

7-6-2022

"Damn, man. The time that I lost": Power and the Process of Diagnosis for Women with Chronic Illnesses

Kaitlin Roquel Yeomans
Portland State University

Follow this and additional works at: https://pdxscholar.library.pdx.edu/open_access_etds



Part of the [Sociology Commons](#)

Let us know how access to this document benefits you.

Recommended Citation

Yeomans, Kaitlin Roquel, "'Damn, man. The time that I lost": Power and the Process of Diagnosis for Women with Chronic Illnesses" (2022). *Dissertations and Theses*. Paper 6195.
<https://doi.org/10.15760/etd.8045>

This Thesis is brought to you for free and open access. It has been accepted for inclusion in Dissertations and Theses by an authorized administrator of PDXScholar. Please contact us if we can make this document more accessible: pdxscholar@pdx.edu.

“Damn, man. The time that I lost”: Power and the Process of Diagnosis for Women with
Chronic Illnesses

by

Kaitlin Roquel Yeomans

A thesis submitted in partial fulfillment of the
requirements for the degree of

Master of Science
in
Sociology

Thesis Committee:
Amy Lubitow, Chair
Hyeyoung Woo
Tina Burdsall

Portland State University
2022

© 2022 Kaitlin Roquel Yeomans

ABSTRACT

Historical sociological research on people with chronic illness has examined their navigation of their lives post-diagnosis. Diagnosis has been considered with regard, not to its process, but rather to its definitions. While a rich literature has been produced by such approaches, how people experience the process of diagnosis has largely been ignored. This research looks at the process of diagnosis as a series of moments, all of which hold specific meaning in the interactional context of the patient-provider relationship. Looking at diagnosis from the patient's perspective demonstrates how information about health and illness is exchanged, navigated, and negotiated. Importantly, this research also reflects that healthcare inequalities, namely those based on race and gender, are intrinsic to all medical processes. This research outlines the concept of linear and non-linear diagnostic experiences and the role of power and disempowerment in medical encounters.

DEDICATION

I dedicate this thesis to the people who took the time to let me interview them, and who gave me glimpses into some of the most vulnerable and powerful moments of their lives.

Hope is the thing with feathers

That perches in the soul,

And sings the tune without the words,

And never stops at all,

And sweetest in the gale is heard;

And sore must be the storm

That could abash the little bird

That kept so many warm.

I've heard it in the chillest land,

And on the strangest sea;

Yet, never, in extremity,

It asked a crumb of me.

–Emily Dickinson, “Hope is the Thing with Feathers”

ACKNOWLEDGMENTS

This thesis was not an individual undertaking. First, I would like to thank my advisor, Dr. Amy Lubitow, for dealing with my desire to take not only the path less taken, but literally every single path that has ever presented itself to me. I appreciate you guiding me toward research that is sociologically fruitful and personally rewarding. I would also like to thank my committee members—Dr. Hyeyoung Woo and Dr. Tina Burdsall—whose expertise in medical sociology were essential in conceptualizing and completing this project.

I would also like to thank Dr. Dara Shifrer for her support and faith in my ideas through every stage of their development. I would be remiss not to thank Dr. Dan Jaffee for his encouragement, and especially his tip on automated transcript software, which did nothing short of saving this entire project from certain doom.

I would not be able to be a sociologist without the foundation given to me by my “home” field of study—German. For that, I thank the faculty of the UO German department, particularly my OG committee of Dr. Michael Stern, Dr. Sonja Boos, and Dr. Camisha Russell, as well as Dr. Jeffrey Librett, Dr. Dorothee Ostmeier, and Dr. Martin Klebes.

To the CAREER Analysts, former and current: your suggestions are ultimately what made this thesis what it is. Thank you so much for accepting me into your group and helping me figure out what it means to engage my sociological imagination.

To my family—one day I will be done with grad school. But until that day, thank you for listening to my impassioned rants about random theorists who you have never heard of.

To Christy—I am forever grateful that you and I were partnered up in class in Fall of 2020. All of our adventures over the past 2 years have been just as wacky and zany as any soap opera should be. I appreciate you being there, even when, as we say, “it’s a mess”.

To the 2021-2022 Executive Board of GEU and GEU Bargaining Team: there are not enough words to describe the ways in which union labor has benefited me, both personally and professionally. Thank you for your solidarity.

And of course, to my cat, Rodney—you continue to be the light of my life.

TABLE OF CONTENTS

ABSTRACT.....	i
DEDICATION.....	ii
ACKNOWLEDGMENTS.....	iii
LIST OF FIGURES.....	vi
INTRODUCTION.....	1
LITERATURE REVIEW.....	3
SOCIOLOGY OF CHRONIC ILLNESS & DIAGNOSIS.....	3
HEALTHCARE INEQUALITIES: RACE & GENDER.....	4
THE CULTURAL HEALTH CAPITAL FRAMEWORK: PATIENT & PROVIDER INTERACTIONS.....	6
CLARIFYING DIAGNOSIS: UNDERSTANDING PROCESS & POWER...9	
METHODS.....	10
FINDINGS.....	15
THE PROCESS OF DIAGNOSIS.....	15
LINEAR DIAGNOSES.....	17
NON-LINEAR DIAGNOSES.....	18
WILDCARD DIAGNOSES.....	20
RACE & GENDER IN DIAGNOSIS.....	21
THE LIMITS OF THE DIAGNOSTIC SPECTRUM.....	24
POWER & DISEMPOWERMENT.....	27
THE GOD COMPLEX.....	28
WEAPONIZED INCOMPETENCE.....	29
DEPLOYMENT OF UNCERTAINTY.....	31
THE CONSEQUENCES OF DISEMPOWERMENT.....	36
DISCUSSION.....	38
CONCLUSION.....	41
REFERENCES.....	43

LIST OF FIGURES

Figure 1: Racial/ethnic make-up of sample.....	12
Figure 2: Participants visualized across the diagnostic spectrum.....	26

INTRODUCTION

Fans of the popular medical drama “House, M.D.” can tell you: “It’s never lupus”. And indeed, on “House, M.D.”, only one patient was ever diagnosed with lupus (Kandell 2020). Lupus, specifically, systemic lupus erythematosus (SLE), belongs to a group of illnesses called autoimmune diseases. Autoimmune disease, and chronic illness in general, has been included in the sociological eye for a long time, with the clearest example of this perhaps being Bury’s (1982) study on women with rheumatoid arthritis, which concluded that disease symptoms transformed into illness experiences that were disruptive to patients’ identities prior to their diagnosis. Charmaz (1983) unearths a similar concept and names this “loss of sense of self” as part of the fundamental suffering of those diagnosed with chronic illness—separate from the physical and manifestations of the illness. Both of these groundbreaking pieces explored the experiences of people with chronic illness post-diagnosis. Because sociological literature has focused on illness as a discrete phenomenon (pre-diagnosis and post-diagnosis), it has missed the experience of diagnosis itself as an area for rich sociological discovery. This study seeks to begin an exploration of diagnosis and illness, not as static states, but rather as negotiations of reality that are constantly in flux.

This paper aims to: 1) establish the process of diagnosis as a sociologically relevant event that is vital to understanding the experience of people with chronic illnesses and 2) examine the structure of power and its influence in the interpersonal dimension of diagnosis. I utilize data from 17 in-depth interviews with women with chronic illnesses to formulate a model of diagnosis that highlights differences and

similarities in diagnostic processes. I also use this data to examine the interactions between patient and provider and to look at power as a key influence in these interactions.

In the next pages, I turn to the diagnostic moment, or series of moments, which lead up to the diagnosis. This process is interactive and it is linked to both individuals and institutions, with patients and providers both operating as agents with free will, while also being restricted in their actions and movement by systemic and institutional constraints. I argue that, at an individual level, the process of diagnosis can be either linear or non-linear, indicating either a quick and straightforward diagnostic process or, in contrast, a disorganized and disjointed diagnostic process. Regardless of where participants fell on this spectrum of diagnosis, there were clear physical and social psychological instances of extreme suffering. The pain of being dismissed, ignored, or belittled by providers indicates that, in the relationship between provider and patient, power plays an integral role in how patients navigate their diagnoses within the medical system. I describe the means by which providers harness and deploy power in these interactions, and how patients experience this utilization of power.

In short, this thesis adds to a growing body of literature on the sociology of diagnosis with empirical examples of how women go through the process of diagnosis. Secondly, I unravel some of the ways in which power is at play in interactions between patients and providers. Additionally, I articulate that the understanding of social characteristics and identities is crucial to understanding how people navigate and negotiate their diagnoses in medical settings.

LITERATURE REVIEW

Given the focus of this project on chronic illness and the experience of diagnosis, I review the relevant literature on: 1) sociology's insight into chronic illness and diagnosis, 2) historical and contemporary healthcare inequalities as they relate to chronic illness and diagnosis, and 3) the cultural health capital framework and its utility for understanding patient-provider interactions.

SOCIOLOGY OF CHRONIC ILLNESS & OF DIAGNOSIS

As mentioned in the introduction, Bury (1982) and Charmaz (1983)'s qualitative studies put forth in the 1980s created a fertile ground for improving sociology's understanding of illness, specifically chronic illness. We understand chronic illnesses as existing in separate frameworks from that of temporary illnesses (Bury 1982; Charmaz 1983). Chronic illnesses occupy this unique space precisely because they interrupt our perception that illness is demarcated by a clear end (Bury 1982; Charmaz 1983). However, this conceptualization is at odds with the current American medical system, which attempts to cleanly categorize disease (and associated symptoms and experiences) as ephemeral states that can be cured in entirety by current medical advances (Bury 1991; Varul 2020). This brief overview of some historical and contemporary sociological pieces illustrates the ways in which chronic illness disrupts individual and institutional expectations. However, despite the sociology of chronic illness being a well-established subfield, our understanding of the sociology of diagnosis is limited by a lack of empirical research on the process of diagnosis.

Despite this limitation, important theoretical pieces contribute to our current conceptualization of the sociology of diagnosis. It is impossible to decouple chronic illness and the experience of diagnosis, as diagnosis is the process by which diseases are categorized and legitimized, or, as Jutel (2009) puts it, “being diagnosed gives permission to be ill”. Brown (1990) also emphasizes that diagnosis is not a purely objective science; indeed, social characteristics strongly influence the degree to which diagnoses are distributed among certain populations, affects the “desirability” of diagnosis, and the ways in which providers perceive certain diagnoses. Brown (1995) clearly outlines several typologies of diagnosis, which range from medically legitimized and defined conditions, medically defined but not-legitimated conditions, medically accepted but not defined conditions, and conditions neither legitimated nor defined by medicine.

Brown (1995) stresses that diagnosis is not an objective science, but rather a subjective practice by which medicine and medical providers attempt to organize illness experiences. Following Jutel’s (2009) and Brown’s (1990) linkage of diagnosis to social characteristics, the next portion of literature reviewed provides an overview of how social characteristics play into medical discrimination as well as the assignment of diagnoses.

HEALTHCARE INEQUALITIES: RACE & GENDER

I focus here on gender and racial inequalities as deeply rooted in Western medicine. I acknowledge that other identities such as being a part of the LGBTQIA+ community, age, and socioeconomic status all play a role in how one is perceived in medical settings. However, the research questions, interview questions and the identities

present in the sample restrict empirical findings to those based on racial and gender identities. Therefore, this is not a complete overview of discrimination in medicine, but rather a focused review on how medical inequalities related to identities present in the sample originated and persist within the US medical system.

Accounts of “hysterical” women and racist medical abuse such as the Tuskegee experiment illustrate a fundamental issue with Western medicine: racism and sexism continue to plague the system of medicine and are continually reproduced through medical education and medical practices (Washington 2006; Tasca et al. 2012; Paul and Brooks 2015; Kanaan 2016; O’Brien et al 2020). Understanding that race and gender cannot be separated from one’s illness experience also indicates that race and gender cannot be separated from one’s diagnostic experience.

Lorber (1997) articulates that gender, as a socially constructed phenomenon, is present in all societal structures and the social roles prescribed to men and women may result in different experiences, even if diagnosed with the same illnesses. Despite differences in mortality between women and men, women are perceived as “excessive” utilizers of healthcare while men are perceived as “normal” utilizers of healthcare (Courtenay 2000). Despite “hysteria” being a diagnosis of the past, women are still more likely to be given anti-depressants for symptoms with physical causes, while men receive painkillers (Samulowitz et al. 2018).

Racial disparities in healthcare are also still largely prevalent; racist attitudes about health insurance status, sexual promiscuity, illegal drug use, and faking illness affect the interactions between medical providers and people of color (Ross et al. 2012). Western medicine has also used race as a “genetic” explanation for socially embodied

health disparities, such as inequalities in birth mortality rates (Gravlee 2009; Roberts 2015). O'Brien et al. (2020) remind us that race and class are ultimately tied, leading to a racial gap in access to healthcare in a for-profit healthcare system. In essence, people of color are discriminated against by a medical system, which then attempts to explain health inequalities as genetically determined, rather than a result of continuous discrimination.

Much of sociological literature has been devoted to outlining these inequalities, particularly in relation to disease distribution, mortality, and healthcare utilization. These theoretical and empirical findings invite further exploration to understand how exactly these characteristics emerge in the interactions between patients and providers. In the next section, I outline the concept of cultural health capital as a rich framework for looking at interactions in healthcare settings.

THE CULTURAL HEALTH CAPITAL FRAMEWORK: PATIENT & PROVIDER INTERACTIONS

As one can see in the name of the cultural health capital framework (henceforth referred to as “CHC”), it relies on the concept of cultural capital as outlined in many of Bourdieu’s works Shim (2010), one of the founders of the CHC framework, defines cultural capital as cultural practices and products of all kinds, which are transmitted and deployed with dominant cultural capital and its deployment resulting in material benefits. Shim (2010) reminds us that Bourdieu considers cultural capital as something that is domain dependent, and shifts our focus to the domain of healthcare. The basic tenets of CHC are that those who possess it demonstrate knowledge of medical topics and

vocabulary, knowledge of what information is relevant to health care personnel, the skills to communicate health-related information to providers in a medically intelligible and efficient manner, an enterprising disposition and a proactive stance toward health, the ability to take an instrumental attitude toward one's body, belief in the value of self-discipline, an orientation toward the future and its control through calculation and action, a sensitivity to interpersonal dynamics, the ability to adapt one's interactional styles, and the ability to communicate social privilege and resources that can act as cues of favorable social and economic status and consumer savvy (Shim 2010). The laundry list of that which comprises CHC is a guideline for understanding the interactions that providers and patients have in this sample.

Several empirical studies have addressed the ways in which CHC operates in practice. Chang et al. (2016) find that exchange of CHC can mitigate stigma. However, Chang et al. (2016) note that an improper exchange or failure to recognize cultural health capital often results in significant diagnostic difficulties. Dubbin et al. (2013) note that there is a hierarchy to the value of cultural capital and find that differential mobilization of CHC can contribute to misunderstandings and the propagation of inequalities in healthcare resulting from the interactions between patient and provider. CHC situates our perspective of interactions in an "upstream" (rather than "downstream") location by accounting for race, gender, and other differences as things that relate back to the degree of cultural capital held by patients and providers, its disparate deployment, and whether its exchange is successful or unsuccessful (Dubbin et al. 2013). Therefore, the CHC framework allows for a deeper understanding of how power is enacted in medical settings.

Other theoretical framings relevant to patient-provider interactions are those of physician expertise, medical uncertainty, and clinician empathy. Taking yet another interactional approach, Heritage and Maynard (2006) outline the three tenets of the medical interview used in contemporary medical practice: the psychosocial context of the patient, the construction of the therapeutic relationship between the patient and physician, and the education of the patient. Heritage and Maynard (2006) find that physicians who occupy a paternalistic stance toward patients tend to adopt a more narrowly biomedical viewpoint with the underlying assumption that the physicians' interests and the patients' interests coincide, which can be problematic if those interests do not in fact coincide.

Another key aspect relevant here is the concept of uncertainty. Littlejohn and Kimport (2017) explore the instantiation of medical uncertainty in relation to contraceptive care and side effects, noting that uncertainty was often coupled with a desire to lessen patients' concerns. In contrast, uncertainty here is conceptualized as a negative response to the exchange of a patient's CHC. Exploring the experiences of people with diagnosed autoimmune illnesses will reveal how this uncertainty is operationalized as a way of disempowering patients during the diagnostic process. In contrast, Vinson and Underman (2020) bolster the concept of "clinician empathy" as vital to the success of the patient-provider interaction. All of these concepts are relevant in the process of diagnosis, as the process of diagnosis is ultimately dialogic, as evidenced by the CHC framework. The organization of the discourse of medicine, the order of expected articulations in terms of diagnostic process, and the reliance on the expertise of a non-empirical science with a historical basis in racism and sexism mean that power emerges and is operationalized in many different ways (Foucault 1973).

CLARIFYING DIAGNOSES: UNDERSTANDING PROCESS & POWER

Much of the previous literature on chronic illness and autoimmune disease has been on how individuals negotiate their lives post-diagnosis. Less well-understood is the fluid experience of the process of diagnosis. Additionally, this research specifically examines the role of race and gender in interactions with healthcare providers and within the healthcare system, which will contribute to the literature on healthcare disparities by providing concrete examples of the role of patients' racial and gender identities during the process of diagnosis. In short, this research aims to explore participant's experiences of diagnosis, center such experiences within an interactional framework of patient-provider interaction, clarify how power works in such a relationship, and assess the role of race and gender in both the process of diagnosis and the interactions that precipitate and follow diagnosis.

METHODS

I conducted 17 in-depth semi-structured interviews. In these interviews, I asked women about their experiences being diagnosed with an autoimmune disease, and the role race and gender played in their process of diagnosis. Participants had to have a diagnosis of either multiple sclerosis (MS), Crohn's disease (CD), or systemic lupus erythematosus (SLE), identify as a woman, be between the ages of 18-60 and reside in the United States. The sample of participants is a convenience sample. Despite the small sample, saturation was reached and this data provides relevant information about a relatively understudied population and phenomenon.

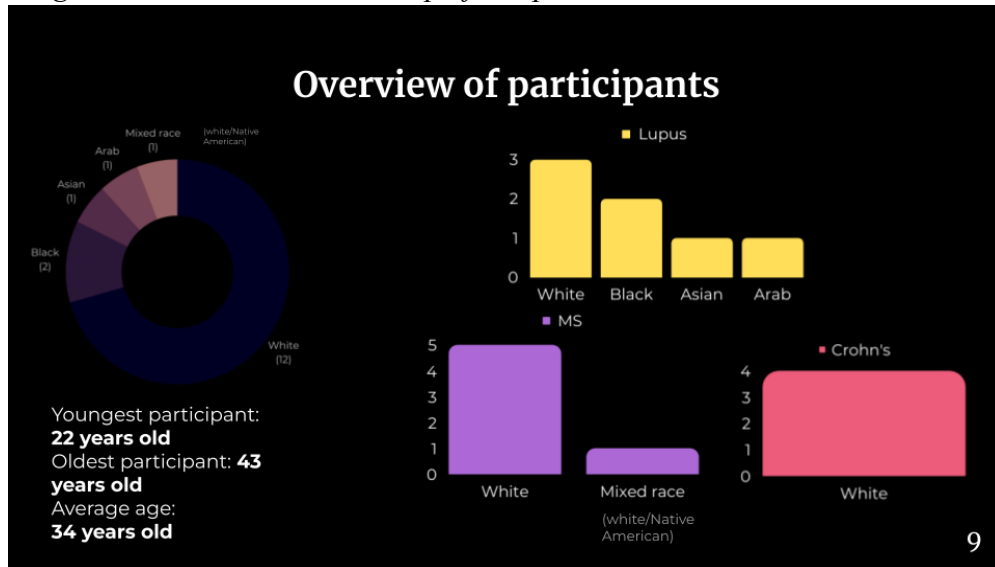
I used social media including Facebook, Instagram, Twitter, Tumblr, Nextdoor, and Reddit to find participants. I also asked my friends, family, and colleagues to share the study information with their circles. I conducted these interviews from June of 2021 through August of 2021. Interviews took place on Zoom, a video conferencing platform, and interview times ranged from 15 minutes up to 60 minutes. For clarity and brevity, systemic lupus erythematosus is sometimes represented as "lupus" in this paper, Crohn's disease as "Crohn's" and multiple sclerosis as "MS".

For the interviews, I was in my apartment at the time in Spokane, Washington. Participants appeared to be in their living spaces as well, though a few participants chose to attend the interview from their cars. All but one of the participants were located in the US; one participant was a resident of Canada. Audio and video data were recorded on Zoom and the audio was transcribed with the help of Temi.com, an automated transcription service. I edited transcripts for accuracy and clarity. I assigned pseudonyms

to every participant. Identifiable locations, institutions, and other persons are redacted in the data presented in this manuscript. While I am a woman with an autoimmune disease (though it is not the primary diagnosis of any participants in this study), I did not disclose this to all participants, electing to share when prompted or when such information seemed relevant (such as when a participant shared their diagnosis of the same illness I have as comorbid with their primary diagnosis).

Participants ranged in age from 22 to 43 with an average age of 34. 16 of the 17 participants identified as female. One participant identified as genderqueer, though their assigned gender at birth was female. The racial and ethnic distribution of the sample was: 2 Black/African American participants, 1 Asian (East Asian/Korean) participant, 1 mixed race (white and Native American) participant, 1 Arab American participant, and 12 white participants. White participants had a mixture of European heritages, including Scotch-Irish, Irish, English, Italian, broadly Mediterranean, Sicilian, German, and Solá (Catalonian). Figure 1 shows the racial and ethnic make-up of the sample. Figure 1 shows the racial breakdown of all participants, the participants by illness, and the age range and average age of participants. Racial labels are derived from participants' self-reports when asked about race and ethnicity. The figure appears on the following page.

Figure 1: Racial/ethnic make-up of sample



I used Dedoose to code my interviews. I approached the data using an approach most in line with the flexible coding approach outlined in Deterding and Waters (2018) as well as thematic analysis outlined in Braun and Clarke (2006). Looking into the background literature on the sociology of diagnosis informed the interview questions. Questions revolved around the diagnosis participants received, their diagnostic story, their opinions on their providers, and their assessment of how their identities and their providers' identities influenced their interactions. After collecting the data, I approached the data in a broad strokes way, making general categories of codes based off of preliminary readings of the interview data. Broad codes included topical categories such as “gender” or “race” to identify when respondents were discussing themes. After coding the data broadly, I began to make the codes within each broad section more granular to identify the different ways in which the overarching themes appeared. For example, diagnosis was further divided into “linear”, “non-linear”, and “wildcard” categories. I then looked at the frequency of the codes to determine what the main analytic

cornerstones of this paper were. In line with thematic analysis, I wrote memos relating codes and interviews to each other. I also checked codes to ensure that they aligned with the themes I distinguished within the interviews.

I identified several major themes. In this thesis, I zoom in on diagnosis as a phenomenon distinct from the experience of symptoms or illness and the operationalization of power within encounters between patients and medical providers. The themes emerged using different analytical reasoning. The first theme, diagnosis as a phenomenon, was abductively derived in that the interview questions were guided by a theoretical literature, but the theme took shape and direction in accordance with the interviewees'. The second theme, the operationalization of power within the medical encounter, was derived inductively. The interview questions were not informed by any literature on power; this theme arose from the answers given in the interviews. While I had prepared questions to ask specifically about race and gender, and had planned on using a deductive approach, the themes derived ab-and inductively cannot, at their core, be separated from the identity of participants. Therefore, I have chosen to weave the concept of identity throughout my analyses of the process of diagnosis and the concept of power in the medical sphere rather than taping off a specific section to talk about identity separately.

First, I look at differences in diagnostic journeys, defining the difference between and the impact of linear and non-linear diagnostic paths. Then, I examine the role of power within medical encounters between participants and their providers and establish how disempowerment and of patients function in the medical sphere. While the explicit goals noted in the materials for recruitment were related to race and gender in the process

of diagnosis, I decided against including a third theme, choosing to integrate findings about race and gender within the larger framework about the process of diagnosis and the concept of power and disempowerment. Race and gender are salient to all parts of the illness experience, and may be explored further, in isolation from the themes discussed here or integrated, in later pieces to allow adequate space to begin to unpack such concepts fully.

FINDINGS

THE PROCESS OF DIAGNOSIS

The literature on sociology of diagnosis has largely focused on diagnosis as a categorizing tool for illnesses rather than focusing on the process of diagnosis. This section examines diagnosis as a range of experiences best understood along a spectrum. Rather than discussing the myriad ways in which diagnosis organizes illness, I look at the different manifestations of the diagnostic process as highly varied experiences. Similarities between diagnostic processes, as well as differences, provide evidence to organize the range of experiences along a spectrum of non-linear to linear experiences.

Linear diagnoses follow a standard cultural expectation within Western medicine that one goes to the doctor, receives a diagnosis quickly, and is started on appropriate treatments in a timely manner. Contrasting this, non-linear diagnoses do not follow this pattern and are instead characterized by the deployment of uncertainty in the diagnostic phases of illness, leading to long diagnostic times, misdiagnoses, and inappropriate or inadequate interventions to cope with illness. I define linear diagnoses with the following criteria: less than 6 months between first diagnosable symptom and appropriate treatment (if treatment is sought) and 2 or fewer diagnosing medical professionals encountered during the diagnostic process (to allow for the possibility of a specialist referral).

The 6 months, like all numbers, is slightly arbitrary. Despite medical tests that can accurately affirm or disaffirm the presence of autoimmune diseases such as MS, SLE, and CD, the time to diagnosis is highly variable (UVA Health). Studies on MS suggest a time frame of around 2 years (Fernández et al. 2010). (Notably, this study is

representative of Spain, not the United States). The Lupus Foundation of America estimates a time frame of 6 years from the first symptom to be diagnosed with SLE (Lupus Foundation of America). Time to diagnosis for Crohn's disease is estimated between 5-9 months, but can be more than 5 years (Fiorino and Danese 2016). (Notably, this study focuses on European patients). Some delay in diagnosis may be medically legitimate. However, a study of cancer patients by Miles (2018) finds that patients with a longer time to diagnosis undergo a higher number of consultations and experience substandard quality of care. Miles (2018) asserts that the psychological effects of delayed diagnosis have yet to be fully explored. The harms of delayed diagnosis, as evidenced in this thesis, can and do pose material and emotional harm to those eventually diagnosed.

In contrast to linear diagnoses, non-linear diagnoses are much more disjointed and complex, with a wide variety of possible experiences. The unifying trait of non-linear diagnoses is that they are missing one or both of characteristics that define a linear diagnosis. Additionally, diagnosis is related to visible physical characteristics, such as race and gender which influence providers' perceptions of their patients. Wildcard diagnoses are diagnoses that occurred by pure happenstance—which seems like it would be incredibly rare—but 2 of the participants in this small, qualitative study fit the criteria for wildcard diagnoses.

The following section outlines how linear experiences function, how non-linear processes function, the role of identity in the process of diagnosis, and the limits of the model produced to categorize diagnoses (linear, non-linear, and wildcard diagnoses).

LINEAR DIAGNOSES

Starting out with linear diagnoses, we can turn to Bessie and Wren's experiences. Bessie is a 42 year old white woman who has been diagnosed with MS. Wren is a 22 year old black woman who has been diagnosed with lupus. When prompted to talk about her first noticeable symptom, Bessie tells me:

I was having weird sensations in my hand and it didn't go away. And so I went to a doctor and they said, "no, probably carpal tunnel," like "wear a wrist thing". And so I did that for a little while, and then I went back and I said, "not carpal tunnel". And they said, "okay, let's do an MRI". And said that, that showed lesions. So we went from low intervention to a big medical test very quickly.

Bessie's experience highlights perhaps the quintessential linear diagnostic process. She went into the doctor with a symptom and was given an intervention. While the first diagnosis and intervention were not the final diagnosis, Bessie articulates how the second intervention ramped up quickly in intensity, compared to the first intervention. Notably, the second intervention also contributed to a definite diagnosis of MS, which signifies that Bessie's experience of diagnosis is a linear experience. Her experience operates in the way we expect medicine to operate--symptom, diagnosis, intervention, continued symptom, escalated intervention, and differential diagnosis all follow in sequential order and in quick succession. When asked about the total time between her first symptom and her diagnosis with MS, Bessie tells me that it was likely no more than a couple of months total.

Another example of the linear diagnostic process is Wren's experience being diagnosed with lupus. Wren is a 22 year old Black woman. Wren has the unique

experience of having been diagnosed during the COVID-19 pandemic, which she notes impacted her ability to see doctors due to scheduling demands.

It was around the beginning of like right before COVID started I was working at Starbucks at the time and I realized like I would wake up in the morning and I'll be very tired. My hands would be swollen and my feet would be swollen [...] So I went to a doctor to see what the issue was. And at first he said, I had this thing called carpal tunnel. [...] So he gave me these pads to wear on my wrist, so my wrist wouldn't get swollen anymore. So after a while that didn't work and it was like my arm symptoms, which is like the fatigue, me getting inflamed was just getting worse. [...] when I finally did get the appointment with the doctor [...] she told me that I had lupus.

Wren and Bessie's experiences are extremely similar, down to the very first diagnosis and the first intervention given, despite Bessie being diagnosed with MS and Wren being diagnosed with lupus. When asked about time from her first symptom to a diagnosis of lupus, Wren tells me that it took about 3 or 4 months, but attributes that wait time to the delays in care caused by the COVID-19 pandemic. Not all experiences of linear diagnosis have the exact same symptoms and interventions or even differential diagnoses, but they all follow the same upshot of an organized experience from symptom to intervention to diagnosis.

NON-LINEAR DIAGNOSES

In contrast, non-linear experiences of diagnosis are more variable in terms of what occurs between the first identifiable symptom and the final diagnosis. Generally, patients who experienced a non-linear diagnostic process have a comparatively long time between their first identifiable symptom and appropriate medical intervention. Often, they experience medical care in the form of advice rather than treatment. Aspen, a 31 year old

white woman, has experienced symptoms of Crohn's disease that she identifies as starting in her childhood, with clear symptoms as early as 4 years old. This portion of her story picks up 22 years later, when she was 26 and in the emergency room.

The liquid that they give for stomach issues didn't work. The morphine didn't work. I got an emergency [...] CT scan. And they found that not only did I have that snake pattern ulcer in my lower ileum; it was about 32 centimeters, but my organs were starting to shut down because the inflammation was so bad

While the time between her emergent symptoms and diagnosis seems short, Aspen experienced 22 years of uncategorized symptoms. The interventions given by medical professionals were insufficient, leading to Aspen's visit to the emergency room, where sufficient interventions, such as a CT scan, were performed and treatments for Crohn's disease were started.

Franziska, a 38 year old white woman with lupus, has a story that also does not align with the linear expectations of the diagnostic process. Her symptoms began when she was a teenager and continued into her early twenties before she was diagnosed with lupus. Franziska recalls that she attempted to see doctors about serious issues multiple times over the course of many years, only to be repeatedly dismissed.

[The doctors] said nothing was wrong with me and [they were] super mean about it. So I didn't go back for a really long time, even though they said I should. So this time I told my doctor, like, "I'd really like you to look again, my ANA has been positive and I want to make sure that it's not something with that". So she ran extra tests and they came back positive again. And she sent me to the rheumatologist and he did a lot of testing. Like, uh, I want to say like 12 bottles of blood the first time I went to go see him. And he did find it. He looked hard enough to find it.

Aspen and Franziska's stories demonstrate the disjointed experiences of people with non-linear diagnostic trajectories. Rather than a clear path from symptom to diagnosis, they are jostled around in a system for long periods of time, given insufficient or no answers to their problems, and are generally at a crisis point when receiving their diagnosis.

WILDCARD DIAGNOSES

There were several diagnostic processes that did not fit into the organizational schema developed to illustrate the difference between linear and non-linear diagnostic experiences (dubbed “wildcards”), such as Jane's experience of being diagnosed with MS. Jane is a 43 year old white female. Her story begins with symptoms attributed to a mass in her skull called fibrous dysplasia as well as her history of migraine headaches. MS was an incidental finding on her imaging for her other neurological conditions. She tells me about her diagnosis, starting first with the identification of the mass in her skull, leading into the detection of MS lesions on her brain.

So I ended up going into the [...] neuro-oncology department. [...] The fibrous dysplasia, the neurosurgeon and the ENT and the face-head-neck surgeon all recommended that unless, it's hindering my life in some way, keeping me from working, keeping me from being a mom and a parent and a wife and all of that, that it's probably best not to do surgery because the likelihood of this mass being cancer is very, very small.[...] You know, if you don't have to cut into the brain, you don't want to. [...] and through that process, they did start seeing lesions on my brain

Jane's story demonstrates that diagnostic trajectories operate on a spectrum ranging from non-linear to linear, rather than always fitting neatly within the “linear” or “non-linear” category, with wildcards falling directly in the halfway point of that spectrum—neither

classified as linear or non-linear. Her case is unique because she has a low time to diagnosis, as there is no clear symptom to mark the beginning of the diagnostic process. There is also a significant medical intervention early on, but again, the lack of an identifiable symptom confounds this. This type of diagnosis was the least common, though did occur twice in a relatively small sample of people.

RACE & GENDER IN DIAGNOSIS:

One of the main purposes of this research was to look at gender and race and their role in the process of diagnosis. Gender and race were generally seen as salient in the diagnostic process, whether that be in terms of privilege or in discrimination. A rich literature already outlines the influence of gender and race-based discrimination in medicine and medical encounters. Here I aim to illustrate how patients view their race and gender in relation to the process of diagnosis.

Shay, a 38 year old white person with lupus, experienced many years of symptoms before receiving a lupus diagnosis and treatment. Shay identifies as genderqueer, though Shay tells me that at doctors' offices they identify themselves by their birth gender of female. They fall solidly on the non-linear end of the diagnostic spectrum. Shay tells me about their other medical issues and starts off by acknowledging that their skin color and their income resulted in privilege in relationship to diagnosis in general. However, Shay speculates about race, wondering if their race might have led doctors to not look as deep into their symptoms.

Interestingly, like, not as much with some of the other stuff like the celiac and other issues, like if anything being white and moderately well off, I

got pretty quick access to medical care when I realized something was going wrong with my body in early 2012. But I--only because you're asking you in a way, that's making me think about it--I actually had wondered if, if I had had different colored skin, would my lupus diagnosis come sooner? Because it is predominantly--more common with women of color, for example.

Holly, a 26 year old Black woman with lupus, illustrates that Shay's thoughts on skin color are a common one in relation to lupus. Holly points out that lupus is a disease that commonly affects women of color. Despite this, Holly reflects on how race might have impacted her process of diagnosis. She tells me:

I do think [...] my, my being African-American, it's also a minority heavy disease as well. And so I think some of the things that I said might, as I'm getting older, might have been brushed off because of the medical biases that doctors have against African-Americans and that like, "well, you're probably making this up." Or if I explained that my foot is swollen, [...] that it's obviously not going to turn red because I'm brown. [...] But if you look at it on somebody who's fair-skinned, you would see that their foot is swollen and red and obviously see there's something wrong. But looking at my foot, you just see a fat foot. Whatever they learn in medical school to look at the skin, there's nothing that would identify that same issue with, on my skin.

Holly was a participant with a fairly linear diagnostic process, in comparison to Shay's non-linear process. Holly, while emphasizing that lupus commonly affects women of color, points out that other things may have been brushed off due to her race. Similarly, white patients with MS expressed the same sentiment, but reversed--that their whiteness helped them receive a quicker diagnosis of MS. Additionally, Holly highlights that medical education has not provided people of color with the same representation as white people. The example Holly gives with the swollen foot shows how symptoms can be dismissed if they are not represented to medical providers in training.

Both Shay and Holly mention gender in relation to their diagnosis as something that might have expedited the process of diagnosis. Pearl, a 39 year old Arab American woman with lupus, also discusses gender in relation to diagnosis. She talks about gender as a positive thing in terms of getting diagnosed because of the expectation that lupus primarily affects women. She also talks about the implications of diagnosis for women outside of the medical environment, such as in the workplace, telling me:

I didn't know this at the time, but I mean, I know that lupus impacts women nine out of 10 times and that it's generally seen or viewed as a woman's disease, even though obviously there are plenty of men that get it. [...] I mean, I was working full time up until my daughter's diagnosis and newly separated from her father. And I had to take, you know, leave. I took paid family leave, but then I got diagnosed and there was really no accommodation made for me [...] You know, people in our society just don't value us enough and assume that motherhood is just part of our traditional gender association.

While being a woman might increase the chances that doctors consider lupus as a diagnosis, Pearl points out that her diagnosis, which coincided with her daughter's diagnosis of leukemia, was not taken seriously by her workplace because of the expectation of women to be caregivers. Many other participants also discussed the role of parenthood, which may be a topic for further research.

While gender may be seen as an “egg in the diagnosis basket” for many participants, other participants emphasize that their symptoms and struggles were downplayed because of their gender, similar to Holly's experience. While her race may have expedited the diagnostic process, medical providers still hold biases against women of color, and medical education is sorely lacking in equal representation. This study looks

specifically at women and the illnesses I look at are typically perceived as “feminine” illnesses. They are not generally associated with men. For women, this may be a good thing as doctors may be more likely to consider their diagnosis. However, coupled with medical sexism, this benefit may not extend much beyond the initial diagnosis phase. Additionally, many participants had long times to diagnosis, illustrating that the positive effect of gender is hazier than expected. Similarly, race appears to benefit patients who fall into the predicted categories—which for lupus is women of color. Medical providers must often rely on heuristics in order to function in the current American medical system, but this can prove detrimental to patients that do not fit the heuristic model of disease for a specific diagnosis. Further, heuristics easily give into biased thinking patterns that may explain why so many of the women in this sample experienced sexism in the medical sphere, even if they had a linear diagnostic process.

THE LIMITS OF THE DIAGNOSTIC SPECTRUM

The spectrum model of diagnostic trajectories is not a perfect categorizing tool, just as diagnosis itself is not always a perfect categorizing tool. In contrast to the other participants, Ivy, a 25 year old white woman, was diagnosed with her illness in childhood. Her dad was the person advocating for her at her doctor’s appointments. She tells her story starting with when she was an infant experiencing symptoms.

By the time I was two, I got a referral to a GI here [...] And basically my parents were like, “well, there’s family history of Crohn’s”. You know, like my uncle had it really bad and, you know, maybe it’s the same thing. And they were like, “well, she’s too young. It usually affects older people”. This is in 1997. [...] Eventually my dad kind of blocked the door and was like, “look ,” **[laughter]** “you need to

do a colonoscopy on her”. So like six months later I got a colonoscopy and they found out that it was Crohn's. Yeah. That was the start of my journey.

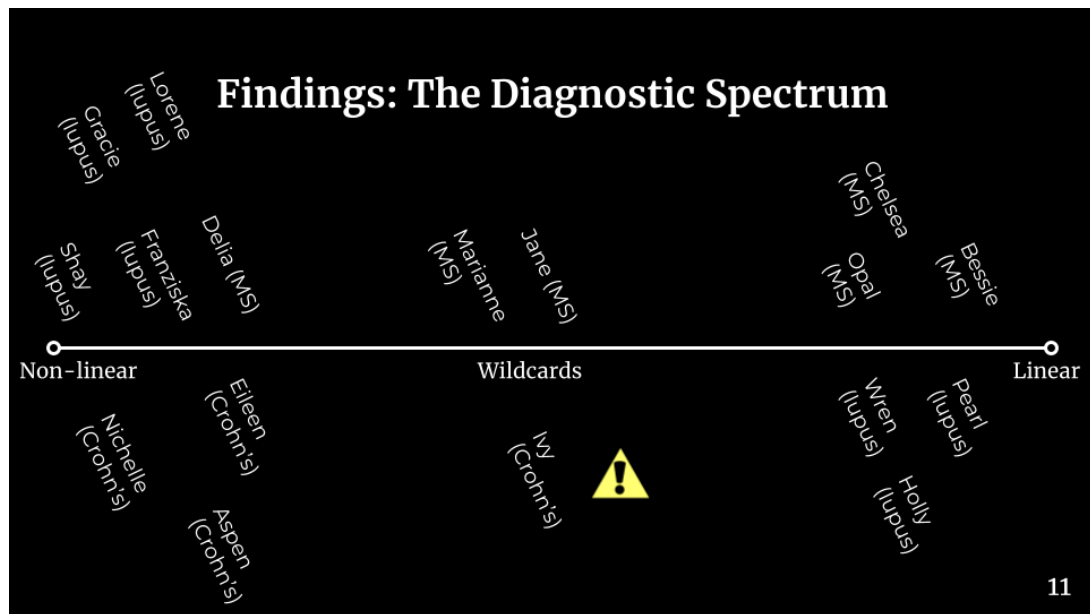
Ivy's story is different from other participants who were categorized along the spectrum of linear to non-linear diagnosis. While her symptoms were not met with immediate intervention, she was diagnosed much earlier than Aspen, who also had symptoms of Crohn's disease at a young age. It is difficult to assess why this is—perhaps this was based on the different doctors encountered by Aspen and Ivy, maybe it was related to the presentation of their symptoms, or possibly it could have had to do with the leveraging of power by Ivy's father (in which he blocks the door and demands testing). Here, I would argue that the third point is probably the most salient. However, it is hard to characterize Ivy's diagnostic process along the same scale as everyone else because she was not the one advocating for herself or navigating the medical system. The spectrum of diagnostic experiences developed here is best suited for adults who are in charge of making their own medical decisions. A different conceptualization may need to be developed for younger patients or people who are not in charge of making their own medical decisions.

Examining power in the medical encounter brings us to the next theme that emerged from the data. However, before fully transitioning to the discussion of power in medicine and in medical encounters, I want to briefly recognize the impact of the moment of diagnosis. Prior literature on diagnosis makes the assertion that the moment of diagnosis can be characterized by immense relief. While many participants voiced that a diagnosis was in a way relieving—an answer to years of unanswered questions and symptoms—participants also talked about the pain and turmoil caused by a life-long

diagnosis, regardless of whether their diagnostic process was a linear, non-linear, or wildcard experience.

The following figure places all participants along the proposed model of the diagnostic spectrum, to allow for clear visualization of the data. While no definitive conclusions can be drawn from this small, qualitative study, it is interesting to note that all participants with Crohn's disease fall squarely on the non-linear end of the spectrum. All white participants with lupus also fall on the non-linear end of the spectrum. Gracie, who is Asian, also falls on the non-linear end of the spectrum despite lupus being considered, as Holly puts it, a "minority heavy disease". Wren and Holly, who are Black, fall into the linear category. Pearl, who is Arab American, also falls into the linear category for lupus diagnoses. MS had the most variety in where participants fell on the spectrum with regards to linear, non-linear, or wildcard diagnostic processes.

Figure 2: Participants visualized across the diagnostic spectrum



POWER & DISEMPOWERMENT:

Diagnosis is related to power, so this section looks particularly at the operationalization of power enacted by medical providers for the participants in this sample. I outline how medical encounters in which power is asserted in negative ways become disempowering experiences for participants, focusing on two main ways that physicians harness power in negative ways: the utilization of weaponized incompetence and the deployment of uncertainty. When these tactics are used, patients become disempowered in seeking the necessary answers to their questions.

Weaponized incompetence occurs in both the private and public spheres. Typically, weaponized incompetence refers to someone's significant other (generally a man in a heterosexual relationship with a woman) who feigns incompetence in order to avoid responsibility. Additionally, weaponized incompetence means that someone *is* capable of performing the task asked of them, and chooses not to—it does not apply to someone who truly does not know the answers or how to perform a task asked of them. In this sample of experiences, we see how the deployment of weaponized incompetence can damage the doctor-patient relationship and disempower patients.

The second way power is operationalized is through the deployment of uncertainty. This is tied to power and weaponized incompetence because it is ultimately related to knowledge. The deployment of uncertainty may revolve around symptoms, test results, or diagnosis. This also serves to disempower patients in that the patient's reality is constantly put into question, rather than being validated.

THE GOD COMPLEX

Weaponized incompetence and the deployment of uncertainty is a tricky subject to tackle in medicine. On the one hand, it can be easy to rationalize why a medical provider would not be able to answer a patient's questions. Medicine and the practice of medicine has become increasingly divided into specialties and subspecialties. Who would expect an endocrinologist to be able to treat lung cancer? Likewise, who would expect an oncologist or pulmonologist to treat polycystic ovarian syndrome? Nevertheless, there is a, or should be, a basis of expected knowledge. A professional sociologist may not be an expert in quantitative methods, but they need to have enough knowledge to assess what types of questions might be answered by a quantitative research study. Likewise, a primary care provider may not know the answers for a patient who comes in with autoimmune symptoms, but they should know enough to direct that patient to the person who can answer those questions. As Holly stated earlier, medical education in the United States is something that must be examined critically. While some of these participants felt failed by their providers, it would be irresponsible to wholly assign blame to individuals when there are systemic mechanisms that also must be considered in tandem with individuals and their actions.

A 38 year-old white participant with MS, Marianne, shares some poignant thoughts about power in the medical system with me. Marianne tells me first about her experience being diagnosed with MS as a completely asymptomatic patient. Her diagnosis occurred because of the migraines she was experiencing while trying to conceive a child, resulting in an MRI. When prompted to speak to social characteristics

that might have played a role in her diagnosis, she elaborates on many things, including gender biases and white privilege. She tells me her thoughts on medicine, specifically the field of neurology:

Neurologists also, I think, sometimes, I think--because I have 2 teams of neurologists--I have a migraine team and then separately I have an MS team, and both of them, have like--they're like infertility doctors, in a way, in which they have a God complex, where they think they're like, "I have all the newest ideas. I am, like, the beholder of all the tricks and tips and the new medicines and everything, and I'm the beholder of knowledge because I'm the MD in the room, and I'm the one who can fix everything". And they--they like--each of them are swollen with power in a different way. And to different degrees.

Here, Marianne identifies a concept that I think is vital in understanding the power dynamic of weaponized incompetence and uncertainty in medical encounters. Marianne highlights that the medical gaze is perceived as the ultimate harbinger of truth by society, which colors medical providers' perceptions of themselves. It may seem counterintuitive to suggest that the "God complex" as Marianne names it relates to weaponized incompetence and the deployment of uncertainty, but this relates to how power is harnessed by medical professionals. The God complex seems to prop medical providers up to choose when to apply their knowledge or when to not (deployment of uncertainty) and how much of their knowledge they are willing to access for a patient (weaponized incompetence).

WEAPONIZED INCOMPETENCE

The next participant's experience demonstrates exactly how this harnessing of power functions when a medical provider utilizes weaponized incompetence. Delia, a 32 year-old white woman with MS, tells me about her experience seeing a non-specialist

neurologist prior to her appointment with her MS specialist. She tells me that she had an appointment scheduled with a specialist in MS at this point, but had decided to go to this appointment with a local neurologist. She tells me:

And so I made an appointment with another neurologist locally who wasn't an MS specialist and it wasn't a great interaction [...] You know, I presented my negative MRI [...] and he was like, "well, everything looks fine. So, you know, it looks like you're fine" And I was like, "well, that's not really all"--at that point again, I had Googled all the tests that like, you might order for an MS workup, but I hadn't gone to that appointment yet. And I was like, "well, that's not all that's needed. It's just MRI. [...]" And so like, I corrected him on that and he was like, "well, that's true", but didn't show any initiative or interest in ordering them.

Delia's experience highlights the way in which individual doctors can dismiss or diminish patient experiences. The doctor says that Delia's tests look fine, and admits, after prompting, that the test results really are not enough to come to a conclusive diagnosis.

Delia points out this weaponized incompetence when she talks about the doctor showing no initiative to order more tests despite acknowledging that more tests needed to be done.

Delia mentions that this is also tied to gender, in that "that first neurologist appointment [...] he kinda just brushed it off and it's like a young girl who's like going to come in and have ideas of what her diagnosis is", which illustrates the intertwined the relationship between power and gender.

Lorene, a 38 year old white woman with lupus, also points out the ways in which medical professionals deploy weaponized incompetence as well as the intersection between gender and the utilization of weaponized incompetence. She tells me about her experiences seeking medical treatment and also draws on other's experiences, which she has heard about through support groups. She tells me:

They [doctors] automatically think it's hysteria. It's ridiculous, really, because I have had [to go] to the ER at times for symptoms. No ER doctor wants to touch a lupus patient. It's too complex for them. It's like, they're all like House. It's either not lupus or they just don't want to handle it. And so many times I felt crazy until I would go to my rheumatologist and sure enough, there was something more severe in the background

Lorene's story touches on one of the cornerstones of power discussed in this section.

First, she highlights the crux of weaponized incompetence ("it's too complex for them").

While the ER may not be the place to get a diagnosis of an autoimmune disease, many participants ended up either having to go to the ER due to their first symptoms potentially being life-threatening or due to doctors deploying weaponized incompetence and diagnostic uncertainty so long that once mild symptoms became potentially life-threatening. As Lorene points out, much of this has to do with gendered assumptions about patients. Lorene's point also leads into the discussion on the deployment of uncertainty—if a doctor cannot accept or provide a diagnosis ("It's either not lupus..."), then what mechanisms do they use in defense to protect their God complex and maintain their power status?

DEPLOYMENT OF UNCERTAINTY

The deployment of uncertainty is one tactic that was utilized fairly often, as seen by the long time to diagnosis for many of the patients in this sample. Uncertainty, to some degree, is just a part of life. It would be unfair to expect doctors to have all the answers all of the time. However, as was illustrated with the God complex example, many doctors feel that they do have all the answers. Additionally, uncertainty becomes unacceptable in instances where it causes detrimental harm to an individual. The deployment of

uncertainty in medical encounters is insidious because it can be deployed as a method to make patient's doubt their experiences and discourage them from seeking out necessary help. Further, uncertainty in diagnostic terms generally means that the patient does not receive a "medically valid" diagnosis, which means that they do not get the necessary treatment until they are at a crisis point, as seen with several participants who took part in this study.

Chelsea, a 39 year old white and Native American woman, talks about her experience in the emergency room for urgent symptoms related to MS. She went to a military hospital late at night due to problems with balance. This was her only opportunity to go in to the hospital because her husband was at home for the night and could watch over their 4 young children. The military hospital she visited did not have a lot of equipment, so they sent her to the hospital in town about an hour out. A CT scan performed at that hospital indicated that she may be having a stroke, resulting in her receiving a helicopter lift to the nearest sufficiently equipped medical facility. When prompted to talk about some of her negative experiences, she tells me:

I mean, when I went into the army hospital, I remember them almost being angry at me that I would come in. I remember the doctor saying, "why would you come in at this time?" Like I wasn't inconvenienced to come in late at night on a Friday. And I just remember thinking like, oh, this is my only chance. You know, I haven't, I'm not going to bring my four children four and under, two infants, to sit with me in a hospital. My husband's gone for weeks at a time, comes home to shower and takes off again. And I just remember just being angry, especially after I go to the other hospital and they think I'm having a stroke and I'm thinking they treated me like this when it was something serious, you know, and they made me feel bad about wasting their time.

Chelsea's experience shows how even in potentially life-threatening situations, uncertainty can be deployed, though Chelsea's illness was not truly life-threatening. Focusing back in on Chelsea's story, one can see how frustrating the experience was for her. Chelsea was able to get to the hospital in town and then get airlifted to a bigger hospital to get diagnosed, but deploying uncertainty, as medical providers so often do, could have also made Chelsea not pursue treatment. Additionally, the deployment of uncertainty seems to compound from experience to experience, as seen with the stories of the next participants.

Nichelle, a 23 year old white woman with Crohn's disease, talks about how her diagnosis of Crohn's disease came about, noting that her doctors are currently reconsidering the diagnosis based on recent test results. For Nichelle, there was a lot of uncertainty in the diagnostic process from the beginning onward. She tells me,

I still don't know if this is even related, but I had like a really bad cough and, um, like burning in my mouth, like anything I would eat [...] so I went to the urgent care for that [...] The other symptoms, you know, really weren't that severe yet. [They] told me it was a virus [that] had to run its course. So for the next couple months, as, you know, losing more weight, it was progressing. I still thought, you know, I must have some sort of virus or I really thought I had mono or something. [...] at this point I'd lost even more weight, um, started out about 95 pounds and I was down 75 and still just didn't really have an explanation. [...] they admitted me [to the hospital] right away and I was there for probably around a month. Yeah, so the first thing they did was an MRI. [...] I needed to have an endoscopy and colonoscopy to get an official diagnosis

Nichelle's experience shows us how uncertainty and lack of urgency combine. Her first diagnoses are vague and the medical providers she saw did not express interest in further pursuing testing until she reached a crisis point.

Gracie, a 24 year old Asian woman with lupus, discusses the implications of uncertainty and the emotional turmoil caused by the deployment of uncertainty (“I felt like it [the medical system] was failing me”). She tells me about her long time to diagnosis despite her lab tests indicating lupus for many years prior to her diagnosis,

I think like when you are looking for lupus, there's like a few lab tests that they can run. And you know, like every single lab test there, a chance that it's a false positive. What really angered me about all of this is that I've tested positive for the same test for years. And every time they ran it they've been positive. So nobody at any point in time thought, “Hmm, maybe this isn't a fluke that you tested positive, like eight times for the same thing”. Yet that's exactly how they viewed it every single time. They were like, “oh, this could be a false positive. We'll just run it again in six months.” And I'm like, why is this the practice? I've had other experiences with the medical system, but this is really the first time where I felt like it was failing me because here I have objective test results, like facts, like about how sick I am and why. And they were just being overlooked over and over again, not even by one doctor by like three or four doctors

Gracie's experience shows us that in spite of objective test results, uncertainty can still be deployed. She also highlights how this experience is not limited to just one doctor—she saw many doctors and was dismissed repeatedly. This demonstrates that deployment of uncertainty is not simply a tactic used by a few select medical professionals. Gracie also mentions that her gender, age, and race all played a role in her providers' interactions with her, with interactions ranging from cloyingly patronizing to overtly racist.

Opal is a 41 year old white woman with MS. Opal's experience of uncertainty is a bit different from Nichelle or Gracie's experiences. Her diagnosis came very quickly (falling very much on the linear end of the spectrum of diagnosis), but later in her journey, she was faced with the deployment of uncertainty. This thought actually

occurred to her post-interview and was sent to me via email. Like Marianne, Lorene, Nichelle, and Gracie she discusses the impact of gender on the patient-provider relationship. She writes,

When I met with the middle aged white male (Italian-American) neurologist who had been recommended to me in Southern Oregon, he was hesitant to accept that the female neuro in [city] had really checked all the boxes necessary to give me the diagnosis. He also treated me very much as a young woman rather than a professional from a different field. He did accept my diagnosis after obtaining all my previous records and a new MRI that showed disease progression consistent with MS.

Opal touches on the gendered aspects of the provider-provider relationship as well as the patient-provider relationship. The male neurologist that Opal saw embodies the God complex extremely well—he refuses to believe in a diagnosis unless he himself “proves” it through repeating tests that had already confirmed Opal’s diagnosis. He deploys uncertainty by casting doubt on the female neurologist’s original diagnosis.

As stated before, the deployment of uncertainty can have different presentations, but always serves to in some way invalidate the patient’s (or in some cases, the other physician’s) knowledge. This is problematic, not only in an emotional sense, but also in a material sense. Pushing people to the crisis point or repeating expensive tests, or doubting their experiences causes wounds deeper than can be treated by medical professionals. Several participants expressed that their experiences with the medical system were incredibly traumatic. Doctors may face wounded pride if the God complex is dismantled, but that is preferable to the damage that the God complex does to patients.

THE CONSEQUENCES OF DISEMPOWERMENT

Eileen is a 38 year old white woman with Crohn's disease. She tells me about her journey of diagnosis over the past 15 years. She tells me about her perspective on why her illness took such a long time to be diagnosed by medical providers, noting both gender as a reason for the lengthy time to diagnosis and acknowledging that the current US medical system is not set up in a way that helps providers succeed—they are overworked and underpaid just like many other workers in the US. Eileen's experience of diagnosis was a long journey, in which doctors utilized both weaponized incompetence and the deployment of uncertainty (such as asking Eileen if *she* thought had Crohn's disease, rather than attempting to diagnosis her). She tells me:

When I look back at the way my life has changed since diagnosis, and the ways that I could have improved my quality of life. I could have been traveling, I could have been more present for my kids. I could have been a better caregiver for my husband during his recovery, if I had had a diagnosis and been in treatment, but I wasn't. And I didn't, and it was, like that's a really hard thing for me to look back on and I don't wanna ever regret the way that I've lived my life, especially as a parent or in a relationship, but like...Damn, man, the *time* that I lost.

Eileen emphasizes the impact that a quick and accurate diagnosis could have had on her life, and how women can slip through the cracks of a simultaneously discriminatory and overburdened medical system. Weaponized incompetence and the deployment of uncertainty mean that people do not get the treatment they need, leading to lost time, along with the emotional injury of regret, as Eileen mentions. Because of the power dynamic in medicine, providers have the power to alter significant portions of patients' lives with their choices. Unfortunately, many providers choose to utilize weaponized

incompetence and the deployment of uncertainty—both of which have deep and irreversible consequences on a person’s life and health.

Despite the focus on disempowerment in this section, I want to acknowledge that almost every participant, when prompted, also shared with me their good experiences with doctors and medical providers—experiences which I would call empowering. The common thread of positive experiences involved participants finding doctors who they felt had high degrees of empathy, who listened to their symptoms, and pursued treatments in a way that made the participant feel that their doctor was trustworthy and reliable. A deeper look into power, specifically empowerment, in medical encounters, is likely necessary to fully understand how power is operationalized within medical settings and within the patient-provider relationship.

DISCUSSION

Diagnosis is a fundamental part of the experience of living with chronic illness. In essence, diagnosis is the process by which diseases are categorized; a disease that is diagnosed is legitimized (Brown 1995). Jutel (2009) writes “being diagnosed gives permission to be ill”. Brown (1995) notes that the process of diagnosis is the set of interactions that lead to the definition of the category. Brown (1995) also articulates how diagnosis can be a useful ontological tool for both the patient and the physician and this sentiment is echoed by Jutel (2009), who defines diagnosis as interpretive and organizational, giving structure to previously unorganized events. Jutel (2009) also claims a duality of diagnosis; while diagnosis is an organizational tool, it can also be a site of contestation.

Brown (1995) and Jutel (2009) clarify the importance of diagnostic categories for both patients and providers. Looking at the process of diagnosis further explores Jutel’s (2009) concept of a duality of diagnosis. Participants experienced a wide range of experiences during the diagnostic process, from fairly immediate medical validation to years of medical doubt and uncertainty. This research supports Brown’s (1995) framework of diagnosis as a series of interactions between patients and their providers.

The main contribution of this piece to the sociological literature is the exploration of diagnosis as a process. This expands on previous literature on chronic illness, which explores biographical disruption (Bury 1982) and loss of sense of self (Charmaz 1983) post-diagnosis, pivoting to a different moment in the lives of people diagnosed with chronic illnesses. It builds on the sociology of diagnosis (Brown 1995; Jutel 2009) by

creating a model in which we might begin to understand the varied processes that individuals go through when navigating the medical system. It also explores clinician uncertainty and empathy (Littlejohn and Kimport 2017; Vinson and Underman 2020) and how the successful exchange of cultural health capital is crucial for patient-provider interactions (Shim 2010; Dubbin et al. 2013; Chang et al. 2016).

An interactional framework is reminiscent of Heritage and Maynard (2006)'s outline of the medical interview as a psychosocial phenomenon. Relating to the God complex, weaponized incompetence, and deployment of uncertainty (Littlejohn and Kimport 2017) is Heritage and Maynard's (2006) concept of paternalism, which disrupts the successful exchange of cultural health capital between patients and providers. As Chang et al. (2016) remind us, negotiating patient-provider interactions is vital in stymieing stigma. Underlying the exchange cultural health capital is the need for clinician empathy, which Vinson and Underman (2020) consider necessary to form positive relationships between patients and providers.

While racial and gendered healthcare inequalities have been studied extensively (Lorber 1997; Courtenay 2000; Samulowitz et al. 2018; Ross et al. 2012; Roberts 2015; Gravlee 2009), this work proves yet again that identities such as race and gender are intimately tied to diagnostic processes. While gender may have benefited participants at certain points, gendered inequalities peppered the stories told by participants. Race was discussed both as a helpful heuristic tool and a harmful heuristic tool. This indicates that race and gender categorizations may sometimes be neutral characteristics, or even helpful characteristics, in medical settings. However, instances of medical sexism and racism are inherently detrimental, not just to the successful exchanging of cultural health capital, but

to the health and wellbeing of anyone with a chronic illness, and further, are harmful to all individuals within society.

I consider the key finding of this work to be the diagnostic spectrum. Further research should focus on categorizing diagnostic processes using these typologies. Looking into other social characteristics, such as income, English proficiency (in the context of the US), and other visible or invisible identities, would be an area for further analysis. It may also be interesting to see how men and gender nonbinary or gender minority people would be categorized using this spectrum. As stated before, autoimmune diseases do have a “feminine” reputation—what does that mean for anyone that does not tick the “female” category? Despite lupus and MS having clear racial distinctions in their diagnosis, the data illustrates that race may not be a sole determinant of whether someone has a linear or non-linear diagnostic process. Wildcard diagnoses and their incidence and psychological impact also strikes me as something to be explored. In short, developing a framework for different typologies of diagnostic processes was the principal contribution of this piece and should be analyzed, considered, and evaluated for its utility in the sociology of diagnosis.

CONCLUSION

This piece found that women diagnosed with autoimmune diseases have varied experiences in their journey to receiving a diagnosis. Some experienced quick, linear diagnostic processes while others experienced drawn-out non-linear diagnostic processes. Still others were diagnosed by pure chance without any outward physical indication of disease. Participants understood their race and gender to play a role in their diagnosis—whether it be a delaying role or an expediting role. In the medical encounters during, leading up to, or post-diagnosis, participants encountered physicians who used weaponized incompetence to deny medical care or the deployment of uncertainty to avoid providing a diagnostic label (despite diagnostic labels bringing significant emotional and physical relief to participants).

Future research can explore different identities in relation to the diagnostic spectrum, such as socioeconomic status or language proficiency. As the COVID-19 pandemic continues, future research may also examine the idea of long-haul COVID as a chronic illness (and test the veracity and reliability of the diagnostic spectrum model in classifying these patients). This paper focused on people who identified as women, which means that further research could focus on gender nonbinary or gender minorities, especially in the context of autoimmune diseases with their “feminine” framing.

Like all studies, this study has several limitations. The sample is a convenience sample, rather than a representative sample. While conducting the interviews on Zoom allowed us to transcend geographic boundaries, the sample was still controlled by my connections and my choice to recruit using social media. The sample is majority white,

and heteronormative. Recruiting from Reddit means that the participants may have been more likely to share negative experiences rather than positive experiences, as the subreddits often function as a sort of support group. This study also only focuses on the patient side of the patient-provider relationship, so providers are presented through the words of the patients.

Many of the problems presented in this paper are larger issues in US society, such as gender and race-based discrimination. Participants point out that medical education may be an area to improve by changing the curriculum to include images of people of color within medical textbooks. The healthcare system, as it stands, is not designed to support complex illness management and while empathy is incredibly important to patients, teaching empathy is a difficult concept. Doctors, nurses, and other medical providers are often overworked and underpaid, leaving little time to develop nuanced relationships and understandings of patients. Neoliberal policies valuing speed, rather than quality, of care and the middle management of providers through insurance companies puts providers in difficult situations. Creating fair workplace conditions for clinicians is vital to moving toward mutual understandings between patients and their providers. Inequality based on race, class, and gender (as well as other characteristics not explored here) propagate through stereotypes and lack of education. In conclusion, while the medical education system and medical system itself continue to perpetuate inequality, shared understanding between patients and providers will be hard to achieve. While capitalism continues to value profit over people, everyone within the system, whether patient or provider, suffers.

REFERENCES

- Braun, Virginia, and Victoria Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3(2):77–101. doi: 10.1191/1478088706qp063oa.
- Brown, P. 1995. "Naming and Framing: The Social Construction of Diagnosis and Illness." *Journal of Health and Social Behavior* Spec No:34–52.
- Brown, Phil. 1990. *The Name Game: Toward a Sociology of Diagnosis*. New York City: Institute of Mind and Behavior.
- Bury, Michael. 1982. "Chronic Illness as Biographical Disruption." *Sociology of Health and Illness* 4(2):167–82. doi: 10.1111/1467-9566.ep11339939.
- Bury, Michael. 1991. "The Sociology of Chronic Illness: A Review of Research and Prospects." *Sociology of Health and Illness* 13(4):451–68. doi: [10.1111/j.1467-9566.1991.tb00522.x](https://doi.org/10.1111/j.1467-9566.1991.tb00522.x).
- Charmaz, Kathy. 1983. "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill." *Sociology of Health and Illness* 5(2):168–95. doi: 10.1111/1467-9566.ep10491512.
- Chang, Jamie, Leslie Dubbin, and Janet Shim. 2016. "Negotiating Substance Use Stigma: The Role of Cultural Health Capital in Provider-Patient Interactions." *Sociology of Health & Illness* 38(1):90–108. doi: [10.1111/1467-9566.12351](https://doi.org/10.1111/1467-9566.12351).
- Courtenay, Will H. 2000. "Constructions of Masculinity and Their Influence on Men's Well-Being: A Theory of Gender and Health." *Social Science & Medicine* 50(10):1385–1401. doi: 10.1016/S0277-9536(99)00390-1.
- Deterding, Nicole M., and Mary C. Waters. 2021. "Flexible Coding of In-Depth Interviews: A Twenty-First-Century Approach." *Sociological Methods & Research* 50(2):708–39. doi: [10.1177/0049124118799377](https://doi.org/10.1177/0049124118799377).
- Dubbin, Leslie A., Jamie Suki Chang, and Janet K. Shim. 2013. "Cultural Health Capital and the Interactional Dynamics of Patient-Centered Care." *Social*

Science & Medicine 93:113–20. doi: 10.1016/j.socscimed.2013.06.014.

Fairweather, DeLisa, Sylvia Frisancho-Kiss, and Noel R. Rose. 2008. “Sex Differences in Autoimmune Disease from a Pathological Perspective.” *The American Journal of Pathology* 173(3):600–609. doi: 10.2353/ajpath.2008.071008.

Fairweather, DeLisa, and Noel R. Rose. 2004. “Women and Autoimmune Diseases1.” *Emerging Infectious Diseases* 10(11):2005–11. doi: 10.3201/eid1011.040367.

Fiorino, Gionata, and Silvio Danese. 2016. “Diagnostic Delay in Crohn’s Disease: Time for Red Flags.” *Digestive Diseases and Sciences* 61(11):3097–98. doi: [10.1007/s10620-016-4298-8](https://doi.org/10.1007/s10620-016-4298-8).

Foucault, Michel, 1926-1984. *The Birth of the Clinic: An Archaeology of Medical Perception*. London :Tavistock, 1973.

Gravlee, Clarence C. 2009. “How Race Becomes Biology: Embodiment of Social Inequality.” *American Journal of Physical Anthropology* 139(1):47–57. doi: 10.1002/ajpa.20983.

Harvard Health. Retrieved (<https://www.health.harvard.edu/diseases-and-conditions/whats-the-deal-with-a-utoimmune-disease>). Accessed 2. May 2021.

Heritage, John, and Douglas W. Maynard, eds. 2006. *Communication in Medical Care: Interaction between Primary Care Physicians and Patients*. Cambridge: Cambridge University Press.

Jutel, Annemarie. 2009. “Sociology of Diagnosis: A Preliminary Review.” *Sociology of Health & Illness* 31(2):278–99. doi: 10.1111/j.1467-9566.2008.01152.x.

Kandell, Zachary. 2020. *House MD: Why It's Never Lupus (And the One Time It Was)*.

Kanaan, R. A. A. 2016. “Freud’s Hysteria and Its Legacy.” Pp. 37–44 in *Handbook*

of Clinical Neurology. Vol. 139. Elsevier.

Littlejohn, Krystale E., and Katrina Kimport. 2017. "Contesting and Differentially Constructing Uncertainty: Negotiations of Contraceptive Use in the Clinical Encounter." *Journal of Health and Social Behavior* 58(4):442–54. doi: [10.1177/0022146517736822](https://doi.org/10.1177/0022146517736822).

Lorber, Judith. 1997. *Gender and the Social Construction of Illness*. Thousand Oaks, CA: Sage Publications.

Lupus Foundation of America. Retrieved (<https://www.lupus.org/resources/lupus-facts-and-statistics#:~:text=On%20average%2C%20it%20takes%20nearly,first%20notice%20their%20lupus%20symptoms/>)

Retrieved 13. June 2021.

Miles, Anne. 2018. "The Psychological Implications of Diagnostic Delay in Colorectal Cancer Patients." Pp. 103–19 in *Timely Diagnosis of Colorectal Cancer*, edited by L. Olsson. Cham: Springer International Publishing.

O'Brien, Rourke, Tiffany Neman, Nathan Seltzer, Linnea Evans, and Atheendar Venkataramani. 2020. "Structural Racism, Economic Opportunity and Racial Health Disparities: Evidence from U.S. Counties." *SSM - Population Health* 11:100564. doi: [10.1016/j.ssmph.2020.100564](https://doi.org/10.1016/j.ssmph.2020.100564).

Paul, Charlotte, and Barbara Brookes. 2015. "The Rationalization of Unethical Research: Revisionist Accounts of the Tuskegee Syphilis Study and the New Zealand 'Unfortunate Experiment.'" *American Journal of Public Health* 105(10):e12–19. doi: [10.2105/AJPH.2015.302720](https://doi.org/10.2105/AJPH.2015.302720).

Ross, Paula T., Monica L. Lypson, and Arno K. Kumagai. 2012. "Using Illness Narratives to Explore African American Perspectives of Racial Discrimination in Health Care." *Journal of Black Studies* 43(5):520–44.

Roberts, Dorothy. 2015. "The problem with race-based medicine" https://www.ted.com/talks/dorothy_roberts_the_problem_with_race_based_medicine?language=en. Accessed 12. May 2021.

- Samulowitz, Anke, Ida Gremyr, Erik Eriksson, and Gunnel Hensing. 2018. “‘Brave Men’ and ‘Emotional Women’: A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain.” *Pain Research and Management* 2018:1–14. doi: 10.1155/2018/6358624.
- Shim, Janet K. 2010. “Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment.” *Journal of Health and Social Behavior* 51(1):1–15. doi: 10.1177/0022146509361185.
- Shur, Peter H. and Bevra H. Hahn. 2021. Retrieved (<https://www.uptodate.com/contents/epidemiology-and-pathogenesis-of-systemic-lupus-erythematosus/print/>) Accessed 13. June 2021.
- Smith, D. A., and D. R. Germolec. 1999. “Introduction to Immunology and Autoimmunity.” *Environmental Health Perspectives* 107(suppl 5):661–65. doi: [10.1289/ehp.99107s5661](https://doi.org/10.1289/ehp.99107s5661).
- Tasca, Cecilia, Mariangela Rapetti, Mauro Giovanni Carta, and Bianca Fadda. 2012. “Women And Hysteria In The History Of Mental Health.” *Clinical Practice & Epidemiology in Mental Health* 8(1):110–19. doi: 10.2174/1745017901208010110.
- UVA Health. Retrieved (<https://blog.uvahealth.com/2014/10/31/detective-work-autoimmune-disease/>). Accessed 2. May 2021.
- Varul, Matthias Zick. 2010. “Talcott Parsons, the Sick Role and Chronic Illness.” *Body & Society* 16(2):72–94. doi: 10.1177/1357034X10364766.
- Vinson, Alexandra H., and Kelly Underman. 2020. “Clinical Empathy as Emotional Labor in Medical Work.” *Social Science & Medicine* 251:112904. doi: [10.1016/j.socscimed.2020.112904](https://doi.org/10.1016/j.socscimed.2020.112904).
- Washington, Harriet A. 2006. *Medical Apartheid: The Dark History of Medical*

Experimentation on Black Americans from Colonial Times to the Present. 1st
pbk. ed. New York: Harlem Moon.