example, politicians are more likely to push for campaigns that will provide the public with tangible goals, such as deaths prevented, as opposed to cures for diseases where the impact is much less visible.

Similar (or perhaps exactly the same) to physician's reluctance to treat patients with medically unexplained symptoms, primary care physicians, if they consider the possibility of an autoimmune disorder, refer that patient to a specialist. In turn, many specialists surveyed about autoimmune disease admit: "I'd rather not see these people."[147] While is some cases this is a good thing, such as a referral to a gastroenterologist for celiac disease or a rheumatologist for lupus, no oncologist-equivalent exists for autoimmune disease, meaning patients get referred to organ-specific specialists, who are, most often, "boxologists... as a patient, you have to meet their narrow criteria to be taken seriously, or you're dismissed" according to Dr. Abid Khan, an expert

[144] Kapur and Webb, "Suicide Risk in People with Chronic Fatigue Syndrome."
[145] Dusenbury 143
[146] Dusenbury 163
[147] Dusenbury 144

in autoimmune disease.[148] While some autoimmune diseases are organ specific, and can be effectively treated by physicians in those areas, many are not, and there exists few physician-experts on these conditions. A specialist in autoimmune disease would be better able to interpret all information, especially necessary as atypical presentations of autoimmune disease are almost as common as typical ones. A 2013 study conducted by the American Autoimmune Related Diseases Association found that almost two thirds of general practitioners "feel 'uncomfortable' or 'stressed' when diagnosing an autoimmune disease." 75% reported they did not learn enough about such disorders in medical school.[149] Another glaring example of physicians failing to consider autoimmune disease enough in relation to its prevalence is that it is not common to ask about autoimmune diseases when taking a medical history even though they are common in families.[150]

In sum, there are many factors that contribute to the ever-increasing numbers of the "chronically undiagnosed" in America, that stem from both the demographic characteristics of those most affected by autoimmune disease and chronic illness, as well as the nature of the diseases themselves. The roots of hysteria governed by sexism, and the legacy of racism, can lead researchers and physicians to brush off women and people of color's pain and other symptoms. This results in underdiagnosis in these demographic groups and in a dearth of research about diseases that are more prevalent among these populations. The symptom profile of many underdiagnosed diseases, such as ambiguous fatigue and transient symptoms, along with common comorbidities and the fact that they are often non-fatal, also contributes to these diseases being under diagnosed and under researched.

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[148] Dusenbury 146
[149] Dusenbury 144
[150] ibid

IV. How Do Illnesses Become Recognized?

To understand how new diseases become accepted into the medical establishment, we must first examine the production of scientific knowledge in general, and how ideological and biological movements become concretized in universal empiricism. In this chapter I will explore the concept of Thomas Kuhn's "paradigm shift," and use the examples of interstitial cystitis (a now uncontested illness with a semi-understood etiology, diagnostic profile, and treatment path) and myalgic encephalomyelitis/chronic fatigue syndrome (a contested illness that was only defined and acknowledged by the Institute of Medicine a few years ago) in order to examine the journey an illness takes from being identified to being accepted, and finally to being understood.

Kuhn's Paradigm

Thomas Kuhn, in *The Structure of Scientific Revolutions*, elucidates the concept of a paradigm shift in scientific understanding as a moment in which the scientific establishment "shifts," or, more dramatically "revolts," away from an existing theoretical framework due to anomalies becoming apparent, and comes to accept an entirely new way of thinking through debate and conflict. After a paradigm shift takes place, the new paradigm completely supplants the older one. Paradigm shifts occur when the dominant paradigm becomes incompatible with a sufficient amount of new evidence. A paradigm shift, or, as he describes it in *The Copernican Revolution*, a "bend in the road," is only visible after the shift has taken place:

> "From the bend, both sections of the road are visible. But viewed from a point before the bend, the road seems to run straight to the bend and disappear.… And viewed from a point in the next section, after the bend, the road appears to begin at the bend from which it runs straight on."[151]

[151] Kuhn *The Copernican Revolution* 86

Essentially, before a large scientific discovery is made, or enough knowledge that goes against the current paradigm is collected that can no longer be ignored (Kuhn's paradigm shift), it seems as though the scientific community only has one answer to a question; their path ahead is straight. For example, before Copernicus suggested that the Earth revolved around the sun instead of the other way around, there was only one theory in the minds of scientists and the public; it appeared as though there was only one way "forward," and the road was straight. However, once Copernicus announced his discovery the road divided into two sections, thought before the bend (the discovery) and after the the bend; it was only after the discovery that both sections of the road could be viewed. Now that we believe with conviction that the earth revolves around the sun, that road is straight again, but that does not mean that sometime in the future there won't be another discovery that will cause us to question that theory; two sections of the road will be visible once more.

This concept is clear in the case of autoimmune disease; it took a decade for the idea that the immune system could attack its own body to be accepted, even though Doctor Noel Rose made the initial discovery in 1957, because it was incongruous with the contemporary paradigm. Researchers were convinced that "the [body's] immune system could not turn on itself,"[152] a theory they called *horror autotoxicus* ("the body's immune system could not develop an autoimmune response"[153]). So, if initial evidence alone is not enough to cause a paradigm shift, what else is needed? Kuhn posits,

> "Observation and experience can and must drastically restrict the range of admissible scientific belief, else there would be no science. But they cannot alone determine a particular body of such belief. An apparently arbitrary element, compounded of personal

[152] Nakazawa *The Autoimmune Epidemic* 32
[153] ibid

> and historical accident, is always a formative ingredient of the beliefs espoused by a given scientific community at a given time."[154]

One element beyond observation and research is necessary for the formation of a new paradigm, and scientific belief in general: personal or historical "accident." It took another ten years for the scientific community to slowly but surely get on board with Rose's autoimmune theory, when evidence of the validity of the new paradigm was too compelling to ignore, and *horror autotoxicus* was abandoned. Kuhn also theorized that those who propel new paradigm shifts are often seen as radicals in the community, as Rose was, which contributes to the lengthy time that often passes in between new discoveries and their acceptance into the wider scientific/medical community. To illustrate how paradigm shifts play out more specifically, let us examine the case of interstitial cystitis.

Interstitial Cystitis

The example of interstitial cystitis, a disease that is now fully accepted as a real condition with a pathological cause, demonstrates how disease can go from not being taken seriously to becoming recognized within mainstream medicine. Interstitial cystitis is a chronic bladder disorder that, while not directly life threatening, can have a significant impact on the individual's quality of life. The exact cause remains unknown, but it is suspected to be related to a leak in the epithelium (the lining of the bladder wall), prior infection, or immune malfunction. Interstitial cystitis was originally considered a psychosomatic disorder that was triggered in women after they went through menopause. It is extremely painful and disabling, characterized by chronic pelvic pain and extreme urinary frequency.[155] Because of the intensity of these symptoms, it is

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[154] Kuhn *The Structure of Scientific Revolutions*
[155] Draucker, "Coping with a Difficult-to-Diagnose Illness."

severely debilitating and inhibits both work and social life. Despite its severity, the disease received little recognition as it primarily affects women and, as explained in chapter three, physicians as well as society in general often interpret women's pain as normal— the natural state of being a woman.[156] In 1983, a medical student named Vicki Ratner was experiencing these symptoms, which she described as akin to a "lit match to the bladder." After seeing fourteen physicians over many years with zero relief, she combed through the literature herself, eventually finding interstitial cystitis and demanding a cystoscopy to diagnose it. Ratner went on *Good Morning America* in 1985 in a desperate attempt to find others with the condition and received 10,000 letters within one week. They were from women who had been experiencing similar debilitating symptoms for years, had seen upwards of ten doctors with no diagnosis and no relief, and who had become completely socially isolated, even starting to believe their symptoms were imaginary "since the doctor had said so."[157] They had to quit their jobs, but were not eligible for disability pay because they had no diagnosis, or even if they did interstitial cystitis "wasn't listed as a qualifying disease."[158] Heartbreakingly, there were many letters from family members of individuals who had suffered from the disease and had committed suicide to escape the pain no one was able to help them relieve.

The leading text on urology in the 1980's described the disease as occurring due to emotional disturbance: "an irritable bladder in an irritable patient."[159] Ratner, after receiving her diagnosis, wrote to that author and that description was removed for the next edition. Even in 1993, 43% of patients "had been told they had an emotional disorder"[160] before achieving their correct diagnosis approximately four years (of frequently intense pain) later. Urologists, 99% of

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[156] "Men & IC - Interstitial Cystitis Association - McLean, VA."
[157] Dusenbury 183
[158] ibid
[159] Dusenbury 182
[160] Dusenbury 184

whom are male, simply "didn't believe it existed."[161] Ratner conducted the first epidemiological study on interstitial cystitis in 1987, finding that the average diagnostic delay for women with the disorder was seven years, individuals with the condition had a suicide rate four times higher than the general population, and for every one patient that received the diagnosis, five more never would.[162] She formed the Interstitial Cystitis Association (the ICA), which successfully lobbied Congress for federal funding for IC research, and the media coverage helped patients gain credibility for their IC symptoms in the doctor's office. Finally, in 1999 interstitial cystitis was included in the curriculum that urologists studied to pass their urology accreditation boards.

Today, interstitial cystitis is accepted into mainstream medicine, taught in medical schools, and functioning treatments exist. The CDC had guidelines for diagnosis (though much of diagnosing IC comes from excluding other possible culprits), and it is suspected that up to 12% of women may have early symptoms of this chronic bladder condition.[163] So how did the switch happen, from psychological to physiological, from unknown to known (though likely still underdiagnosed), from medically unexplained to the beginnings of understanding? Returning to Kuhn's "arbitrary element compounded of personal and historical accident" that contributes to the creation of the currently-accepted body of knowledge, it appears that a determined medical student plagued with IC was the tipping point. Vicki Ratner's particular experience with the condition and subsequent commitment to finding a solution could almost be described as luck for others who had lived with it, suffering in the darkness of the undiagnosed and unheard. While the technology of the time already had the capability to identify interstitial cystitis (a cystoscopy), and the diagnosis existed, it just was not being applied. The paradigm shift here did not come out of a new technological innovation, but a new recognition and reimagining of the disease profile

[161] Dusenbury 184
[162] ibid
[163] "Interstitial Cystitis | CDC."

and prevalence. Ratner's publicization of the condition was a large contributor to the shift in medical understanding and practice. Vicki Ratner was IC's champion, shedding light on how and why a condition can become accepted into the mainstream, and its sufferers into the sick role. From this point in temporality, we have an understanding of why the disease used to be understood how it was, and how it changed; we can clearly see the previous paradigm, as well as the bend, and the road ahead is straight once more.

From "Yuppie flu" to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome to Systemic Exertion Intolerance Disease: the Evolution of a Contested Illness

Systemic Exertion Intolerance Disease (SEID), or, as it is more commonly known, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), is a debilitating, chronic, and highly contested illness about which little is understood. ME/CFS is expected to affect up to 2.5 million Americans, and the economic cost of the disease is believed to be up to $24 billion dollars annually.[164] None of this, however, reflects the true burden of this disease, much of which results from its contested state. ME/CFS is categorized by severe fatigue that impacts the individual's ability to do usual activities, that worsens after physical or mental activity (post-exertional malaise or PEM), and sleep issues. Individuals with ME/CFS also may experience problems with thinking and memory, as well as a worsening of their symptoms when standing or sitting up (orthostatic intolerance), and muscle and joint pain.[165] Symptoms of ME/CFS can vary on a daily, monthly, and yearly basis, but as of February 2021 it was estimated that up to 75% of patients are unable to work[166] and 25% of patients with the condition are

[164] Dimmock, Mirin, and Jason, "Estimating the Disease Burden of ME/CFS in the United States and Its Relation to Research Funding."
[165] "Symptoms of ME/CFS | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) | CDC."
[166] Conroy et al., "Homebound versus Bedridden Status among Those with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome."

homebound or bedbound.[167] ME/CFS is a post-viral syndrome; it is most often triggered by an infection. Though the condition is intensely debilitating, it has been plagued by a long history of connotations of hysteria, somatization, and laziness that pervades physician and lay minds today, effectively acting as a barrier to diagnosis, research, and treatment. The misconceptions of ME/CFS as psychological illness have led to detrimental treatment options, such as graded exercise therapy, that cause more harm than help. Recent estimates report that 84% to 91% of individuals with ME/CFS are undiagnosed, and patients that do have a diagnosis experience a long diagnostic delay; 67% to 77 % of patients have a diagnostic delay of over a year, and one third have a diagnostic journey of over five years.[168] However, even though treatments exist for some of the symptoms ME/CFS patients contend with, a diagnosis often does not lead to relief– not only because there is limited treatment ability, but because they are often "subject to hostile attitudes from their health care providers."[169] As such, patients exist in a state of invisibility, within the medical community as in the social realm. In 2016 *The Guardian* called ME/CFS "the proverbial skeleton in the closet of the medical world."[170] This is exemplified in the hashtag created by Jenifer Brea, an individual with ME/CFS who co-founded the group ME-action: #MillionsMissing.

Despite its severity, its periods of acknowledgement in the past century have not catalyzed widespread research and awareness about the disease. In the 1980s ME/CFS was dismissively dubbed the "yuppie flu," seen to afflict primarily young professionals. It was first acknowledged by the United States Health Service almost 100 years ago, in 1934, though their

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[167] Conroy et al., "Homebound versus Bedridden Status among Those with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome."
[168] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness."
[169] ibid
[170] Cox, "Is Chronic Fatigue Syndrome Finally Being Taken Seriously?"

definition was primarily psychological. In 1997, a coordinating committee was formed to advise the US Secretary of Health and Human Services about ME/CFS, and in 2006 the CDC launched a "Spark Awareness" campaign to include both public awareness (through a media campaign) and awareness among physicians (through distribution of the *CFS Toolkit for Health Care Professionals*).[171] However, the CDC definition remained highly psychosocial. In 2015, the Institute of Medicine released a report asserting that "Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is a legitimate disease that needs proper diagnosis and treatment."[172] They developed new criteria for diagnosing the disorder, suggesting it be renamed Systemic Exertion Intolerance Disease (SEID) so that the name would more accurately express what is understood about the disorder, as myalgia is not a core symptom of the disease and the evidence of brain swelling (encephalomyelitis) is inconclusive. However, ME/CFS is used more widely so that is the label that will continue to be used in this chapter. In the 2015 news release, the authors asserted the condition's legitimacy, while acknowledging that most of the field yet does not: ME/CFS is included in the curriculum for under a third of medical schools, and providers often do not take the symptoms of sufferers seriously.

Sufferers and news outlets have been asserting its legitimacy for years, to little avail. 1991: "'Yuppie Flu' Turns Out to Be Real: Health: Medical authorities are studying the disease--chronic fatigue syndrome--as more cases appear" (LA times). 2002: "'Yuppie Flu' Is a Serious Disease, Says Study" (Independent). 2009: "Yuppie Flu" Isn't Just in the Head: Chronic Fatigue Syndrome Linked to Virus" (Discover Magazine). From all of these articles (and there are many more), it is clear that attempts have been made to shift the pervasive voices hampering patients with ME/CFS (ironically, however, these headlines perpetuate the harmful and reductive

[171] Friedman, "Advances in ME/CFS."
[172] "Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Is a Legitimate Disease."

label of "Yuppie flu"). These and others call for more research, more funding, and more compassion and understanding, in a similar fashion as the IOM 2015 press release. So why, after all this time, have no major breakthroughs occurred? No paradigms shifted?

In an article published in 2019, "Advances in ME/CFS: Past, Present, and Future," Dr. Kenneth J Friedman compares the history of research and funding for ME/CFS and HIV/AIDS, in an attempt to find what would be needed for patients with the former to achieve the same level of treatment as patients with the latter. Although when first reported HIV/AIDS was far more devastating than ME/CFS, the relief now available through groundbreaking treatments and dedicated researchers has altered the disease to be "comparable or less severe than ME/CFS for the majority of patients."[173] Dr. Daniel Peterson stated, "ME/CFS is one of the most disabling diseases far, far exceeding HIV disease [today] except for the terminal stages."[174] The US government does not devote nearly as much money to ME/CFS as it does to other chronic diseases with similar severity. To compare it once again with HIV/AIDS, in 2019 the US spent approximately $2,000 per patient, while in 2017 it was estimated that the research expenditure per ME/CFS sufferer was a mere $5.58.[175] Looking at these numbers, it makes sense that as of today there is no FDA approved drug to treat ME/CFS, despite its severity and prevalence in the country and worldwide. To once again call back chapter three, this is likely influenced by deaths from ME/CFS being quite rare, though as discussed the disease often leads to a complete "disappearance" from society. It seems as though, similar to how belief that interstitial cystitis was "all in their heads" led to diagnostic and treatment delay of IC, and how the persistence of *horror autotoxicus* delayed autoimmune research, pervasive reluctance to confront the physiological fact of the existence of ME/CFS has resulted in research funding not

[173] Friedman, "Advances in ME/CFS."
[174] ibid
[175] ibid

commensurate with the burden of disease; millions continue to suffer, those who become suddenly "missing" from society upon the onset of their disease and are still unable to find relief.

Recent research is examining what appears to be a palpable connection between long covid and ME/CFS. Ed Yong, who has been reporting on long covid since June 2020, observes that discussion about the pandemic involves only the two extremes of covid infection: healthy on one side, and hospitalization or death on the other, ignoring the "hinterland of disability that lies in between."[176] Resultantly, individuals with long covid must fight for recognition and funding largely on their own. The term "long-covid" was conceived by a sufferer, archeologist Elisa Perego, in May of 2020, almost exactly two years from when this thesis will be turned in. It is characterized by numerous symptoms, including but not limited to neurological changes, menstrual changes, post-exertional malaise (a symptom that virtually characterizes ME/CFS, when "mild bursts of activity trigger dramatic crashes"[177]), joint pain, and trouble concentrating.[178] To investigate long covid, researchers have looked at the possibility of reactivated viruses, connective tissues, and diagnostic biomarkers, just as under-funded researchers have been examining with regard to ME/CFS. As Angela Mariquez Vázquez of Body Politic, a queer feminist wellness collective, stated, "We're regenerating an evidence base that already exists."[179] I sat in on a lecture with Terri Wilder, a ME/CFS and AIDS activist, in early February 2022, and, in discussing long covid, she put it simply: "We saw this coming a mile away, why the fuck didn't you pay attention to us forty years ago." ME/CFS sufferers and researchers have long been aware of the likelihood of developing ME/CFS post- infectious onset,

[176] Yong, "Long-Haulers Are Fighting for Their Future."
[177] ibid
[178] CDC, "COVID-19 and Your Health."
[179] Yong, "Long-Haulers Are Fighting for Their Future."

"shouting it from the rooftops" for years, but as Harvard researcher Michael VanElzakker puts it, "it's hard to get people to pay attention."[180]

The similarities between long covid and ME/CFS are glaring to those informed on both conditions, and not regarding them as congruous has adverse effects beyond the redundancies in research. Physicians are still recommending exercise regimes for patients with long covid, even though individuals with post-exertional malaise can experience "extreme physiological crashes" from forcing themselves to exercise.[181] This is a reality that has been understood for far too long by ME/CFS patients, who learned it the hard way and watch in frustration as the ill-advice is perpetuated. Long-covid patients who arguably "made long covid" also face having their expertise and first-hand knowledge of their condition discounted and brushed over.

Similar to individuals with ME/CFS, long covid patients also struggle to get the reality of their condition recognized, an issue that is achingly clear in a November 2021 article titled, "Even Health-Care Workers with Long Covid are Being Dismissed." Yong describes healthcare workers with long covid initially feeling a kinship with their physicians, as a world they were a part of, but that quickly melted away as ER and primary care physicians brushed off their "invisible, subjective symptoms such as pain and fatigue," leaving them "absolutely shatter[ed]."[182] One occupational therapist stated, "The moment I became sick… I was no longer credible in the eyes of most physicians."[183] A few health practitioners described losing faith in the medical establishment they had once seen as "innovative and cutting edge." It no longer looked that way, with their symptoms written off and no effective solutions offered. As one

[180] Yong, "Long-Haulers Are Fighting for Their Future."
[181] ibid
[182] Yong, "Even Health-Care Workers With Long COVID Are Being Dismissed."
[183] ibid

occupational therapist put it, “My view of medicine has been completely shattered. And I will never be able to unsee it.”[184]

Despite widespread initial ignorance, education about long covid is spreading; those health care workers that are well enough to return to their jobs do so with a changed outlook—they ask more questions, spend more time with patients, and, notably, “have become more comfortable admitting uncertainty.”[185] The NIH has launched a long covid initiative, NYU Langone, among other research institutions, is conducting studies, and Mount Sinai has developed a center for post-covid care in New York City. Long-covid patients want physicians and researchers to look at the body holistically, and formal research is just beginning on some of the symptoms that have been reported for many months. Long-haulers have been invited to testify in front of congress, as well as the CDC and WHO, a great opportunity but one that is often difficult to execute as patients have limited energy and funds to get there. In Ed Yong’s words, “It feels like the doors of power have been unlocked but left shut, and pushing them open takes energy that patients don’t have.”[186] Despite these barriers, as the numbers of those with long covid or PASC continue to rise, and sufferers continue to advocate for research, ME/CFS too gains awareness.

There have been outbreaks of ME/CFS before: in Incline Village, Nevada, in 1984 an estimated 160 people became ill with ME/CFS. Clearly, an outbreak of this size hints at the condition resulting from an infectious onset, but when the CDC was called in, they refused to examine the patients. The CDC and NIH insisted there was no evidence of infectious onset, and Stephan Straus’s assessment of the disease outbreak of “depressed menopausal women” is what

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[184] Yong, “Even Health-Care Workers With Long COVID Are Being Dismissed.”
[185] ibid
[186] ibid

created the moniker "Yuppie flu."[187] However, the sheer number of patients with long covid seems a force too difficult to ignore. Estimates of how many Americans have long covid vary widely, but one retrospective study based on the electronic health data of 81 million patients found that 57% of those studies had one or more symptoms of long covid during the six months post-infection.[188] As current estimates of covid cases in America number over 80 million,[189] it is likely that the sheer number of sufferers cannot and will not be ignored. Long-haul covid, or Post-Acute Sequelae of SARS-CoV-2 infection, could very well be the "arbitrary element" necessary to bring ME/CFS into the light, and get the medical establishment past the "bend in the road" that has kept ME/CFS and its sufferers under-researched, under-acknowledged, and under-supported.

[187] ME- pedia, "The Incline Village Outbreak."
[188] Taquet et al., "Incidence, Co-Occurrence, and Evolution of Long-COVID Features."
[189] Times, "Coronavirus in the U.S."

V. Moving Forward

In "Putting a Name to it: Diagnosis in Contemporary Society," Annemarie Goldstein Jutel offers the possibility of moving away from diagnosis as "the be-all and end-all of the medical consultation."[190] She cites Stone et. al (2002), who wrote of the negative connotations induced by "scientifically-neutral" terms such as medically-unexplained, asserting that while the labels may be neutral, "[their] use is anything but."[191] Jutel goes on to discuss the individual and collective implications of diagnosis, concluding that while diagnosis must be collective, as "classification is precisely about collecting," a diagnostic marker "necessarily effaces some individual difference: a point the suffering individual will know better than anyone else."[192] To mitigate the issues surrounding diagnosis and the undiagnosed presented in this paper, a two-pronged approach should be taken. First, there are structural issues to be addressed, such as an avenue for chronically-ill patients without diagnoses to receive government benefits, and increased medical education and research about contested illness, autoimmune disease, and how to properly support patients with medically unexplained symptoms. But the individual level must be examined as well. It is important to address the ways in which patients in these communities support each other and create resources for others with similar conditions; it is imperative to advocate for raising the voices of individuals that embody contested illnesses and medically-unexplained symptoms to have a real role in helping each other navigate their way through the "chaos narratives" that are far more common than recognized.

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[190] Jutel 117
[191] ibid
[192] ibid

Increased Medical Education and Research

In a study conducted in England in 2006, researchers Salmon et. al set out to examine how "GPs' attitudes to patients with MUS might inhibit their participation with training to improve management."[193] Essentially, they were operating under the assumption that those who view medically unexplained symptoms negatively may be less likely to take training courses in how to help patients with MUS, thus perpetuating the problem further. They devised a study that invited general practitioners to receive training that would help them aid patients with MUS in attributing their symptoms to psychosocial occurrences, lifestyle, or innocuous causes, and found that 65% of those they reached out to reported disengagement from patients with MUS. They received comments that included: "patients' complaints were not legitimate demands on medical care, reflect[ed] the absence of 'real' illness; it was impossible to help them, or it was pointless to try."[194] While the sample size of this study was small, it still adds evidence that offering educational courses to already certified physicians has its limitations; physicians set in their beliefs about how they consider this "type" of patient thus hold an unwillingness to learn more. Of course, this attitude is not universally shared by the entire medical profession, but as noted throughout this thesis, this dismissiveness is prevalent enough that it not only makes patients feel unheard in that appointment, but also discourages them from seeking other opinions in fear of being dismissed once more.[195]

A study conducted in the United Kingdom in 2018 had similar findings, eventually concluding that "as only doctors with positive attitudes towards FS patients [functional syndromes, the study's label for physical symptoms unexplained by organic pathology] and

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[193] Salmon et al., "Why Do General Practitioners Decline Training to Improve Management of Medically Unexplained Symptoms?"
[194] ibid
[195] ibid

confidence managing them are likely to access post-qualifying training, a potentially better strategy to reach those with greatest need is ensuring that training about FS occurs earlier in doctors' medical careers."[196] There is limited information on exactly how much is universally taught in medical schools about the right way to handle medically unexplained symptoms and contested illness, but general consensus is that it is far too little. One survey cited in the paper that was conducted in the UK found that in some schools it was completely absent, and where it was present less than a day was dedicated to the subject. It also found that the information was usually given during psychiatric placements, likely "reinforcing the controversial view that [MUS] are mental health problems."[197] Additionally, MUS's absence from medical school curricula serves to reinforce the idea that MUS are not real medical issues.

In the article, "Training tomorrow's doctors to explain 'medically unexplained' physical symptoms: an examination of UK medical educators' views of barriers and solutions," Researchers Joyce et. al surmised that this leaves young physicians to base their understanding of and care for patients with "physical symptoms unexplained by organic pathology" on "negative attitudes from experienced practitioners."[198] They devised a study to interview medical educators on why these symptoms are under-taught in undergraduate medical training, and found three main barriers; the complexity of the symptoms, MUS being considered low priority for teaching time (this goes back to chapter three of this paper, being considered less important in a packed teaching schedule than a condition that could result in loss of life), and the influence of the professors' negative attitudes on students. The educators interviewed recommended three strategies to increase future doctors' knowledge and comfort in treating patients with physiologically unexplainable symptoms: mitigating educators' negative attitudes, exposing

[196] Joyce et al., "Training Tomorrow's Doctors to Explain 'Medically Unexplained' Physical Symptoms."
[197] ibid
[198] ibid

students to patients with medically unexplained symptoms, and identifying credible individuals at the school to be "champions" of teaching how to handle these situations.[199] The study found that educators who themselves had a vested interest in MUS/FS were more likely to be able to engage students in the importance of knowing how to handle these situations. Additionally, early exposure to both literature about and patients with medically unexplained symptoms would lead young physicians to consider the possibility that even though they cannot identify a cause for a patient's symptoms, it does not mean that they are not legitimate in all cases.

This study was small, and not conducted in the United States, but it may be possible to generalize the conclusions more broadly. Though physicians may be set in their views and unwilling to learn more, taking care not to pass on connotations of medically unexplained symptoms as psychosomatic, or not worth the time it would take to learn about, will help ensure that future generations of physicians do not readily dismiss patients with these complaints. Instead they must listen and work with patients to fight and control their symptoms, or uncover an underlying cause in the cases that they are identifiable. However, this approach should not just be taken in medical school, but continued through physician residency, as well as in nursing and medical social work training.

As discussed previously in this paper, a dearth of research funding leads to less knowledge production, and therefore diminished abilities to diagnose (when possible) and treat these conditions. Women are more often plagued with contested illnesses (they are three to four times more likely to have ME/CFS[200] and account for 80 to 90% of fibromyalgia patients[201]), as well as with medically unexplained symptoms and autoimmune disease, which likely contributes to less research funding for these conditions, leading to less awareness, overlooked diagnoses,

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[199] Joyce et al., "Training Tomorrow's Doctors to Explain 'Medically Unexplained' Physical Symptoms."
[200] Faro et al., "Gender Differences in Chronic Fatigue Syndrome."
[201] "Why Fibromyalgia Predominantly Affects Women." Healthline

and more harm. Form follows funding; with more money set aside specifically for these and related conditions, researchers will be more likely to study them and therefore more likely to discover answers.

Patient Engagement in Research and Activism

A general consensus among sufferers of contested illness is that policy, research, and advocacy work is not productive if it occurs without including those for whom it is meant to support. Brown et. al in "Embodied Health Movements: New Approaches to Social Movements in Health," points out how patients with the same or similar conditions form collective illness identities and social groups, and how those groups become politicized to mobilize and advocate for themselves politically. Embodied health movements (EHMs) are health social movements composed of individuals with the condition, or their loved ones, such as parents, partners, or caretakers. EHM's require three components: introducing the biological body (they highlight the embodied experiences of those with the illness in their activism), challenging existing scientific knowledge, and collaborating with scientists for treatment and research.[202] As Brown et. al emphasizes, other types of movements also challenge science and dominant epidemiological paradigms, but what sets embodied health movements apart is that their critique of science is based on their embodied experiences, on "intimate, firsthand knowledge of their bodies and illnesses."[203] Many of the long covid and ME/CFS advocacy movements are embodied health movements, driven and run by those who truly understand the social, political, and physical toll of the illness, as they embody it themselves. Integrating EHMs into planning, research, and

[202] Brown et al., "Embodied Health Movements."
[203] ibid

policy groups is what many long covid and ME/CFS groups are pushing towards, as exemplified in a letter written by the Long Covid Alliance on February 25th, 2021.

The letter was addressed to the director and three deputy directors of the National Institutes of Health (NIH), as an attempt to share the knowledge and recommendations of the Long Covid Alliance (an organization composed of patient advocates, scientists, and drug developers). Examining the Long Covid Alliance's recommendations for the NIH also sheds light on how best to approach research and treatment for other illnesses about which little is understood. In it, the writers lay out six specific recommendations they hope to see implemented in the NIH's Long Covid planning. For the purposes of this section, I will be focusing on the first two: prioritizing patient engagement and inclusion, and capitalizing on existing infrastructure and expertise from related diseases.[204] The latter of course calls back discussion of the relationship between ME/CFS and long covid from chapter four; long covid research should make use of the body of knowledge held by ME/CFS patients, activists, and researchers. Importantly, the first point on their list is also the most relevant: prioritizing patient engagement and inclusion or, in other words, participatory planning (those most affected by decisions included in the process of making those decisions). With all conditions, it is crucial to listen to those affected, but this is especially apparent when the current scientific paradigm actually has less knowledge than those who embody the illness every day, whether that is simply due to neglect of the issue (ME/CFS), complicated diagnoses (autoimmune disease), or other factors.

Social Support

As discussed in Chapter Two, CB Drucker identifies one of the coping challenges for patients with undiagnosed illness, medically unexplained symptoms, or contested illness as

[204] Long Covid Alliance, "Long COVID Alliance Recommendations to the NIH."

"blocked information seeking." For one, there is a lack of an information base about these conditions for people to look to. Second, they inhabit a state of "diagnostic limbo," a deeply personal diagnostic journey, and have no label for their disease, making it hard to find others in similar circumstances. As discussed in this thesis, individuals whose symptoms and/or conditions are dismissed by medical practitioners can experience "embodied doubt," thinking that they are in fact not real or psychological, and as such may be embarrassed and reluctant to share their pain with others. Some experience disruption of their relationships with their communities and families due to both functional limitations and embarrassment.[205] With these conditions, the umbrella term of "medically unexplained symptoms" can actually be very useful, as it allows individuals to seek out others in similar boats through the medium of online forums and chat rooms, or in-person support groups.

A study conducted by Marcinow et. al in 2021 aimed at evaluating the benefits of facilitated support groups for patients with medically unexplained symptoms identified three major findings; attendants found validation in realizing their peers had similar experiences, learned practical coping skills and pain management from each other, and gained new perspectives on how to communicate with their primary care providers.[206] They felt that even with familial and other interpersonal support systems, their loved ones could not understand as well as other people with MUS feelings of "living with uncertainty, feelings of frustration, coping with chronic fatigue or pain."[207] Participants in the support group found it immensely useful to learn both from the facilitator and speakers they brought in, as well as from each other about practical strategies to help them accomplish daily responsibilities, such as "sleep, physical

[205] Bury, "Chronic Illness as Biographical Disruption."
[206] Marcinow et al., "Making Sense of Symptoms, Clinicians and Systems."
[207] ibid

activity, nutrition, and stress relief techniques."[208] One even mentioned the usefulness of a "sock-putter-onner" suggested by the facilitators. Research literature suggests that when confronted with medically unexplained symptoms, "Health care professionals should shift attention from 'curing' to 'caring and coping.'"[209] They argue that the biomedical model does not offer the patient-centered approach necessary for helping individuals with MUS, or individuals who are undiagnosed in general, and as both society and the medical profession are "quick to question the legitimacy of an undiagnosed illness," spaces in which chronically undiagnosed individuals receive support and guidance from "peers who are empathetic and non-judgemental"[210] are invaluable.

The digital space provides a platform for patients with MUS and/or contested illnesses to share coping strategies and connect over shared experience, creating hubs of support and belonging for individuals who often feel alone in their conditions. In addition, there exists a huge amount of patient-created online resources for more specific advice, if one knows where to look. For example, a self-advocacy resource called *How to Get On* that is aimed towards ME/CFS patients is a colorful wordpress site that holds what can only be called a treasure trove of useful, practical information run by the admin Sleepygirl. It holds guides to self-advocacy with ME/CFS, advice on how to apply for home aids, affordable housing and disability accommodation guides, and guidance on surviving financially while applying for disability. It also holds information on how to travel, how to adapt (and have fun) if an individual is bed bound, and sample housing letters. There is a forum on which people can ask questions and others can respond. It is accessible, helpful, beautiful, and above-all, not condescending or delegitimizing. The page is rife with comments such as "I spoke with so many people within the

[208] Marcinow et al., "Making Sense of Symptoms, Clinicians and Systems."
[209] ibid
[210] ibid

systems who didn't have answers, but your blog helped me find a resource I desperately needed," and "I've learned more here in 30 mins than I have in a year of confusion. Not knowing who to ask and really not sure what to ask." One woman wrote, "Hope is replacing despair." It is true that there is no one perfect treatment for ME/CFS yet, but if physicians directed their patients towards resources like these, instead of dismissing them or offering little support, that could be a crucial step towards help. A move towards humble physicians who do not doubt their patients' testimonies but instead acknowledge gaps in empirical knowledge and direct their patients towards support groups and resources such as these, pointing to patients as experts, would be a move in the right direction.

By relying on those who have the embodied experience of these illnesses to inform the way that the scientific community moves forward, patients, physicians, and researchers can work together in the most efficient way possible. To reiterate, activism will struggle to take hold without widespread knowledge, so increasing medical education as well as research funding is imperative as well. Finally, physicians pointing to other patients as experts in situations where they do not know the answers would go a long way towards easing the "chaos narratives" of the chronically undiagnosed.

Conclusion: The Botanist vs Gardener Mindset— Creating a Model to Make Space for the Undiagnosed

Ultimately, for the treatment of and stigma around chronically undiagnosed individuals to change, the model must make space for not knowing everything. Lousie Stone, in her 2013 paper "Being a Botanist and a Gardener: Using Diagnostic Frameworks in General Practice Patients with Medically Unexplained Symptoms," asserts that the biomedical framing of diagnosis necessitates medical practitioners behaving as "botanists," "bent on scientific classification."[211] This model is of course incompatible with diseases or symptoms we cannot yet classify, leading to dismissiveness and subsequent embodied doubt, as well as limited access to support resources for individuals in these circumstances. "Gardeners," on the other hand, are "bent on nurturing and making things 'grow,'" thus following a more holistic biopsychosocial model.[212]

The Norwegian study discussed in chapter three of this thesis, aimed at exploring how patients with MUS are treated in the doctor's office, found that the more patient-focused biopsychosocial model resulted in more effective care in focus groups. The researchers concluded the main difference was that the biomedical framework induced physicians to rely on formal scientific knowledge (problematic for patients whose symptoms have no observable pathological basis), while physicians using the biopsychosocial framing tended to rely more on their past clinical experience, which led them to "make clinically efficacious distinctions between patients with MUS that give direction to clinical judgment."[213] The "botanist" model effectively barrs the chronically undiagnosed from fully being accepted into the sick role, inhibiting both access to care and social support. As seen in chapter one, this model stems

[211] Rasmussen and Rø, "How General Practitioners Understand and Handle Medically Unexplained Symptoms."
[212] ibid
[213] ibid

naturally from its historical context, the advent of "precision medicine" and technologies of disease. However useful the biopsychosocial patient-focused model is, it has limited widespread use for a number of reasons previously discussed (stigma, etc), especially as the necessity of diagnosis is implicit in the regulations of insurance companies and government regulations.

For it to be more medically and socially acceptable for doctors to treat patients without diagnoses, the definition of disability and being "sick" must become more inclusive to allow benefits and care not just to those with a diagnosis. Here, we can look to sectors of medicine that are already focused on treating symptoms regardless of the causes, such as geriatrics. In geriatric medicine, physicians focus on function rather than cause. When physicians treat geriatric patients, it is common to shift their focus from the diagnostic model of care examined in this thesis to a more holistic one that is primarily concerned with optimizing function and well-being. Because geriatric patients often have multiple diseases overlayed with the effects of aging on the body and brain, the diagnostic model has less utility. Geriatricians' assessments of their patients include understanding the patient's sleep patterns, overall sense of well-being, appetite, quality of social relationships, mobility, and ability to carry out the normal activities of daily living. This assessment will also include an understanding of what is most important to the patient so that efforts to intervene will be appropriately prioritized. For example, for one patient the most important goal may be continuing to be able to drive a car, or being able to breathe easier when lying down, or to avoid the use of a wheelchair for as long as possible. These stand in sharp contrast to typical goals in the more reductionist biomedical model which are more aimed toward identifying disease, and treating said disease should they find one.

That is not to suggest that geriatricians are not concerned about individual disease. On the contrary, their goal is to strike the right balance between management of those diseases and the

broader picture of how the patient is doing overall, and how best to optimize their health and well-being. The approach is not completely disparate from the diagnostic model, but about finding the right balance between the models, providing a useful window into how the medical profession could more broadly incorporate the two approaches. It would do no good to throw the baby out with the bathwater, abandon the diagnostically-minded botanist in favor of the nurturing, patient-focused gardener, but meeting closer to the middle and expanding our understanding of disease and therefore who qualifies for the sick role would help to ensure that ill individuals, lacking their diagnostic "keys," are not gate kept from needed services and societal understanding.

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