You don't look sick: Epistemic injustice, ethos, and embodied expertise in narratives of chronic illness.

Caitlin Burns Allen  
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YOU DON’T LOOK SICK:
EPISTEMIC INJUSTICE, ETHOS, AND EMBODIED EXPERTISE IN NARRATIVES OF
CHRONIC ILLNESS

By

Caitlin Burns Allen
B.A., University of Alabama, 2017
M.A., University of Alabama, 2019

A Dissertation
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for the Degree of

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in English/Rhetoric and Composition

Department of English
University of Louisville
Louisville, Kentucky

May 2024
DEDICATION

This dissertation is dedicated to

Dr. Raymond Dewie Germany, Sr. (PhD)

1936–2021
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ABSTRACT

YOU DON’T LOOK SICK:
EPISTEMIC INJUSTICE, ETHOS, AND EMBODIED EXPERTISE IN
NARRATIVES OF CHRONIC ILLNESS

Caitlin Burns Allen

April 12, 2024

This dissertation project emerges at a cultural moment when diagnoses of chronic illness are increasing, and heightened attention is being paid to gendered medical bias and chronically ill women’s negative experiences both within and outside of the medical system. Analysis of personal narratives written by women and nonbinary people with chronic illnesses revealed deeply entrenched cultural logics related to health and gender and the significant affective and material consequences for the mobilization of those logics.

Chapter One of the dissertation describes the exigence of the project in more detail, provides a robust overview of the dissertation’s methods, and reviews related literature in the rhetoric of health and medicine. In Chapter Two, I argue that everyday conversational moves, such as providing unsolicited medical advice, both reveal and reinforce epistemically harmful cultural logics, which can be interrupted by practices of rhetorical listening. Chapter Three uncovers how the cultural logics identified in Chapter Two rhetorically construct a "normal patient”—a trope that creates a rhythmically
disabling environment for patients who do not align with it. Chapter Four argues that, because of the “normal patient” ideal, embodied experiences and other nondominant knowledge-making practices are not considered legitimate in medical settings; this imbalance can be harmful for marginalized patients, so I call for a negotiated understanding of expertise in clinical settings that embraces the variance inherent in chronic illness. To conclude, Chapter Five discusses the rise and perception of long COVID and provides an overview of future research directions.

Content Note: This dissertation discusses potentially sensitive topics including medical trauma and experiences of racism and sexism. There are mentions of medical procedures, pain, infertility, sex, and illness symptoms. Please take care while reading.
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CHAPTER I
INTRODUCTION: RHETORICS OF CHRONIC ILLNESS

This dissertation emerges at a cultural moment when diagnoses of chronic illness are rising and heightened attention is being paid to chronically ill women’s negative experiences both within and outside of the medical system. Roughly half of all adults in the United States have been diagnosed with a chronic illness, including about 23.5 million people who have an autoimmune disorder (Boersma et al. 2020, Orbai). Autoimmune disorders disproportionately affect women, who make up eighty percent of the total number of people affected by this type of illness (Orbai). In the following narrative, I share my own story of being diagnosed with an autoimmune disorder to establish my positionality relative to this topic and to begin to demonstrate the barriers and hurdles that exist on the way to a chronic illness diagnosis. My personal experiences function as a telling example of the ways that embodied knowledge are often dismissed in medical settings, and the obstacles that can arise during the diagnosis process.

I was in my last year of college when one of my hands started to hurt. I thought maybe I had slept on my hand strangely or that I had imagined it, but the pain became persistent. At my next appointment with my endocrinologist, who I already saw for an
autoimmune disorder that affects my thyroid, I mentioned the pain. My doctor
decided to test me for lupus, but after a couple of days, he ruled out a lupus diagnosis. I
brought this new pain up at an appointment with my general practitioner a few months
later, who referred me to a rheumatologist.

In the small exam room at the rheumatologist’s office, the doctor did not
acknowledge me when he entered the room and, for the most part, only talked to the
physician assistant while focusing his attention on the laptop screen in front of him. He
did not ask me questions, though he sometimes directed them at my mom, who came
with me for moral support. He began the physical examination by grabbing my arm and
moving it, all without asking me or telling me what he was going to do. He diagnosed me
with juvenile arthritis, citing my age as a reason—he mentioned that I was sixteen. I
realized he had barely looked at my chart, so I interrupted him to remind him that I was
twenty-one and about to graduate college. The diagnosis was amended to something
“rheumatoid,” then the doctor wrote a prescription and left the room. As the phlebotomist
drew my blood to run more tests, I had a panic attack, overwhelmed by the lack of
engagement, empathy, or awareness of my embodied boundaries during the appointment.
After another uncomfortable follow-up appointment with this first rheumatologist, I
decided to ask for a referral to another doctor.

I was referred to a new rheumatologist, who sat down and made it clear that she
had time for me. She asked me questions about my symptoms—where was I experiencing
discomfort? What was different from the way that my body normally felt? She took my
answers seriously. During the physical examination, she asked if she could touch and
move my limbs before she did so and narrated her actions as she checked each joint.
When my bloodwork came back without any demonstrably abnormal results, she ordered X-rays, which revealed subtle inflammation in the joints in my hands. If the new doctor had not asked what I was feeling and listened to me, I would not have been diagnosed correctly with seronegative rheumatoid arthritis (RA) or started taking the specialty biologic medication that alleviates my pain and protects my joints against further damage. In the meantime, while I’d been in pain for two years, I’d tried a lot of things at the advice of many people in my life and from many online resources. I massaged my hands a lot and tried heat or ice to try to reduce pain and swelling. I tried a fully “anti-inflammatory” diet. I drank more turmeric lattes. But ultimately, the only thing that made a noticeable difference is medication, which I now inject every ten days.

Overall, my diagnosis story is a positive one. I am a white, cisgender woman who grew up in a relatively wealthy home where I had access to healthcare. I lived close to a metropolitan area with an excellent hospital system and have had, with one exception, overwhelmingly positive experiences with medical professionals and in medical settings. After the negative experience with the first rheumatologist, I was able to see another doctor covered by my insurance. It only took two years for me to be diagnosed with RA—some chronic illnesses diagnoses take much longer and require visits to far more than two doctors (American Autoimmune Related Disease Association, 2017). I have access to the medication I need, and insurance that covers it.

Even with all of these privileges, the diagnosis process for RA was long and stressful for me. I often doubted that anything was actually wrong with me. When doctors drew blood for testing, nothing ever flagged as out of the ordinary, so my experiences felt like they often were all in my head. However, I knew deep down that something was
wrong with my body; I had developed deep embodied knowledge based on my sensory experiences, my past history, and my pain. Stories like mine are quite common among people with chronic illnesses, especially for women. In this project, I set out to explore the role that rhetoric plays in our understandings of and discussions about chronic illness, as well as health and gender more broadly.

Drawing on scholarship from the rhetoric of health and medicine, disability studies, and feminist rhetorics, my dissertation project investigates how women and other marginalized individuals with chronic illness understand and share embodied knowledge to work within and against dominant medical and cultural discourses. I draw on a methodological framework of feminist epistemology which foregrounds situated knowledge and prioritizes the amplification of marginalized voices. In alignment with this framework, I analyze a set of memoirs and personal essays written by women and nonbinary people about their chronic illnesses, such as endometriosis or Crohn’s disease. Through this project, I have developed a rhetorical account of gender-based bias in medicine that places its origins in ubiquitous and often unquestioned cultural norms and discursive practices. I argue that everyday conversational moves, such as providing unsolicited medical advice or downplaying an individual’s experience, can both reveal and reinforce epistemically harmful cultural logics. Personal narratives show how these repeated moments carry immense rhetorical weight, affecting how we frame chronic illness and disability.¹ I show that normative expectations in medical settings create a

¹ I want to be cautious in conflating chronic illness and disability. G. Thomas Couser (2018a) highlights several issues with the uncritical consolidation of these two categories. One such point of friction is that this move can align, intentionally or not, with a medical model that “tends to pathologize disability” and “project a desire for cure where it does not exist” (p. 5). At the same time, though, some people with chronic illness rely on medical interventions to manage their conditions or seek improvement for their chronic pain or other harmful symptoms. This tension is important to note, and I work to avoid superficially merging disability and illness. However, chronically ill individuals and disabled individuals often share
rhetorically disabling environment for women and other marginalized individuals, who face diminished ethos and discounted expertise. To counter this harm, I call for a negotiated version of expertise in clinical settings that acknowledges the significance of patients’ embodied knowledges. The project pushes rhetoric and composition to recontextualize key terms such as rhetorical listening and ethos and broadens our understanding of the intersections of health, gender, and rhetoric.

Given the concerns I have laid out so far, this dissertation project is guided by the following questions:

- How do women with chronic illness understand and share embodied knowledge to work within and against dominant medical discourses? What are the consequences when embodied knowledge and biomedical knowledge do not align, especially for women with chronic illness?
- How do every-day discursive practices represent and reinforce shared cultural logics? What happens when an audience refuses to recognize a speaker as a knower or a rhetor on an interpersonal level because of cultural norms and logics? How can we account for this refusal in rhetoric and composition?
- What can a focus on chronic illness reveal about norms in medicine? How can we account for the role of bias, stigma, and stereotype in medical settings? What are the limits, challenges, and opportunities of individual ethos-building strategies?
- How is expertise negotiated in clinical settings? How is the expert role defined in medicine? How do embodied knowledge overlap and interact with other medical knowledges or sites of authority?

In order to address these questions, this chapter first reviews relevant literature in the rhetoric of health and medicine (RHM), specifically related to chronic illness. Then, I describe my methodological approach and methods for selecting and analyzing data. Finally, I provide overviews of each of the following chapters.

concerns that emerge from ableism or other structures that impact their lived experiences, so I at times highlight these overlaps or do not separate my analysis along these lines.
Rhetorics of Health and Medicine

Broadly, this dissertation investigates questions related to knowledge production and rhetorical activity related to medicine. As a result, I locate the project within the rhetoric of health and medicine (RHM), a growing interdisciplinary area of inquiry that the co-editors of *Rhetoric of Health and Medicine As/Is* describe as “concerned not only with the discursive aspects of health and medicine as a set of discrete practices, but also with how health-care and medical issues circulate in all the social, cultural, economic, and political aspects of our world” (Melonçon et al., 2018, p. 1). The label *rhetoric of health and medicine* was put forth by J. Blake Scott, Judy Z. Segal, and Lisa Keränen (2013) as a term to “to signal a broad array of health publics, their nomoi, and their discursive practices” (pp. 1-2). This dissertation belongs in RHM not only because of its subject matter, but also due to its attention to persuasion in conversations about health and medicine and its dedication to effecting change in cultural values related to health and medicine.

RHM importantly highlights the role of persuasion in medicine. Medicine relies on persuasive action from providers and patients—like many other technical and scientific contexts, understanding the impact that communication and persuasion have on those interactions is key to understanding them. In their introduction to their 2018 collection on methodologies in RHM, J. Blake Scott and Lisa Melonçon note that RHM is characterized by several "interrelated qualities," including an attention to "persuasive agents and functions of health and medical discourse" (p. 5). RHM scholarship asks “who [or what] is persuading whom of what?” (Derkatch & Segal, 2005, p. 139, qtd. in Melonçon & Scott, 2018, p. 5). This dissertation project aligns with this pattern in RHM,
as I investigate how women with chronic illness work to persuade others to listen to them, as well as the outcomes when contextual and cultural factors prevent them from being taken seriously as rhetors and knowers. As Judy Segal (2005) points out, rhetoric and rhetorical theory are useful frames for understanding how medicine works and how we understand it. Segal claims that “rhetorical study—essentially, the study of persuasion—is a good means of illuminating and recasting problems in health and medicine” and that “persuasion is a central element in many medical situations” (p. 1). Segal writes that medicine is “rhetorical as a system of norms and values operating discursively” (p. 3). My research seeks to uncover some of these norms and values that we often take for granted.

Another exigence for working in RHM is its ameliorative aims. RHM is dedicated to creating change in not only how we talk about health and medicine, but also, ultimately, how healthcare functions and how we treat each other, especially when we’re sick, chronically ill, or disabled. As Lisa Melonçon and Erin Frost (2015) write, RHM provides researchers opportunities to "make significant change” (p. 9). Scholarship in RHM can “expand the sometimes myopic vision that generally plagues the current medical system where patients, families, care givers, and others’ views are often discounted in favor of a positivist hierarchical view that doctors and science are the only viewpoints that matter” and “directly intervene into many of the problems plaguing our health care system” (p. 9). Scott and Melonçon call for the recognition of RHM as an area of study that can “inform…medical education, health communication, health policy-making, medical research, and the practice of medicine” (p. 19). RHM scholarship often
has clear goals of improving people’s experiences with health and medicine widely, a value shared by this dissertation project.

The most significant change this dissertation calls for is for greater attention to and reduced instances of gender-based bias in medicine. This project explores how shared cultural values about gender and illness affect the experiences of women with chronic illness both in and out of medical settings. Women face worsened outcomes and gender-based bias in medicine, and these problems are often compounded in the case of chronic and autoimmune disorders, which can be “invisible” or difficult to diagnose. Gender-based bias and discrimination in medicine is, at least partially, a rhetorical problem that is upheld through cultural and discursive norms. Erin A. Frost and Michelle F. Eble (2020) write about how “female bodies in particular are disproportionately pathologized” (p. 4). As a result, women—and other patients with chronic illness—are often dismissed or disbelieved in medical settings when they report symptoms or other forms of embodied knowledge. This project seeks to uncover the rhetorical mechanisms and shared cultural beliefs that enable and perpetuate that dismissal.

This dissertation works to add to the small but growing conversation in rhetoric and composition and the rhetoric of health and medicine about chronic illness. For example, Molly Margaret Kessler (2022) explores the rhetoricity of chronic autoimmune conditions, such as Crohn’s disease. She writes that:

as people develop, are diagnosed, and live with chronic conditions, the meanings of themselves, their bodies, and their conditions are often transformed in profound ways through a diverse set of influences at work within individuals’ lived experiences including cultural expectations, norms, material forces, and structures, … public and private stories, language used by healthcare providers, and many others (p. 7).
Many scholars in RHM have reflected on how this transformation affects people’s perceptions of their own illness and how broader cultural views of chronic illness affect them as well. Sarah Ann Singer and Jordynn Jack (2020) call our attention to issues of (mis)representation for people with chronic conditions navigating “limited and limiting rhetorics of chronic illness” (p. 125). They put forth the concept of chronicity—which I explore more deeply in Chapter Four of this project—as a “rhetorical process of identification” that “positions users as active, empowered agents” (p. 127). Similarly highlighting medicine’s tendency to view patients as non-agents, Lora Arduser (2017) argues that “an interdisciplinary effort with a foundation in rhetorical theory can drive changes in the discourses and practices of health and medicine” that can become “more empowering for people living with chronic disease” (p. 165). Arduser also points to the increasing prevalence of chronic conditions, highlighting that “as people live longer and live chronic,” we need to focus on “deep language changes in medicine” at the systemic level (p. 166). Arduser and Bennett (2022) cite a similar exigence for their special issue of the RHM journal on chronicity, writing that “chronic illness is often positioned by government officials and medical practitioners as one of the major health crises of the 21st century” (p. 123). This dissertation responds to this exigence. As the incidence and impacts of chronic illness continue to increase, I aim to increase our understanding of its rhetoricity and the role of persuasion in conversations centering chronic illness, as represented in first-person narrative writing.

**Methodology**

This dissertation employs a theoretical and methodological framework based in feminist epistemology, as defined in the fields of philosophy and rhetoric and
composition. Patricia Hill Collins (2008) writes that epistemology “investigates the standards used to assess knowledge or why we believe what we believe to be true” and that it “points to the ways in which power relations shape who is believed and why” (p. 247). As a theory, feminist epistemology is concerned with “the ways in which gender does and ought to influence our conceptions of knowledge, knowers, and practices of inquiry and justification” (Anderson, 2020). I draw on key tenets of feminist epistemologies, including the belief that “all knowledge is situated in the knower” and the idea that knowledge is iterative and generative, rather than “fixed, static, or stable” (Griffiths, qtd. in Hughes, 2002, p. 155) in order to interrogate epistemological norms about health and medicine, which are often gendered.

It is important to first recognize that early theories of feminist epistemology have been critiqued for proposing an essentializing view of gendered “ways of knowing” and that feminist philosophers have pushed back against this essentialism. Alcoff and Potter (1993) argue that there is no one feminist epistemology and that there is not a universal understanding of knowledge. Elizabeth Anderson (1995) writes that there is “little persuasive evidence” for claims that “women have gender-typical ‘ways of knowing’” (pp. 61–62). Instead, Anderson argues, feminist epistemology “investigates the influence of socially constructed conceptions and norms of gender and gender-specific interests and experiences on the production of knowledge” (p. 54, emphasis original). Lennon and Whitford (1994) concur, writing that feminist epistemology centers “epistemological concerns arising out of feminist projects, which prompt reflection on the nature of knowledge and our methods for attaining it” (p. 13). Rooted in these important critiques and definitions of feminist epistemologies, I similarly position this project as an
investigation of embodied knowledge-making practices and the ways in which those practices are both taken up and dismissed in medical and cultural contexts. In particular, a feminist epistemological framework allows us to unpack the ways in which our beliefs about knowledge are highly influenced by normative ideas of gender.

In this dissertation, I identify patterns in personal narratives of chronic illness to expand our conception of knowledge-making to include situated and lived experiences. From a feminist epistemological perspective, knowledge and knowledge production are deeply tied to experience and the viewpoint of the knower; within this framework, situated knowledge is foregrounded (Haraway, 1988, p. 581). Anderson (2020) defines situated knowledge as “knowledge that reflects the particular perspectives of the knower.” Haraway (1988) also demonstrates that knowledge emerges from experience and situatedness, emphasizing the stakes of epistemological work and noting that being seen and heard should not rely on aligning with objectivity and normativity:

I am arguing for politics and epistemologies of location, positioning, and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims. These are claims on people’s lives. I am arguing for the view from a body, always a complex, contradictory, structuring, and structured body, verse the view from above, from nowhere, from simplicity (p. 489).

As Haraway writes, this project is an attempt to identify a view from “somewhere,” rather than the objectivity of “nowhere.” Working to counter the normativity of dominant medical discourses, which often seems to perpetuate the “view from nowhere,” this dissertation values and amplifies contextual and situated knowledge, located in specific, lived experiences. However, this dissertation also explores the complexities of locating these specific experiences as they are represented in textual narratives.
Feminist epistemology from a philosophical view aligns with feminist work in rhetoric and composition, especially in their shared values of foregrounding women’s experiences and situated knowledge. An interdisciplinary lens that includes both philosophy and feminist rhetorical studies is an effective method for understanding the deep intersections between rhetorical practices and epistemology. As Jacqueline Jones Royster and Gesa E. Kirsch (2012) describe, “feminist-informed practices enrich” the creation of knowledge (p. 42). At the same time, Eileen Schell (2010) argues, “epistemology was and is a central framework in feminist studies” (pp. 7–8). Taken together, feminist epistemology and feminist rhetorics strongly influence each other and create a powerful frame for research which can uncover tacit beliefs about knowledge-making and rhetoric. For example, feminist epistemology reveals the complex and imbalanced power dynamics that mark our culture and rhetorical practices, which often are not made explicit. Glen McClish and Jacqueline Bacon (2002) write that “by emphasizing the way rhetoric that emanates from a particular perspective can unmask power relations, stand-point theory underscores the value of the work of those who are subjugated and exposes the usually ‘invisible’ assumptions that often underlie traditional discourse” (p. 31). Following this methodological frame, this dissertation uncovers some of these “‘invisible assumptions” that mark our conversations about and understanding of embodied knowledge in medicine and in our broader culture.

Rhetorical work on feminist epistemology emphasizes the legitimacy of different and nondominant ways of knowing; Nedra Reynolds (1993) notes that, as feminist epistemology emerged as a theoretical orientation, different ways of knowing began to be considered “valuable rather than wrong” (p. 330). Working from a feminist
epistemological framework requires acknowledging and valuing multiple types of knowledge and knowledge-making practices, while simultaneously avoiding the reproduction of gendered binaries. Caitlyn M. Jarvis (2021) asserts that feminist epistemologies “rest on the assumption that there are many ways of knowing beyond those of gender difference” and, “consequently, knowledge construction can take many forms (p. 5). These other forms of knowing can include embodiment and lived experiences.

Some scholars in rhetoric and composition have asserted that all knowledge is embodied, though this idea is challenged by dominant discourses. A. Abby Knoblauch and Marie E. Moeller (2022) argue in their work on embodied rhetorics that “knowledge and meaning are never disembodied—they are always made by somebody” and call for greater attention to the role of the body in knowledge production (p. 8, emphasis original). Leigh Gruwell (2015) similarly notes that our bodies and experiences affect “how and what we know,” arguing that “women’s embodiment specifically affords them a different, privileged understanding of patriarchal systems (p. 119). Gruwell writes that “situated knowledges are embodied knowledges” that “arise from lived experience” (p. 121). In many cases, contextual, embodied, and experiential knowledge-making practices are diminished or dismissed, as this dissertation project will show in Chapter Four. For example, in a study of Wikipedia editors, Gruwell (2015) demonstrates how the “values of [a] male-dominated discourse community discount feminist ways of knowing, thus alienating and silencing alternative epistemologies and subjectivities” (p. 120). In order to preserve the traditional hierarchy of epistemologies, embodied knowledge and lived experience are delegitimized. To counter this move, Jarvis (2021) calls for
“epistemological equality,” which does “not negate traditional, dominant knowledge, but rather makes room for other forms of knowing” (p. 10). One way to move towards epistemological equality is to study the mechanisms that prevent its uptake, as well as the genres and rhetorical practices that have begun to explore different ways of knowing.

Personal narratives are a way for writers to combat the dismissal of alternative knowledge-making practices and demonstrate the significance of situated knowledges. Gruwell (2015) illustrates the connection between embodiment and narrative, writing that narrative can function as “an especially powerful way of knowing, because it can potentially call attention to our embodied subject positions and to the contingency of knowledge” (p. 75). Within RHM scholarship, the role of narrative in knowledge production and circulation has been explored as well; Jarvis (2021) describes the ways in which personal narratives of infertility can work “as a counter-discourse to the rhetoric of medical paternalism,” which “negates patient autonomy and disregards the uniqueness of the individual's diagnosis” (p. 6). Like the narratives in Jarvis’s study, the memoirs in this dissertation work to push back against harmful medical rhetorics and offer alternative ways of viewing their experiences.

In many contexts, rhetoric and composition takes up feminist epistemological viewpoints as a way to expand our ability to listen to, amplify, and learn from the subjects of our research. One practice for doing so is Royster and Kirsch’s (2012) concept of critical imagination, which calls for feminist researchers to “gain a deeper understanding by going repeatedly not to our assumptions and expectations, but to the women—to their writing, their work, and their worlds, seeking to ground our inquiries in the evidence of the women’s lives” (p. 20). The practice of turning to situated knowledge
is central to feminist rhetorical work. This attention to women’s experiences, rhetorical activity, and situated contexts parallels the philosophical view of feminist epistemology. This dissertation project is informed by this work in feminist epistemology and builds on these existing traditions.

**Methods**

In the following sections, I describe how and why I chose to center published narratives of chronic illness in this project and the strategies I use to analyze themes within the narratives. The genre of memoir aligns with the feminist epistemological framework I describe above. It has strong potential to elucidate the personal and social aspects of chronic illness and importantly to function as a mechanism for self-representation for authors—though the genre also requires interrogation as an object of study. The primary method used in this dissertation project is the coding of qualitative data, which allows for the identification of patterns across texts while simultaneously prioritizing individual authors’ experiences and voices.

*Objects of Analysis: Narratives of Chronic Illness*

I selected published personal narratives as the artifacts for this dissertation project in order to access the robust reflections of and to explore the rhetorical work undertaken by memoir authors. Selecting first-person narratives as the objects of study for this project aligned with my dedication to listening to women’s perspectives. Memoirs, essays, and other personal writing provide a valuable opportunity to understand writers’ experiences as they understand them, and to practice “listening deeply, reflexively, and multisensibly” to the data (Royster and Kirsch, 2012, p. 20). Approaching the data this way is supported by my feminist epistemological methodology, which foregrounds
situat ed knowledge and legitimates lived experience. This chapter prioritizes people’s voices and perspectives that highlight, in writers’ own words, how prevalent harmful comments and actions are in everyday interactions and medical settings.

Moreover, memoirs illustrate not only individual experiences, but also the cultural contexts in which they are written. Memoirs often reflect larger cultural trends; Katherine Mack and Jonathan Alexander (2019) highlight that memoirs can be understood as a genre in which “personal stories can be connected to larger systemic issues—culturally, socially, or politically” (p. 49). Mack and Alexander highlight that memoirs help us “imagine novel ways of mobilizing the personal to enact substantive and systemic social and political critique,” meaning that memoirs are “not just an immensely popular but also an exigent genre for rhetoricians to consider now” (pp. 50-51). Illness narratives, in particular, are capable of concurrently demonstrating the deeply personal and individual experience of being ill and the broader social and cultural factors that influence the personal level.

Personal narratives create space to counter stigma related to illness. G. Thomas Couser (2001), a major scholar of life writing, writes that the value of autobiographical writing resides both in the genre’s accessibility and its openness to “self-representation” for authors (p. 78). Couser highlights autobiography’s “considerable potential to counter stigmatizing or patronizing portrayals of disability because it is a medium in which disabled people may have a high degree of control over their own images” (p. 78). Couser does point to a few “obstacles in the way of realizing the counterhegemonic potential of the disability memoir;” including negotiating a publishing process that often prefers “stories [that] conform to preferred plots and rhetorical schemes,” such as
narratives of triumph (pp. 78-79). The memoirs in this current study reflect a small shift towards removing these obstacles, as few of them follow clear plots or fall into standard curative timelines. The corpus in this study begin to fulfill Couser’s hope for the future at the end of his 2001 work, in which he looks towards how disability memoirs might more successfully function as counter-discourses (p. 89). The memoirs I discuss below harness the power of autobiographical self-representation while also often simultaneously tackling stigma and dominant narratives of what illness “should” look like.

Katie Rose Guest Pryal (2010) and Pamela Takayoshi’s (2020) studies of mood memoirs and asylum memoirs, respectively, demonstrate the value of memoir as a way to illustrate authors’ rhetorical agency and increase awareness and understanding in readers. Pryal builds on Couser’s work and highlights the power of mood memoirs, which are “ideally suited for their rhetorical purposes of removing taboo from mood disorders, of talking back to the medical profession, and of generating a stronger ethos for the psychiatrically disabled” (p. 483). Pryal describes these memoirs as “political counter-narratives to the dominant psychiatric narratives about mental illness” (p. 483). In writing memoirs, authors can make “more apparent the rhetorical challenges faced by oppressed groups” and reclaim or “gain rhetorical authority” (Pryal, p. 499). Similarly, Takayoshi highlights memoirs’ ability to create “a shared rhetorical space with the audience” that demonstrates the authors’ rhetorical agency (p. 164). In the asylum memoirs Takayoshi studies, writers show their agency through “drawing on their own experiences and by creating a rhetorical position from which their readers would feel the trauma of the asylum experience” (p. 165). Through this combination of personal narrative and creating affective responses in their readers, memoirists can position themselves as
knowledgeable or as experts, working to counter the epistemic injustice they face. Drawing on these previous studies, I have curated a collection of memoirs about chronic illness by women and feminine-presenting people.

While memoir as a genre invaluably “foregrounds the meeting of the personal and political” (Mack and Alexander, 2019, p. 67), there are some caveats to acknowledge when centering research on memoirs, including reliability and representation, as well as, in the case of this set of illness narratives, a possible skew towards negative experiences and their distance from their subject matter. It is important to highlight the fact that I only have access to representations of complex interpersonal interactions; memoirs are rooted solely in an individual’s subjective experience. I did not observe conversations and clinical encounters taking place, and so I cannot—and don’t strive to—ascertain whether these authors are remembering and representing these events precisely. Rather than focus on validity and triangulation, my concern is for the patterns and echoes that emerge across texts and what these shared experiences can tell us about the consequences of epistemic injustice and rhetorical listening more generally.

More specifically, I want to mark that the writers in this corpus write primarily about negative experiences with the people in their lives and in medical settings. The issue of representation and distance from the “truth” of an interaction is particularly fraught for these situations. This imbalance may provide skewed perspectives on interpersonal interactions in day-to-day life and in medicine; because this set of memoirs is, at least on some level, dedicated to enacting change in how we treat and discuss chronic illness, their content slants towards experiences that will be most typical of what needs to change. I argue that this narrower focus is an important part of this genre of
illness narratives. As a tool for advocacy and community-building, memoirists and essayists’ decisions to highlight their worst experiences can be an effective rhetorical move for eliciting empathetic anger and desire for change in readers. The goal of this dissertation project is to demonstrate that there are shared tropes and experiences among women with chronic illness and call for a shift in these circulating norms—focusing on moments of friction helps us see the harm being done and work towards change.

I also need to acknowledge the shortcomings that result from focusing on published texts. Publishing is an overwhelmingly white industry. A 2019 survey conducted by multicultural children’s book publisher Lee & Low found that “76 percent of publishing staff, review journal staff, and literary agents are White.”\(^2\) This pattern is reflected in the demographic makeup of authors whose books are published by major publishing houses, such as the “Big Five.”\(^3\) A 2020 study conducted by *The New York Times* based on the research of Richard Jean So, an assistant professor of English and cultural analytics at McGill University, concluded that only 11% of books published in 2018 were written by people of color. The whiteness of the publishing industry limits whose voices are foregrounded, often reinforcing hegemonic narratives; when a majority of the memoirs published about chronic illness are written by young, cisgender white women, the face of chronic illness becomes just that—a young, cisgender white woman. Chronically ill Black and Indigenous women and other women of color’s stories, as well as those of trans, nonbinary, and gender nonconforming people, are rarely represented in more mainstream venues, which may contribute to the overall epistemic injustice and

\(^2\) The Lee & Low survey also found that out of the 7,893 respondents, 11% are disabled—compared to 26% of all adults in the U.S. (CDC, 2023a).
racism they face in medical settings. In Chapter Three, I provide a more thorough
discussion of how individuals and their bodies are treated differently based on
perceptions of their racial and/or ethnic identities and how systemic racism affects
outcomes and access to healthcare.

For my project, I have worked to build a more diverse corpus of texts to better
align with the realities of chronic illness and counterbalance the disproportionate
representation of white women in published texts. Most of the book-length texts included
in this dissertation are by white women; women and feminine-presenting people of color
are somewhat more widely represented in the selection of essays, likely as a result of the
racial dynamics and makeup of the book publishing industry. In addition, I expanded my
criteria to include a more diverse group of authors, as noted below.

However, gaps remain in this collection of personal narratives; for example, this
corpus does not include writing by women from Hispanic or Latinx backgrounds or from
multiethnic backgrounds. This study is also limited in terms of gender identity; while one
author, Johanna Hedva is non-binary, the majority of authors represented here are
cisgender women. Moreover, this study is geographically limited to authors residing in
the United States, so transnational perspectives are missing. Future research in this area
will need to more fully account for the breadth and diversity of chronic illness
experiences.

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I do want to recognize that, although I use the term “women” in this study to describe the group of
individuals most affected by gendered cultural logics in medicine, “women” is not a stable category of
identity. I have chosen to focus on and refer to women in this study because of the category’s ability to
show the harmful effects of patriarchal power structures. I use the descriptor “feminine-presenting” to work
towards including gender-nonconforming individuals who are still read or marked as feminine within those
patriarchal power structures.
With all of the above concerns and goals in mind, I developed criteria for what texts would be included in this dissertation. The criteria require that an included text:

1) is written about first-person experiences about a specific time or part of the author’s life and engages with the author’s experiences with a chronic or autoimmune disorder, in order to foreground the actual lived realities of being chronically ill;
2) is written for a popular audience, not an academic one, to explore how understandings and narratives of chronic illness are circulating in the wider public;
3) was published between 2017 and 2022, to reflect the ways in which this conversation has rapidly expanded in recent years in popular discourse and to ensure that this project is timely; and
4) is written by a woman or feminine-presenting author, to reflect the disproportionate frequency with which women and feminine-presenting people face dismissal and bias in medical settings and in our broader culture.

Using these criteria, I built a list of twelve books and sixteen essays (see Appendix).

Many of the books selected had wide readership or critical acclaim; Meghan O’Rourke, Samantha Irby (2017), and Esmé Weijun Wang’s memoirs were all New York Times bestsellers, and many other authors received various awards or starred reviews. I conducted my search primarily using Amazon, where the “frequently bought together” feature highlighted related texts, blog and magazine lists of illness memoirs, and search terms on Google such as “chronic illness memoir” and “illness narrative.” Casting a wide net in this way allowed for the curation of a broad set of texts. Relying solely on one venue of discovery may have inadvertently reinforced disparities related to publishing and public circulation.

5 In recognition of the intersecting axes of oppression and increased structural obstacles faced by women and feminine-presenting people of color, exceptions have been made to the publication time criterion to include texts by a more racially diverse group of writers, such as Samantha Irby’s 2013 debut essay collection *Meaty.*
By foregrounding the reflections and voices of chronically ill people, this project seeks to demonstrate the prevalence and consequences of bias and epistemic injustice—which I unpack in more detail in Chapter Two—faced by chronically ill people and how memoirs and personal writing work against this harm. Sharing personal experiences through public writing allows for a “snowball” effect to build, thereby building community and providing an opening for “collective social political action” (Fricker, 2007, p. 8). Each author that shares their story contributes to a larger movement and builds a community that becomes more and more difficult for others to ignore. Over time, this collective effort can create change in cultural logics of health, gender, and illness, improving outcomes and experiences for chronically ill people.

Method of Analysis: Coding

In Ethical Dilemmas in Feminist Research, Gesa E. Kirsch (1999) lays out a number of commitments that are central to feminist work in rhetoric and composition, several of which are actionable in this text-based study. These include a commitment to “ask research questions which acknowledge and validate women’s experiences;” to “correct androcentric norms by calling into question what has been considered ‘normal’ and what has been regarded ‘deviant,’” to “take responsibility for the representation of others in research reports by assessing probable and actual effects on different audiences;” and to “acknowledge the limitations of and contradictions inherent in research data, as well as alternative interpretations of that data” (pp. 4–5). Throughout the development of this project, I foregrounded these commitments in an effort to conduct ethical feminist research by prioritizing women’s lived experiences and material realities,
as well as recognizing women with chronic illness as knowers and valuing their varied knowledges.

In order to keep women’s voices and epistemic practices at the center of the project, I chose to employ coding qualitative data as my primary method of analysis. I selected coding, as described by Johnny Saldaña (2016), because the method provides an opportunity to preserve women’s experiences as they represent them and to center the situatedness of their knowledges. I used two forms of coding to identify recurring patterns and develop my analysis: descriptive coding and in vivo coding. Descriptive coding “summarizes in a word or short phrase – most often as a noun –the basic topic of a passage of qualitative data” (p. 88). For example, within my corpus, a passage about a doctor who did not believe an author about her symptoms would be labeled with the code “disbelief.” Saldaña argues that descriptive coding can be a valuable method for epistemological projects, writing that these projects and research questions “suggest the exploration of participant actions/processes and perceptions found within the data” (p. 61). However, descriptive coding isn’t sufficient on its own; it “may not enable more complex and theoretical analyses as the study progresses,” so I supplemented the descriptive codes with in vivo coding, which “keeps the data rooted in the participant’s own language” (p. 7, p. 91). In vivo coding’s reliance on and preservation of participants’ language aligns with my methodological allegiance to listening and attending to women’s lived experiences and knowledge-making practices. Chronically ill writers often shared experiences of being disbelieved, denied, or dismissed; preserving their language and voice is a way to amplify their embodied knowledge and to write with the memoirists, rather than about them. As I work towards a greater understanding and theorization of
embodied knowledge, the combination of descriptive and in vivo coding creates opportunities to both identify patterns across narratives and maintain the integrity of women’s experiences and knowledge.

To begin my analysis, I conducted a preliminary round of coding. I identified sections of text within each memoir and essay that described an experience of tension, harm, or another demonstration of a significant aspect of life with chronic illness, then entered short excerpts from these passages as in vivo codes in my codebook. A section of text became an in vivo code if it discussed dialogue with other people; internal thoughts or reflections; instances of cliches, advice, or dismissal; moments of conflict and tension; or larger cultural attitudes. These in vivo codes were then categorized into groups based on the most relevant context in which they took place: self, everyday interpersonal interactions, medical settings, and public. As the dissertation project developed, two categories became most salient for my analysis: the interpersonal and the medical. Chapter Two focuses on findings from the interpersonal category, exploring representations of typically mundane conversations with writers’ friends, family, partners, and strangers. Chapters Three and Four unpack data from the medical category, which proved a rich site for understanding the intersections of cultural norms, gender, and illness. After my initial round of in vivo coding and categorization, I conducted a round of descriptive coding. This second round involved confirming the original category from the round of rough coding, then assigning each piece of data a more refined code based on further reflection, allowing for clearer identification of patterns across texts.

While coding is a valuable method for analyzing qualitative data, I want to acknowledge that coding and categorization do sometimes necessitate collapsing the
nuance inherent in representations of lived experiences; few passages in the corpus could solely and neatly be placed into one category. For example, in her memoir *The Tiger and the Cage*, Emma Bolden describes the volume of postsurgical bleeding she experienced after her hysterectomy to a medical provider as a “gush.” Bolden describes the provider’s response: “‘Do you mean that there was a little blood,’ he said, as if offering a correction” (p. 303). As I coded this passage, I considered several descriptive codes to capture the themes in it, including “embodied” to describe Bolden’s physical sensations and visual observation; “paternalism” to describe how Bolden labels the provider’s attitude of “correction;” and “expertise” to highlight the tension between Bolden’s knowledge of her body and what was happening and the provider’s presumed understanding of the situation. In my codebook, I attached each of these descriptions to the excerpt as a form of “subcoding” (Saldaña, 2016, p. 267). However, I ultimately used “embodiment” as the primary code for the selection, as that code most fully captured Bolden’s bodily knowledge and experience. When possible, I included discussions of the nuance of passages in my written analysis in each chapter to recenter and accommodate some of the intricacy of women’s experiences and the inevitable overlap between categories. Johnny Saldaña describes the complexity built into qualitative research: “We do not need to reconcile the contradictions [of qualitative inquiry]; we only need to acknowledge the multiplicity of them” (p. 259). In the following chapters of this dissertation project, I have attempted to navigate this multiplicity while, at the same time, uncovering shared experiences across writers’ narratives.
Outline of Chapters

Contrary to normative cultural logics that devalue embodied knowledge and women’s experiences, this dissertation argues that embodied knowledge is an important epistemological concept that can both supplement and challenge dominant medical discourses. Chapter Two, “But Have You Tried….? Testimonial Injustice, Cultural Logics, and Rhetorical Listening,” challenges our view of rhetorical action to include and account for mundane comments and conversational moves, which reflect shared cultural values and beliefs. The chapter sets out to establish the prevalence of epistemic injustice in the lives of women with chronic illnesses, and argues that rhetorical listening can be a useful frame for countering that injustice. Chapter Three, “Well, Your Labs are Normal: Rhetorically Constructing the Normal Patient,” investigates how one specific cultural norm, the idea of a standardized normal patient, works to maintain medical systems that create and reinforce gender-based bias. This chapter argues that epistemic injustice is enacted in medical settings through the maintenance of these spaces as rhetorically disabling environments in which individual strategies to bolster ethos and credibility cannot succeed. The last body chapter, Chapter Four, is titled, “This is All in Your Head: Negotiating Expertise in Health and Medicine,” and examines how expertise is defined and controlled in medicine. Chapter Four demonstrates that challenging the problem of gender-based bias at an individual level is ineffective and argues for larger-scale structural change. Together, these chapters explore the complex cultural and rhetorical factors that manufacture and maintain bias against women in medicine, while also gesturing towards a more hopeful future for everyone with chronic illness.
CHAPTER II

BUT HAVE YOU TRIED…? TESTIMONIAL INJUSTICE, CULTURAL LOGICS, AND RHETORICAL LISTENING

You don’t look sick. You should try going for a walk every day. Have you cut out dairy and gluten and sugar and nightshade vegetables? You need to relax—have you tried deep breathing? Comments like these are familiar to most people with chronic illnesses. It can be difficult to navigate conversations about symptoms, treatments, and health without receiving unsolicited medical advice or remarks that imply that the chronically ill person doesn’t really know what’s best for them or their body. The experience is so common that it has inspired online memes and forums, podcasts like Have you Tried Yoga?, and merchandise like Spoonie Sister Shop’s autumnal “pumpkin spice and no unsolicited medical advice” T-shirt (Fig. 1). While these suggestions are often well-intentioned, the reality is that they and other naysaying conversational moves are ultimately more harmful than helpful. Recognizing the prevalence of individuals affected by chronic and autoimmune
disorders, especially women and feminine-presenting people, this chapter responds to this shared experience and uncovers the larger cultural logics inherent in these comments.

Informed by the feminist epistemological methodology I describe in Chapter One, this chapter examines how rhetoric and composition accounts for the failure of audiences to truly listen to the chronically ill, using testimonial injustice and rhetorical listening as key frameworks. Through examples of everyday interactions from memoirs and personal essays by people with chronic illnesses, I explore how naysaying conversational moves, such as cliches and dismissals, function as testimonial injustice, uncover cultural logics about health, gender, and wellness, and deny chronically ill people recognition as rhetors and knowers. Because many chronic illnesses are “invisible” (Dobson, 2021), chronically ill people often have to explain their conditions and attempt to make their experiences legible to others. The rhetorical success of these explanations can differ based on the speaker and their discursive choices, but there are many situations where the audience’s uptake and response determine the success of the communicative exchange. Chronically ill individuals may face reluctance, condescension, or dismissal from their audiences, often as a result of cultural aversions to disability and illness or cultural logics surrounding health and gender. In these cases, testimonial injustice is enacted, resulting in the denial of embodied and lived experiences and of people with chronic illnesses as legitimate knowers or rhetors.

I focus on representations of interpersonal interactions to unearth cultural logics of health, gender, and knowledge production, as well as how those cultural logics manifest through rhetorical and discursive means. The excerpts from memoirs and personal essays I discuss below demonstrate the negative affective consequences of
audience refusal and dismissal. I argue that audience refusal can function as epistemic violence—testimonial injustice specifically. This violence can be countered with greater rhetorical listening from family, friends, partners, and strangers, increased awareness of and attention to the reflections and voices of chronically ill women, and the strengthening of networks and communities for people with chronic illness.

**Literature Review**

To explore how cultural logics enable and create harm in everyday conversations for women, I draw on literature on rhetorical listening and epistemic violence. Rhetorical listening provides a frame for understanding the connections between audience intent, negotiated meaning-making, and normative expectations of communication. Epistemic violence, a concept from philosophy, is a key idea for understanding the negative outcomes of audience dismissal, such as chronically ill people not being viewed as credible knowers or rhetors. Together, these two threads of scholarship provide a view of the rhetorical and material consequences of everyday interactions, revealing the cultural norms and logics that make them possible.

**Rhetorical Listening and Normativity**

In this chapter, I draw on discussions of listening in rhetoric, composition, and literacy studies because this conversation informs my interpretation of the everyday interactions described by chronically ill writers. A foundational place to locate the beginning of this conversation is in 1996, when Jacqueline Jones Royster asked the field: “How do we listen? … How do we translate listening into language and action, into the creation of an appropriate response?” (p. 564). Krista Ratcliffe answered this call with her concept of *rhetorical listening*, which was first introduced in 1999 and has been
frequently developed and taken up by others in the field. Ratcliffe argues that, despite its origins as a “cornerstone of Western rhetoric,” listening has been “neglected” in twentieth century scholarship and has “almost ceased to be theorized or taught as a rhetorical strategy” (p. 195–196). Ratcliffe argues that rhetorical listening, as a “trope for interpretive invention” (p. 204), functions as a way to “facilitate cross-cultural dialogues about any topic,” though her focus most often is on dimensions of race and gender (p. 196). Though Ratcliffe puts rhetorical listening forth as a primarily pedagogical concept, Ratcliffe mentions it can be used “to hear discursive intersections of…any cultural positions” including patients and doctors (p. 196). I extend conversations about rhetorical listening by examining the interpersonal, affective, and social repercussions of a lack of rhetorical listening outside of the classroom context. I take up Royster and Ratcliffe’s calls because listening—and the lack thereof—can be the source of many conflicts for people with chronic conditions.

Theorizing and analyzing listening as a key concept entails understanding the complexity of audience intentions and contexts, as well as any impact on the speaker. Ratcliffe argues that rhetorical listening requires that a listener intends and chooses to meet a speaker’s “desire to be heard” (p. 206). If, instead of doing so, a listener “meets this ‘desire to be heard’ with counter-desires—pretending the desire to be heard does not exist, hoping it will disappear, or waiting for someone else to handle it—[they] stymie potential dialogue” (pp. 206–207). I argue that we need to attend more deeply to the consequences of these counter-desires, and acknowledge that the consequences can be more severe or more material than obstructed dialogue; they can perpetrate epistemic injustice and discredit people with chronic illnesses altogether. I expand Ratcliffe’s
discussion of rhetorical listening to more completely address instances in which a listener could decide to listen rhetorically and does not, or tries to listen rhetorically and is unsuccessful because of entrenched cultural norms and logics.

While it is important to acknowledge intent, understanding a speaker or a listener cannot stop at the level of their individual intent because the larger cultural context is also a factor in everyday interactions. Ratcliffe writes that rhetorical listening “champions a responsibility logic” which pushes listeners to take a speaker’s intent into account in context alongside the “historically situated discourses that are (un)consciously swirling around and through the person and…to evaluate politically and ethically how these discourses function and how we want to act upon them (p. 208). Ratcliffe argues that speakers should be interpreted with intent and larger cultural discourses in mind simultaneously; I build on this assertion, asking us to apply this interpretive frame to listeners as well. We must understand how cultural logics, politics, and ethics inform both speaker and listener. Ratcliffe illustrates the power of the underlying “metonymic echoes of larger cultural discourses” that influence speakers and listeners, which can interrupt dialogue and understanding (p. 197). We need to position rhetorical listening as the responsibility of interlocutors in conversations about chronic illness, while also acknowledging the broader cultural forces that make harmful comments or a lack of awareness possible. By shifting our focus from speakers’ intentions to the effects of discursive interactions, we can learn more about the importance and nuances of rhetorical listening.

Rhetorical listening provides a rich frame for understanding the complex relationship between speaker and listener and a mechanism for interrupting epistemic
injustice. However, our conception of rhetorical listening must be expanded to include and foreground marginalized perspectives and a broader range of embodied experiences. In doing so, frameworks for understanding listening can create spaces for previously unheard voices to be heard on their own terms and challenge the normativity inherent in the original conception of rhetorical listening. In recent years, scholars of queer theory, decolonialism, and disability have begun to expand rhetorical listening to account for marginalized and embodied experiences. For example, Romeo García (2018) offers community listening as an alternative that accounts for oversights in Ratcliffe’s work. García argues that Ratcliffe’s rhetorical listening, and academic listening in general, are “characteristically reflective of a colonial unconsciousness” (p. 13). García calls attention to the way that the original framing of rhetorical listening “empowers white people to believe they can stand outside their positionality or identification within a dominant white culture,” highlighting the need to include marginalized perspectives and decenter white ones (p. 13). García’s concept of community listening “reminds us that while everyone is marked by gender and race, lived experience matters” (p. 13). García’s call to attend to lived experience and existing practices of listening and communicating in marginalized communities is a foundational goal of this dissertation project. Using rhetorical listening as a frame may improve outcomes and understanding for chronically ill people in everyday interactions, but it is not sufficient without also acknowledging intersecting

Ratcliffe has also worked to revise and expand rhetorical listening in her further scholarship. Following her 1999 article, she published *Rhetorical Listening: Identification, Gender, Whiteness* (2005), which focuses more fully on race and gender and expands the initial article’s argument. This monograph was followed by a 2011 edited collection co-edited with Cheryl Glenn, which wove Ratcliffe’s work on listening with Glenn’s work on silence and silencing. Most recently, Krista Ratcliffe and Kyle Jensen’s *Rhetorical Listening in Action: A Concept-Tactic Approach* lays out a “rhetorical education grounded in rhetorical listening that cultivates writers who can listen across differences in preparation for communicating and acting within and across those differences” (p. 3).
axes of oppression. Similarly arguing for the importance of paying attention to embodiment and positionality, Timothy Oleksiak (2020) puts forth *queer rhetorical listening* as one way to account for the embodied experiences of both speakers and listeners and to attend to “the specific embodied experiences of queer people and the unique forms of listening that they engage.” Queer rhetorical listening, then, allows us to “think through the theoretical concerns that rhetorical listening advances” without its normative expectations. This dissertation contributes to this ongoing expansion project by calling our attention to the voices of people with chronic illness.

Expanding rhetorical listening must also attend to disability and neurodiversity. Scholars in rhetoric, disability studies, and the rhetoric of health and medicine have recognized the importance of Ratcliffe’s contributions, while also critiquing their somewhat normative expectations that can be harmful to marginalized communities. From a disability perspective, Ratcliffe’s version of rhetorical listening is only available to able-bodied and neurotypical individuals. Margaret Price (2011) writes that there is not enough consideration of “the rhetors who cannot be ‘listened’ to—because ze⁷ is not present, or fails to participate in discussions, or fails to ‘make sense’ on a neurotypical scale” (p. 44, emphasis original). Price’s critique argues that rhetorical listening perpetuates a normative view of ability; rather than create a pedagogical environment where all students can be full participants, Ratcliffe’s first iteration of rhetorical listening still requires a normative version of communicating without sufficient acknowledgment of disability or neurodiversity. Price raises a question of whether students “must still speak well to access this new pedagogy of listening” (p. 44).

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⁷ A gender neutral personal pronoun. For more, see: [https://pronouns.org/ze-hir](https://pronouns.org/ze-hir)
Like Price, J. Logan Smilges (2020) argues that Ratcliffe’s original concept demands neurotypicality and that uptakes of rhetorical listening need to shift to accommodate disabled and neurodivergent listeners. Smilges offers a valuable reminder that listening is not a singular activity, but a negotiated and contextual process that often rewards dominant and powerful groups while harming marginalized ones. Price and Smilges’s complications of rhetorical listening reflect a tension inherent in studying intersections between rhetorical listening and epistemic injustice—in calling for audiences to rhetorically listen to chronically ill people, it is important to avoid the assumption that everyone is always able to rhetorically listen following Ratcliffe’s original conception and to bear witness to the harm done to those who are not able to conform to normative assumptions by those in privileged positions.

Some scholars have demonstrated what attending to a broader collection of embodied experiences might look like as a practice, providing valuable models for expanding rhetorical listening. Michael J. Faris (2020) argues for understanding listening as an embodied practice, expressing concerns with Ratcliffe’s focus on the “discursive and epistemic at the expense of the embodied and material.” Faris reframes listening as a “habituated practice over time rather than isolated moments of listening” (emphasis original). Faris points to the variable nature of listening as a process, indicating that, despite the dominant perspective that cultural logics and practices are fixed, change is possible. One version of listening as a practice comes from Asao Inoue (2019), who suggests a practice of deep listening that expands rhetorical listening by considering the consequences and impact of communicative exchanges. Acknowledging Ratcliffe’s position as a white academic largely writing to other white academics, Inoue calls his
white colleagues into practices of deep and compassionate attending and assessment (p. 362). He reframes the goals of writing assessment, encouraging teachers to rethink their guiding questions when responding to student writing, shifting towards: “‘Do I understand you enough? Am I making you suffer? Please help me to read your languaging properly” (p. 363). Inoue’s questions demonstrate how practices of communication can involve collaboratively negotiating meaning-making. Inoue’s frame of deep listening demonstrates priorities of care, collaboration, and openness, which are often discouraged by normative boundaries.

Oleksiak, García, Price, Smilges, Faris, and Inoue’s calls for greater attention to nonnormative perspectives in understanding rhetorical listening support this dissertation project’s prioritization of marginalized voices and embodied knowledges. Placing our interpretive emphasis on embodiment and lived experience is a valuable addition to our understanding of rhetorical listening. Whereas discussions of epistemology and listening can feel abstract, returning to the body grounds these conversations. By centering the perspectives and embodied experiences of chronically ill people, I aim to update important frameworks in rhetoric and composition, like rhetorical listening, in order to demonstrate how discursive patterns and cultural logics enact epistemic injustice. In doing so, I move towards imagining better futures for chronically ill people and other marginalized groups.

*Epistemic Violence: Testimonial Injustice and Microaggressions*

This dissertation draws on epistemic violence, a concept from philosophy that accounts for situations in which audiences deny a speaker their capacity as a knower. Epistemic violence can help rhetorical scholars reframe and understand the causes and
outcomes of communicative failures that cannot be traced back to the speaker’s rhetorical strategies, tactics, or choices. Philosophical scholarship, in tandem with conversations about listening from rhetoric and composition, can help us better understand instances of rhetorical failure as a result of naysaying audiences.

Epistemic violence is the harm caused by denying someone’s ability to share knowledge credibly. Feminist philosophy has been concerned with epistemic violence for decades; for example, Gayatri Chakravorty Spivak (1988) writes that epistemic violence is a mechanism that contributes to the silencing of marginalized groups (pp. 76–78). Scholarship in feminist philosophy has taken up this concept more fully and expanded definitions and categories of epistemic violence. In *Epistemic Injustice: Power and the Ethics of Knowing*, Miranda Fricker (2007) builds a robust account of epistemic injustice; she defines epistemic injustice as “a wrong done to someone specifically in their capacity as a knower” (p. 1). Kristie Dotson (2011) picks up Fricker’s work and deeply explores “practices of silencing” (p. 237). Dotson argues that speakers depend on audiences to be “willing and capable of hearing” them (p. 238), and that epistemic injustice is “a failure of an audience to communicatively reciprocate, either intentionally or unintentionally, in linguistic exchanges owing to pernicious ignorance” (p. 242). Epistemic injustice as a theoretical frame aligns well with concerns common to work in rhetoric and composition: audience, power, and agency.

In the frameworks developed by Fricker and Dotson, epistemic injustice can take two forms: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when “prejudice causes a hearer to give a deflated level of credibility to a speaker’s word,” while hermeneutical injustice is perpetrated when “a gap in collective interpretive
resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (Fricker, 2007, p. 1). While hermeneutical injustice can also occur in chronically ill people’s everyday interactions, I privilege testimonial injustice here in order to adequately attend to the roles of ethos and cultural logics in these interactions. As a frame, testimonial injustice provides insight into instances where chronically ill people’s ability to be seen as credible knowledge-makers and to share their embodied experiences is curtailed by others. Testimonial injustice denies a speaker their “capacity as a giver of knowledge, as an informant” and Fricker argues that it results from preexisting notions of identity and social power on the part of the hearer. Kristie Dotson asserts that testimonial injustice is the product of pernicious ignorance, or harmful gaps in knowledge (2011, p. 238). Dotson introduces the concepts of testimonial quieting, in which speakers are not recognized as knowers by the audience, and testimonial smothering, in which speakers alter or hold back their testimony as a result of unsafe or risky communicative environments (pp. 242–244). Through both testimonial quieting and testimonial smothering, testimonial injustice can illuminate cultural patterns and norms that influence how chronically ill people interact with and are viewed by other individuals, including family, friends, and partners.

While existing scholarship on epistemic injustice is a strong area of research, there is room for these conversations to engage with disability and chronic illness more deeply. This work has already begun in philosophy; Ian James Kidd and Havi Carel have extended understandings of epistemic injustice to healthcare contexts. In their 2017 article, “Epistemic Injustice and Illness,” they examine both patient and physician

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8 Chapters Three and Four of this project will investigate the ideas of patient ethos and expertise more deeply.
complaints, and make two central claims: “the first being that chronically ill persons are especially vulnerable to epistemic injustice, owing to prevalent negative stereotypes of illness and certain structural features of contemporary healthcare practice” and the second that “the concept of epistemic injustice can therefore help to explain, at least to some degree, patients’ complaints about their healthcare experiences” (p. 175). My project examines these claims from a rhetorical point of view, framing Kidd and Carel’s identification of people with chronic conditions as especially vulnerable to epistemic injustice as exigence.

Epistemic injustice encountered by people with chronic illnesses is often manifested through comments and questions from other people that can take the form of microaggressions. While seemingly small, the repetition and volume of these comments causes harm. As defined by psychologist Derald Wing Sue (2010), “microaggressions are the brief and commonplace daily verbal, behavioral, and environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial, gender, sexual-orientation, and religious slights and insults to the target person or group” (p. 5). Microaggressions can target any marginalized group, including disabled people (p. 5), and cause significant biological and psychological stress (p. 87–90). However, as Lauren Freeman highlights in her introduction to the edited collection Microaggressions and Philosophy, there is a dearth of scholarship centered on microaggressions experienced by disabled people. Previous to this 2020 collection, Freeman notes that there had only been “one academic article …written on microaggressions experienced by people with disabilities” (p. 18). The article that Freeman refers to here is Keller and Galgay’s 2010 “Microaggressive Experiences of
People with Disabilities,” from the field of psychology. Based on findings from two focus groups, Keller and Galgay identified eight domains that “can be used as a framework for interpreting the microaggression experiences” of disabled people. The domains include denial of identity, denial of privacy, helplessness, secondary gain, spread effect, patronization, second-class citizenship, and desexualization. In their discussion, Keller and Galgay write that microaggressions related to disability can cause significant negative affective responses such as “frustration, anger, rage, embarrassment, insult, and invalidation” (p. 258). The authors note that there is a need for a greater understanding of the strategies used by disabled people to “deal with the disability microaggressions,” such as humor and community-building.

Joining Keller and Galgay’s article is Jeanine Weekes Schroer and Zara Bain’s (2020) study of disability microaggressions that appears in the collection *Microaggressions and Philosophy*. The authors argue that “central to conceptualizing microaggressions is understanding their mixed legibility”—meaning microaggressions’ ability to “deliver different messages to different audiences or multi-tiered messages to general audiences” (p. 226). For example, Schroer and Bain describe a case in which a physically disabled woman is told “you’re too pretty to be disabled” (p. 228). The authors argue that this comment demonstrates the “inconsistent sets of messages” packed into microaggressions, as the message is simultaneously that the woman in the case “is pretty, but too pretty to be disabled—because disabled folk aren’t pretty” (p. 241). Schroer and Bain demonstrate that “microaggressions’ mixed legibility is crucial to their role in maintaining an epistemology that polices disability in general and disabled people in particular” (p. 227) and argue that microaggressions function as a way “to feed
epistemologies of oppression” (p. 237). Schroer and Bain’s analysis highlights the ways in which microaggressions can be interpreted differently across speakers and audiences, resulting in different uptakes. In my analysis below, I will demonstrate the varied impacts of microaggressions, building on these ongoing conversations in philosophy.

In addition to the rich body of literature in philosophy, there is a burgeoning conversation about microaggressions within rhetoric and composition. In their 2019 article “Rhetorical and Pedagogical Interventions for Countering Microaggressions,” Rasha Diab, Beth Godbee, Cedric Burrows, and Thomas Ferrel work to call rhetoric, composition, and literacy scholars’ attention to microaggressions in both higher education and in our daily lives. As the authors point out, rhetoric and composition scholarship has a long history of being “invested in understanding violence and injustice,” both on a large scale and on interpersonal levels (pp. 457–458). However, as Diab et al. argue, discussions of interpersonal violence have not always explicitly named microaggressions as a mechanism of that violence.

Despite the lack of scholarship that overtly names microaggressions in rhetoric and composition, Diab et al. argue that rhetoric is a valuable lens for understanding microaggressions. They write that “microaggressions are mediated by rhetorical acts, assume many forms, are complex, evoke historical discourses, silence their recipients and mandate a rhetorical response” (p. 460). Diab et al. assert that rhetorical scholars are capable of understanding and identifying microaggressions for several reasons, including that they can “explain what happens in communicative moments—in interactions, utterances, and texts—in which microaggressions occur” (p. 463). I recognize the value in examining microaggressions as an emerging rhetorical scholar working to understand
how microaggressions work rhetorically to reinforce dominant perspectives on health, wellness, and illness.

Diab et al. highlight the epistemic violence inherent in microaggressions, especially microinvalidations. Microinvalidations “undermine people as knowers,” thereby also “undermin[ing] full personhood, which includes having one’s experiences acknowledged by others, being able to construct new knowledge, and being able to contribute as a knowledgeable agent within one’s community” (p. 464). Diab et al. call for greater affirmation and protection of students’ and writers’ epistemic rights. Diab et al.’s article is a crucial contribution to our understanding and awareness of microaggressions as teachers and rhetoricians. I extend their work to include contexts beyond the writing classroom and to add to their already robust discussion of microaggressions. Diab et al.’s piece focuses on microaggressions related to race; this dissertation project takes up this framework from a disability and RHM perspective to better understand mechanisms of epistemic violence faced by disabled and chronically ill individuals.

Epistemic injustice can contribute to understandings of bias and marginalization in rhetoric and composition. In turn, approaching epistemic and testimonial injustice from a rhetorical perspective extends current conceptions of this injustice to better understand the role communication and language play in reinforcing dominant narratives and perspectives. Scholarship on epistemic injustice also closely aligns with RHM and disability studies work on the concept of rhetorical disability, which serves as a guiding

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9 Microaggressions can be broken down into three categories: microinsults, microassualts, and microinvalidations—categories developed in 2007 by Derald Wing Sue and his coauthors. Diab et al. focus primarily on microinsults and microinvalidations (pp. 461–462).
frame in Chapter Three of this project. I’ve chosen to focus on epistemic injustice here to highlight not only the “polydisciplinarity” of work in RHM (Segal, 2020, p. ix), but also to demonstrate the overlaps in rhetorical practices and processes of knowledge production. Within this chapter, testimonial injustice and rhetorical listening work together as valuable frames, opening opportunities to study and amplify chronically ill women’s experiences in interpersonal interactions.

Methods

This chapter centers memoirs and personal essays written by women and feminine-presenting individuals with chronic illnesses as a way explore the impact of naysaying conversational moves and harmful cultural logics on people with chronic illnesses. I focus on the interpersonal category of data in this chapter, which included conversations with or comments from friends, family members, partners, and strangers. Emphasis was placed representations of communicative interactions that are often overlooked as important rhetorical practices. As I mention in Chapter One, this project relies on representations of experiences, rather than observations or first-hand knowledge. As a result, I can only draw conclusions based on the patterns I identify within those representations. Representations of commonplace discursive practices in memoirs and personal essays often clearly demonstrated testimonial injustice and its affective effects on writers with chronic illnesses.

After the initial identification of interpersonal data through in vivo coding, I conducted another round of more refined, descriptive coding. Then, I classified each code into one of five categories based on common patterns and threads across the data: advice, shame, denial of experience, blame, and positive connections. The categories were
developed in recognition of similar experiences across several codes and were dependent on the frequency of each pattern in the texts\(^\text{10}\) (see Fig. 2). Each category represents several codes; for example, “denial of experience” includes data coded as “dismissal,” “condescension,” and “perceptions of youth and health.” In these cases, I determined the primary theme for the text and included it with that category, while also noting the additional categories it aligned with. Drawing on these examples from the interpersonal category, the next section analyzes memoir and personal essay writers’ uncovering of dominant cultural logics, framed by the concepts of testimonial injustice and rhetorical listening.

*Figure 2: Frequency of Interpersonal Categories*

![Category Frequency-Interpersonal](image)

**Analysis and Discussion**

In this section, I analyze examples from my selected texts that fall into the overarching *interpersonal* category. Within the larger group, five categories emerged that

\(^{10}\) In the analysis and discussion section, themes are primarily discussed in descending order of frequency. However, the *shame* section appears after the section on *blame* in order to examine the relationship between these two patterns.
each demonstrate the presence of testimonial injustice and microaggressions in interpersonal interactions for chronically ill people, as well as the role and impact of rhetorical listening. Each category or pattern also revealed a cultural logic about being chronically ill. For this project, I understand cultural logic to align with the concept of doxa, or “common knowledge and shared opinions” (Armossy, 2002, p. 369). I use cultural logic as a key term to mean the underlying shared beliefs and ideas that are taken to be true or natural in a given social context—these logics often enter conversations as “counter-desires” that work to dismiss people’s experiences and rhetorical practices11 (Ratcliff, 1999, p. 206). I argue that repetition of naysaying conversational moves over time create negative cultural logics surrounding chronic illness, while, at the same time, cultural logics naturalize those discursive practices. Highlighting this cyclic process, Cathryn Molloy (2020) asserts that analyzing “everyday rhetorical acts” can reveal “the logics of doxa;” she writes that: “popular opinions are heavily influenced by and profoundly manipulate every-day exchanges” (p. 14). Cultural logics are a powerfully persuasive force that guide and bound how we think about and talk about health and gender. Rhetorical listening, I argue, can interrupt this cycle, improving outcomes and dialogues for people with chronic illness and attending to a broad range of embodied experiences.

In each subsection below, I introduce a discursive pattern that emerged in the corpus of memoirs and essays, then connect the pattern to a specific cultural logic that both underlies and reinforces that pattern. Then, I provide examples of the pattern to

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11 These logics are contextual; they “vary across time and cultures” (Gibbons, 2014, p. 430). While they certainly did not begin in the last five years, the chronologic and geographic limitations of this study mean that the cultural logics identified in this chapter are specific to the United States in the mid-2010s and early 2020s.
illustrate its impact on chronically ill writers. Table 1 below lays out each discursive pattern along with the cultural logic(s) it reveals, as well as a representative example of each pattern.

**Table 1: Discursive Patterns and Cultural Logics Identified in Memoirs and Personal Essays**

<table>
<thead>
<tr>
<th>Discursive Pattern</th>
<th>Cultural Logic(s)</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsolicited Advice</td>
<td>Individual responsibility for wellness</td>
<td>“Have you tried yoga? Have you tried standing on your head seventeen times a day? Have you tried taking the very common and popular over-the-counter medicine referred to as ‘Advil’?” (Parker, p. 80)</td>
</tr>
<tr>
<td>Denial of Experience</td>
<td>“Seeing is believing”</td>
<td>“But you look just fine!”                                                                                                             (Ramey, p. 17)</td>
</tr>
<tr>
<td></td>
<td>Toxic positivity</td>
<td>“This too shall pass”                                                                                                                 (Miller, p. 10)</td>
</tr>
<tr>
<td>Blame</td>
<td>Double bind of individual responsibility</td>
<td>“I know you think you’re doing the right thing, … but aren’t you just making yourself sicker?” (O’Rourke, p. 203)</td>
</tr>
<tr>
<td>Illness as a burden</td>
<td></td>
<td>“My father also told me a few times that I should leave, that they were peaceful without me, that he wanted his happy life with his wife back” (Khakpour, p. 188)</td>
</tr>
<tr>
<td>Compulsory sexuality</td>
<td></td>
<td>“The prevailing theory seemed to be that I had so much pain with sex because I didn’t like it” (Norman, p. 181).</td>
</tr>
<tr>
<td>Shame</td>
<td>Stigmatization of illness (external and internalized)</td>
<td>“I try not to ever talk about this business [Crohn’s disease] with strangers because the word ‘disease’ is off-putting and scary” (Irby, 2013, p. 181)</td>
</tr>
</tbody>
</table>
“Just Do Yoga:” Unsolicited Advice

The most frequent pattern across the memoirs and essays I coded was unsolicited advice, especially medical advice, offered by family, friends, and strangers. Codes in this category included “advice,” “misunderstanding,” and “knowing better.” Several suggestions repeated across texts, such as trying yoga, essential oils, or experimental devices or procedures. In each instance, the writer represented receiving uninvited advice and the negative emotional impact of this advice, which implies that chronically ill people are lacking expertise about their own bodies and experiences.

Unsolicited advice reflects the cultural logic of *individual responsibility for wellness*. Colleen Derkatch (2022) terms this logic the “moral imperative of wellness discourse” (p. 53). The idea that everyone is in control of their own health through personal behaviors and decisions is deeply culturally embedded. However, this narrative leaves out the fact that there are many complex determinants of health and “the emphasis on individual responsibility for self-care in wellness culture inadvertently short-circuits potential opportunities for systemic change in the landscape of illness, health, and wellness” (Derkatch, 2022, p. 17). Suggestions to try “green juice or positive thoughts” (Ramey, p. 9) were frequent in the data, demonstrating a broad cultural buy-in to the idea of the “moral imperative” and an attempt to persuade the receiver of these comments to similarly take up this belief. Taking individual actions or changing one’s behavior is seen as the most logical way to improve one’s symptoms, pain, or other negative embodied
experiences. Because suggestions to pursue wellness are viewed as natural and logical, even well-meaning comments from friends and family can create epistemic injustice and negative affective responses for people with chronic illness. The cultural logic of wellness also leads to a belief that illness is always acute and progress towards health is linear. However, the reality of chronic illness—that it is ongoing and often does not improve over time—runs counter to this idea. Tessa Miller, in her list of seven “secrets” that people with chronic illness want to share with their loved ones, summarizes the tension between perceived individual responsibility and the realities of chronic illness well:

Secret #1: We’re sick (no pun intended) of unsolicited advice. Our friends and families want to be supportive. They want to feel useful, to take an active role in our health. But chronic illness is just that—chronic, meaning a cure doesn’t exist yet. Yoga, essential oils, aloe juice, apple cider vinegar, fad diets, meditation, prayer, chiropractors, prebiotics, probiotics, and acupuncture aren’t going to magically stop an illness that doctors, researchers, and other scientific minds can’t yet crack. Simplifying wellness into ‘drink more water’ or ‘just do yoga’ abandons all the complexity of what makes up health: an array of genetic, environmental, and social issues. Among ourselves, chronically ill people joke about how rich we’d be if we had a nickel for every time someone recommended Pilates or told us to shove rose quartz up our butts. (pp. 234–235).

Miller highlights the simultaneous positive intentions and epistemic injustice of unsolicited advice. For chronically ill women and feminine-presenting people, positive intentions do not counterbalance the epistemic harm that results from deeply embedded cultural scripts, such as wellness culture.

Unsolicited advice can function specifically as testimonial injustice, as it creates a credibility deficit for chronically ill people. This type of advice, whether well-intentioned or not, implies a lack of knowledge on the part of the chronically ill person. Samantha Irby expands on the ways in which epistemological concerns emerge when unsolicited medical advice is offered. She writes:
I don’t know if it’s something about me, or if people walk around just dispensing unfounded medical advice to everyone they’ve ever met with a health issue, but more often than I’m comfortable with, some asshole with a high school diploma wants me to sit me down and talk at me about how they can cure my wretched-gut disease (2017, p. 156).

Here, Irby’s mention of a high school diploma demonstrates how, despite the actual level of knowledge held by either the advice-giver or the chronically ill person, the ill person’s perceived knowledge gap due to their condition creates a credibility deficit. When advice is given to fill the perceived knowledge gap, testimonial injustice is enacted, as the writer is denied their capacity as a knower, viewed in a credibility deficit, and may experience testimonial smothering—meaning that a chronically ill person may be less likely to share their experiences in the future to avoid negative affective consequences. Their ability to share actual embodied and affective testimony is limited, which positions the chronically ill person as unaware of and unable to understand their own body and illness. The discursive pattern of unsolicited advice works rhetorically to persuade a chronically ill person that they are less knowledgeable and therefore must rely on others to provide information about their conditions.

Uninvited medical advice creates negative affective effects for people with chronic illness. Abby Norman writes about feeling “betrayed” when, after relating the pain with sex she experiences as a result of her endometriosis, she is met with “the constant rhetoric of ‘you just haven’t had enough sex with enough people’ from a few female friends” (p. 192). Keah Brown describes conversations with strangers in which she is repeatedly told to try “essential oils, prayers, hypnosis, experimental surgeries, special creams, holy water, and yoga” as “exhausting” (pp. 90–91). Similarly, Liz Moore
shares that they\textsuperscript{12} do not have the energy to explain to others that they have tried yoga, kombucha, “crystals and healing drum circles and prayer and everything” (81). Although some writers, like Melissa Hung, have “learn[ed] not to attach any emotion to possible solutions” offered by people who will “tell you about …the $1,000 LED light therapy device that healed their mom,” the predominant emotional effect of unsolicited medical advice in interpersonal interactions is negative (“Meditation”). Lara Parker writes about the compounding nature and affective impact of these suggestions:

I feel very confident saying that there is not a single person on this planet who is living with a chronic illness who has not attempted to make it better in some way. … We are trying. When people suggest a million things that we should do to feel better, it can make us feel as if they think we haven’t tried at all. Have you tried yoga? Have you tried standing on your head seventeen times a day? Have you tried taking the very common and popular over-the-counter medicine referred to as ‘Advil’? Have you tried breathing? Have you considered seeing a Doctor? Maybe try drinking some celery juice? Maybe just, I don’t know, stop being sad? LOL! Have you considered going into the forest and lying under a tree and letting the sunlight hit you three to seven times a day while rubbing dirt on your arms? (pp. 80–81).

Parker’s visceral frustration in this excerpt stems from repeated suggestions over time. The implication that she has not thought to try any of these suggestions or that she is not an expert on her own body causes harm, demonstrating that epistemic injustice causes significant affective consequences for disabled and chronically ill people. Offering unsolicited medical advice places emotional pressure and labor on disabled and chronically ill people and, while also denying their embodied experiences and knowledges.

\textsuperscript{12} Liz Moore uses they/them pronouns.
“Well, You Look Great:” Denial of Experience

Another significant recurring category in the data was audiences’ denials of authors’ experiences. Codes in this category included “positivity,” “perceptions of youth and health,” “expectation,” “denial,” and “dismissal.” Writers shared comments and attitudes from family, friends, partners, and strangers that worked to diminish and discredit their experiences with their chronic conditions. Keller and Galgay (2010) write that denial of experience “occurs when disability-related experiences are minimized or denied” (p. 249). Embedded in this minimization, they argue, is the message “your thoughts and feelings are probably not real and are certainly not important to me” (p. 249). This pattern of denial can enact testimonial injustice, as well as lead to patterns of blame and shame, which will be discussed in the two following subsections.

Comments that deny a chronically ill person’s experiences reveal two cultural logics: seeing is believing and toxic positivity. First, denial of illness experiences can demonstrate a wide cultural belief that illness is always visible and easily identifiable. Jennifer Dobson (2021) highlights that, within the realm of medical care, “seeing is believing is a prominent orientation,” leading to inadequate support, insufficient empathy, and worsened outcomes. As Dobson writes, when people with invisible illnesses are not listened to, “progress stalls, distrust grows, and no one feels better.” While Dobson and others in medicine highlight the impact of this seeing is believing paradigm and the related stigmatization of invisible illnesses (Joachim & Acorn 2000) in medicine itself, this cultural logic is profoundly ingrained in contexts beyond medicine. Several authors shared stories of what happened in everyday conversations when their perceived youth and outward appearance did not align with the symptoms they felt. Many wrote about
receiving nearly identical responses from others when they shared their diagnoses, symptoms, or pain:

- “Well, you look great, in any case, not ill, not ill in that way” (Khakpour, p. 205)
- “But you look just fine!” (Ramey, p. 17)
- “You look great,” people kept saying, almost in disbelief (O’Rourke, p. 34)
- “But you don’t look sick!” (Miller, p. 248)
- “You don’t look sick,” her eyes glared (Li, p. 59)

In the repeated assurances of “you don’t look sick,” women’s embodied experiences are denied by their audiences—their own embodied knowledge is delegitimized. Women with chronic illness know that they are sick, experiencing symptoms, or are otherwise affected by their chronic illness, but comments like “you look just fine” work to invalidate that knowledge. Comments in this vein function to both deny a chronically ill person’s knowledge, as well as their identity as a knower, thereby enacting epistemic injustice.

The second cultural logic that is exposed by dismissal and denial of experience is toxic positivity. Toxic positivity, or forced positive discourse, is “discourse imbued with an overly exaggerated positive outlook on the world” (Lecompte-Van Poucke, 2022, p. 1).¹³ In her linguistic analysis of two Facebook pages for people with endometriosis, Margo Lecompte-Van Poucke (2022) writes that discursive patterns of toxic positivity create the idea that endometriosis and its effects are “controllable,” thereby manufacturing a “stereotypical image” of someone who has had a negative experience (p. 8). Forced positivity, Lecompte-Van Poucke points out, places blame for negative

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¹³ One origin for the concept of toxic positivity is the field of psychology. Neil D. Weinstein (1980), in his study of “unrealistic optimism” found that the students in his study believed that they were less likely to experience negative events in the future than others. Weinstein partially attributes this belief to students’ belief that their “personal actions, plans, or attributes” would “affect their chance of experiencing the events” (p. 819).
experiences on the ill person, who is seen as not taking the appropriate actions to avoid pain and other symptoms. Like wellness culture, toxic positivity, relies on a pervasive idea of individual responsibility; toxic positivity demands that an individual maintain a wholly positive outlook on their experiences, regardless of the actual impact of their chronic condition.

Within memoirs and essays, toxic positivity emerges in the form of positive cliches such as “this too shall pass” (Miller, p. 10), upbeat reassurances such as “if you didn’t have CP [cerebral palsy], you wouldn’t be you” (Brown, p. 23), and refusals to engage with illness such as “let’s just focus on good things now” (Khakpour, p. 181). Within Ratcliffe’s frame of a speaker’s “desire to be heard” and an audience member’s “counter-desires,” toxic positivity works to shut down conversations about the more difficult and uncomfortable parts of chronic illness (p. 206). The frequency of forced positivity discourse demonstrates the level of saturation that toxic positivity has reached as a cultural logic. Even caregivers, family members, and friends with greater understanding of and compassion for what it means to live with a chronic illness can default to cliches or scripts of positivity. The embeddedness of cultural logics can lead to a lack of awareness that there are other ways of thinking, being, and communicating—cultural logics seem natural. Unfortunately, while statements of positivity from family members and friends may be well-intentioned, their ultimate impact is often to dismiss or shut down the chronically ill person, who then may experience testimonial smothering and alter or restrict what they share in future conversations. As a result, the chronically ill writers are denied not only their experiences but their capacities as knowers and rhetors.
“What is Wrong with You?”: Blame

Memoir authors also frequently shared experiences of being blamed for their illnesses or the effects of their illnesses on family, friends, and partners. At times, women were faced with implications that they were at fault, again demonstrating the ubiquity of harmful cultural logics surrounding health, wellness, and gender. Family, friends, and partners do often show support for their chronically ill loved ones, but the pressures placed on these networks by cultural logics of individual responsibility can manifest in faulting a chronically ill person, rather than broader systems of ableism and marginalization. Discursive patterns of blame are rich sites for uncovering several cultural logics, including the double bind of individual responsibility, viewing illness as a burden, and compulsory sexuality. Codes in this category include “blame,” “anger,” and “relationship.”

As discussed above, the cultural logic of individual responsibility can manifest in unsolicited advice, but it is also central to instances of blaming women for their negative experiences and creating a double bind. For example, Meghan O’Rourke describes her experience taking a new combination of medication and supplements to improve symptoms of Lyme disease, Ehlers-Danlos syndrome (EDS), postural orthostatic tachycardia syndrome (POTS), and other chronic illnesses. Although O’Rourke initially experienced an unpleasant reaction to the combination, it eventually abated, and her overall wellbeing improved dramatically. While O’Rourke was “as sick as [she] had ever been,” a colleague asked, “‘I know you think you’re doing the right thing, … but aren’t you just making yourself sicker?’” (p. 203). While the colleague’s comment was probably well-intentioned and does show concern for O’Rourke’s wellbeing, the
comment is also represented by O’Rourke as somewhat condescending, and is interpreted
to mean that O’Rourke does not actually know what is best for her or her body. Rather
than trusting O’Rourke’s embodied knowledge, the colleague says that they “know” that
O’Rourke “think[s] [she’s] doing the right thing,” highlighting a perceived epistemic
imbalance and credibility deficit. As a chronically ill person, O’Rourke is, in this
moment, questioned as a knower of her own embodied experiences. At the same time,
O’Rourke is blamed for the worsening of her illness—although she is not seen as a
credible knower of her body, it is still her obligation to care for it in the way that others
expect. This contradiction is a double bind for women with chronic illness; even as
O’Rourke attempts to align her behavior with the cultural logic of individual
responsibility, her efforts are still perceived as falling short.

The combination of blame and responsibility logic appears often in chronic illness
memoirs and essays, demonstrating a cultural logic of illness as a burden. Authors shared
memories of being held responsible for others’ negative feelings and experiences.
Chronic illness is isolating and requires individuals to rely on others for support and
community. Kristen L. Cole (2022) writes that “friends, family members, and even
coworkers are not just passive observers (or victims) of chronicity, they are deeply
embedded in chronic timelines” (p. 230). This embeddedness can be positive and
affirming, but the all-encompassing nature and labor required of chronically ill people
and their networks can have a negative impact. Notably, caregivers experience high rates
of fatigue, stress, and burnout (Choi et al., 2014; Morgan et al., 2022; Sallim et al., 2015)
and there is a lack of cultural and material support for family caregivers (American
Psychological Association, 2011). Porochista Khakpour remembers the blame placed on
her by her parents, who also served as some of her caregivers as she navigated a chronic Lyme disease diagnosis:

Things were very bad with my parents. The more we tried to make them good, the worse they got. My mother began crying whenever I started to get into my illness, locking herself in her room not to hear me anymore. She was drinking more than usual, I noticed. My father also told me a few times that I should leave, that they were peaceful without me, that he wanted his happy life with his wife back (p. 188).

In this excerpt, we can see the ways in which Khakpour and her illness are seen as responsible for her parents’ negative experiences. The stress and unhappiness expressed by her parents is understandable; however, Khakpour’s parents’ responses simultaneously position Khakpour and her care needs as burdens. Her presence as an ill person—rather than the larger systemic issues that enable the illness is burden logic—is blamed for preventing them from pursuing their “happy life.” This blame damages not only the relationship, but also Khakpour’s ability to share her experiences and persuade her parents to listen to her.

Further highlighting the strain that chronic illness can place on relationships, Cynthia Li describes an argument with her husband in her memoir Brave New Medicine. As Li works towards understanding and improving symptoms of her thyroid disorder, the stress caused by lifestyle changes and her pain and symptoms reaches a boiling point for the couple. In their argument, Li expresses her despair and frustration with the couple’s situation:

“If things are so bad for you...if I can’t be social enough or sexual enough or anything enough for you...I mean, if I can’t pull my own weight financially...if

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14 A 2009 study of heterosexual marriages from the journal Cancer (Glantz et al.) found that marriages are six times more likely to end in divorce or separation after a diagnosis of cancer or multiple sclerosis if the diagnosed partner is female than if the male partner is diagnosed.
all we do is bring each other down, if you won’t see a marriage counselor…if this just fucking sucks, why are we together?” (Li, p. 86).

This quote, taken with Khakpour’s above example, reveals how deeply cultural logics can be embedded for chronically ill people and their loved ones. Within this partnership, it appears as if both partners blame Li and her illness for their relationship stress. While it is not uncommon for individuals in partnerships to argue and disagree with each other, the argument Li writes about demonstrates the particular tensions that arise from one partner being chronically ill and the stakes for chronically ill people to maintain those relationships. Chronic illness, under our current cultural and medical paradigms, can upend familial networks. Cultural logics tend to place the culpability on the ill person and their care and accessibility needs. While rhetorical listening alone cannot solve these multidimensional structural barriers, increased empathy for and listening to women with chronic illness and their family, caregivers, and partners may be able to push against harmful cultural logics.

Blame also emerged as a theme in the authors’ descriptions of sexual experiences—especially those diagnosed with endometriosis, which can cause pain during sex. Instances of women being blamed for not being sexual enough because of their illnesses reveal what feminist critic and scholar Kristina Gupta (2015), building on the works of C. J. DeLuzio Chasin and Elizabeth Emens, has termed “compulsory sexuality.” In feminist and sexuality studies, compulsory sexuality is used to describe “the assumption that all people are sexual and to describe the social norms and practices that both marginalize various forms of non-sexuality, such as a lack of sexual desire or behavior, and compel people to experience themselves as desiring subjects, take up sexual identities, and engage in sexual activity” (Gupta, 2015, p. 132). Gupta highlights
how entrenched this perspective on sexuality and sexual activity is in the United States, creating a sense of isolation, shame, or alienation for people who either do not or cannot align with the expectations of compulsory sexuality. Gupta also notes how compulsory sexuality affects people differently in gendered ways; in a review of feminist literature on the related concept of compulsory heterosexuality, Gupta demonstrates “how women may be compelled to participate in heterosexual activity by a variety of norms and practices,” including a “sense of duty” or “the idea that a modern woman should enjoy sex” (p. 135).

Memoirists described the impact of this pressure: Abby Norman, who has endometriosis, writes that “the prevailing theory seemed to be that [she] had so much pain with sex because [she] didn’t like it” (p. 181). This response from others rhetorically reinforces for Norman that there is a problem with her attitude or perspective on sex, rather than an embodied issue as a result of her illness or any other cause. Lara Parker describes a similar negative experience with a sexual partner:

And as you can probably guess, my attempt at being sexually active didn’t end well. It lasted about forty-five seconds and ended with me screaming out in pain and him looking at me like I was crazy. He was visibly frustrated. What is wrong with you? (Parker, p. 103).

In this situation and others like it that Parker shares in her memoir, Parker’s pain and illness are seen as a shortcoming on her part—something is “wrong” with her, and she is “crazy”—bringing to mind accusations of hysteria. Parker’s partner’s frustration reflects several facets of the cultural logic of compulsory sexuality, namely that sexual intercourse should be easy and that women owe sex to their partners. As Parker and Norman relate, women with chronic illness can be positioned as defective for not being able to participate in or enjoy sexual activity in the way that their partners and dominant
cultural logics expect them to. In failing to align with the cultural norms for women, such as compulsory sexuality, they are unable to be seen as knowledgeable and trustworthy about their bodies and their relationships.

As each of the author’s stories show in this section, women with chronic illnesses often are blamed not only for their own pain, discomfort, and other negative outcomes, but they are also often held responsible for the comfort and wellbeing of others. This responsibility echoes Kate Manne’s (2018) definition of misogyny, which she argues results from the cultural view that women should occupy the role of a “giver” of feminine-coded goods—nurturing or other forms of “emotional and social labor” and “more tangible reproductive and domestic services” (p. 110). When women are chronically ill or otherwise unable to fulfill these roles, they are met with misogyny, anger, and disappointment, often from family, friends, colleagues, and partners. These types of responses cause epistemic harm and cause significant stress for chronically ill women and feminine-presenting people, which can surface as internalized shame.

“Some Awful Dirty Secret:” Shame

As one of the consequences of the above instances of testimonial injustice, chronically ill writers shared moments and experiences of shame, with both relative strangers and in intimate relationships. Codes in this category included “isolation,” “shame,” “discomfort,” and “identity.” After being blamed or held responsible for their negative experiences so often, chronically ill people can internalize these negative attitudes. Descriptions of feeling shame revealed the cultural logic of illness stigma. Molly Margaret Kessler (2022) explores the role stigma plays in our understanding of and conversations surrounding chronic illness, especially gastrointestinal conditions.
Building on Erving Goffman’s work, Kessler articulates a definition of stigma as “enmeshed in material-discursive rhetorical systems composed of persuasive practices” (p. 18). Kessler points to the way that stigmatization occurs for “bodies that deviate (read: basically all bodies),” including disabled and chronically ill people (p. 139). Illness stigma can be enacted through a “condescending comment,” as discussed in this subsection, but it can also be materialized as “the absence of a bathroom on every floor and the internal cringe that crawls up your spine reading about poop” (pp. 18–19).

Kessler writes that “stigma, specifically surrounding chronic conditions, is rhetorically perpetuated and challenged”—processes that are also illuminated by the memoirs and essays at the center of this chapter (p. 7). Illness stigma is a powerful cultural logic that creates shame and affects both the perception of women with chronic illness from outside sources and from within.

Memoirists and essayists faced stigma from external and internal sources. For example, Tessa Miller writes that one publisher rejected her manuscript for What Doesn’t Kill You because “‘poop stuff is too hard to read about’” (p. 233). The publisher’s comment not only reflects severe stigmatization of chronic illness broadly and gastrointestinal disorders specifically, but also works to persuade Miller that she should also buy into that stigma—it’s offered as a legitimate reason that her memoir should not be published. Miller describes how she felt after receiving the feedback: “That comment made my cheeks burn with embarrassment, as though there was something wrong with writing the truth about my body” (p. 233). Illness stigma is so pervasive that it is often internalized because it is seemingly natural.
Samantha Irby also provides an example of the tension between shame and openness related to her Crohn’s disease:

I try not to ever talk about this business [Crohn’s disease] with strangers because the word ‘disease’ is off-putting and scary and I don’t want anyone to ever move his or her chair away from me in public. But then that makes me feel all ashamed, like I’m hoarding some awful dirty secret. And lately I am trying to operate from a shame-free place (2013, pp. 181–182).

Irby’s experiences here demonstrate our cultural aversion to mentions of illness and our overall cultural logic that illness is embarrassing or inappropriate to discuss. This cultural aversion can create immense shame for chronically ill people, thereby creating feelings of isolation and loneliness and leading to testimonial smothering. When faced with shame and isolation, chronically ill people may become less willing or likely to discuss their experiences with others, especially if that audience has already expressed disgust or discomfort with the topic. We can see this mechanism in action in Irby’s writing; she tries to avoid mentioning her illness in anticipation of negative reactions from her audience.

Whereas the previous discursive patterns I’ve discussed focus on harmful comments and attitudes made by others, the pattern of shame demonstrates the ways that those attitudes become internalized by chronically ill people. Irby’s determination to “operate from a shame-free place” works in friction to the cultural logics that tell her she should be embarrassed and refrain from sharing her experiences.

Miller and Irby describe the negative affect that results from shaming from strangers; Lara Parker writes about the intense internalized shame that can emerge in closer relationships, such as with a romantic partner. Parker reflects:

But more than anything, I hated the way my partner reacted to my pain. He would refer to me as cold or tell me that I didn’t smile when I didn’t feel well. … It was a constant battle—not necessarily between my partner and me, but between me and myself. I would enter another pain cycle and do my best to get through it, but
then the bad mood and anger would begin to swell inside me. And from there, I began spiraling (p. 145).

This excerpt from Parker’s memoir reveals several cultural logics at play simultaneously, resulting in the internalization of these logics and negative affect. Parker’s partner’s description of her as “cold” brings up the logics of compulsory sexuality and misogyny—again, Parker is positioned as deficient for not engaging in sexual activity or being nurturing or warm when she is not feeling well. Moreover, the critique of Parker’s lack of smiling will sound familiar to women and others who have experienced harassment on the street or in professional spaces (Herrera & McCarthy, 2023; Jackson, 2019). Sara Ahmed’s (2010) concept of the “happiness duty” is relevant here; Ahmed argues that there is a cultural pressure to be a cause of happiness, and that doing so is conflated as a moral good (p. 20). Women’s negative emotions are shamed and there is pressure to repress them. By not smiling and being “cold,” Parker is perceived as depriving her partner of happiness, and therefore her partner “distance[s] himself” from her (p. 145). As a result of negative interactions with her partner, Parker begins to internalize this shame and negative affect. Describing anger at herself and her body, Parker notes that she “reprimanded [herself] constantly” for “not doing enough” or not being a “better partner” (p. 145). As discussed above, chronic illness affects relationships, especially because illness is seen as both a burden and often an individual responsibility. Parker demonstrates how cultural logics of health and gender can become strongly intertwined, resulting in the internalization of cultural logics, shame, and frustration for women with chronic illness.

Epistemic injustice creates an environment in which damaging, misogynistic cultural scripts can be internalized by both chronically ill women and their partners. The
examples provided by Parker and others represent the impact of cultural logics on an interpersonal scale; cultural norms, logics, and scripts affect individuals’ attitudes towards others and beliefs towards themselves. Whereas interpersonal relationships can be a source of pain and negative emotional experiences, they can also be a source of great joy and support.

“To Be Seen”: Positive Connections

In contrast to the previously discussed discursive patterns, one category, positive connection emerged as a counterweight. The experiences represented by the above sections shared negative or stressful experiences, which work to demonstrate the stakes of the authors’ writing, the material realities of existing in the world as a chronically ill person, and the cultural logics that mediate and help people make sense of those realities. The discursive patterns of unsolicited advice, denial of experience, shame, and blame enact epistemic injustice by diminishing writers’ identities as knowers and rhetors. These patterns function as the standard set of discursive strategies when someone shares an illness experience; interlocutors tend to default to these conversational moves that feel natural or unquestionable.

However, authors also shared moments of joy and validation resulting from being seen and listened to by able-bodied, disabled, and chronically ill family and friends. Rather than moving directly to the default of harmful cultural logics, these instances show times in which someone slows down to connect more fully with someone with a chronic condition and embrace their lived experience and embodied knowledge. Codes in this category included “help,” “positive,” and “connection.” These moments represent the importance of community and demonstrate how this community can support writers as
they push back against epistemic injustice. The positive connections described in the memoirs I examine typically demonstrate some degree of rhetorical listening, as friends and family members seek to understand and support a chronically ill. By choosing to listen and meet the speaker’s “desire to be heard” (Ratcliffe, 1999, p. 206), supportive community members can serve as accomplices as disabled and chronically ill writers convey their embodied experiences and knowledge. Positive interpersonal connections and rhetorical listening work to unsettle the status of harmful discursive patterns and cultural logics as the default in conversations about chronic illness—interrupting the cycle of epistemic injustice.

Women with chronic illness wrote about the importance of being seen and heard by able-bodied community members. Porochista Khakpour discusses her complicated relationship with her parents at various points in *Sick*. As discussed above, conversations about her illness and symptoms are typically described as contentious or uncomfortable, especially as her chronic Lyme disease worsens. Khakpour does also include moments of positive connection, though, when her parents take her seriously and listen to her experiences fully. She describes the positive affect that emerges after her parents truly listen to her: “To be seen, to be heard, to exist wholly, whether in beauty or ugliness, by a parent often felt like another big step to wellness. I experienced it rarely, but when I did, I felt something light in me that I had long thought had burnt out” (p. 82). It is affirming to be seen and heard instead of ignored and talked over by an audience foregrounding their own “counter-desires” (Ratcliffe, 1999, p. 206). Khakpour was already a valid knower before, but becoming legible to her parents as a rhetor and as a knower is a valuable experience that empowers her to take more ownership of her experiences in her writing.
Similarly, Emma Bolden describes the affirmation that results from the empathy and shared outrage of a friend. After a hysterectomy intended to solve Bolden’s struggles with endometriosis, she shared with a friend that she was still experiencing bleeding and having a period. Bolden describes her friend’s response:

She said, “HOW IS THAT POSSIBLE,” and I said, “I DON’T KNOW,” and both of us said it just like that, in all caps with no punctuation marks. “It’s like RAIN FROM NO SKY,” she said, which might be more accurate than anything any physician, emergency or otherwise, ever told me about my body (p. 334).

Like Khakpour, Bolden’s experience of sharing her embodied knowledge and receiving support from her network is encouraging. Moreover, the support from this friend works to counter cultural logics of illness stigma and illness as burden; Bolden’s friend does not shy away from the details of her experience and approaches the conversation with openness and empathy. Through this comment, Bolden’s friend backs up Bolden’s experience and expertise, providing an important counterweight to the other information Bolden has received. Being witnessed by someone can contribute to writers’ abilities to oppose instances of testimonial injustice.

In addition to receiving support and building connections with able-bodied family and friends, authors also emphasize the importance of building a community and network of disabled and chronically ill people who share their experiences. Esmé Weijun Wang relates an experience of finding similar experiences and viewpoints with another chronically ill person on a trip to Chimayó, New Mexico. As the pair plan their day, Wang’s friend reminds her that they can “see how [they] feel” during the day’s activities (p. 173). This recognition of shared experience demonstrates the significance of building community. The barrier to understanding can be much lower when discussing symptoms, struggles, and obstacles with someone with similar life experiences. Wang and other
chronically ill people are able to find community with able-bodied and disabled people, but this experience related by Wang demonstrates the value of communication, care, and listening among chronically ill people. Echoing the impact of being in community with fellow disabled and chronically ill friends, Keah Brown reflects on the value of her friendship with other disabled women:

Vilissa, Alice, Maysoon, and Rebecca are my sistagirls who have physical disabilities, too. They keep me laughing, sane, and unapologetic in the face of problems within the disability community. We ride for each other and share opportunities when one of us can’t afford to take something else on. They know what it is like to live in a world that wasn’t designed with bodies like ours in mind. They also understand what bad days are like, how it is possible to be confident in who you are and still frustrated by the everyday small things that are hard to do like zip up jackets, close doors, grip objects, and navigate public spaces (p. 211).

Brown highlights the importance of building a network of friends and community members that allows chronically ill people and disabled people a place to talk about experiences, struggles, and opportunities. Whereas nondisabled allies may listen and sympathize, these authors demonstrate the significance of sharing life experiences with people who can truly understand what someone is going through. In an ableist society, building a network and community is crucial to the work of interrogating and dismantling epistemically harmful cultural logics.

In some ways, this corpus of memoirs works to build its own kind of community, sharing similar experiences to corroborate each other and create camaraderie. This network can lead to “collective social political action,” as laid out by Miranda Fricker (p. 8); many of these memoir writers are also advocates for increasing awareness, acceptance, and justice for chronically ill people and disabled people\footnote{For example, Keah Brown created the #DisabledAndCute hashtag on social media, which became a viral movement for self-love and confidence.}. Memoirs can
function as one tool for this advocacy, providing a clear view into the harms and consequences of epistemic injustice. By adding their testimonies to the ongoing conversation, each author adds legitimacy and weight to the others, working to counter the harmful cultural logics and epistemic violence discussed in this analysis section. Taken as a whole, this body of work opens doors for greater empathy, understanding, and support from a broad audience.

Conclusion

This chapter has demonstrated how broad cultural logics authorize and create epistemic violence in everyday interactions for women with chronic conditions. Audience refusal to listen to and believe women with chronic illnesses reveals the cultural scripts that repeat across individual interactions. Memoirists and essayists, in their representation of their experiences, highlight the negative impact caused by conversational patterns of unsolicited advice, denials of experience, blame, and shame, as well as the importance of positive connections and community building. Using both rhetorical listening and epistemic injustice as theoretical frames allows us to understand the overlap between being validated as a knower and as a rhetor, showing the daily effect of naysaying conversational moves. I argue that an expanded form of rhetorical listening can be a powerful tool to counter this harm. An expanded model of rhetorical listening must fully account for a multitude of perspectives and embodied experiences, as well as be available for the widest group of listeners and speakers possible, in order avoid the replication of normative structures, as the scholars in the literature review above highlight.

In the next chapter, we move from day-to-day interpersonal interactions to medical settings more specifically. Framed by conversations on ethos and rhetorical
disability, I will show that the cultural logics identified in this chapter remain present and powerful in clinical encounters, creating negative outcomes for women and marginalized patients who do not align with a rhetorically constructed *normal patient* archetype.
CHAPTER III

WELL, YOUR LABS ARE NORMAL: RHETORICALLY CONSTRUCTING THE
NORMAL PATIENT

This chapter responds to a cultural moment during which increasing attention is
being paid to women’s negative experiences with the medical system. A number of
popular press nonfiction books on the role of sexism in medicine have been published in
recent years, pointing to a
burgeoning reckoning in
public discourse (Fig. 3).
Journalists have also
extensively covered gender
bias in medicine (Billock,
2018; Fassler, 2015; Fetters,
2018; Moyer, 2022; Pagán,
2018; Pawlowski, 2019),
often sharing the same
alarming studies on

*Figure 3: A selection of popular press nonfiction books about gender bias in medicine published between 2018 and 2021.*
women’s interactions with the medical industry. Women are more likely to be given sedatives for reported pain, while men are more likely prescribed pain medication (Hoffman & Tarzian, 2001). Women are more likely to be misdiagnosed while having a heart attack (Nabel, 2000) or stroke (Newman-Toker et al., 2014). Women wait on average 16 minutes longer to receive pain relief than men when reporting acute abdominal pain in the emergency room (Chen et al., 2008). Medical outcomes are differentiated across race as well; the maternal mortality rate for Black women is 2.9 times the rate for white women (Hoyert, 2021). These statistics repeat across article after article, demonstrating both the systemic nature and the material consequences of medical bias.

Some of these patterns can be traced to a widespread lack of research into women’s health. Until 1993, clinical research funded by the National Institutes of Health (NIH) was not legally required to include women or other marginalized groups (NIH Revitalization Act of 1993). The NIH only began “to consider sex as a biological variable in preclinical research” in 2016, recognizing that people can metabolize drugs, experience pain, and present diseases differently based on their sex (NIH, 2015). These issues are also compounded in the case of chronic and autoimmune disease, which are often less “visible” or easily locatable (Dobson, 2021). Although there has been some advocacy and recognition of the need for change, such as Senators Duckworth and Schakowsky’s 2022 resolution to expand women’s health research, gendered differences in medical treatment and attitudes are still far too prevalent.

In addition to increasing research into women’s health, some movements in medical education and practice have emerged to improve patients’ experiences with medicine. One of the most well-known efforts in this area is narrative medicine,
introduced by Rita Charon (2001). Charon argues that physicians must develop both scientific competence and "narrative competence,” or “the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf” (p. 1897). Charon emphasizes the importance of building an empathic relationship between physician and patient, noting that listening to patients improves not only this relationship, but also clinical outcomes. Narrative medicine has been taken up as a valuable method by medical schools and programs; most notably, Columbia University offers a graduate degree in narrative medicine, directed by Charon. While Charon’s 2001 article does not engage overtly with gender, narrative medicine represents a concerted effort to increase empathy, connection, and positive patient experiences in clinical settings. Despite the uptake of narrative medicine and other shifts in the current medical paradigm, there is still a lack of widespread change in the way that the medical industry approaches women’s pain and experiences.

This chapter investigates the roots of gender bias in medicine and works to understand why—despite relatively high public awareness—this pattern remains a significant problem. I argue that gender bias and negative outcomes for women and feminine-presenting people exist and persist because of harmful cultural logics, such as those identified in Chapter Two, and medical discourses that rhetorically construct an idealized normal patient model. Judy Segal (2005) argues that people are constructed as patients by interactions with medicine, writing that “medical practice includes rhetorical activity that

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16 Personalized medicine (Vogenberg et al., 2010) seeks to move away from a “one size fits all” approach to medicine by focusing on an individual’s biology and genetics. Some major hospitals and clinics, such as the Massachusetts General Hospital Cancer Center, have introduced integrative therapies such as acupuncture, yoga, and music therapy to supplement more traditional cancer treatments. These movements demonstrate that there is energy to change the current medical system and frameworks to more fully account for a patient’s individual needs and their entire body more holistically.
makes patients and, even makes their disorders” (p. 39). Segal claims that patients’ clinical experiences and outcomes are affected by medical discourse (p. 50). I expand her work by arguing that not only are people rhetorically constructed as patients, but they are then also compared to the normal patient. The normal patient adheres to norms of identity and position (white, cisgender, economically privileged) and behavior (compliant, unemotional). Women, feminine-presenting people, and marginalized people face negative consequences, such as diminished ethos, for not aligning with this biased norm.

In this chapter, I uncover how women and marginalized people with chronic conditions are further marginalized by medical structures and norms. I first review scholarship from the rhetoric of health and medicine (RHM) on patient ethos and rhetorical disability in order to frame my identification and interrogation of the normal patient archetype. Then I review my methods for selecting data from the corpus of memoirs and personal essays. Finally, I analyze the chosen data, in which writers with chronic illnesses demonstrate both how the normal patient is constructed through rhetorical means, and its impact on women’s experiences and outcomes in medical settings.

**Literature Review: Ethos and Rhetorical Disability in Health and Medicine**

In this chapter, I draw on two key terms from rhetorical theory and the rhetoric of health and medicine (RHM)—ethos and rhetorical disability—in order to uncover the creation, maintenance, and impact of the normal patient trope. First, scholarship on the function of ethos in medical settings highlights existing deficiencies in the current biomedical paradigm and demonstrates how patients may be able to work within and
against those structures. In general, RHM scholars have shown how patients are at a
disadvantage in terms of establishing credibility in medical contexts. Second, I discuss
work on rhetorical disability in order to identify the consequences of minimizing patient
*ethos*. Scholarship about rhetorical disability emphasizes the role of audience and
environment in the determination of a rhetor’s legibility or credibility. Together, these
threads of scholarship provide a lens through which to uncover the underlying structures
that enable normative perceptions of what it means to be a patient and the sources of
gender bias in medicine. Chronic illness provides a telling case of the complexities of
patient *ethos* and the patient role because it interrupts many of our assumptions
surrounding health and medicine.

*Ethos in the Context of Health and Medicine*

Understanding *ethos*, or the persuasive force of the “character of the speaker,” is
central to understanding many rhetorical acts (Aristotle, *On Rhetoric*, 1.2.3). As
scholarship in rhetoric and composition has demonstrated, *ethos* is highly contextual, as it
depends on an individual’s identity and knowledge, as well as their location, position, and
individual’s *ethos* cannot be determined outside of the space in which it was created” (p.
329). Moreover, *ethos* reflects the values of the speaker’s location and context. As S.
Michael Halloran (1982) points out, virtue (*arete*) was essential to a classical
understanding of a speaker’s character. Halloran points out that “to have *ethos* is to
manifest the virtues most valued by the culture to and for which one speaks” (p. 60).
Being seen as a credible rhetor, then, can rely on a speaker aligning with the dominant or
normative values and expectations of a given culture or context. As scholars in RHM
demonstrate, medical contexts can emphasize existing power structures and cultural norms, which bestow and reinforce credibility in patients who correspond with those norms. As a result, the issue of diminished *ethos* for women and other marginalized patients is exacerbated.

This chapter extends existing analyses of patient *ethos* in RHM, such as Judy Segal’s (2005) foundational book *Health and the Rhetoric of Medicine*. Segal’s work demonstrates the obstacles patients face to be seen as credible speakers in clinical settings, using hypochondria as a central example. Her analysis provides an important frame for this project, given its focus on medical bias and the dismissal of women’s experiences. Segal argues that people experiencing hypochondria “bear the burden” of convincing others that they need care, and that “only rhetorical resources are available to them for this purpose” (p. 75). Segal asserts that understanding hypochondria requires a rhetorical account that acknowledges that the “ill person himself or herself is without authority of diagnosis,” resulting in a decrease of the “*ethos* or presenting character of the patient, whose attempts at making a case for illness undermine themselves by *being* such attempts” (p. 81). Segal’s analysis of hypochondria is particularly relevant to this chapter, as people with chronic illness often are not believed or taken seriously by medical professionals and, often, the harder they work to become credible, the less credible they become.

Building on Segal’s work on patient credibility, Cathryn Molloy (2020) argues for the importance of studying vernacular rhetorics and everyday interactions as a way to complicate understandings of *ethos*. Highlighting the role of bias in medical settings, Molloy writes that “specious beliefs about a person’s credibility based on demographic
markers interfere with clinical judgment” (p. 2). As will be discussed later, writers with chronic illness describe the role bias plays in interpersonal and institutional interactions with medical professionals, and how it interferes with patients’ credibility beyond the extent that Segal describes. To begin to counter the impact of bias, Molloy (2020) calls for “theorizing rhetorical ethos…beyond earned or deserved credibility” (p. 3). This chapter responds to Molloy’s call to focus more thoroughly on medical bias and to remove the connection of worth or merit from our understanding of ethos.

Recognizing the tension surrounding patient ethos and the rhetorically disabling effects of dominant medical discourses—which will be discussed below—patients have developed a number of strategies to bolster their ethos. RHM scholarship has analyzed some of these strategies, such as recuperative ethos, invitational ethos, and demonstrating scientific literacy. Recuperative ethos, as defined by Molloy (2015), is the “day-to-day discursive practices through which a person might regain credibility and, as a consequence, rebuild the personal, social, and professional standing that is often compromised in acute phases of mental illness” (2015, p. 140). The appeals attached to recuperative ethos—such as displays of astuteness, strong human connections, and religious topoi—are meant to show that speakers are “worthwhile and reliable speakers, thinkers, lovers, friends, and community members” (2015, p. 144). Building on Molloy’s work, Reed and Meredith (2020) offer “invitational ethos” as a strategy used by advocates and mothers of children with Down Syndrome to develop credibility collectively. In their study, Reed and Meredith demonstrate how advocates “disrupt disability stigma, while keeping their ethos intact,” often by making rhetorical decisions about the venue or audience for their messages, demonstrating that they are “familiar
with medical expertise,” or choosing to “affirm the controlling values of prenatal situations” (p. 260, 273, 276). Similarly, Holladay (2017) writes that displaying “scientific literacy” can be a way of “demonstrating ethos” in online communities such as mental health discussion forums (p. 14). Demonstrating awareness of and literacy with medical knowledges is a strategy deployed by patients with chronic illnesses as a way to support their ethos and counterbalance power structures in medical settings. Individuals’ ethos-building strategies are valuable tools for patients facing bias and stigma both in and out of medical settings and demonstrate significant rhetorical awareness. However, I argue that we must also attend to the larger structural forces that make these strategies necessary.

In spite of the rhetorical savvy of strategies like recuperative ethos or invitational ethos, the power of the normal patient ideal and its attendant values and norms can still overpower individual rhetorical strategies. Because ethos relies on cultural contexts and normative values, patients who do not align with the normal patient can enter medical interactions at a credibility deficit that can be partially but not fully addressed by individual strategies. This imbalance and the complexity of patient ethos in medical contexts mean that medicine can be a rhetorically disabling environment, as described in the next section.

Understanding Rhetorical Disability

Scholarship on rhetorical disability17 illustrates the stakes of discounting patient ethos. Medicine can become a rhetorically disabling context that denies a patient’s

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17 The concept of rhetorical disability has significant overlap with the idea of epistemic injustice, which frames my analysis in Chapter Two. I have chosen to use rhetorical disability in this chapter due to its more specific concern with rhetoricity. Because patients rely so heavily on being able to persuade providers to treat them, rhetorical disability better suits the context of the data in this chapter and allows us to see the
credibility and rhetoricity, often as a result of normative assumptions and values about ability, communication, and embodiment. Since its introduction in 2001, rhetorical disability has shifted from a way to understand how mental illness affects rhetorical legibility for individual speakers to a broader concept for theorizing the influence of cultural norms and structures in the rhetorical environment. I examine how rhetorical disability has been expanded to account for the rhetorical environment and its impact in various arenas of life, such as healthcare settings and politics, as a way to uncover the impact of diminished patient ethos.

Within rhetoric and composition and disability studies, rhetorical disability can be traced to Catherine Prendergast’s (2001) discussion of mental illness and rhetorical legibility. Framed by the experiences of a friend with schizophrenia, Prendergast demonstrates how perceptions of mental illness inhibit the perceived rhetorical ability of individuals with mental illnesses. Even as a schizophrenic individual speaks, their illness and identity as a schizophrenic person has a negative impact on their credibility (p. 47). Prendergast emphasizes the severe effects of stereotypes of mentally ill individuals, which function to “place the mentally ill and schizophrenics in particular in a rhetorical black hole” (p. 53). Within this black hole, schizophrenics and other mentally ill people are denied what Prendergast terms rhetoricability, or legibility as a “rhetorically enabled subject” (p. 56). Prendergast claims that “to be disabled mentally is to be disabled rhetorically” (p. 57). This claim has been taken up and revised by several scholars in the decades since Prendergast’s essay, including Prendergast herself.

stakes of rhetorical practice in medical settings more specifically. Used together, as they are in this chapter, the concepts illuminate the important similarities in epistemic and rhetorical practices, while still providing key frames for understanding representations of both everyday conversations and medical interactions.
Catherine Prendergast (2014) updates her previous concept of rhetorical disability to account for advances in medical care for mentally ill or disabled people and for the complexity of schizophrenics’ relationships with the medical model. Understanding rhetorical disability and the writing of people with schizophrenia or other chronic conditions requires us to “reckon with complexity” and nuance at every stage (p. 61). Prendergast argues that it is our responsibility to focus on the humans at the center of these conversations, rather than becoming bogged down in critiquing mainstream medicine. I concur with Prendergast’s call to center the people affected by chronic conditions and to acknowledge the good that medicine has done and will continue to do to improve patients’ lives. At the same time, I argue that this process of putting people at the center must simultaneously involve addressing the epistemic and material harm created by the current biomedical system.

Building on Prendergast’s work, disability studies scholars, including Cynthia Lewiecki-Wilson and Margaret Price, argue for expanded definitions of rhetoricability or rhetoricity that account more deeply for disability. Lewiecki-Wilson (2003) calls for a mediated version of rhetoricity, asking us to consider that “people who have psychiatric and cognitive disabilities that interfere with communication exercise rhetorical agency” (p. 157). Her article critiques a traditional “emphasis on the individual rhetor who produces speech/writing, which in turn confirms the existence of a fixed, core self, imagined to be located in the mind” (p. 158). Instead, Lewiecki-Wilson argues for “a revised understanding of rhetoricity as potential” that “can help us see that collaborative and mediated rhetoric, co-constructed through a reading of bodily rhetoric, can constitute rhetorical actions as much as individual speech or writing” (p. 164). Margaret Price
(2011) highlights the stakes of this expanded view of rhetoricity, writing that “to lack rhetoricity is to lack all basic freedoms and rights, including the freedom to express ourselves and the right to be listened to” (pp. 26–27). Price argues that “if one can communicate and be received as a valid communicator, one can be included in various humanist projects...if one lacks that particular ability, one is generally overlooked—or rather, obliterated as a speaking subject, placed into Prendergast’s ‘black hole’” (p. 27, emphasis original). Together, Lewiecki-Wilson and Price offer a clear view of the consequences of ableist views of rhetorical agency and illustrate the potential of rhetoricity as a theoretical and practical concept. In illuminating the rhetoricity of people with mental or psychiatric disabilities, Lewiecki-Wilson and Price’s scholarship set an important precedent for my project, which similarly argues for the rhetorical agency, ethos, and legibility of people with chronic illnesses.

Uptakes of rhetorical disability have also emphasized the role of audience perception and expanded the concept beyond psychiatric or cognitive disabilities. For example, Kim Hensley Owens (2009) expands Prendergast’s argument “to include those who are (or are viewed as) rhetorically disabled because they are experiencing pain,” such as women in childbirth (p. 265). Owens argues that women create birth plans “as a way of rectifying this situation where their ability to speak for themselves is (or is expected to be) temporarily disabled” (p. 248). Birth plans function as a way to reinforce women’s agency and the validity of their bodily knowledge—defined here as “an intuitive, tacit understanding of what one’s body is doing and can or must do” (p. 251). Owens also discusses how bodies are read and voices are heard in the context of childbirth, noting that medical providers prioritize either verbal requests or embodied
actions depending on which more closely aligns with standard medical practices\(^\text{18}\) (p. 250–251). Owens importantly demonstrates how rhetorical disability, like ethos, can be highly dependent on context, hinging on the intersections of audience perception, space, and time. Owens also shows the impact of gender in the manifestation of rhetorical disability in medical settings. By focusing on women’s experiences during childbirth specifically, Owens calls attention to the additional barriers women face in being seen as rhetorical subjects in clinical contexts. At the same time, Owens points to the rhetorical power of the medical environment itself. Medical contexts, especially potentially higher-risk ones like childbirth, can amplify the existing credibility deficit women face; being in pain or in a possibly emergent situation significantly contributes to the creation of rhetorical disability for patients, particularly ones that do not match the normal patient model.

While previous discussions of rhetorical disability center individual speakers, there has been a shift to include other elements of the rhetorical situation more overtly in our understanding. Jenell Johnson (2010) argues that we must also take the circulation of cultural norms and ideas into account; she defines “rhetorical disability not as the property of an individual rhetor, but as a failure of the rhetorical environment” (p. 461). Johnson also argues that stigma produces a "disabling rhetorical effect” that she terms “\textit{kakoethos} or bad character” (p. 461). Johnson highlights that this process occurs regardless of the strategies or tactics rhetors use to appeal to their audience; there are

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\(^{18}\) For example, if a woman who, before birth, asked to not be given an epidural does ask for one during birth, her voice is more likely to be prioritized. In comparison, a woman who has declined pain relief verbally is more likely to be given pain relief if her body appears to be in pain—either the body or the voice are legitimized when they align with medical convention, not when they make “effective” arguments (p. 267).
situations in which no amount of rhetorical cunning or métis can persuade an audience to listen. Johnson provocatively asks us to question the responsibility of individual rhetors to accommodate the audience and to acknowledge the power of dominant discourses and structures. Johnson writes:

> When rhetorical disability enters the attention of rhetorical scholars, it is usually as a moralistic tale of overcoming... We explore, often with our students, how writers and orators might best accommodate the audience, but rarely examine the limits of that accommodation or question the idea that the responsibility of accommodation falls on the rhetor (p 476).

Johnson’s work, as well as this project, push us to consider more complicated understandings of the rhetorical environment. Johnson’s argument that the conditions of the rhetorical environment can be the source of failure, rather than the speaker themselves, is central to my argument that cultural logics of health and illness are rhetorically disabling forces that originate in the rhetorical environment.

Discussions of rhetorical disability have also expanded to include how perceptions of bodies themselves can be rhetorically disabling through stigma and stereotypes, often using the intersection of health and politics as case studies. Elisabeth Miller (2019) combines rhetorical disability with Molloy’s concept of recuperative ethos—as discussed above—to investigate the functions of fat stigma in her analysis of former presidential candidate Chris Christie (p. 64). Miller argues that “fat stigma is rhetorically disabling in the cultural logics of the obesity epidemic” (p. 62). Like Johnson (2010), Miller examines the role of stigma, arguing that it “creates ‘rhetorical disability’

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19 In the same spirit, Heilker and Yergeau (2011) point to obstacles or barriers faced by autistic rhetors in rhetorical environments that expect and prefer neurotypicality. They write that: “The autist, as medically constructed, is self-focused, a two-pointed rhetorical triangle floating outside the context bubble. And yet such a stance on autism and audience awareness is itself audience unaware. … When audience issues occur on the part of the autist, the result is considered pathological” (p. 494–495). Their article highlights how rhetorical disability is enacted differently based on the context of the speaker.
when material and social contexts prevent individuals with certain kinds of bodies and minds from being perceived as capable rhetors” (p. 62). Also drawing on the political arena as a case study, Neville-Shepard and Nolan (2019) focus on Hillary Clinton’s 2016 presidential campaign and the instances in which she was maligned as “hysterical” or not healthy enough to serve as president. Their article argues that “kakoethos in terms of health is inherently sexist”—creating double binds for women. Within these double binds, “women are judged for both the rumored illness and perceptions that they have tried to keep it a secret” (p. 75). In these two articles, scholars show how deeply embedded cultural logics, such as stigmas surrounding bodies and gender, are and the powerful impacts they can have on communication. The data analyzed in this chapter demonstrates the consequences of these logics on individuals and on the medical environment overall.

Rhetorical disability emerges as a useful frame for this chapter because of the literature’s focus on environment and context, as well as its questioning of dominant norms of rhetoricity. Medicine can be an environment rife with rhetorical disability for patients, who are typically assigned kakoethos in clinical settings if they don’t align with the normal patient. To investigate this process, I move towards my corpus of memoirs and essays by chronically ill women and nonbinary people. The data from this collection of texts describes writers’ experiences of rhetorical disability and decreased ethos when opposing the normal patient model.

Methods

Like the previous chapter, this chapter centers a collection of memoirs and personal essays written by women and feminine-presenting individuals with chronic
illnesses as a way to better understand the relationship between rhetoric, gender, and chronic illness. This chapter also emerges from the preliminary coding described in Chapter 1. In this chapter and in Chapter 4, I focus on the medical category from the data, which included conversations with or interactions with medical providers, or experiences with the medical system more broadly.

After the first round of coding medical experiences, I conducted another round of more refined coding. Each code was grouped with data with similar themes into four categories: structural barriers to care, constructions of the normal patient, negotiations of expertise, and dismissal of experiences. The categories were developed in recognition of similarities across several codes and were dependent on the frequency of each pattern in the texts. The representations of these experiences showed the rhetorically disabling effects of medical structures, such as the idea of a normal patient—the focus of this chapter—and how expertise is negotiated in medical settings, which I will investigate in Chapter 4.

This chapter draws solely on data in the normal patient category, to allow for full engagement with this paradigm. After isolating data from the normal patient category, I conducted a final round of coding to identify similar characteristics of the normal patient. This process involved identifying the primary sources of tension, negative emotion, or harm in each interaction. Often, excerpts from memoirs and essays included several codes, reflecting the inherent complexity of understanding interpersonal interactions, especially in a medical setting. Through this recursive process, I identified two aspects of embodiment that demonstrate the tension between the idealized normal patient and the realities of actual patients. These aspects are (1) identity, or how a person’s body is
perceived or received based on their demographic characteristics; and (2) behavior, or how a person’s actions or embodied reactions are perceived or received. For each area of embodiment, patients are compared to the normal patient standard, as I will discuss below. Table 2 displays each category of patient characteristics, along with its frequency and themes. Each theme represents a place of friction between the normal patient and the actual patient. The sections of analysis below are organized around each category, moving in order of frequency.

### Table 2: Patient Characteristics

<table>
<thead>
<tr>
<th>Aspect of Embodiment</th>
<th>Description</th>
<th>Themes (with frequency)</th>
<th>Total Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>Demographic characteristics</td>
<td>gender (27)</td>
<td>71</td>
</tr>
<tr>
<td></td>
<td></td>
<td>reproduction (12)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>pain (10)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>race (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>socioeconomic status (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>weight (3)</td>
<td></td>
</tr>
<tr>
<td>Behavior</td>
<td>Actions or embodied reactions</td>
<td>compliance (24)</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td></td>
<td>time (12)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>emotion (9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>geography (2)</td>
<td></td>
</tr>
</tbody>
</table>

Based on these categories, my analysis describes the how gender bias and discrimination are represented and realized in personal writing by women with chronic illnesses, framed by scholarship on patient *ethos* and rhetorical disability.

### Analysis and Discussion

Building on my analysis of everyday interactions and identification of cultural logics in the previous chapter, this chapter examines how those cultural logics become fixed as norms in medical settings and the consequences for women with chronic illnesses. As Molly Margaret Kessler (2022) points out, norms are “expansive arguments
that cultural majorities (implicitly and sometimes explicitly) agree on and enforce” (p. 139). Norms are ubiquitous, but often imperceptible. Erving Goffman (1963) argues that “the general identity-values of a society may be fully entrenched nowhere, and yet they can cast some kind of shadow on the encounters encountered everywhere in daily life” (p. 128-129). I argue that it is crucial to call attention to norms in medicine precisely because of their simultaneous embeddedness and invisibility; even though norms can often feel obvious—especially for those who don’t align with them—their salience in narratives of chronic illness demonstrates their cultural power and impact. By shining a light on norms and tropes such as the normal patient, we can begin to dismantle them and improve outcomes for marginalized patients.

Through their representations of interactions with medical providers and systems, memoirists and essayists with chronic conditions reveal how pervasive the idea of a normal patient is to our current medical landscape and how this idea is created and upheld by rhetorical actions. By describing the consequences for contradicting this idealized expectation, women with chronic conditions demonstrate how the medical establishment is intended to serve a specific type of individual and the ways in which outcomes and experiences are worsened by not aligning with that model. As discussed above, I argue that the normal patient is constructed and can be observed across two axes of embodiment: identity and behavior. Medicine, as a result of the creation and maintenance of this trope, becomes a rhetorically disabling environment for patients who exist outside of what is considered normal. In spite of individual strategies to bolster ethos, patients are unable to gain credibility in this environment. In the sections that follow, I discuss examples from memoirs and essays that demonstrate the prevalence of
these characteristics of the normal patient and highlight the power of this ideal to
diminish patient ethos and create a rhetorically disabling environment.

*The Normal Patient: Identity*

The most common characteristics of the normal patient are related to norms of
identity. Examples from memoirs and essays revealed the friction that can emerge when
patients who do not conform to these norms enter a clinical setting. The codes included in
this category include:

- **Gender:** The normal patient is male; if the patient is female or female-presenting, their pain is a normal part of womanhood, and their primary concerns are their fertility and weight.
- **Race:** The normal patient is white.
- **Socioeconomic status:** The normal patient is able to afford their care easily and does not face any financial hardships.

Because of these identity-based norms, women and other marginalized groups face a
credibility deficit in medical settings; their ethos is discounted because they do not align
with the normal patient identity.

Gender is threaded through nearly all medical interactions described by the
memoirists and essayists in my corpus; as a theme, it often coincided with other codes.
Despite its saturation, it is important to discuss gender as a separate category in this
analysis while simultaneously acknowledging that separating out any of these themes as
concrete and isolated is impossible because communication and cultural norms are
always more complex and nuanced than discrete categories of analysis allow. I argue that
gender is still a valuable theme to parse out because of its impact on clinical settings and
the deep embeddedness of gender bias in medicine.

The central tension related to gender and the normal patient ideal is that the
normal patient is constructed as male. As discussed in the introduction above, this
construction is rooted in medical history, as medical research and knowledge has been traditionally based only on men’s bodies and experiences. Frost and Eble (2020) point to the pathologization of female bodies, meaning that they are “medicated, labeled as nonnormative, and brought under surveillance and disciplined by the biomedical sphere” (p. 4). This view of women as always already nonnormative entrenches the idea that male bodies are the default, resulting in worsened outcomes for women and other marginalized genders. The medical focus on male bodies became evident in the data at several points. For example, Emma Bolden writes about being prescribed a drug used to treat prostate cancer that is sometimes also prescribed to patients with endometriosis, though this use is much less common. Despite the FDA’s announcement that the drug could have serious side effects—some of which could be fatal—Bolden’s doctor did not share these risks with her. Bolden explains:

There was no reason for him to inform me. I was a female patient. All of the FDA’s tests, warnings, suggestions, revisions, and notifications related to the use of Lupron in male patients and male patients only. In their May 2010 news release, the FDA did acknowledge that ‘some GnRH agonists are also used in women,’ however, they didn’t say if female patients faced the same risks as male patients. That wasn’t because GnRH agonists don’t cause problems for female patients. It was because neither the FDA nor the pharmaceutical companies knew if GnRH agonists caused problems for female patients. No one had tried to find out (p. 163).

Bolden’s experience highlights the dangers of making men the default in medical settings. The lack of awareness, interest, and research into women’s health creates negative outcomes for women.

Writers also directly addressed their diminished ethos in clinical settings, pointing to gender as a key factor in that process. Abby Norman describes how it “suddenly seemed like doctors started to listen” to her concerns about pain with sex after she began bringing her male partner, Max, with her to appointments (p. 165). Norman writes that
this shift in taking her concerns seriously “either meant that they hadn’t believed me in the absence of Max as an alibi, or that they had believed me, but my suffering alone wasn’t enough to inspire action. Becoming a disappointment to a man, though, seemed to do the trick” (p. 165). This example demonstrates the complexities and limits of ethos-building strategies for chronically ill women. Bringing a supportive partner—what Cathryn Molloy (2020) terms a “credibility proxy” (p. 71)—to appointments did convince medical providers to listen to Norman’s symptoms. However, in this case, the success of this strategy reveals how significantly entrenched a preference for male bodies and opinions can be in medical settings and in larger cultural contexts. Karen Kopelson (2019) points to the “additional authority” that “masculinity” can bestow on a speaker, particularly when they critique or “write against the ethos of medicine” (p. 269, emphasis original). While Kopelson focuses on male doctors in her article on memoirs of death and dying, I extend this argument to also include patients and their advocates; her analysis shows that masculinity is a valued characteristic in medicine that can enable speakers to push back against entrenched norms. Norman was not listened to because she is a woman; her partner’s corroboration and description of “his own frustration” (p. 165) was a sufficient persuasive force, at least in part, because men’s experiences are foregrounded in medical contexts and men are already assumed to be credible.

Laboratory results and tests were discussed as an additional mechanism for discounting women’s experiences and symptoms and contributing to the rhetorical disability created by medical environments. Chronic illness is especially primed to oppose norms of how disease appears; many chronic conditions are difficult to diagnose or are less well-known, causing friction for physicians and patients when laboratory tests
come back “normal.” Several authors shared similar experiences hearing that their “lab work looked fine” (O’Rourke, p. 13) or “everything looked perfectly normal” (Ramey, p. 101). Relying on the objectivity of laboratory tests and visual observation can prevent clinicians from providing adequate care and force women to continue feeling pain or other symptoms longer than necessary. Vyshali Manivannan (2017b) highlights how this “ocularcentric objectivity” functions as way to deny the legitimacy of embodied sensations and ways of knowing. Cynthia Li points out that this belief begins with medical education; when experiencing her own mysterious symptoms, she still “believed in medicine as [she] had been taught. The tests were objective. They had the final word” (p. 51). Our current medical system prioritizes certain types of evidence over others, allowing the perceived objectivity of laboratory tests to speak over women’s embodied experiences. Depending solely on what is considered typical can prevent providers from appropriately listening to and treating the individual patient in front of them, while also normalizing pain and discomfort as an inherent part of being a woman.

Writers often revealed how pain can be tied directly to gender, as there is a pervasive cultural norm that pain is fundamental to being a woman. Several writers shared memories of feeling pain, fatigue, and other unwanted symptoms only to be told that “everyone has cramps” (O’Rourke p. 12) or “periods are supposed to hurt” (Parker, p. 4). Comments like these run counter to women’s own embodied experiences, and women’s pain is simultaneously dismissed and normalized. Caroline Reilly (2018, “It’s All”) points to this duality in her writing on endometriosis:

Existing in tandem with the disbelief of female pain is the notion that women should experience pain—that it’s ingraind in the “feminine” experience. In the ER we’re asked, “Are you sure it’s not that time of the month?” When we complain to our parents, or peers, or doctors that our cramps are debilitating,
we’re handed painkillers and heating pads but rarely answers. We’re told that
periods are supposed to hurt. We’re told that symptoms like nausea, headaches,
and debilitating abdominal pain are all just part of the ride. We’re told that
everything looks “normal.”

Because pain is viewed as a “normal” part of being a woman, the threshold for a medical
provider to take a woman’s account of her pain as a serious issue worth investigating is
much higher than it would likely be for a man. This norm related to pain therefore creates
a rhetorically disabling environment for women—they are not viewed as credible rhetors
when describing their embodied experiences.

For cisgender women, the “normal patient” is also constructed as being concerned
with her fertility above all else, as evidenced by the prioritization of reproductive
potential by medical providers. In several memoirs, themes of fertility emerge as points
of tension. Abby Norman writes: “the things that actually did concern me…didn't seem to
carry the kind of weight that concerns about my reproduction did” (p. 196). Norman’s
reflection demonstrates that medical and cultural norms expect that women will be
primarily focused on their ability to have biological children, often to the detriment of
other priorities or concerns. As a result, the normal patient construction shares this
priority, and women with chronic illnesses face friction when their values and plans run
counter to this idea, such as plans to pursue a career or higher education. Emma Bolden
remembers being told by doctors: “if I wanted to have a baby, I'd better do it young. … I
was thirteen” (p. 79). Bolden also explicitly names the tension between women’s career
and educational plans and the expectation of childbearing, remembering an appointment
years later with a fertility specialist. She writes that the doctor tells her: “Don't wait until
you're 38 and on your fifth PhD to realize you forgot to have a baby” (p. 201). This focus
on reproduction can even prevent clinicians from addressing women’s pain. Meghan
O’Rourke describes an appointment for severe pain in which she is told she likely has endometriosis; the doctor informs her that her diagnosis “doesn’t really matter unless you want to get pregnant: it can cause infertility” (p. 12). O’Rourke describes feeling “puzzled by the way my pain had been relegated to a sign that my fertility might be compromised, not a problem in its own right” (p. 12). The prioritization of women’s potential fertility over their current discomfort or other symptoms reveals the deeply embedded cultural logic that pain should be accepted as an inherent part of womanhood, only becoming a problem worth treating when reproductive potential is threatened.

Similarly, weight is implied to be a central concern for women in medical settings, revealing a cultural emphasis of body size and appearance. For example, Samantha Irby, who has Crohn’s disease, relates a time when a nurse asked if she might “wanna hop on the scale just for fun” after observing that Irby’s face looked “so slim!” (p. 162). Tessa Miller remembers how the doctor who diagnosed her with Crohn’s disease “made a bad joke about how I could eat Big Macs and not gain any weight…as though my disease was lucky: Don’t you know women value being thin above all else?” (p. 40, emphasis original). While weight emerged less frequently than reproductive issues or gender more generally, these examples demonstrate the values and virtues that female patients are expected to carry with them into clinical settings. As discussed previously, ethos relies on a speaker sharing a culture’s values; when women disrupt this paradigm by having other priorities, their ability to be seen as credible speakers is denied.

The normal patient is also white, creating a hostile and often rhetorically disabling environment for patients of color. In my corpus of memoirs and essays, race is discussed most fully in Jen Deerinwater’s essay “Checkbox Colonization: The Erasure of
Indigenous People in Chronic Illness.” Deerinwater describes the anger she feels at being asked to check a box on a form to describe her identity:

Native people are often asked to define ourselves with these white supremacist, settler-created racial categories like “American Indian.” I am not an “American Indian.” I am a citizen of the Cherokee Nation of Oklahoma. I am Tsalagi. When filling out official forms, including medical forms, I’m often forced to swallow my rage and check “American Indian” or write in “Native American”—another term I detest—in the “other” category. … And even when I mark one of these categories, I am still listed as “white” in my medical records. Erasing my Indigeneity ensures that I never receive the medical care I deserve. (p. 47)

Deerinwater’s frustration at this standardized intake form demonstrates the structural, institutional entrenchment of a specific set of racialized norms. The checkbox functions as a microcosm for the wider medical establishment—the fact that there is not room for Deerinwater’s full identity in her records reflects a broad pattern of erasure of nonwhite identities in much of medicine. Porochista Khakpour also describes how her Iranian American identity is erased as she seeks medical care, writing “every part of me in illness became the white woman of their dreams” (p. 129). Whiteness becomes assumed as the baseline, as the norm.

In addition to erasure, writers also shared reflections on the physical, emotional, and epistemic harm caused by systemic racism in medicine. Deerinwater relates experiences of being denied pain medication and fielding “degrading and humiliating questions and comments from medical providers” including racial slurs, often while in vulnerable positions (pp. 47-48). Similarly demonstrating the devaluing of patients of color’s experiences, Destiny O. Birdsong writes about being told to wait out the adverse side effects from the biologic medication\(^{20}\) prescribed for her autoimmune disorder. Her

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\(^{20}\) According to the FDA, biologics are “medications generally made from living sources like bacteria and yeast. Biologics treat many conditions like arthritis, diabetes, kidney conditions, cancer, macular
essay “Build Back a Body” describes the paternalism she encountered during this process, a result of intersecting forces of sexism and racism:

Biologics can be dangerous for many reasons (weakening the immune system is only one of them), but they were prescribed for my eventual good; after all, they’d never done this to anyone my doctor had seen before. My body, Black and woman, was not special. It would eventually adjust.

Here, Birdsong’s demonstration of how oppression can manifest in worsened outcomes and lead doctors to accept negative consequences and inadequate care for Black patients and other patients of color. As Birdsong points out in another essay, “Surviving Karen Medicine,” Black patients are assumed to have a higher pain tolerance than white patients—a pattern that can be traced back to nineteenth-century physician “James Marion Sims’s horrific surgeries without anesthetics on enslaved Black women,” which extended to other widely held beliefs about racially differentiated pain tolerances in the nineteenth century and today. As discussed above, women’s pain in general is treated as normal and a part of life, and the intersection of misogyny and racism, also known as misogynoir (Bailey, 2010; Bailey & Trudy, 2018), furthers this perception.

In addition to gender and race, the normal patient is constructed in terms of socioeconomic status. The normal patient is assumed to have health insurance and the financial stability to pay for medications, doctors’ appointments, and other care.

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Racially biased beliefs about pain tolerance persist into the twenty-first century. Hoffman et al. (2016) demonstrated that “individuals with at least some medical training hold and may use false beliefs about biological differences between blacks and whites to inform medical judgments, which may contribute to racial disparities in pain assessment and treatment.”

In actuality, the CDC’s National Center for Health Statistics reported that: “in 2022, 27.6 million people of all ages (8.4%) were uninsured” (Cohen & Cha, 2023). This percentage was higher in 2019 (10.3%).
Johanna Hedva, in “Sick Woman Theory,” demonstrates the financial barriers to receiving answers and quality care in their journey to a fibromyalgia diagnosis:

…my “primary care” doctor (which I put in quotes to mark the absurdity of this claim) had referred me to see a neurologist, rheumatologist, and immunologist, so I could begin testing for MS and other autoimmune diseases that some of my symptoms pointed to. My insurance never approved these referrals, nor could it find a specialist within 150 miles who was covered by my plan; the neurologist who diagnosed my fibro agreed to see me out-of-network, cash-only, as a favor to my psychiatrist who was his friend (section 3).

Hedva’s description of only being able to receive a formal diagnosis and adequate care as the result of a personal network and “a favor” highlights structural issues in our current model of medicine. Because the normal patient is constructed as financially secure, there can be a lack of a safety net for patients who are not. This can leave patients to either hope for a situation like the one Hedva describes or sacrifice necessary care. For example, Samantha Irby highlights the consequences of relying on the expectations set forth by the normal patient ideal, writing: “My heart is enlarged and in the early to middle stages of failure because for a long time I couldn't afford this medicine I was supposed to take” (p. 169). Memoirists and essayists negotiate sharing experiences of being denied care while also acknowledging the even broader systems of marginalization and oppression that often intersect to create credibility deficits and rhetorically disabling environments. Beyond norms of identity, expectations surrounding behavior also have a significant impact on patients.

The Normal Patient: Behavior

Patients’ behavior, both in a clinical setting and outside of it, emerged as a rich site for understanding the normal patient. Examples from memoirs and essays revealed
norms of behavior and action that patients were expected to adhere to. The codes included in this category include:

- **Compliance**: The normal patient often sacrifices autonomy in medical contexts, is comfortable with lacking autonomy, and adheres exactly to medicine’s advice and expectations.
- **Geography**: The normal patient is geographically stable.
- **Time**: The normal patient moves at the same pace as medicine.
- **Emotion**: The normal patient does not express emotion beyond what is considered appropriate or acceptable to medical providers.

Across each of these dimensions, the norms of patient behavior prioritize stability and efficiency—at the jurisdiction of healthcare providers and institutional policies—and imply that patient credibility is tied to aligning with these expectations.

Themes of compliance emerged often in the data—on its own, this theme was the most common code after gender. Patient compliance is a complex topic that requires rhetorical consideration, as scholars such as Judy Segal (2005) and Daniel Skinner and Berkeley Franz (2018) highlight. In this chapter, though, I focus on compliance as a way to describe how patients’ bodily autonomy is treated and the attitude and behavior that patients are assumed to bring into medical spaces. Across memoirs and essays, writers described situations where their bodily autonomy was expected to be sacrificed, often without hesitation or without any process of informed consent. For example, Sarah Ramey, who experiences severe pelvic pain, underwent a surgical procedure to attempt to address the pain, believing that the surgery would be “relatively noninvasive” (p. 270). Upon waking from anesthesia, Ramey learned that, instead, her doctor had performed an “outdated” and “totally different” surgery than what had been described beforehand (p. 271-272, emphasis original). Other women described procedures performed without their full informed consent; Tessa Miller’s physician “insisted” on performing an unwanted
rectal exam that Miller “was not ready for” (p. 8). In these cases, women were presumed to accept these outcomes and experiences; the norms within the medical context removed their ability to be rhetorically legible as important stakeholders in their own health and bodies.

The idea of a patient as compliant is reinforced in medical education, in comments made to patients, and, sometimes, in patients’ own attitudes. Cynthia Li, who writes from the perspective of both a physician and a patient, reflects on how the norm of compliance was taught to her during her rotation in trauma surgery in medical school. Li describes being tasked with inserting a N-G tube23 into a noncritical patient’s nose and throat. Although the patient removed the tube herself, Li is coached to replace it; a “junior resident” asks Li, “Who’s in charge here?” (p. 18). Li reinserts the tube, and later asks why the tube was necessary. The resident replies: "it wasn't…but this is how you learn" (p. 18). While the realities of trauma surgery and emergent care must of course be acknowledged, this moment clearly affected how Li framed her medical practice and revealed a deeply held attitude in medicine regarding patient consent and compliance. In this example as Li represents it, a patient’s compliance was expected and could be forced—whether necessary or not. This attitude is then taken up by other medical professionals. Destiny O. Birdsong (2021) remembers a dietician forcefully recommending a specific diet plan to address Birdsong’s Crohn’s disease. Although the plan contradicted Birdsong’s religious practices, Birdsong writes that the dietician said: “Listen,” she huffed. “Do you want to end up in the hospital, hooked up to an IV with a

23 “This was a nasogastric tube. Placed correctly, it would pass through the nose down to the stomach, thereby protecting a semiconscious or unconscious patient from inhaling stomach contents in case they vomited” (Li p. 18).
doctor cutting out your insides? If not, then you need to listen and follow this plan.” The threatening tone of this comment reveals that compliance is a key component of the normal patient trope, and the negative consequences for deviating from it. This attitude then can be internalized by patients as well. Abby Norman writes that, while undergoing an MRI for muscle weakness, she “had no fear, because [she] trusted that doctors knew how to fix people—so long as they wanted to be fixed” (p. 35). Norman’s confidence that positive medical outcomes rely at least partially on patient behavior and trust reveals the ubiquity of compliance as a medical norm.

Behavioral norms also impact patients’ movement through space and time. Maintaining access to medical care limits patients’ geographical mobility. Samantha Irby (2017) writes that she would be unable to move cities: “I can’t get out…my doctor is there” (p. 4). Similarly demonstrating how medicine can control patients’ mobility, Tessa Miller describes the difficulty of having her infusion treatment for her Crohn’s disease completed at an out-of-state infusion center during the COVID lockdowns in 2020—normally a resident of New York, Miller relocated to live with family in North Carolina “during the worst of New York’s outbreak” (p. 228). Over the course of two full pages, Miller provides a litany of the copious steps she had to complete to accomplish the move. After two infusion treatments, the insurance company refuses to cover more, and Miller is required to return to COVID-stricken New York: “What an American problem, to be faced with flinging myself back into a virus hot zone because my health insurance

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24 I do want to flag here that Miller’s ability to leave New York also demonstrates some economic and class privilege; being able to relocate to a family vacation home was not an option available to all vulnerable people living in New York during COVID lockdown. Miller acknowledges this tension, writing: “I wasn’t sure if we were doing the right thing; to me, it felt like fleeing, just like those rich folks of yesteryear” (p. 228).
company says I have to” (Miller, p. 230). Here, Miller displays familiarity with how medical systems, such as an insurance company and their policies, can limit geographic mobility, treatment options, and, ultimately, medical outcomes and consequences for patients. Irby and Miller’s acknowledgements of geography show that the normal patient is not expected to want to move for personal, career, or safety reasons.

In terms of time, the normal patient should be comfortable moving at the same pace as medicine. That is, when a procedure is rushed or a diagnosis takes several years, the normal patient should not complain. Highlighting this tension perfectly, Destiny O. Birdsong (2020) writes that “whenever [she] complained, [she] was told to wait” after experiencing abnormal side effects to a prescription medication. Some writers noted the lengthy amount of time a diagnosis can take for chronic illness, such as Zipporah Arielle and Samantha Irby (2013). Others described how quickly medicine can move, leaving patients feeling hurried. Meghan O’Rourke describes being “patronized…and rushed out the door” (p. 63), and Emma Bolden recalls one appointment that felt as though the provider’s “goal was actually to move me through and out of the office as quickly as possible” (p. 62). At an extreme end, Tessa Miller underwent a painful procedure without any analgesics or other pain relief without being told ahead of time because her doctor was not “able to schedule an anesthesiologist in time” (p. 143). In each of these examples, patients are intended to adapt their time to the needs and norms of the medical system, regardless of their personal suffering.

25 I provide a more thorough discussion of time and chronicity in Chapter Four.
26 Etymologically, both the noun and adjective forms of the word patient come from the same Latin root, meaning “to suffer or bear” (Neuberger, 1999).
The last category of behavioral norms is tied to emotion. The normal patient does not display inappropriate emotion. Women are told, either implicitly or explicitly, to not express their discomfort, anger, or distress. The writers in this current study demonstrated awareness of this affective requirement. Sarah Ramey describes the consequences women face in expressing emotion in front of medical providers. Describing a particularly painful gynecological procedure, Ramey notes that when her “composure fell apart…[her] tears seemed to fuel disproportionate levels of disgust, anger, and even tamped-down rage on the other side of the stirrups” (p. 201). Her provider’s negative affective reaction to Bolden’s tears reinforces the idea that showing emotion as a female patient is penalized; patients then sometimes internalize this idea. For example, Emma Bolden, suffering “extreme pain, bleeding, and humiliation” after a gynecological surgery, writes that she “never told the gynecologist that [she] was angry with him” (p. 134). Bolden ties her suppression of her anger to “how [she’d] wanted to be a good patient at all times, no matter what that meant” (p. 134). This awareness and internalized control of emotion becomes especially relevant for Black women; Birdsong writes about navigating the “‘angry Black woman’” trope in medical settings and points to the centuries of medical racism that continue to impact the quality of care that Black patients receive. Writing about an appointment with a new dermatologist, Birdsong remembers how a doctor discounted how frustrated Birdsong deserved to be with her previous care: “‘Dr. O messaged me about what happened during your last visit and how frustrated you are. I understand that, but it’s important to remember we’re here to help.’ Moments later, I heard her outside, joking with one of her residents about my case.” This provider’s comments reveal a paternalistic attitude that not only functioned to minimize Birdsong’s
affective and lived experience, but also to overall reinforce the idea that patients who are emotional are abnormal.

Across each of the norms of behavior discussed here, medicine is revealed to have specific standards for how patients act, move, and emote in clinical settings—how to be a “good patient.” When patients fail to adhere to those standards, they face obstacles to quality treatment such as structural barriers, negative attitudes from providers, and increased bias.

**Conclusion**

In this chapter, I have discussed the ways in which medical discourse rhetorically constructs an idealized normal patient. This ideal discounts patients’ *ethos*, creating a rhetorically disabling environment for anyone who does not align with it—especially women and other marginalized people with chronic illnesses. Patients can use individual strategies to increase their credibility, but the diminishing of women and other marginalized patients’ experiences is a systemic issue. While the *normal patient* standard is not the only source of gender-based discrimination in medicine, the friction between the expected and the actual patient uncovers some of the cultural forces at work that maintain medical gender bias. Working to counter this archetype and improve patients’ experiences in clinical settings will require change at the level of both individual providers and the broader medical institution.

In the next chapter, I explore how various forms of knowledge are constructed and understood in medical contexts. Because of cultural logics like the normal patient trope and other current structures, embodied knowledge is typically discounted. To call
attention to this troubling pattern, I investigate how the expert role is tightly controlled through rhetorical means in medicine.
In November 2021, seven women filed suit against Yale University. While patients at the Yale University Reproductive Endocrinology and Infertility (REI) clinic, the women had undergone invasive in vitro fertilization (IVF) procedures, such as egg retrievals, without sufficient pain management (Fig. 4). Without the knowledge of patients or clinic employees, one nurse had stolen much of the clinic’s supply of fentanyl, an opioid analgesic, and replaced the drug with saline. As a result, women

27 An investigation into the matter by several government agencies revealed that “approximately 75 percent of the fentanyl given to patients at the Yale REI clinic from June to October 2020 was adulterated with saline” (U.S. Attorney’s Office, District of Connecticut). While only seven women sued Yale initially, their lawsuit claims that it is possible that the number of women affected could be, and likely is, much higher—possibly in the hundreds (Collins, 2021). By June 2023, the number of plaintiffs had increased to 68 (Lindner, 2023).
experienced immense pain during and after their egg retrievals. One patient said in a podcast interview: “it felt like someone had been inside me and gutted me. … It was someone had been inside me, scraped me hollow, it was burning” (Burton, 2023a).

In addition to the harm and pain caused by the lack of pain management, the women allege in their suit that “when they told staff of their extreme pain during and after the procedures, their concerns were dismissed” (Collins, 2021). Patients tried to alert providers to their pain and to the fact that the medication wasn’t working during the procedures. One patient describes the experience: “I was just like, I feel everything you’re doing. And that was when I — I remember actually saying to them, I could drive myself home right now. I’m that alert” (Burton, 2023a). The women’s pain was sometimes believed, but their knowledge that something was wrong was not taken seriously. After the procedures, women describe feeling as if they were “annoying” their doctor, being treated “like I was nuts for still being in pain,” and being prescribed anxiety medication before their next retrieval, despite experiencing “severe pain, not anxiety” (Burton, 2023a). Another patient, who is a physician, knew something was wrong, both because of her professional expertise—“I know what fentanyl does”—and her own personal history of receiving fentanyl during a prior retrieval—"I said I know exactly this was saline. I can taste the saline in my mouth, and it’s not the feeling of fentanyl” (Burton, 2023b).

Providers at the clinic did not realize that there was a larger issue until an employee noticed a loose cap on a vial of fentanyl. After this discovery, Yale mailed patients a letter assuring them that the clinic had “closely monitored patients for signs of discomfort during every procedure” and was “confident that our patients stay
comfortable, even if one medication is not working” (Burton, 2023a). Despite patients’ experiences to the contrary, Yale supported their policies and procedures, revealing a dedication to maintaining the current biomedical paradigm that prioritizes institutional and systemic norms, sometimes to the detriment of individual outcomes. Women at the REI clinic were not only forced to endure painful procedures without any analgesia—an incredibly harmful act on its own—but their pain was also dismissed. They were not considered experts about their own bodies and experiences.

This friction between professionalized, institutional expertise and personal, embodied expertise is at the center of this chapter. The Yale clinic case and the experiences shared by women with chronic illness in their memoirs and essays reveals a hierarchical structure in medical settings that tightly controls who is allowed to be an expert, what kind of knowledge “counts,” and whose knowledge is validated as expertise. This chapter does not seek to place one kind of knowledge above the other. It is not productive to argue that embodied expertise is more legitimate or more important than medical expertise, and framing the chapter this way would put forth a binary of expertise that does not reflect the realities of knowledge production—that is, the fact that physicians also have their own embodied expertise and patients are able to gain medical knowledge through their own research practices. However, I do argue that embodied knowledge, especially for women and other marginalized people, is discounted, ignored, and dismissed in medical settings and patients often are denied the role of expert.

This chapter seeks to understand how we define and mobilize expertise in clinical settings in order to better address worsened outcomes and experiences for women in medical situations. I argue that a rhetorical account of professional and embodied
expertise can work together to advocate for a more inclusive and effective medical system, using the concept of chronicity—which accounts for the variance and temporal instability inherent in chronic illness—as a frame. We need a negotiated version of knowledge production in medicine that incorporates everyone’s expertise, especially when dealing with chronic illness. Embracing chronicity and the variability inherent in chronic conditions may be one way to achieve this goal. Drawing on rhetorical scholarship on expertise and perspectives on chronicity from the rhetoric of health and medicine and disability studies, I return to the collection of memoirs and essays I analyze in Chapters 2 and 3 to demonstrate the mobilization of expertise in medical settings related to chronic illness and how medical rhetorical practices place boundaries around the expert role for patients.

**Literature Review: Expertise and Chronicity**

In this chapter, I frame my discussion through two lenses: expertise and chronicity. Together, these concepts help illustrate how various forms of experience and knowledge are inequitably legitimized in medical settings and propose chronicity as a potential solution to this issue. First, scholarship on expertise demonstrates that the expert role is highly rhetorical and that the label of expertise depends on how a speaker is interpreted. In medicine, patient experiences are typically denied as expertise because embodied knowledge is not always considered reliable, which illustrates how the medical system works to maintain disciplinary boundaries around the expert role. To further illuminate this denial, I draw on work about chronicity, a body of literature that highlights the fluidity and liminality inherent in chronic illness. Incorporating chronicity as a frame
in discussions of chronic illness and expertise may lead to the acceptance of expertise as an equally fluid concept.

**Expertise: Framing Knowledge Rhetorically**

As discussed in Chapter Three, the *normal patient* trope creates a rhetorically disabling environment for people with chronic illnesses in which their ethos is dismissed. In this chapter, I unpack one mechanism of this process—the mobilization of expertise in medical settings. Communication studies scholar E. Johanna Hartelius (2011) highlights expertise’s “fundamental rhetoricity,” recognizing how it is “instituted and negotiated” across various rhetorical situations (p. 3). As this chapter will show, expertise is highly contextual and dependent on circulating cultural logics. Consequently, I interrogate how normative perceptions of expertise work to either validate or discount a person’s experience; medical providers’ experiences are codified as professional expertise, while patients’ embodied experiences are not classified as legitimate expertise or knowledge.

To define embodied knowledge, I draw on previous literature in rhetoric and composition that argues that the body is a legitimate source of knowledge. Hui Niu Wilcox (2009) argues that bodies can be “agents of knowledge production” (p. 105). Similarly, Cynthia Lewiecki-Wilson and Jen Cellio (2011) argue that “in liminal spaces, cultural constructions of the subject and situated embodied experiences intermix, and from/in this fluid boundary state, resistance to cultural scripts and emergent knowledge can potentially arise” (p. 2). I also work from A. Abby Knoblauch’s (2012) concept of embodied knowledge as a “generative force” that can “highlight difference instead of erasing it in favor of an assumed privileged discourse” (pp. 55, 62). Identifying and
studying embodied knowledge allows for the recognition of nondominant discourses and perspectives on chronic illness.

I work from an understanding of embodied knowledge based in sensory experiences, which work in tandem with memory and other past experiences. Rhetoricians have demonstrated how sensory knowledge plays a role in workplace settings. Beverly A. Sauer (2003) describes the “pit sense” developed by miners to prevent and respond to dangerous conditions. Sauer writes that this sense is a form of “embodied sensory knowledge” that is “grounded in embodied sensory experience,” such as “physical signs or sensations in their bodies” (p. 182). This knowledge then allows miners to “react to unknown and unpredictable variables” (p. 214). Specifically addressing medical settings, Lillian Campbell and Elizabeth L. Angeli (2019), in their study of emergency medical services providers, describe this kind of knowledge as intuition. They argue that intuition can be defined as “a type of intelligence that develops from experience, and from the ability to be attuned to the surrounding environment and material conditions of a workplace”—or, a type of knowledge that relies on embodiment and experience (p. 353). As these scholars show, embodied or lived experiences can function as a form of expertise; however, in medical settings, this view of intuition often only applies to providers, not to patients.

This imbalance in who is considered an expert can be traced to the role of context in negotiating expertise. The conferral of expertise depends on not only an individual’s identity and knowledge, but also their position within an institutional dynamic (Hartelius, 2011, p. 9). Medicine provides a clear example of the role of context in understanding expertise; physicians are considered experts, at least in part, because of their positions as
physicians. Because of this, physicians and other providers’ intuition and experiences are considered expertise. Medical settings can emphasize existing power structures, typically resulting in expert opinion and experience being elevated to expertise, while patient experience is diminished. As Carolyn Miller (2003) notes, within scientific or technical settings—like medicine—professional experience can easily become expertise. Miller shows that expert opinion, in situations of risk, often is treated as “factual evidence” (p. 184). In medicine, physician expertise can rely on the naturalization of their experiences and opinion. I argue that, while professional training and expertise are vital parts of the medical landscape, their unquestioned elevation should be challenged; our discussions of medicine should expand to include the intuition of patients more fully.

People with chronic illnesses develop expertise and become experts about their conditions and bodies, often based in their lived experiences. Demonstrating the rhetoricity of expertise, Hartelius (2011) notes that people who are not typically considered experts, such as eyewitnesses or people living with chronic conditions, still have and share expertise. Linking this type of expertise to embodied experiences, she writes: “they offer their ways of knowing as inextricably linked to their bodies; they know things because their bodies know things” (p. 21). Within RHM, Edwell, Singer, and Jack (2018) introduce the concept of “health techne,” or “patients’ experiential knowledge and embodied practices that enable them to determine and administer care to their own bodies” (p. 52). Edwell, Singer, and Jack demonstrate the necessity of “alternative narrative strategies to come to terms with living with a disease that will never go away” for individuals with chronic illnesses, who often face misrepresentation or disempowering dominant narratives (p. 59). Edwell, Singer, and Jack’s work
demonstrates the expertise developed by people with chronic illnesses about their bodies and their conditions. At the same time, though, Lora Arduser (2017) reminds us to not view patient expertise as a fixed concept; because expertise is rhetorically grounded, people with chronic illnesses move through “a number of subject positions and switch among them depending on the needs of a situation” (p. 116). As I will discuss in the next section of this literature review, chronic illness experiences are marked by this fluidity.

Scholarship in RHM has started to theorize how patient and physician expertise are negotiated in context, though this negotiation needs to become a more commonplace practice in medicine. Notably, Judy Segal (2005) traces shifts in models of patient compliance over the last several decades, which have attempted to move from a paternalistic relationship between patient and healthcare provider to a more equality-focused concordance model. The concordance model places physician and patient knowledge on the same level of credibility, despite the fact that, as Segal points out, physicians do have greater knowledge of medical topics than patients. While the concordance model is meant to even the playing field for patients and doctors, the model is too general—that is, some patients, such as those with chronic conditions, can be considered “expert” based on their “research and experience” and invited by their doctors to continue their education, while others refuse any kind of medical advice, such as that to immunize their children (p. 146). Segal highlights that “a single model for participatory decision making does not take divergent cases properly into account,” and instead offers a view of patient adherence to physician advice based in rhetorical theory that “suggests a negotiation of expertise” (pp. 146-147). This rhetorical model argues that
“patient expertise is not an imitation of medical expertise, it is a different expertise” (p. 147).

Since Segal’s 2005 book, scholarship has emerged on negotiated medical expertise in action. For example, Abigail Bakke (2019), in a discussion of a physician-moderated online forum for patients with Parkinson’s disease, explores the relationship between professional and personal expertise and how expertise on medical topics has been “democratized” (p. 158). Bakke notes that it is important to value both medical and embodied expertise and highlights the role of social trust in understanding the deployment of expertise. In her study, Bakke demonstrates that “patients do generally trust both forms of expertise, but at times prefer one over the other” (p. 162). Bakke’s article demonstrates that expertise in medical settings is nuanced; there is rarely a situation that demands entirely either professional or personal expertise, rather than a negotiated combination.

I concur with Segal’s and Bakke’s arguments; clinicians have education, training, and experience that patients do not, and these scholars do acknowledge patients’ unique expertise. Simultaneously, I argue that we need to extend Segal’s interrogations of both forms of expertise more fully to account for both divergent cases and for systemic biases. That is, we need to question the existing biases that are built into medical education and research\(^\text{28}\); as the memoirists and essayists in this current study show, paternalism, bias, and the dismissal of patient expertise are still present in the medical system, resulting in the perpetuation of harmful cultural logics. At the same time, I want to avoid calling for replicating the same issue of unchallenged expertise for patients; it is important to not

\(^{28}\)For example, sociologists Patricia Louie and Rima Wilkes (2018) found that only 4.5% of images in widely used medical textbooks depict dark skin.
draw definitive, universal conclusions based on individual lived experiences. Instead, I argue that decision-making in most clinical encounters should be based on deep, individualized communication and the experiences and expertise of both providers and patients.

This chapter argues that while experiential expertise is certainly distinct from medical expertise, patients’ knowledge is crucial to forming a complete understanding of chronic illness and its rhetoricity. I illustrate that the expert role in medicine is deeply rhetorical and contextual, often in ways that discounts patients’ expertise. This rhetorical understanding of expertise can show the ways in which an increased uptake of chronicity might affect our conversations about and experiences with medicine.

*Chronicity: Embracing Change and Fluidity*

This chapter also draws on literature on chronicity, a key term that has become more prevalent in disability studies and RHM in recent years, because of its potential to expand our current conceptions of knowledge in medical settings and improve doctor-patient communication. Broadly, chronicity can be defined as the state of continuing over a period of time without a definitive end. In RHM and disability studies, chronicity’s definition and application varies, but the concept’s rhetoricity is typically emphasized. In their introduction to their 2022 *RHM* special issue on chronicity, Arduser and Bennett argue for the inherent “rhetorical character of chronicity,” as it is highly contextual and fluid (p. 123). They go on to highlight chronicity’s connection to knowledge and expertise, writing that the definitions of chronicity in the special issue call for “a relational, fluid concept of agency that blurs the boundaries between medical experts” (p. 126). Rhetorics of chronicity demonstrate the fluidity of both chronic illness and
expertise, as their definitions and experiences shift depending on their context and surroundings.

Chronicity is a frame for this chapter not only for its overt relationship with chronic conditions, but also because it embraces one of the central characteristics of chronic illness—change. As Cristina De León-Menjivar (2022), writes, “chronic illness is only stable in its chronicity, but not in any other way.” Chronic illness is marked by unpredictability, as symptoms, treatment, side effects, and other aspects of a condition often change—sometimes day-to-day. In her writing on diabetes, Lora Arduser (2017) argues that liminality and multiplicity are key characteristics of chronic illness (pp. 14–15). This instability can run counter to the expectations of our current biomedical model, which is better suited for acute illnesses and injuries; chronic conditions require greater attention to and appreciation of patients’ deep awareness and knowledge of the variability that they live with. Ada Hubrig similarly points to chronicity’s alignment with “variance and change,” noting that the concept works towards a “rejection of the stable, normate bodymind” (p. 339). Hubrig argues that chronicity is a queer concept, as it destabilizes normative ideas of embodiment. With this understanding, “chronicity rhetoric creates space to claim agency and work against ableist heteronormative systems by embracing the changes and differences that accompany chronic illnesses and/or disabilities” (p. 342). Incorporating chronicity as a framework into medical settings can counter the normative cultural logics and tropes discussed in Chapters 2 and 3. Scholarship on chronicity

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29 Vyshali Manivannan (2017a) writes that “when pain is chronic it becomes so ordinary it ceases to signify;” when pain or an illness moves from acute to chronic, the medical industry too often stops taking it seriously or viewing it as treatable (p. 31).
reflects the importance of variability in conversations related to time and representation and unsettles who we view as legitimate holders of the expert role.

Chronicity calls for a nonnormative view of time. Arduser and Bennett (2022) note that chronicity can refer specifically to time that is “fractured or fluid” (p. 124). Building on Arduser and Bennett’s connection to time and the more traditional definition of chronicity, Kristen L. Cole (2022) explores chronicity’s relationship with normative expectations of time in her article on direct to consumer pharmaceutical advertisements (DTCPAs). She writes that “constructions and negotiations of time,” such as those portrayed in pharmaceutical ads, “serve to authorize certain experiences and uses of time, while pathologizing others” (p. 214). Working from Alison Kafer’s (2013) concept of the “curative imaginary,” Cole “highlights dominant temporal configurations that privilege immune-typical conceptions of time through their representation of chronicity as curative” (p. 220). Cole reveals that, in DTCPAs, “chronicity is constructed as a temporal affliction, an attack on the sanctity of straight time” (p. 224). DTCPAs implicitly and explicitly argue for normative “straight time” and position the temporal realities of living with a chronic illness as problematic. However, the truth of many chronic illnesses is the realization that one’s “own conception of time [will] never be the same” (p. 236). As I discuss later in this chapter, chronic illness and chronicity demand flexibility in understandings of time and embracing the resulting variability.

Moreover, scholarship on chronicity acknowledges the always ongoing processes of identification that individuals with chronic illness exist within, reflecting the constantly changing nature of chronic illness itself. Chronicity enters conversations in rhetoric and composition largely from medical anthropology, as Sarah Ann Singer and
Jordynn Jack (2020) note, where it means “a shift in identity that can be problematic for patients” after a diagnosis (p. 125). Moving the term into RHM scholarship, Singer and Jack (2020) define chronicity as “a rhetorical, multilayered process of identification that depends on available representations of chronic illness and how individuals engage with them” (p. 125). Singer and Jack’s view of chronicity welcomes fluidity by challenging existing views of diagnosis and illness as “singular and stable;” they assert that after diagnosis, identity is “constituted through an ongoing, always incomplete, yet potentially productive rhetorical process of identification” (pp. 126–127). Singer and Jack demonstrate the always ongoing nature of chronic illness, and highlight how that continual process can be invaluable to people with chronic illnesses, as it can provide them with opportunities to define their own identities in the face of widespread cultural logics and normative medical discourses that discourage them from feeling empowered or like legitimate sources of knowledge. Because chronicity focuses on the ongoing and changing process of identification, chronically ill individuals can develop alternative constructions of time and knowledge beyond the static understanding of expertise that is typical in medicine. Chronicity allows for multiple sources of knowledge to be considered valid—challenging medicine’s stable, linear view of diagnosis, symptoms, and illness as a whole. Embracing the change inherent in chronic illness through chronicity can strengthen individuals’ sense of belonging, demonstrating the value of chronicity as an interpretive frame.

In this chapter, I demonstrate how embracing chronicity and its essential variance counters the normative expectations of our current biomedical model. In the analysis below, I show how writers with chronic illness are already negotiating expertise in
clinical settings through rhetorical strategies rooted in chronicity, as well as the progress we still need to make. I call attention to the need for a paradigm shift in medicine that would include multiple forms of expertise and knowledge. Understanding chronic illness and chronicity as rhetorical animates this chapter, as this frame underscores that context and cultural logics affect the mobilization of expertise in medical settings.

Methods

As in Chapters One and Two, the analysis in this chapter is based in examples from my corpus of memoirs and personal essays written by women and gender-nonconforming people about their chronic illness experiences. My initial round of coding demonstrated that the representation of medical encounters was a major theme in the data. In this chapter, I continue my analysis of the medical category, specifically focusing on examples related to the themes of negotiation of expertise and dismissal of experiences. With these themes isolated, I conducted a further round of coding to identity patterns, focusing on representations of various forms of knowledge and any tension that emerged. I returned to the corpus of memoirs and essays with increased attention to moments when writers used words like “know,” “feel,” “understand,” and “expert.” Returning to the data as a whole allowed for a more expansive view of how knowledge is represented in personal narratives. This method generated the following categories: sources of knowledge, provider responses, and obstacles to understanding. Each category was made up of several codes, as shown below in Table 3.

Table 3: Categories and Codes Related to Expertise

<table>
<thead>
<tr>
<th>Category</th>
<th>Codes (Frequency)</th>
<th>Total Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sources of Patient Knowledge</td>
<td>Intuitive (70)</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td>Research (28)</td>
<td></td>
</tr>
</tbody>
</table>

30 Types of knowledge that are present in data; analysis is not comprehensive of real-world interactions.
Two types of patient knowledge were represented often in the data: intuitive or embodied knowledge and knowledge gained from research. As the following section will show, neither of these sources of knowledge is counted as valid expertise and both are often disparaged in medical encounters when invoked by patients. In representations of these encounters, women wrote about several responses from their providers, including conflating physical and psychiatric illnesses and disbelief. In addition to the responses from individual providers, narratives of chronic illness also pointed to larger cultural and discursive obstacles to their knowledges being seen as legitimate, including language, normative understandings of time, and medical uncertainty. As in the previous chapters, examples from memoirs and essays often could be coded in a number of ways or fall into more than one category—I have tried to account for this nuance in my analysis while also acknowledging that coding and categorization will inevitably and necessarily flatten some of this complexity. In the analysis that follows, I define and provide examples of each source of patient knowledge and provider response. Then, I identify the additional barriers that arise that can prevent patient knowledge from being seen as genuine expertise. Ultimately, I argue that this collection of illness narratives demonstrate the value of chronicity as a frame for understanding the variance that is fundamental to illness experiences.
Analysis: Types and Uptakes of Patient Knowledge

Within a clinical setting, patients are typically viewed as having less expertise than their providers. In many ways, this is true; as Segal writes in her rhetorical account of medical expertise: “the physician is an expert in disease, and the patient in illness; the physician in nosology, the patient in experience” (2005, p. 147). Healthcare providers undergo extensive education and training to gain specialized knowledge that patients do not share. However, patients do have expertise in their own bodies and experiences, and can gain knowledge through research practices. This expertise is often rooted in the idea of chronicity, as women and other people with chronic illnesses can have a deep understanding of how their bodies, symptoms and conditions fluctuate over time. This expertise—especially for women—is often downplayed, ignored, or dismissed outright, as the expert role is not available to them in a clinical encounter. As represented in my corpus of memoirs and essays, women’s knowledges are not considered valid forms of expertise, but rather discounted through rhetorical moves from providers that aim to maintain a normative balance of who counts as an expert and a linear view of health.

In this section, I first introduce the types of knowledge that memoirists and essays write about most often. These knowledges are not elevated to the level of expertise and often receive negative responses from providers. Within my corpus, two primary types of knowledge emerged as salient for chronically ill writers: intuitive knowledge based on embodied sensations and past experience, and knowledge based on textual and digital research. As I discuss each form of expertise, I will also illustrate the normative response to the knowledge being shared in a clinical encounter, such as a patient being told that their symptoms are “all in their head” or to “stop Googling.” Then, I will turn to the
obstacles that emerged as patterns in the data: recurring themes that work as roadblocks expanding the category of legitimate knowledge to adequately include varied ways of knowing. The primary obstacles that were represented in the data included normative perspectives on time, issues related to language (such the ineffability of pain and other embodied sensations), and tensions related to medical uncertainty in general. Each obstacle demonstrates how the current medical paradigm privileges stability and predictability, which directly contradict the realities of chronic experiences. Together, these discussions demonstrate that, within the context of medicine, expertise is tightly controlled and is affected by larger cultural and discursive factors.

**Intuitive Knowledges Based in Embodied Sensations and Past Experiences**

First, writers described intuitive knowledge, drawn from embodied sensations and past experiences. In the corpus, the typical representative responses from healthcare providers are that these experiences are primarily psychogenic, or “all in the head,” and other forms of dismissal and disbelief. As discussed in the literature review above, Campbell and Angeli (2019) argue that intuition can be understood as the integration of “previous experiences with situational awareness and sensory knowledge” (p. 353). While Campbell and Angeli describe the “taxonomy of sensory cues” used by medical professionals in their work, I argue that their framing of intuition as a form of intelligence and expertise is equally applicable to patients. Particularly relevant to this discussion is Campbell and Angeli’s description of internal sensory cues, which emerge from a person’s “felt sense about a situation or intervention” (p. 372). These cues are often termed a “‘gut feeling’ or a ‘funny feeling on the back of your neck’” (p. 372). Just as the EMTs and nurses at the center of Campbell and Angeli’s study—or Sauer’s miners with
their “pit sense”—chronically ill individuals develop intuitive awareness of their bodies’
functions and sensations over time.

This deep awareness then creates opportunities for patients to notice when
something is amiss. For example, Emma Bolden writes that her leg “just didn’t feel right”
after a procedure (p. 161), and Porochista Khakpour notes that she has “always known
something was off” in her body (p. 180). Cynthia Li remembers that, during her diagnosis
process, she “only had one thing to go by—[her] subjective experience that [her] inner
workings were all scrambled up” (p. 62). Writers shared similar language to providers
when relating internal sensory cues: a “gut feeling” or “gut instinct” that something was
wrong (Norman, p. 230; Khakpour, p. 158). At times, these cues come directly from the
emergence of new symptoms. Khakpour writes that her “entire body was statically
charged” (p. 243), and Li describes a “faint flutter” in her chest (p. 39). Meghan
O’Rourke writes about “a bone-deep, a cell-deep conviction” that the barrage of new
symptoms she was experiencing indicated a medical issue. Writers often describe an
intuitive awareness of their bodies, demonstrating the prevalence of this type of
knowledge.

For individuals experiencing chronic illness, pain becomes familiar and
understood all too well. This familiarity then becomes its own form of intuitive expertise;
patients are transformed into experts about their bodies and their pain. Many authors
wrote about their pain, including Melissa Hung’s chronic headaches, Caroline Reilly’s
pain during her period, and Lara Parker’s endometriosis flares. Emma Bolden notes that
“it was almost friendly, the way pain felt familiar” (p. 253), and Abby Norman describes
pelvic pain as a “familiar feeling [that] crept” into her body (p. 42). Parker ties the
sensation of pain directly to knowledge of her body and the reality that her “vagina problems” will always be with her: “I've felt my own pain inside my body too many times to not have an inkling of what's going on” (p. 73). Linda Chavers, who has been diagnosed with multiple sclerosis (MS), similarly emphasizes the “level of self-awareness” that chronic illness demands: “I think of that old childhood jingle, ‘the neck bone's connected to the…’ and I think, ‘Damn, that shit's really true.’” Writers’ past experiences with pain and other embodied sensations function as a source of knowledge, positioning themselves as experts on their own bodies. The familiarity of embodied sensations demonstrates the value of viewing illness through the lens of chronicity; this knowledge is created contextually and through time.

However, authors note that this expertise is not always taken up by medical providers, creating tension between patients and providers in office visits and beyond. Johanna Hedva writes that they are “antagonistic to the notion that the Western medical-insurance industrial complex understands me in my entirety, though they seem to think they do,” and Sarah Ramey illustrates that, despite her “tremendous respect” for providers’ “incredible breadth of knowledge, skill, and training,” she “really might know more about [herself] and [her] body than they did” (p. 279). As Abby Norman phrases it, she might not be an expert in endometriosis, but she was an “expert in [her] endometriosis” (p. 229). Providers can be experts in subject matter and generalities regarding chronic conditions, but they cannot be experts about individual experiences in the same way that people living with those conditions can be. I, along with the memoirists and essayists in this study, do not believe that it is the desired outcome for

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31 Hedva’s pronouns are they/them.
clinicians to gain that type of first-hand experience; rather, the writers in the dataset are discouraged and rightfully frustrated when they attempt to share their intuitive expertise and are met with negative reactions. They often represent instances of being dismissed or disbelieved when sharing embodied sensations or knowledge drawn from past experiences.

Narratives of chronic illness included moments in which women’s intuitive knowledges were not just discounted, but outright not believed to be true. Abby Norman writes about wanting to “scream at [doctors] that they should have believed me what I said I needed help” (p. 90). O’Rourke riffs on *Pride and Prejudice*’s famous opening line: “And so it is a truth universally acknowledged among the chronically ill that a young woman in possession of vague symptoms like fatigue and pain will be in search of a doctor who believes she is actually sick” (p. 103). Lara Parker includes a “Letter to the Doctors Who Didn’t Believe Me” in her memoir (pp. 201-207). At times, the existence of pain itself is even denied. Emma Bolden wrote that a physician rejected the idea that she was in pain at all (p. 165). As Kim Hensley Owens (2009) describes, there is sometimes a clear separation between women’s speech and their embodied actions for healthcare providers. In the case of chronic illness, there are situations where neither a woman’s voice nor body is believed. As represented in several memoirs and essays, both verbal descriptions of symptoms and embodied evidence can be dismissed when a patient presents with symptoms or experiences that are difficult to diagnose. For example, Kate Horowitz describes the process of learning that she has Hypermobile Ehlers-Danlos syndrome, postural orthostatic tachycardia syndrome, and mast cell activation syndrome—three conditions that are known for taking several years to correctly
diagnose. Horowitz writes about being named “a malingerer, hypochondriac, hysteric, drama queen,” referred to a psychiatrist, and threatened with institutionalization. Horowitz's body was not sufficient evidence to bolster her discursive descriptions of her symptoms; she writes: “An allergist told me I was breaking into hives because I wanted attention. ‘You must like feeling special,’ he said.” In Horowitz’s description, we see a moment in which neither her discursive strategies nor her embodied experience are sufficiently rhetorically effective to “count” as expertise. More specifically, one of the primary mechanisms for this dismissal comes through the conflation of physical and psychiatric illnesses.

Women’s conditions and symptoms are often dismissed as psychogenic—as “all in their head.” Many women shared comments from healthcare providers that implied or directly indicated that their reported symptoms were psychological in origin (all emphasis added):

- Dr. Modell was not the first doctor to imply that my symptoms were psychosomatic, but he was the first to literally say the words “This is all in your head” (Norman, p. 252)
- For years, Dr. M implied that my disabling illness was the consequence of complex post-traumatic stress disorder, which I interpreted as a formal way of saying that it was all in my head, a form of hysteria (Wang, p. 181)
- …the defeat of visiting doctor after doctor only to hear it's “all in your head” (Miller, p. 10)
- Furthermore—he said, removing his glasses and speaking now directly to my parents and not to me—from what he could gather from our experience together, he had concluded that my problem “like many young women her age” was psychological (Ramey, p. 40)
- [The doctor] told [my mother] that I had no endometriosis, that there was no physical evidence of any physical cause for my pain. “It is my opinion,” he told my mother, “that the pain is not in Emily's body. It is my opinion that the pain is in Emily's head.” (Bolden, pp. 181–182)

Repeatedly, women’s intuitive knowledges about their bodies are disbelieved in clinical encounters and their negative symptoms are labeled as psychiatric instead. Their
experiences are discounted as a result of gendered cultural logics, such as those identified in Chapters Two and Three, which allow for the systemic dismissal of women’s knowledges as expertise. This repeated pattern not only increases the stigma of mental health conditions, but also can result in clinicians belittling patients and preventing them from providing adequate care. As Cathryn Molloy (2020) argues, the combined effects of demographic markers such as gender and stigmas surrounding mental illness diagnoses affect clinician’s attitudes towards patients, and “a provider’s belief that a patient is unreliable could mean missed opportunities for appropriate care” (p. 30). The physicians quoted above are particularly egregious examples, but the experience represented by these excerpts occurs often in medical settings at various levels of severity. Molloy asserts that treating symptoms as “separable into discrete categories of ‘in the body’ or ‘in the mind’” is “virtually impossible” (p. 30). Instead, Molloy suggests that medicine could move towards assuming that “all manifestations of illness are both psychogenic and physiological in nature” and “physicians should, thus, listen to subjective patient reports with heightened sensitivity to complexity and context if they wish to mitigate potential biases” (p. 29)\(^ {32} \). However, under our current medical structures as represented in personal narratives of chronic illness, women’s embodied knowledge is dismissed and undermined in clinical environments, thereby gatekeeping the role of expert.

*Patient Research as Expertise*

In addition to their representations of intuitive expertise, writers explained their efforts to conduct research on their own about their symptoms and conditions and demonstrate technical knowledge. Writers describe being driven by a desire to understand

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\(^ {32} \) As I do in Chapter Two of this project, Molloy calls for increased rhetorical listening; in this case, physicians would shift from clinical listening to rhetorical and ethical listening (pp. 37–38).
their conditions more fully and to identify the source of their symptoms after being dismissed by doctors or doctors being unable to diagnose them. When faced with mysterious symptoms or contested diagnoses, women turned to more traditional forms of expert knowledge, such as academic research or medical literature. Meghan O’Rourke writes about her “homegrown research” (p. 34), Sarah Ramey describes how she “swan-dove into JSTOR [and] PubMed” (p. 64), Lara Parker notes that she has done her “best to read (and comprehend!) medical study after medical study” about her health issues (p. 54), and Cynthia Li asserts that her actions to improve her thyroid condition “were based in hard science” (p. 121). Women also wrote about the discursive strategies they employed to demonstrate their knowledge in medical settings, such as using medical language. Abby Norman writes that, early in her Crohn’s diagnosis journey, she wrote a “a very thorough History and Physical of myself--as though I were the doctor for a moment and not the patient” (p. 169). Porochista Khakpour notes that she has discovered that to be taken seriously in a hospital, she must recite a “script:’ ‘My case is a CDC-level Lyme case,’ I’d learned to say, which was true’ (p. 21). In taking up scientific or technical discourse, these authors demonstrate engagement with Cathryn Molloy’s (2020) framework for counteracting the credibility deficit patients face in medical settings; in particular, the preparation stage, which involves textual research, and the performance stage. Because intuitive knowledge is not sufficiently constructed as expertise, some women and gender-nonconforming patients work to acquire institutional medical knowledge.

However, clinicians sometimes interpret patients’ research as subversive, and discourage patients from conducting research at all. Patients can face negative
consequences for seeking information beyond the physician’s provided advice or direction. Sarah Ramey remembers being told to “stop Googling” her symptoms when she mentioned less traditional causes for her symptoms (p. 190), while Abby Norman reflects on how patients who bring in a “heap of research” are “often chastised and usually advised to refrain from consulting Google” (p. 45). Similarly, Porochista Khakpour is discouraged from “digging too much” into the probability of her having Lyme disease after expressing “too much of an interest in the diagnosis—or any interest at all” (p. 144). Meghan O’Rourke writes about the tension attempting to even see her own medical records: “Some doctors flat-out told me they didn't want me to have copies of my lab results because I would 'make myself worried' or 'get confused' (p. 59). Abby Norman remembers being “humor[ed]” by a physician who said: “You're clearly very intelligent. Very clever” when Norman pointed out that the doctor was dismissing her concerns (p. 253, emphasis original). These statements uncover how medicine seeks to maintain ownership over its knowledge base, revealing the importance of these types of disciplinary boundaries to medicine (Derkatch, 2016). Patients, especially women, are paternalistically pushed away from gaining expertise beyond their own embodied knowledge, while at the same time, that embodied experience is dismissed.

The fact that Google specifically recurred several times in physician comments points to a larger tension related to digital health information. Writing in 2009, Judy Segal critiques the idea that the Internet is a purely empowering, democratizing force when it comes to patient education. Segal argues that “the problem is not just that laypeople do not know what doctors know; it is that they cannot know” (p. 353, emphasis original). Segal places the blame for this discrepancy not on patients, but on the medical
system more broadly; she writes that while medicine’s institutional structures remain in place, “the Internet cannot produce the empowered patient” (p. 354). Segal points out that there are institutional barriers in place that prevent patients from being seen as experts, even as they gather all the information available to them. Karen Kopelson (2009) provides an overview of arguments made in medical literature about “e-patients”\(^\text{33}\), including that e-patients can become active participants in a “partnership” with their providers (p. 377). Although the idea of patients being seen as experts or as equals in care seems like a positive move, Kopelson points out that “the self-managing, expert e-patient is fast becoming a normative identity construct which…marginalizes alternative subjectivities and serves dominant interests—in this case, those of the medical power structure” (p. 357). That is, placing expectations on patients to become experts in their care places a burden onto them, shifting the labor crisis in medicine onto patients rather than solving larger issues. I agree with Kopelson’s argument that e-patients should not be expected to become experts and partners in their care; at the same time, the memoirists and essayists in this current study show that, in their representations of their experiences, there was not a systemically appropriate way to learn about their care from online sources or from any source that was not their physician. Even seeking out published medical literature is reduced to “Googling” and is overtly discouraged. Women with chronic illnesses and autoimmune disorders, which are often less common and thereby difficult to

\(^{33}A\) type of individual who seeks out online health information. As Kopelson describes, these include presenting the e-patient as “dangerously…misinformed” (p. 360), the “demanding, participatory, empowered” patient (p. 361), “victimizers of some very beleaguered doctors” (p. 364), a “passive recipient of medical knowledge and treatment” (p. 370), “expert patients” (p. 376), and as a part of a “partnership” that shares labor with medical providers (p. 377).
identity, diagnose, and treat, attempt to bolster their intuitive knowledge with textual and
digital research, but typically run into roadblocks.

Obstacles to Understanding

While many of the negative experiences described in the previous sections can be
ascribed to the attitudes of individual clinicians, several obstacles also emerged in the
data at the institutional or macro level. These include (1) language, as symptoms and pain
can be difficult to explain; (2) time, as chronic illnesses and autoimmune disorders often
go through cycles of severity and the medical system relies on a normative perspective on
time; and (3) uncertainty, which can plague medical providers when attempting to
diagnose and treat rare diseases or less common chronic illnesses. I have included
discussions of these obstacles in order to explore how existing structures contribute to the
dismissal of women’s knowledges and maintain a system that prioritizes standardization
and stability.

First, language serves as a hurdle when patients try to share their embodied
experiences and intuition, as embodied sensations need to be described in a way that is
understandable to providers. It can be nearly impossible to explain, in any communicative
mode, exactly what we are feeling in our bodies in a way that someone else can
understand. For example, Meghan O’Rourke writes that she was unable to describe her
intuitive sense that “something was wrong” with her body in “clinical language” (p. 56).
In particular, pain refuses to be translated into words, much less words that are clear and
concise. As Lara Parker writes about her endometriosis pain:

It’s hard to describe this pain after the fact, which is what makes it so frustrating.
You can tell someone that you fantasize about knocking yourself out by throwing
your head against the closest dresser, or that you wish for death to take you just so
the pain will stop, but unless you witness this type of attack, it’s often unimaginable (p. 51).

Pain is a subjective and individual experience that is difficult to understand from the outside.34

Abby Norman similarly points out how language can contribute to misdiagnosis of conditions like endometriosis, noting that “when symptoms do present, they can be vague, difficult to articulate, and embarrassing” (p. 51). Norman, like Parker, highlights the inherent ineffability of certain symptoms and pains, while also illustrating the role that stigma plays in perpetuating misunderstandings and knowledge gaps related to chronic illness, especially those related to gastrointestinal or gynecological systems. As I introduced in Chapter Two, the stigmatization of illness is a pervasive cultural logic related to chronic illness that can often affect how people with chronic illnesses view and discuss their conditions. The shame associated with illness and “embarrassing” symptoms can serve as a major hurdle to embodied knowledge being shared at all. As Molly Margaret Kessler (2022) argues in her work on ostomies, “one of stigma’s most profound rhetorical effects is its silencing power” (p. 94). In a clinical environment in which intuitive and embodied knowledge is already discounted, there is immense pressure to express sensations and symptoms in a way that is legible to providers. Language serves as an additional obstacle to women and other marginalized patients seeking diagnosis and treatment.

34 Recognizing this obstacle, clinicians can use various tools to aid in the measurement of pain, such as numerical rating systems patients that ask patients to assign a number from 0 to 10 to their pain. However, several writers demonstrated how these types of scales can be ineffective, removing nuance and complexity from their experience. Melissa Hung notes that the pain scale “only considers the intensity of pain, not its duration. Not sorrow over the things I can no longer do” (“Headache”).
As I briefly discuss in Chapter Three, time recurs as an obstacle in memoirs and personal essays on chronic illness. This is unsurprising, as chronic illnesses are defined temporally—that is, they are distinguished from other diseases and syndromes by their duration. In particular, many people with chronic and autoimmune disorders experience flares, or periods where symptoms become more severe. For women with chronic illnesses who are relying on their bodies to serve as some kind of evidence of their intuitive knowledge, the fluctuations associated with chronic illness can be a hurdle to being seen as a credible expert. As mentioned in the previous chapter, part of being an acceptable “normal patient” is moving at the same pace as medicine—being willing to wait when required while also accepting limited or abbreviated time with a provider. This alignment with “straight time,” as Kristen Cole (2022) terms normative time, is evidenced through writers’ descriptions of long waits to see physicians and short appointments. Kate Horowitz writes about the “lengthy waiting list” she was placed on to see a physician described as a “diagnostic virtuoso.” Abby Norman similarly describes wishing she could “devise a way to speed up time” in between doctor’s appointments (p. 237). Once in a clinical setting, writers illustrate the impact of structural and systemic enforcement of straight time, such as brief appointments. Sarah Ramey writes that treating diagnosis as a “quick” and “mechanical” process “gets the job done of seeing twenty or even thirty patients a day, which many doctors have to do if they want to make a living and participate with insurance companies” (p. 11). The timing of clinical appointments needs to align with symptoms’ flares or presentations, and this is often impossible due to both institutional structures and the nature of chronic illness. Rather than asking chronic illness and patients to align with straight time in order for their
knowledges to be taken seriously as expertise, I argue that moving towards a view of time more in line with chronicity would benefit patients and providers alike.

While normative perspectives of time are prioritized in medicine, time through the lens of chronic illness is understood as unpredictable. Many writers describe how the symptoms and other realities of living with chronic illness require them to become both more aware of time and more flexible in how they understand it. For example, Linda Chavers writes about the impact her MS has had on her conception of time: “I have to plan out my weeks with precision. Living with chronic illness forces a specific consciousness of the body in relation to time.” Because many chronic illnesses like MS bring on increased fatigue or other symptoms that fluctuate or are affected by exertion or activity, individuals with chronic illness learn to adjust their schedules, plans, and routines to accommodate their conditions. At the same time, pain and other symptoms can be abrupt and immediate, interrupting any understanding of time beyond the present moment; Lara Parker writes that, in intense moments of pain, she “cannot see a future or a past” (p. 175). Chronic illness demands both careful planning and attention to time and, simultaneously, often interferes with those plans. As noted in the literature review above, Ada Hubrig (2022) argues that chronicity and chronic illness are marked by this “variance and change” (p. 339). In her writing about her chronic headache, Melissa Hung describes the flexibility and acceptance that people with chronic illness oftentimes must develop: “Those of us with chronic health issues already live with uncertainty. Flares happen. Pain comes calling after a good spell, reminding us of the truth: We are never really in control” (“Water”). Christa Teston, in her 2017 work on medical uncertainty, terms this ever-shifting nature of bodies as “flux,” writing that “bodies are in perpetual
flux” (p. 8). People with chronic illnesses become experts in this nonnormative view of time, understanding instability as an inherent part of their experiences.

Uncertainty was the third obstacle that emerged in the data; several writers discussed how their symptoms and experiences seemed to puzzle their providers and describe visiting several different doctors from a variety of specialties in an attempt to obtain a name and treatment for their pain and other symptoms.35 Meghan O’Rourke writes that “none of the doctors can figure out what it is” when she begins experiencing new symptoms (p. 19). Lara Parker shares a similar experience in regard to her endometriosis and other gynecological issues: “most medical professionals I’ve seen over the years are just guessing what might help” (p. 49). Melissa Hung discovered that swimming reduces the pain from her chronic headache, but is not sure why; she writes that “doctors don’t [know] either. What doctors know about are drugs, but the ones they’ve prescribed, dripped into my veins, or injected into my head and face haven’t made much of a difference” (“Water”). Patients and physicians both face uncertainty, but the current medical paradigm does not make room for patient expertise as an asset in contending with this obstacle.

These obstacles reveal the ongoing issue of patients, especially those who present as women or more feminine, being dismissed in clinical settings. Already at a disadvantage due to harmful gendered cultural logics and the rhetorically disabling normal patient trope, women and gender non-conforming patients, can be further marginalized in their conversations and attempts to share knowledge with providers.

35 It is important, though, to note that this experience is itself also a privilege. Being able to travel to, afford, and have the time and access to multiple healthcare providers is not a universal experience available to everyone with mysterious symptoms.
Rather than create a binary between professional and personal expertise, between scientific and embodied knowledge, I illustrate the rhetorical nature of the expert role in medicine, and illuminate the need for a shift in that treatment of women with chronic illness.

**Conclusion**

Despite the systemic harm being represented in the data, some writers do describe the power of being understood and seen as experts about their own bodies. Destiny O. Birdsong writes that “it also feels good to be proven right. But it feels far better to be seen” ("Surviving"). Abby Norman relates the importance of a clinician’s support, emphasizing the value in a doctor “regard[ing] the work I’d done to become an expert in my own body as worthwhile” (p. 231). Instead of positioning medicalized knowledge as the absolute authority, Norman and Birdsong’s doctors opened the interaction up to multiple types of expertise, improving the situations for both physician and patient. These interactions were unfortunately rare in the dataset—only eight instances emerged during coding. They are marked by descriptions of their scarcity; Sarah Ramey notes that one physician was the “first and only doctor” to fully engage with her about the “complexity of chronic illness, the problems of the medical system, and the reality of the nightmare no one else in a white coat with a gold-leaf degree would acknowledge for a decade” (p. 147).

As narratives of chronic illness show, expertise and the expert role are fraught in medical contexts. Women entering doctors’ offices with “gut feelings” that something is wrong can, as represented by memoirists and essayists, face an uphill battle as they try to understand what is happening within their bodies. While women with chronic illness are
experts in their own bodies and can gain additional knowledge through research and engaging with institutional medical expertise, they often encounter dismissive or paternalistic responses from their healthcare providers or other obstacles to the legitimization of chronicity. I argue that this demonstrates how the expert role is managed in medicine and restricted to those within specific positions. Expertise is contextual, and we see the outcome of its rhetoricity clearly in medicine. In the next and concluding chapter of this project, I will draw on my analysis in this and the previous chapters to explore the larger stakes for this project, as well as future directions for research on the intersections of chronic illness and rhetoric.
This dissertation calls our attention to the value of embodied knowledge and the obstacles to its legitimization, which have become even more pronounced since this research began. The COVID-19 pandemic provides a telling case of these obstacles. Although many people recover quickly from a COVID-19 infection, others are affected long beyond the initial acute phase of the illness. This chronic condition stemming from COVID-19 is known as Long Covid. The Centers for Disease Control and Prevention (CDC) defines Long Covid as “a wide range of new, returning, or ongoing health problems that people experience after being infected with the virus that causes COVID-19” (CDC, 2023b). Symptoms of Long Covid are wide-reaching, including fatigue, post-exertional malaise, fever, respiratory and heart symptoms, neurological symptoms, digestive symptoms, among others (CDC, 2023b).

Because Long Covid is new and arose so quickly, we are actively creating our body of knowledge about the condition and its effects. Long Covid has unsettled what we know about how medical knowledge is developed; scientific research, particularly in the early days of the pandemic, could not move fast enough to keep up with the emergence of
Long Covid. Instead, patients served as the first experts about Long Covid. In the first section of this chapter, I explore how Long Covid serves as an example of the many intersecting forces that create a rhetorically disabling environment for women with chronic illnesses, while also demonstrating the promise and potential of incorporating patient expertise into our understanding of chronic conditions.

Like many other chronic conditions, patients with Long Covid describe their intuitive sense that something was wrong with their bodies. Samantha, a Long Covid patient, described her experience with Long Covid after an initial acute infection, noting that her body “was overwhelmed” and that she was “short of breath, fatigued and in pain” (Northwestern Medicine, 2023). Samantha describes feeling like “something was just not right.” Samantha’s language echoes the experiences of many of the memoirists and essayists in this dissertation. In addition to her nameable symptoms, Samantha experienced an inherent sense that something was abnormal about her body. Patient descriptions of Long Covid demonstrate the prevalence of intuitive embodied knowledge36 and argue for its importance in understanding chronic conditions.

Beyond the centrality of embodied knowledge, the experiences of patients with Long Covid have unfortunate and unsurprising overlaps with those of the women with chronic and autoimmune disorders in this current project. Long Covid patients encountered several of the cultural logics and harmful discursive patterns I identify in Chapter Two as they sought diagnosis and treatment, including denial of experiences, shame, and blame. First, Long Covid patients often faced the dismissal of their symptoms

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36 In addition, the concerns of Long Covid patients are likely to align with those of patients with other chronic conditions, particularly because it’s believed that women are affected by Long Covid at greater rates than men (Berg, 2022).
and embodied knowledge being dismissed. While Long Covid was “added as a recognized condition that could result in a disability under the Americans with Disabilities Act (ADA)” in July 2021 (CDC, 2023b), people with Long Covid and their advocates have faced an uphill battle in their concerns being taken seriously. Karina Gonzalez, a Long Covid patient from Texas, spoke about her experience in an interview on PBS’s *News Hour*:

> I even started to have a heart attack symptoms. … I did end up going to the E.R. because I was really scared. I didn't know what was going on … And, basically, my experience was that, every time I would go to doctors or to the hospital, they would just tell me, oh, no, you're fine (Brangham, 2023).

In this interview, Gonzalez demonstrates the pervasiveness of patients’ experiences being disbelieved. While Long Covid is still an emerging diagnosis and medical researchers have had to work at an accelerated pace to understand and identify treatments for it, patients’ experiences show that their embodied knowledge is not always treated as legitimate. Moreover, a study of online Long Covid narratives found that patients describe both “feelings of shame (towards themselves) or perceived blame (from others)” (Rushforth et al., 2021, p. 5). According to Rushforth et al. (2021), “it was evident that both the acute illness and—in particular—its longer-term sequelae provided a test of character for participants which they had been unable to meet heroically” (p. 5). That the patterns of denial, shame, and blame emerged nearly as quickly as Long Covid itself is clear evidence of the frequency and deep embeddedness of epistemic injustice and rhetorical disability in cultural logics of health and medicine.

> Medicine’s enactment of epistemic violence inequitably affect patients of color, especially Black women. In an article for NBC News, Chimére L. Smith, a Black woman with Long Covid, remembers being called “aggressive” by medical providers for seeking
care. She describes her experience of sharing her symptoms with doctors: “…they would not hear me. They wouldn’t listen to me. They would treat me as if I was a child and I didn’t know my body” (Bellamy & Adams, 2022). As many of the writers in this current study describe, being treated as an unreliable knower of one’s body is alarmingly common, and this problem is often compounded for marginalized patients. In the same article, other Black women, including social epidemiologist Dr. Margot Gage Witvliet, describe similar encounters. Witvliet recounts being “infantilized” when she sought treatment, accused of being on drugs after a seizure, and treated by a physician who only conversed with her husband, who is white. Smith and Witvliet’s experiences are unfortunately not outliers. Zackary Berger, Vivian Altiery Dejesus, Sabrina A. Assoumou, and Trisha Greenhalgh (2021) note that both acute COVID-19 and Long Covid are “strongly influenced by…structural inequalities such as racism and discrimination” (p. 519). Long Covid disproportionately affects women of color; Jennifer Cohen and Yana van der Meulen Rodgers (2023) found that “Black and Hispanic women have significantly higher odds of developing Long Covid compared to all non-Black and non-Hispanic individuals and compared to Black and Hispanic men” (p. 7). As I argue in Chapter Three, patients of color face heightened instances of harm and rhetorically disabling forces in medicine; Long Covid does not deviate from this pattern.

In general, patient experiences often are not taken seriously. However, Long Covid has been termed a “patient-defined illness,” meaning that it was initially identified by people experiencing it and that it “gained legitimacy largely through the stories and actions of online communities” (Rushforth et al., p.8). Affected by Long Covid themselves, UK scholars Felicity Callard and Elisa Perego (2021) trace how the
identification and naming of Long Covid occurred primarily through social media in the spring and summer of 2020. Callard and Perego note that although official advice from the UK’s Chief Medical Officer stated that most people infected with COVID-19 would experience “mild illness” for a short period of time, this description did not fit for those whose symptoms continued or were more severe (p. 2). As a result, patients shared their experiences on platforms such as Twitter, creating networks and support groups to find community with others facing similar struggles. Callard and Perego also describe how the terms “Long Covid” and “long-haulers” (a label some Long Covid patients use for themselves) emerged from patients’ posts on Twitter (p. 2). Some of the authors at the center of this dissertation project describe how important social media and online communities are for their advocacy, education, or connection with other chronically ill people. Long Covid demonstrates how significantly and quickly patients and their digital rhetorical choices can shape the definitions of a disease.

Long Covid is also unique because its discovery and definition relied on patient expertise. Patients were experiencing Long Covid long before medical or academic research could identify it. As Callard and Perego describe, “patient-made evidence,” such as a first-person case study published by British infectious diseases professor, was “important when no peer-reviewed articles had yet documented long-lasting symptoms” (p. 2). Callard and Perego highlight how patients’ anecdotal experiences were, at least in the early phases of the pandemic, treated as evidence of Long Covid’s existence; they write that Anthony Fauci referred to “patient-made material from informal channels … as evidence prior to data being formally available from scientific studies” (p. 3). While patients report facing dismissal on an individual level, Long Covid is an example of the
power of collective experience and action. Callard and Perego argue that “patient expertise and knowledge should be incorporated in the pandemic evidence base” and call for “patients’ ongoing contributions to be recognised and used to combat the suffering of multitudes” (p. 4). Long Covid’s legitimization through patient expertise demonstrates that patients’ experiences should be taken seriously not only in their own care, but also in broader conversations about health and medicine—during complex and quickly changing public health crises and in more mundane contexts.

Because Long Covid is such a novel and rapidly developing condition, improving the lives of “long-haulers” will require collaboration between patients of all backgrounds, physicians, and researchers that makes use of all stakeholders’ experiences and expertise. This collaboration has potentially serious implications, as Long Covid has the potential to debilitate or disable those who are affected by it. A review of Long Covid studies found that the condition can have negative “consequences on quality of life, social and family life, as well as on employment” (Nittas et al., 2022, p. 7). Moreover, as the experiences of Chimére L. Smith, Margot Gage Witvliet, and other Black women demonstrate, accounting for intersectional identities in Long Covid scholarship and advocacy is crucial. The systemic racism and economic inequality reflected in our current model of healthcare results in more frequent incidences of Long Covid for marginalized people; scholarship on Long Covid and other chronic conditions should recognize the multiple axes of oppression that affect Long Covid patients and include strategies for rectifying these harmful structures. As Sarah A. Devoto (2023) argues: “disability scholars must center disabled, working-class BIPOC in Long Covid research in order to best understand the most severe consequences of the condition and to advocate for an equitable public
response” (p. 527). The consequences for both patient-provider collaboration and scholarship are important to attend to.

Increasing rates of Long Covid means that the stakes of RHM research into chronic illness more generally are rising as well. There are significant material consequences associated with chronic and autoimmune conditions. For example, a 2018 study found that “four inflammatory diseases and two related syndromes...have an estimated cost of at least $90B annually” (Wylezinski et al., p. 2). While the costs of chronic conditions are significant, they are worsened by delayed diagnoses and misdiagnoses (p. 16). Beyond the financial burden, this dissertation project has shown the harmful affective, interpersonal, and health-related impacts that delayed care and inadequate treatment have on women with chronic illnesses. We need to understand the importance of women’s embodied knowledge and listen to chronically ill voices in order to improve outcomes for women and other marginalized groups, as well as create change in the structures of our medical system more broadly. This dissertation project is one step towards that goal. In the remaining sections of this chapter, I review the project’s findings and contributions, reflect on the complexities of studying memoir and personal narratives, and discuss directions for future research.

**Project Findings**

This project has sought to understand and provide a rhetorical account of gender-based bias in medicine related to chronic and autoimmune conditions. Analyzing representations of chronic illness in a set of memoirs and personal narrative essays revealed the rhetorical underpinnings of this type of bias. Chapter Two of the project

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37 Inflammatory diseases studied included multiple sclerosis, ulcerative colitis, Crohn’s disease, and rheumatoid arthritis. Related conditions included irritable bowel syndrome and fibromyalgia syndrome.
demonstrated that gender-based medical bias has roots in widely shared cultural logics, such as the “moral imperative” of wellness (Derkatch, 2022, p. 53) or stigma. Cultural logics enable epistemic injustice, leading to the view that chronically ill women are not valid or credible knowers. These logics also illustrate pervasive and typically unmarked conditions that have material consequences for women with chronic and autoimmune disorders; this harm, I believe, can be countered with increased rhetorical listening from others. Chapter Three described some of the mechanisms that maintain these cultural logics—namely the concept of the normal patient. The normal patient ideal creates and upholds a rhetorically disabling environment for women and marginalized individuals in medicine. Regardless of individual rhetorical strategies to establish credibility, women and others with chronic illnesses cannot be seen as reliable rhetors because they do not align with the identity and behavior expectations associated with the normal patient. The normal patient ideal, like all cultural logics, is accepted as the default—it is so entrenched in how we approach medicine that it is not often noticed or challenged. Chapter Four then turned to illustrate why structural change is necessary in medicine, rather than only calling for change on an individual level. Epistemically harmful cultural logics and a rhetorically disabling environment create and reinforce systems where patients, especially women and other marginalized groups, cannot be seen as experts, even based on their own embodied knowledge and research. Change at the structural level will require reconsidering who can be a knower and what counts as valid evidence and expertise.

Within RHM and rhetoric and composition, this dissertation makes a set of interrelated contributions. First, my analysis reiterates scholarship in the field that argues that the body is a legitimate source of knowledge, while also calling attention to the ways
in which that knowledge is ignored and dismissed through discursive means. In particular, this project builds on Jenell Johnson’s (2010) work on rhetorical disability, bolstering the argument that environments and contexts can be rhetorically disabling. Medicine functions as a rhetorically disabling environment; there are situations where individual rhetorical strategies meet their limit in the face of structural barriers and powerful cultural logics. Broadly, medicine as a system is highly influenced by hierarchical power structures that use rhetorical means to control the expert role and the ownership of knowledge.

A second contribution this scholarship makes to RHM and rhetorical studies is the unveiling of rhetorical processes that can enable harmful ideologies. The project demonstrates that these practices, such as offhand comments from friends or standardized advice from medical professionals, are often overlooked because of their mundaneness. Greater consideration of everyday rhetorical practices can bring our attention to the larger structures and systems they represent. The findings of this project call attention to harmful norms and explain how those norms come to be reinforced discursively. This increased awareness may lessen the frequency of harmful discursive practices and increase moments of connection through rhetorical listening or similar strategies.

Memoirs as Objects of Study

Memoirs and other genres of life writing are valuable tools for community building, advocacy, and empowering their authors. In particular, illness narratives function as important rhetorical artifacts that counter circulating dominant cultural norms and narratives. As G. Thomas Couser (2018b) argues, “personal narratives of illness and disability” are tools “for taking back the experience of somatic dysfunction from medical
authority and *talking* back to medical discourse” (p. 347, emphasis original). As this dissertation has shown, there are themes and patterns that recur often across memoirs and personal narratives that demonstrate commonalities in the writers’ illness experiences. These commonalities have deepened our understanding of the intersections of rhetorical practices and chronic illness and called our attention to the harm that our current medical paradigm enacts. Although memoirs were a rich site of analysis, this project also demonstrated some of the complexity inherent to working with memoirs, which I explore in the following section.

It is important to acknowledge the limitations of memoirs as a genre, including several issues related to different facets of representation. Some of the tensions related to representation are a result of whose memoirs are considered worthy of being published and what types of stories are foregrounded. I discussed a few of these limitations in Chapter One, such as the demographic-based barriers to publishing memoirs—the bulk of most published memoirs on chronic illness are written by young, white women from English-speaking countries. In addition, Couser (2022) highlights several compounding limitations of trends in publishing that affect studying published memoirs, including the fact that the conditions most commonly written about in memoirs are not always the conditions that affect the largest number of people. Couser writes that the “proportion of texts devoted to particular conditions in no way corresponds to the incidence of those conditions in real life; for example, there are far more narratives of breast cancer than of lung cancer, though the latter kills more women” (p. 307). I agree with Couser’s assessment this disparity is an interesting methodological question for studies of memoir, as “gender and gender politics are clearly influential in the production of disability
memoir” (p. 307). At the same time, though, memoirs of less well-known conditions are also valuable contributions to conversations about disability chronic and autoimmune diseases. Research into disability and illness memoirs should attend to this concern and consider what stories are prioritized and why.

In addition to questions of who is able to publish a memoir, there are also genre-based limits to what type of narratives are considered publishable. Couser (2022) notes the ways in which chronic conditions defy market and reader expectations:

Chronic conditions may get better; they may get worse; overall, they defy the comic plot. They lack the ‘narrative arc,’ the sense of resolution, the closure so desired not just by patients but by readers. The literary marketplace favors unthreatening narrative. The strong preference of the reading public for this plot—catered to by publishers—presents a real barrier to candid testimony about some conditions: precisely those that frustrate physicians, those that are difficult to diagnose and less amenable to cure (p. 313).

Chronic illness—and its associated flares and long diagnostic journeys—defies a predictable narrative structure. For example, Porochista Khakpour’s Sick: A Memoir describes her experience with chronic Lyme disease through a non-traditional narrative structure that defies reader expectations of the improvement of her condition. While the publication of the memoirs in this study represent a small shift in reader and publisher preferences, there is still a dearth of memoirs and other life writing that centers chronic illness. As Couser also points out, it is likely that some of these limitations will be addressed in the near future as readers and publishers move to acknowledge the rapid increase of conditions like chronic Lyme disease and Long Covid (p. 313).

Another major concern to consider when using memoirs as objects of study is the tension that can emerge when using descriptions of individual experiences to name larger patterns or themes—as this current study attempts to do. As a genre, memoirs center one person’s experiences and perspectives, which can limit our ability to draw broader
conclusions. Katherine Mack and Jonathan Alexander (2019) note that memoir can “occupy the murky borderland that separates individual and representative experience” (p. 67). They ask us to consider how we can “ethically engage and understand the rhetorical work” of texts that rely on an individual’s experience (p. 50). One way our work with memoir can better address these concerns is by including a wide array of texts in research projects from a multitude of voices and venues. In doing so, we can more effectively identify patterns across individuals’ experiences, while still acknowledging the limited scope of each text.

Moreover, studying personal narratives requires attending to the potential for these texts to reproduce certain norms or dominant perspectives. Mack and Alexander argue that “a practice of reading memoirs that accepts uncritically their representation of experience is problematic,” as “the source of a memoirist’s rhetorical power—the self speaking itself—is never free of the norms and ideologies that enable that self to be legible to others” (p. 53). In this project, I have made an effort to mark instances in which individual authors replicate existing norms. For example, this meant acknowledging moments when authors might not acknowledge the class or financial privileges that enabled them to visit multiple doctors or pursue expensive alternative treatments. Simultaneously, though, Mack and Alexander note that “memoirs by queer folks, people of color, the disabled, and others differently positioned within a dominant culture might aim to question, interrogate, or overturn existing norms” (p. 54). Memoirs of chronic illness, as this study has shown, call our attention to and critique cultural norms of gender and medicine. Conducting research with memoirs within rhetorical studies requires
attending to the interplay of individual and common experiences, in order to bring light to harmful dominant discourses while also avoiding universalizing writers’ perspectives.

Lastly, this project revealed the complexities of the goals and rhetorical purposes of the genre of the illness memoir. The memoirs and essays selected for this dissertation project have a similar rhetorical aim beyond sharing individual experiences. As people who have been harmed by structural norms in medicine and cultural logics in their broader lives, these writers also intend to call out that harm, often by highlighting specific individuals who have wronged them. As a result, the memoirs and essays centered in this project, in some ways, function as mechanisms of revenge and resistance. Couser (2011) describes this phenomenon, writing that non-celebrity memoirs tend to “record worst-, not best-case scenarios” (p. 230). Reporting instances of epistemic and material violence is an important part of these illness narratives, as the affective response created in readers can work to animate change and garner support for writers. However, at times, the texts may stop short of naming and defamiliarizing the structures that motivate and perpetuate harm. In focusing on individual bad actors, memoir can unintentionally absolve the structures that enable those bad actors. Understanding gender bias as a systemic issue can help us more accurately target efforts for effecting change, while also making space to acknowledge the harm caused by individuals. As a genre, memoirs are useful to build community and respond to silencing medical discourses—but, in our study of them, it is important to return to questions of ethical representation. We need to consider who is a part of our research and who is potentially being excluded, while also constantly contextualizing and exploring the nuances of the narratives we include.
A Chronic Future: Directions for Research and Looking Forward

In her article on direct-to-consumer pharmaceutical advertisements, Kristen L. Cole (2022) reflects on her own relationship to time based on her Crohn’s disease. In contrast to a normative and “straightforward” understanding of time that “disregards divergent, embodied experiences” and always seeks a cure and return to normalcy, Cole writes that her “body tells a counter narrative that reveals a chronic rather than a curative rhetoric” (p. 236). She notes that this counter narrative results in “temporal paradigm shifts, an irrevocable capacity for living with uncertainty, and a new perspective on life” and calls for “a chronic future, where the chronically ill and immune-typical co-conspire to retreat from the curative imaginary” (p. 236). Working towards a chronic future will likely require change from both individuals and from larger systems. Doctors, family members, and other able-bodied and “immune-typical” individuals can work to interrupt the cycle of epistemic violence by avoiding harmful conversational patterns and more fully listening to people with chronic illnesses about their experiences. At a structural level, creating a chronic future might require policy change such as providing better funding for caregivers, making it possible for providers to spend longer with patients during appointments, or increased research into chronic and autoimmune conditions. In the spirit of chronicity, though, each of these changes will require ongoing reflection to meet the changing needs and priorities of chronically ill people and their communities. Further research in RHM focused on chronic illness, gender-based discrimination, and cultural logics and norms of health and medicine will be necessary to progress towards this chronic future.
This dissertation project has made important strides towards making sense of the relationship between rhetoric and chronic illness. There remain, however, many directions for future researchers to pursue and questions to answer related to expertise, ethos, and embodied knowledge. One possible direction for future RHM scholarship is to continue gathering first-person narratives and reflections on chronic illness through person-based research methods, such as interviews. An interview study of women and other marginalized people with chronic illness would likely be able to include a wider array of voices, especially from those who are unable or do not want to publish their personal narratives. Collecting a broader set of narratives of individuals’ diagnosis stories, experiences with medical providers, and reflections on illness experiences can further develop our conception of the impact of cultural norms and logics on those with chronic illnesses.

Second, research in RHM might investigate how expertise is created and boundaries for the expert role are reinforced for healthcare providers. In order to do explore these questions, scholars might survey medical school curricula or other pedagogical materials, or conduct observations of new physicians, nurses, or other healthcare providers being trained or mentored. This type of work may reveal how providers are enculturated into their professions, including how they are professionalized into the norms and expectations of their disciplines. Studying medical education may show us how new physicians and healthcare providers are trained to understand gender, race, and other identities, and how their training may affect the care they provide patients,

38 For example, Caitlin E. Ray (2023) has conducted an interview study to “examine how rare disease patients utilize rhetorically savvy strategies to transform these [healthcare-specific] commonplaces and access resources they need.”
especially those with chronic and autoimmune conditions. In turn, RHM scholars may then be able to offer a more detailed view of the extent to which expertise is a rhetorical force in medicine.

Third, there is significant potential in exploring connections between the rhetoric of health and medicine and digital rhetorics. Future projects might analyze how wellness culture is maintained in digital media spaces, such as social media platforms, and how this cultural logic has been developed as a response to patient knowledge being dismissed in clinical settings. In the narratives from this current project, writers would often turn to online sources when they had mysterious symptoms or were dismissed by a doctor. While social media is rich with resources for patient advocacy, it can also perpetuate misinformation and reflect a culture of rampant consumerism in which individuals’ anxieties and concerns about their health and wellness can be taken advantage of. Examining the circulation of online content creators’ claims related to individual responsibility for wellness and health can demonstrate how prolific and persuasive appeals to alternative authority can be in virtual spaces. Additional projects that trace how knowledge is developed, shared, and taken up will strengthen our understanding of the role of rhetoric in definitions of expertise and how those definitions affect experiences and outcomes for women and other marginalized groups in medicine. Studying chronic illness and the discursive practices that surround it provides substantial opportunities for future work.

In both this dissertation and future projects, I am deeply invested in exploring issues of equity in cultural norms and practices related to medicine, health, and gender. This investment comes from not only my own positionality in relation to this project, but
also the numerous conversations I have had with others as I have worked on it over the last few years. The way that this dissertation has resonated with many people I have talked to has surprised me. At conferences, usually at least one audience member will stay behind to share their experience with me. At craft night at my local yarn store, women of all ages share stories of times when doctors dismissed their pain or missed an important diagnosis. It seems that every time I describe the project to someone, especially another woman, I’m met with comments like “that happened to me” or “I have a story like that.” I’ve shared the statistics and studies earlier in this project about gender-based medical bias, but it’s moments like these—when I talk to another individual who has gone through these experiences—that the stakes of the project truly emerge. It’s one thing to know that women face worsened outcomes in medicine, and something else entirely to listen to and empathize with someone who is evidence of those statistics. It is my hope that this project and others like it will serve as a way for the stories that many of us share to become actionable and improve women’s experiences in medical settings and in their daily lives.
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## APPENDIX: CORPUS OF MEMOIRS AND PERSONAL ESSAYS

### Table 4: Author Backgrounds

<table>
<thead>
<tr>
<th>Author Background</th>
<th>Frequency for Memoirs</th>
<th>Frequency for Essays</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian American</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Indigenous</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Middle Eastern and North African</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>White</td>
<td>6</td>
<td>4</td>
<td>10</td>
</tr>
</tbody>
</table>

Note: The data for this table was determined by noting if authors self-identified in their writing, in an online bio, interview, or other material. This table is not meant to totally summarize each author’s ethnic, racial, or cultural identity, but rather to demonstrate larger patterns within the corpus and trends in the publication of personal narratives.
### Table 5: Book-Length Memoirs

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bolden, Emma</td>
<td>The Tiger and the Cage: A Memoir of a Body in Crisis</td>
<td>2022</td>
</tr>
<tr>
<td>Brown, Keah</td>
<td>The Pretty One: On Life, Pop Culture, Disability, and Other Reasons to Fall in Love with Me</td>
<td>2019</td>
</tr>
<tr>
<td>Irby, Samantha</td>
<td>Meaty</td>
<td>2013</td>
</tr>
<tr>
<td>&quot;</td>
<td>we are never meeting in real life</td>
<td>2017</td>
</tr>
<tr>
<td>Khakpour, Porochista</td>
<td>Sick</td>
<td>2018</td>
</tr>
<tr>
<td>Li, Cynthia</td>
<td>Brave New Medicine: A Doctor's Unconventional Path to Healing her Autoimmune Illness</td>
<td>2019</td>
</tr>
<tr>
<td>Miller, Tessa</td>
<td>What Doesn't Kill You: A Life with Chronic Illness - Lessons from a Body in Revolt</td>
<td>2021</td>
</tr>
<tr>
<td>Norman, Abby</td>
<td>Ask Me About My Uterus: A Quest to Make Doctors Believe in Women's Pain</td>
<td>2018</td>
</tr>
<tr>
<td>O’Rourke, Meghan</td>
<td>The Invisible Kingdom: Reimagining Chronic Illness</td>
<td>2022</td>
</tr>
<tr>
<td>Parker, Lara</td>
<td>Vagina Problems: Endometriosis, Painful Sex, and Other Taboo Topics</td>
<td>2020</td>
</tr>
<tr>
<td>Ramey, Sarah</td>
<td>The Lady's Handbook for her Mysterious Illness</td>
<td>2020</td>
</tr>
<tr>
<td>Wang, Esme Weijun</td>
<td>The Collected Schizophrenias</td>
<td>2019</td>
</tr>
</tbody>
</table>

### Table 6: Personal Essays

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Date</th>
<th>Venue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arielle, Zipporah</td>
<td>Selma Blair Became a Disabled Icon Overnight. Here’s Why We Need More Stories Like Hers.</td>
<td>2020</td>
<td>Disability/Visibility</td>
</tr>
<tr>
<td>Birdsong, Destiny O.</td>
<td>Surviving Karen Medicine</td>
<td>2/18/21</td>
<td>Catapult</td>
</tr>
<tr>
<td>&quot;</td>
<td>Build Back a Body</td>
<td>Fall/Winter 2020</td>
<td>Ecotone Magazine</td>
</tr>
<tr>
<td>Chavers, Linda</td>
<td>My Body Is No Longer My Own and I am Terrified</td>
<td>5/6/16</td>
<td>Elle Magazine</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Date</td>
<td>Publication</td>
</tr>
<tr>
<td>---------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Deerinwater, Jen</td>
<td>Checkbox Colonization: The Erasure of Indigenous People In Chronic Illness</td>
<td>6/8/18</td>
<td>Bitch magazine39 “In Sickness Issue” (also published in Disability/Visibility)</td>
</tr>
<tr>
<td>Hedva, Johanna</td>
<td>Sick Woman Theory</td>
<td>3/12/22</td>
<td>Topical Cream</td>
</tr>
<tr>
<td>Horowitz, Kate</td>
<td>Performance of a Lifetime: On Invisible Illness, Gender, and Disbelief</td>
<td>6/5/18</td>
<td>Bitch magazine “In Sickness Issue”</td>
</tr>
<tr>
<td>Hung, Melissa</td>
<td>Drum Head: Playing Through My Chronic Pain</td>
<td>10/6/20</td>
<td>Catapult</td>
</tr>
<tr>
<td></td>
<td>Longing for the Water</td>
<td>6/3/20</td>
<td>Catapult</td>
</tr>
<tr>
<td></td>
<td>How Meditation Helped Me Feel More Comfortable in My Body</td>
<td>3/9/20</td>
<td>Catapult</td>
</tr>
<tr>
<td></td>
<td>The Headache Diaries</td>
<td>2/7/20</td>
<td>Catapult</td>
</tr>
<tr>
<td>McDeid, Reyma McCoy</td>
<td>Lost Cause</td>
<td>2020</td>
<td>Disability/Visibility</td>
</tr>
<tr>
<td>Moore, Liz</td>
<td>I’m Tired of Chasing a Cure</td>
<td>2020</td>
<td>Disability/Visibility</td>
</tr>
<tr>
<td>Reilly, Caroline</td>
<td>It’s All in Your Head: The Dangers of Disbelieving Female Pain</td>
<td>6/5/18</td>
<td>Bitch magazine “In Sickness Issue”</td>
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<td></td>
<td>The Endo Look: Body Positivity Needs to Tackle ChronicIllness</td>
<td>6/8/18</td>
<td>&quot;</td>
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<td>Samuels, Ellen</td>
<td>Six Ways of Looking at Crip Time</td>
<td>2020</td>
<td>Disability/Visibility</td>
</tr>
</tbody>
</table>

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39 Bitch magazine ceased operations in June 2022. I archived copies of the essays included in this dissertation.
CURRICULUM VITA

Caitlin Burns Allen

615-881-6778 • caitlin.burns@louisville.edu

EDUCATION

PhD in English, Rhetoric and Composition  May 2024, anticipated
The University of Louisville
Dissertation Project: “You Don’t Look Sick: Epistemic Injustice, Ethos, and Embodied Expertise in Narratives of Chronic Illness”
   Committee: Mary P. Sheridan (Chair), Karen Kopelson, Gesa E. Kirsch, Susan Ryan

M.A. in Composition, Rhetoric, and English Studies  May 2019
The University of Alabama, Tuscaloosa
Capstone Project: Ethics and Access in Mental Health Archives
   Committee: Amy Dayton (Chair), Jessica Kidd, Sara Whitver

B.A. in English, with Honors  May 2017
The University of Alabama, Tuscaloosa
Instructional Experience

First Year Writing
EN 101: English Composition
EN 102: English Composition
ENGL 101: Introduction to College Writing (Distance Education)
ENGL 102: Intermediate College Writing (Distance Education)

Upper Level Writing
BUS 301: Business Communication
ENGL 303: Scientific and Technical Writing
ENGL 306: Business Writing (Distance Education)
PUBLICATIONS


- Received 2024 CCCD Outstanding Book Award Honorable Mention in the Edited Collection category


*Conferencing toward Antiracism: Reckoning with the Past, Reimagining the Present.* Co-editor and co-author of issue introduction with Andrea Olinger, Alex Way, and Michael Benjamin. Special issue of *Writers: Craft and Context*, vol. 3, no. 1, 2022, [https://journals.shareok.org/writersccjournal/issue/view/4](https://journals.shareok.org/writersccjournal/issue/view/4)


*Unsettling the Archives*, Co-editor with Gesa E. Kirsch, Romeo García, and Walker P. Smith and co-author of “Introduction to Part II: Bearing Witness in Unsettling Ways” with Romeo García. Double Special Issue of *Across the Disciplines*, vol. 18, no. 1–2, 2021, [https://wac.colostate.edu/atd/special/archives/](https://wac.colostate.edu/atd/special/archives/)

SELECTED CONFERENCE PRESENTATIONS

“Well, Your Labs are Normal: Chronic Illness Narratives, Embodied Epistemologies, and Rhetorical Constructions of the Normal Patient”
*Rhetoric Society of America, May 2024*

“Maybe It’s Just Stress: Embodied Epistemologies, Chronic Illness Narratives, and Medical Bias”
*Conference on College Communication and Composition, April 2024*

“You Don’t Look Sick: Cultural Logics, Testimonial Injustice, and Chronic Illness” (Poster)
*Feminisms and Rhetorics Conference, September/October 2023*

“But Have You Tried Yoga: Wellness Culture, Chronic Illness, and Circulation in Online Spaces”
*Conference on College Communication and Composition, February 2023*
Respondent, “Unsettling as a Pedagogical Imperative: Archival Research and the Classroom”
*Conference on College Communication and Composition, February 2023*

Co-presenter, “Modal Responsivity: Ethical Pivots to Meet Pandemic-Induced Distance Education Challenges”
*Computers and Writing Conference (Virtual), May 2022*

Co-presenter, “Antiracist and Inclusive Conferencing: Co-Constructing Access, Attending to Power, and Practicing Accountability”
*Conference on College Communication and Composition (Virtual), March 2022*

Respondent, “Unsettling Archival Research: Engaging Critical, Communal, and Digital Archives”
*Conference on College Communication and Composition (Virtual), March 2022*

“Preserving Patient Voices: Access and Mental Health Archives” (Canceled due to COVID-19)
*Conference on College Communication and Composition, April 2021*

“Rhetorics of Representation in Surveys from the Kentucky AAUW Displaced Homemaker Project”
*Carolina Rhetoric Conference (Virtual), March 2021*

“Attending to Affect in Community Engagement”
*Annual Engaged Scholarship Symposium, Louisville, KY (Virtual), March 2021*

“Ethics and Access in Mental Health Archives” (Canceled due to COVID-19)
*Conference on College Communication and Composition, March 2020*

Co-presenter, “Unfamiliar Genre Project to Diversify Pre-Service Teachers’ Multilingual Writing Pedagogies”
*College English Association, 2019*
  - Paper selected as CEA Best in Section

**FELLOWSHIPS AND AWARDS**

The University of Louisville
  - University Fellowship, provides two years of funding during doctoral program

The Filson Historical Society, Louisville, Kentucky
  - David Armstrong History Fellows Award, provided one year membership and research support

The University of Alabama
  - Graduate Council Fellowship, provided one year of funding during master’s program

**ADMINISTRATIVE AND EDITORIAL EXPERIENCE**
**BizComm Coach (Writing Consultant and Editor)** 2022–2023  
*The University of Louisville, College of Business*
- Managed standalone writing center for the College of Business community
- Conducted in-person and virtual tutoring sessions with students
- Edited article manuscripts for and consulted with faculty members to ensure clarity, concision, and citation accuracy

**Assistant Director, Thomas R. Watson Conference on Rhetoric & Composition** 2020–2022  
*The University of Louisville*
- Collaborated to plan and carry out the 2021 Watson Conference, "Toward the Antiracist Conference: Reckoning with the Past, Reimagining the Present"
- Recruited speakers for and organized Pre-Conference Workshops for Graduate Students prior to the 2021 Watson Conference for a total audience of 128 graduate students from 62 institutions globally

**Assistant Editor, Kairos: A Journal of Rhetoric, Technology, and Pedagogy** 2020–2023  
- Reviews design elements, corrects citation practices, and copyedits webtexts and entries for PraxisWiki, a subsection of open-access journal on digital writing and pedagogy
- Ensures publications meet requirements for accessibility and usability

**Multimodal Editor, Cardinal Compositions** 2021  
*The University of Louisville*
- Reviewed and selected student writing to be published in open-access journal
- Edited multimodal pieces for accuracy, accessibility, and alignment with fair use
- Co-authored introduction to section on “Multimodal Composition and Writing for Social Change,” [https://ir.library.louisville.edu/cardcomp/vol5/iss1/1/](https://ir.library.louisville.edu/cardcomp/vol5/iss1/1/)

**Graduate Student Assistant Director, UA Writing Center** 2018–2019  
*The University of Alabama*
- Maintained a positive social media presence for the center on Twitter (over 1,300 followers) and Facebook (over 640 page likes)
- Mentored undergraduate and graduate tutors
- Designed and delivered writing-focused workshops and promotional class visits to over 130 students in various disciplines (Fall 2018)
- Coordinated Writing Center events, such as the Personal Statement Workshop
- Promoted from intern to tutor to assistant director

**COMMUNITY ENGAGEMENT**

**Mentor, READY Mentoring Program** 2023–2024  
*Student Success Center, The University of Louisville*
• Mentored first-generation first-year student in areas relating to transitioning to
college and academic success

**Writing Tutor, Cotter Cup Storytelling Contest** 2021
• Mentored elementary school students in creative writing and poetry as a part of a
University of Louisville Writing Center partnership with the Western Branch of
the Louisville Free Public Library

**Writing Tutor, Family Scholar House, Louisville, Kentucky** 2019–2020
• Served as a writing tutor and resource for participants of the Family Scholar
House as a part of the community outreach efforts of the University Writing
Center at the University of Louisville
• Promoted writing tutoring services to new participants at weekly orientations

**Volunteer, Frazier History Museum, Louisville, Kentucky** 2019
• Collected oral histories to contribute to the museum’s archives and add to
“Celebrating the Sounds of Kentucky” exhibit
• Collaboratively created a digital, interactive map of prominent musicians, venues,
and other locations in the history of Kentucky music

**DEPARTMENTAL SERVICE**

Treasurer, English Graduate Organization 2020–2021
*Department of English, The University of Louisville*

English Department Representative, Graduate Network in Arts and Sciences 2020–2021
*The University of Louisville*

MA Candidate Representative, Graduate Studies Committee 2018–2019
*Department of English, The University of Alabama*

**PROFESSIONAL DEVELOPMENT AND SKILLS**

• Introduction to Antiracist Composition Pedagogy Course, The University of
Louisville Composition Program, January 2022
• RSA Summer Institute Workshop on Medical Ableism, June 2021
• Secondary Literary Area in Afrofuturism and Black Speculative Fiction
(completed oral exam November 2021)
• Certificate in Online Writing Instruction, The University of Louisville
Composition Program, March 2020
• Extensive experience with manuscript preparation, Microsoft Office, BlackBoard
Learn course management system, WC Online Writing Center software, Setmore
scheduling software, Zoom
• Professional memberships: Rhetoric Society of America; Coalition of Feminist
Scholars in the History of Rhetoric and Composition