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FROM “SMART TALK” TO “LIVING WELL”: COMMONPLACES AND THEIR
ROLE IN NARRATIVES OF RARE DISEASE

By

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B.A., Hamline University, 2009
M.A., University of Nebraska at Omaha, 2015

A Dissertation
Submitted to the Faculty of the
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In Partial Fulfillment of the Requirements
For the Degree of

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In English/Rhetoric and Composition

Department of English
University of Louisville
Louisville, Kentucky

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A Dissertation Approved On

November 14, 2023

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DEDICATION

To my family.

ACKNOWLEDGEMENTS

I joke that I never take the easy path to complete anything. And so, after over six years of working on this dissertation, there are simply too many people with whom I share this accomplishment. First, thank you to my committee—for sticking with me and giving me encouragement when I thought this dissertation was an impossible task. To Karen Kopelson, who made me a better writer by carefully reading my work and challenging me to fully think through my ideas; to Andrea Olinger, who made time to co-write with me when I was struggling to make progress and for checking in and helping me find a path through even the most challenging moments; to Kristi Maxwell, who managed to constantly encourage me in comments and email to keep going; and to Remi Yergeau, who reminded me of the importance of this project even when I was in doubt.

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ABSTRACT

FROM “SMART TALK” to “LIVING WELL”: COMMONPLACES AND THEIR ROLE IN NARRATIVES OF RARE DISEASE

Caitlin E. Ray

November 14, 2023

As healthcare becomes more complex, automated, and bureaucratic, patients often suffer from a lack of resources, agency, and visibility when seeking medical care. Rhetoric and Composition, specifically the subfield of Rhetoric of Health and Medicine (RHM), is interested in studying and intervening into such issues. One way to challenge our current understanding of healthcare is to consider how the rare disease patient experience reveals the gaps, limitations, and assumptions of illness and health. I argue here that through rare diseases, rhetoricians of health and medicine can better understand the representation, advocacy, and patient experience within healthcare, and potentially lead to improved patient outcomes.

Over the five chapters of this dissertation, I first identify commonplaces, or ideologically constructed assumptions that underpin arguments, that are made visible through the rare disease patient experience. Then, after identifying healthcare-specific commonplaces, including *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health*, I examine how rare disease patients utilize rhetorically savvy strategies to transform these commonplaces and access resources they need—such

as diagnoses, treatments, and health policy changes. First, in Chapters 2 and 3, I examine how commonplaces shape various texts, including popular medical dramas and testimonials from rare disease advocates. These texts use commonplaces to engage their audiences, and while medical dramas uphold them, rare disease advocates will often subvert these commonplaces to make a point about rare disease and call for specific legislation or political action.

I then move to a qualitative study of one rare disease patient community, those with the rare, idiopathic inflammatory muscle disease, myositis, in Chapter 4. Through interviews with eight patients, I identify how patient communities transform commonplaces and potentially become generative sites of empowerment. In Chapter 5, the conclusion, I consider the implications of commonplaces and rare disease narratives in RHM, disability studies, and narrative. Ultimately, I argue that rare disease narratives allow us to trace the role commonplaces play in our interactions with healthcare, and once we better understand those interactions, we can create interventions to better support this community, both in and out of the clinic.

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CHAPTER ONE

INTRODUCTION

Despite medical advances during the last half-century, more people are diagnosed with chronic and complex medical conditions daily, including rare diseases. About one in ten people in the United States are classified as having a rare disease, and while that number initially seems like a small subset of patients, put together, rare diseases affect 30 million people in the United States and 350 million people globally (Genetic and Rare Diseases Center, N.D.). Further, the National Institutes of Health (NIH) estimates that 50% of people affected by rare diseases are children, making rare diseases especially deadly for children worldwide (Global Genes, 2021). People with rare diseases often struggle with getting a diagnosis and treatment and articulating their experiences to the broader public.

The rare disease experience has a unique relationship to activism, representation, and narrative, making it an important area of study for rhetoric and composition. The definition of rare disease, initially created through legislative action to increase patients' access to medical treatments, underscores this connection. Abbey Meyers, the founder of the National Organization of Rare Diseases (NORD), details how rare disease activism began in her memoir *The Orphan Drug Act: A Global Crusade*. In June 1980, Meyers

and other caregivers for people with rare diseases testified in front of congressional representatives about the lack of access to potential treatments for conditions like Tourette Syndrome because pharmaceutical companies would not invest in researching, developing, and manufacturing drugs known to treat those conditions (called “orphan drugs”). She writes:

We walked into a large hearing room that was empty except for the four of us sitting at the witness table. In the audience were my husband Jerry, and Pat Eagan who ran the Washington DC chapter of the [Tourette Syndrome Association], and her husband. The remainder of the audience in the cavernous hearing room was a sea of empty chairs and one unidentified young man sitting in the very last row.

(p. 54)

The pharmaceutical companies refused to come to this hearing. Later, Meyers asked a legislative staffer, Bill Corr, what was “next” since there was a lack of interest in their concerns. He responded, “That’s up to you. Get public opinion on your side, get newspaper and magazine stories about orphan drugs, and the public will eventually demand that something should be done” (p. 55). However, Meyers and other TSA advocates were already on their way to national attention. The “young man” in the audience was a reporter from the *Los Angeles Times*, who wrote an article that appeared in the paper on June 27, 1980, called “Young People Urge Lawmakers to Pass ‘Orphan Drug Act’” (p. 56).

That *Los Angeles Times* article drew notice from a writer of the 1980s television show *Quincy, ME*, starring Jack Klugman. His brother, Maurice Klugman, was also a writer on the show and had a rare bone cancer himself, so he decided to create an episode

in response to the orphan drug issue. In the episode, a man with Tourette Syndrome was killed. Quincy, a forensic medical examiner, used that death to confront pharmaceutical companies who refused to manufacture existing drugs known to treat the condition because they would not make a profit. This episode led to thousands of people sending letters to the Tourette Society of America asking for more information about rare diseases and conditions as well as orphan drugs (p. 64). The episode also prompted attention on Capitol Hill, where another hearing was held about orphan drugs. The March 1981 hearing included Jack Klugman as a speaker and was standing room only. This time, the pharmaceutical companies showed up to testify. The Orphan Drug Act, a law that provides incentives to pharmaceutical companies to research rare disease drugs, was passed in 1983, and many give retroactive credit to Klugman and his brother for their willingness to feature the issue on national television.

The story of the passage of the Orphan Drug Act and its role in defining rare diseases in the U.S. illustrates how the representation of rare diseases in a popular television show can impact real-life access to care and treatment. The resulting advocacy done on Capitol Hill to increase pharmaceutical treatments led to more patient groups lobbying for improved healthcare and resources for people with rare diseases. The relationship between representation and advocacy is connected through narrative—specifically in how stories about rare diseases highlight gaps in care and can effect change. Throughout this project, I examine the role of representation, advocacy, and narrative and how they connect people with rare diseases to various audiences.

Throughout the history of rare diseases, activism, representation, and community engagement have all played important roles in furthering diagnostics, research, and

treatment access. Rare disease narratives have been employed in various ways. While understudied in Rhetoric of Health and Medicine (RHM), rare disease narratives provide important insight into illness, wellness, and the role of patients in medicine. By examining narratives of rare diseases, I aim to better understand the rhetorical nature of such narratives in various contexts. To do this, I identify three healthcare-specific commonplaces, or ideologically constructed beliefs shared by a community, that underpin the narratives of rare diseases that I collected and analyzed. Then, I examined different texts (TV medical dramas, rare disease advocate testimonials, and interviews from a rare disease patient community) to understand more fully how people develop ways of talking about their rare disease experience and how public-facing narratives of rare diseases impact those diagnosed with such conditions. This project will be of interest to disability scholars, rhetoricians of health and medicine, and those who do narrative analysis.

Definition and Exigency of Rare Diseases

The term “rare disease” was first used in the Orphan Drug Act of 1983, which addressed the lack of industry focus on pharmaceutical research and development (R&D) for “orphan” diseases—diseases that were so rare that they lacked commercial viability and profitability of the diseases they could treat (National Organization for Rare Diseases, 2021). The law specifically addresses the reasoning for its existence here:

Because so few individuals are affected by any one rare disease or condition, a pharmaceutical company that develops an orphan drug may reasonably expect the drug to generate relatively small sales in comparison to the cost of producing the drug and consequently to incur a financial loss; [there] is reason to believe that some promising orphan drugs will not be developed unless changes are made in

the applicable Federal laws to reduce the costs of developing such drugs and to provide financial incentives to develop such drugs; and [it] is in the public interest to provide such changes and incentives for the development of orphan drugs.

(Orphan Drug Act, 1983)

The law incentivizes pharmaceutical companies to research drugs that will most likely never give them a clear profit. Incentives include tax breaks for undertaking rare disease research and patent exclusivity on medications developed. This bill is the first time a definition of “rare disease” is offered:

[The] term 'rare disease or condition' means any disease or condition which occurs so infrequently in the United States that there is no reasonable expectation that the cost of developing and making available in the United States a drug for such disease or condition will be recovered from sales in the United States of such drug. (Orphan Drug Act, 1983)

The subsequent Rare Diseases Act of 2002 further defined and created additional incentives for research into rare diseases, including specific research groups through the NIH and FDA (like the Office of Rare Diseases Research). This law also clarified the definition of a rare disease in the United States as any condition that affects less than 200,000 people.¹ This definition means that approximately one in ten people in the US have a rare disease. The Orphan Drug Act is considered successful as more than 600 drug indications have been approved since its passage (Gabay, 2019). Thus, the term “rare disease” was created within the network of governmental legislation, pharmaceutical

¹ These numbers reflect prevalence versus incidence. 200,000 people is how many people *in total* are affected by the disease, not how many people are diagnosed a year.

company needs, and patient lives. However, there is more to the term “rare disease” than research costs and legal definitions. Sociologist Caroline Huyard (2009) emphasizes that the term “rare” is not a medical or clinical designation but one created out of pharmaceutical and patient necessity. She traces the origins of the term “rare disease” and notes that rare disease is not a term used by doctors or even medical research broadly but originated as a legal term and then was taken over by patient advocates to build cross-coalitions between disease groups (p. 464). Creating disease coalitions allows for more lobbying power and influence, as separate disease communities are too small to effect much change on their own. Cross-coalition rare disease groups also reveal the commonalities of rare disease communities—including a complex and lengthy diagnostic process and challenges in finding appropriate treatments.

Rare diseases are fascinating study sites because they challenge fundamental beliefs of modern medicine. In undertaking this project, I ask:

1. How do representations of rare diseases reveal gaps, limitations, and challenges in healthcare?
2. What shared narratives exist between representations of illness and the lived experiences of rare disease patients? Do rare disease representations influence rare disease illness narratives? If so, how?
3. How do narratives change when told by people with illness within a shared patient community?

To examine these questions, I examine three sites of rare disease rhetorical work. The first is the TV medical drama, where I analyze rare disease representation. From these medical dramas, I identify commonplaces, or ideologically constructed beliefs shared by

a community, that shape the healthcare-specific narratives told. Then, I look at rare disease advocate testimonials told at the Rare Disease Congressional Caucus. I use the previously identified commonplaces to better understand how those beliefs influence advocate testimonials when told to the high stakes audience in Washington, D.C. Lastly; I interview people within one specific rare disease community to understand how illness narratives and the commonplaces within them potentially transform in shared patient communities.

Intersecting and Interdisciplinary Fields as Framework

This project primarily situates itself within the fields of RHM, disability studies, and narrative. Broadly, I am interested in how representations of rare disease can highlight typically hidden commonplaces in narratives of healthcare. This section will overview the relevant literature from the three major fields intersecting in my work.

Rhetoric of Health and Medicine

Generally, RHM is guided by the belief that texts about health and medicine are rhetorical, persuasive, and can “offer insight to medical research and practice” (Derkatch & Segal, 2005, p. 138). Judy Segal (2005) writes that medicine is rhetorical in how arguments about health and illness intersect with various stakeholders (p. 3). That is, rhetorical study in the fields of health and medicine is not limited to written texts but also in how we think and perceive medicine—and, as an extension, what constitutes “health” and “illness.” Additionally, RHM is interested in the relationship of power, agency, and the sociocultural forces that shape our interactions with medicine.

Medical rhetoricians have written many articles and book-length monographs on specific illnesses, including migraines (Segal, 2005), infertility (Britt, 2001), diabetes

(Arduser, 2017), and HIV/AIDS (Scott, 2003). These works consider the interconnections between medical care, public policy, and patients as a way to investigate the rhetoricity of health and medicine. More recent texts have featured patients more explicitly, collecting experiences and discussing patient agency, narrative, and the work patients do to control chronic disease (Arduser, 2017; Kessler, 2022). Additionally, RHM scholarship works to unpack how language operates within specific texts. For example, RHM research examines the role of metaphor, such as the body as a machine, medicine as war, medicine as a business (Segal, 2005), or genetics as a blueprint or recipe (Condit & Condit, 2001). Genre analysis has also been an effective mode of inquiry within RHM, including health policy and document evaluation (McCarthy, 1994; Solomon, 1995), breast cancer “awareness” movements (King, 2008; Pezzulo, 2003; Kopelson, 2013), medical advertisements (Segal, 2011; Barker, 2011), and birth plans (Owens, 2011).

Additionally, RHM has considered illness through narrative. RHM scholars, including Judy Segal (2007), Lora Arduser (2017), and Diane Price Herndl (2014), critique narratives and counternarratives about specific diseases and examine their impact on the public’s understanding of health and illness. Most prominent is the critical scholarship about breast cancer, where narratives are used to consider how the ideal “breast cancer patient” is constructed. For example, Segal (2007), in her analysis of the public rhetoric of breast cancer narratives, argues that many breast cancer stories fit into an already accepted and popular narrative of illness that teaches “how shall one be ill” with cancer (p. 16). Breast cancer stories are a recognizable narrative, starting with the discovery of a lump in the breast and ending with the person who has survived cancer writing their story for others. These narratives tend to be more conservative, highlight

individual responsibility, and ultimately believe that “*normal* is still the ideal [and] illness and disability still constitute that *other* (shameful) state” (p. 9). Segal argues that these personal, individualized stories of illness proliferate in the public at the expense of other more “renegade” ones that might disrupt familiar narratives that uphold the status quo (pp. 15-16). Elizabeth Davis’ (2005) analysis of the National Cancer Institute’s pamphlets argues that these documents “tell a ‘story’ about the breast cancer patient and the breast cancer experience, constructing an idealized patient identity that serves a prescriptive function for women and situates all women as being ‘at risk’ for breast cancer” (p. 65).

I also draw on how RHM considers technology a key theme in diagnostics and disease visibility. RHM offers critical examinations of technology, with articles examining how online spaces and advancing technology shape experiences with healthcare. Critical examinations of technology are particularly important for illnesses that may or may not be visible without diagnostic testing. Additionally, online health communications are helpful when considering how connections developed on the internet empower people with rare illnesses to find one another and create community (Segal, 2009a; Kopelson, 2009; Koerber & Still’s 2008 *Technical Communication Quarterly* issue). Scholarship on internet communications highlights how technology builds community between people united with a specific diagnosis, including Kristin K. Barker’s (2011) analysis of electronic support groups for fibromyalgia and Kuang-Yi Wen et. al’s (2009) work about breast cancer. Both comment on the ways that patient-centered electronic support groups can help people with illness “shar[e] embodied expertise” (Barker, 2011, p. 20) and allow identification among each other (Wen et al.,

2009, p. 331). Through a qualitative study of each electronic support group site, these articles argue for the importance of communication channels in forming communities and empowering people with specifically gendered and contested illnesses (Wen et al., 2009, p. 353). However, such power in the community is often limited by a more powerful medical system (Barker, 2011, p. 30). How communities are built in online platforms is important in considering how it impacts people with rare illnesses. It is in part because of technology that these communities can exist and that more robust studies of people with rare illnesses are possible.

Disability Studies

Disability studies is also an important area of scholarship I will use to inform how I collect and analyze my data. Because disability is a guiding lens in my analysis, it is important to understand the unstable and fluid term that is “disability.” The category of disability is social and contextual rather than fixed and simply reflective of a specific “deficit” or medical diagnosis. As Linton (1998) writes, disability is “a linchpin in a complex web of social ideals, institutional structures, and government policies” (p. 162). Additionally, people may or may not identify with this category since they may age in or out of disability, or they might have invisible disabilities that allow for some to “pass” (Pearson & Trevisan, 2015; Shakespeare, 2006; Brueggemann & Modellmog, 2002). The shifting definition of disability must continually contend with the historically informed attitude that disability is a “deficit.” The “deficit model” also depends on disability being contingent on some sort of medical diagnosis, that “the person with a disability has a deficit which must be corrected” (Pfeiffer, 2002). The medical model of disability, a variation of the deficit model, argues that a person cannot function

“normally” due to a health condition. More recent work in disability studies challenges this model.

Disability studies also considers the role of language in constructing ideas of illness, pain, and the body. James C. Wilson and Cynthia Lewiecki-Wilson’s (2001) collection *Embodied Rhetorics: Disability in Language and Culture* works to unpack the way language constructs a “natural” or normalized view of the body (p. 2). Additionally, the role of “disclosure” in disability theory is another way that language and other cues—particularly for those with invisible illness—indicate disability. “Disclosure” is a complex topic encompassing overt and covert acts, from storytelling to changing the body to signify disability (Siebers, 2004; Kerschbaum, 2022; Samuels, 2017). Siebers and Samuels interrogate the role of “passing” and disclosure, noting how speech acts, such as illness narratives, are a performance that can make disability visible to others.

The subfield of “crip studies” furthers the connection between language, rhetoric, and social action. By reclaiming the word “crip” (derived from the word “cripple”), disability scholars move further into questions of the body, bringing together queer and feminist theories in order to critique the political and economic structures that socially construct ideas of disability (McRuer, 2006; Kafer, 2013; Mitchell & Snyder, 2015). “Crip” is defined as the acceptance of disability as “a viable identity variable to be recognized, acknowledged, and celebrated.” (McCruer, 2006). Crip theory also “recognizes the importance of the intersectionality of one’s disability identity with all other identity variables.” The term “crip” works to highlight, rather than hide, the difficulties that an able-bodied world creates for people with disabilities (Williams, 2017). When Nancy Mairs declares herself not “disabled” (and therefore lacking) or

“handicapped” (implying that someone “disadvantaged” her), but as “crippled,” she encapsulates the complicated relationship she has with her body. She writes, “People—crippled or not—wince at the word ‘cripple,’ as they do not at ‘handicapped’ or ‘disabled.’ Perhaps I want them to wince” (Mairs, 1992). The ways that disability is theorized as a political and disruptive identity marker through the idea of “crip” studies is useful in critical analyses of illness narratives.

Like the RHM, disability studies also critically examines narrative but does so for a more overtly political end. Disability scholarship tends to use first-person writing and utilizes ethnography and autoethnography, including examples like Brueggemann’s (2009) “‘Writing Insight’: Deafness and Autobiography,” Audre Lorde’s (1980) *The Cancer Journals*, and Susan Wendell’s (1998) *The Rejected Body: Feminist Philosophical Reflections on Disability*. Moves in these texts create a critical reflection within scholarship that adds insight into the experiential nature of disability. Critical reflection through first-person narration can make powerful rhetorical points by forging compelling connections and reaching new audiences. Feminist scholar Einat Avrahami cautions, though, that “some [people] are more skillful in the rhetorical deployment of these potentially powerful words to influence the behavior of others in the desire to receive support, to keep others at a distance, to obtain time alone, to convey anger, to conceal shame, and so forth” (p. 11). Avrahami points to the rhetorical power of illness narrative and the rhetor’s ability to shape a narrative for an audience. Scholarship on disability, narrative, and critical reflection helps us understand the rhetorical nature of these stories.

In addition to using disability studies as a theoretical lens, I will also use it to inform methods and methodologies used in my research. Historically, people with disabilities have been the unwilling or unknowing subjects of research and have felt oppression, stigma, and even death due to these subjugated positions. As a result, when using people with disabilities as research subjects, the researcher must be careful to treat this population ethically and with consideration for their autonomy and personhood. Building on a legacy of feminist methodologies (Garland-Thompson, 2005; Brueggemann, 1996; Dolmage & Lewiecki-Wilson, 2010), disability-informed methodologies consider four major traditions that include access, activism, identification, and representation (Price & Kerschbaum, 2016, p. 25). Such methodologies also call for increased accessibility for research subjects and researchers, ways for research projects to directly benefit those being researched, and how research subjects can be given continual autonomy over data collected. Margaret Price and Stephanie Kerschbaum also consider Mike Oliver's call that "disabled people should be not the objects of research on disability, but the producers of it" (qtd. on p. 23). As a disabled researcher with the rare illness I examine in Chapter 4, I am interested in how to be a researcher and producer of scholarship and how disabled researchers can provide new insights.

Narrative Analysis

I will use narrative to both collect and analyze data in this project. Both disability studies and RHM use narrative, whether through life-writing, ethnography, or a rhetorical analysis. As a methodological inquiry, narrative is also interested in the structure and function of a story and its social and cultural context. Narrative analysis considers the relationship between the storyteller and the audience and how a collection of narratives

can tell a diverse story of a phenomenon (Leavy, 2015; Merriam, 2009; Creswell, 2012).

Throughout this dissertation, I consider how illness narratives have been used in popular culture, advocacy, and patient communities. Critical scholarship on illness narratives, including that of Anne Juricec (2012), argues that illness narratives—popular with readers but treated with suspicion by critics—interrogate the ways that we write and make meaning of “living *at risk*, *in prognosis*, and *in pain*” (p. 4, emphasis hers). While Juricec writes from a literary studies perspective, G. Thomas Couser (2009) examines first-person illness narratives from a sociocultural lens. Specifically, he analyzes “life writing” and disabled writers, arguing that the disability memoir is not a “spontaneous self-expression but as a response—indeed a retort—to the traditional misrepresentations of disability in Western culture generally” (p. 7). The representation of the body in life-writing makes illness narratives important to their authors and readers.

Additionally, illness narratives are increasingly used in the research and training of new healthcare workers in narrative medicine. Qualitative healthcare research collects stories from patients and medical practitioners and offers interdisciplinary insight into the patient experience, diagnostic journey, and treatment plans. The subfield of narrative medicine brings together illness narratives, along with case studies (a detailed investigation of a single or group of patients) and pathographies (broadly, writing about disease), to consider the importance of patient stories and the role of storytelling in medical practice (Heale & Twycross, 2018; Jutel & Russell, 2021). Narrative medicine is guided by two main points: First, the stories of patients ought to be collected, written up, and used to teach medical practitioners the experience of disease. These stories are often written by doctors about patients. Second, narrative medicine should incorporate

narrative as part of the healing process of people with illness and the educational experience of medical professionals (Charon, 2006; Frank, 1995; Kleinman, 1988). By studying how narrative functions within illness, doctors, either for themselves or for the benefit of patients, examine how stories connect to embodied experience (Brody, 1987; Berkenkotter, 2008). Arthur Frank (1995), in *The Wounded Storyteller*, articulates three specific types of illness narratives: the “restitution narrative,” “the chaos narrative,” and “the quest narrative.” He argues that illness is an isolating experience for people, especially if that illness does not follow a typical restitution masterplot (which is: “Yesterday I was well, today I am sick, but tomorrow I will be well again”) (Frank, 1995, p. 77). Additionally, Frank describes serious illness as a type of “narrative wreckage” that we attempt to repair through storytelling (p. 54). However, there are serious concerns about how narrative medicine uses stories of people with illness and the ownership of these stories, particularly without patients' or their families' continual (or even preliminary) permission (Linton, 1998, p. 140).

This dissertation broadly examines how narrative is studied within RHM and disability studies. I ask: What are the limitations and affordances of studying narrative? Can representation, advocacy, and patient communities help us understand the complex relationship between medical systems, doctors, and the nature of rare diseases? In triangulating disability studies, medical rhetoric, and narrative theory, I hope to look towards a methodologically sound study design and a considerate theoretical frame to position this project.

Intervention: Healthcare-Specific Commonplaces in Narrative

Here, I completed a two-part research project, with a rhetorical analysis of rare disease narratives in the first two chapters—one about the representation of rare diseases in *House* and *Grey's Anatomy* (Chapter 2) and the second about rare disease advocate testimonials (Chapter 3). Then, I conducted a qualitative analysis based on eight interviews of people within one rare disease patient community (Chapter 4). Throughout, I use the rhetorical concept of commonplaces as my analytic lens.

Background on the term “commonplace”

I use commonplaces as my intervention to understand better the use of narrative in health and medicine and how stories about the rare disease experience reveal the gaps and barriers to healthcare. While commonplaces are often understood as nearly interchangeable with *topoi* or topics of argument, I use Sharon Crowley's (2006) concept of commonplaces, defined as ideologically constructed beliefs within a specific community (pp. 70-75). These assumptions are not important because they are truthful (they often are not), but because of the *frequency* with which they are called on within specific communities, and that repetition justifies their presence. Commonplaces construct, maintain, and reproduce beliefs and are so powerful that even if they are not explicitly accepted by a rhetor, they often are hidden within their discourse. To illustrate this, Crowley writes about feeling pride when watching a flyover by the Air Force at a baseball game, despite knowing that such a display is a “[celebration] of my country's capacity for surveillance and killing” (p. 70). Additionally, Crowley contends that “each [commonplace] presupposes and encapsulates fairly extensive arguments that are not often uttered, but that can be deduced and reconstructed” (p. 70). Because of the pervasiveness and invisibility of commonplaces in arguments, they can create insidious

and dangerous rhetoric. However, commonplaces can be rendered visible through rhetorical analysis. Thus, it is imperative for rhetoricians to uncover and deconstruct them.

Ralph Cintron (2010) also uses “commonplaces” (interchanged with *topoi*) to examine democratic ideals and civic engagement. He writes, “At the heart of my discussion of democracy is the notion of *topoi* (commonplaces) as storehouses of social energy. The basic claim here is that *topoi* organize our sentiments, beliefs, and actions in the lifeworld” (p. 100). Cintron’s definition demonstrates how commonplaces are often in motion, even as they are hidden within our “sentiments, beliefs, and actions.” Commonplaces animate our actions and beliefs, and, again, it is the role of rhetoricians to examine and understand how they perpetuate shared beliefs in a community.

I use “commonplaces” instead of other related rhetorical terms, such as *topoi* or *doxa*. However, an overview of both terms is helpful. In Aristotle’s *Rhetoric*, *topoi* refer to different topics of argument—general or special. Lawrence J. Prelli (1989) summarizes general and specialized *topoi*: “One must talk as others talk, and one must talk about specific subjects” (p. 74). Both accessibility to a general audience and specific knowledge on a topic are needed when crafting arguments. While there is debate over what Aristotle precisely meant in his writing about *topoi*, some hold that Aristotle’s topics “were aids to memory, a checklist or inventory of forms of argument or available premises for enthymemes to help a rhetor convince an audience of a judgment already held” (Laur, 1996, p. 724). Others interpret Aristotle’s topics as “heuristics—socially shared instruments for creating probable knowledge” (Laur, 1996, p. 724). Each definition considers how an argument is constructed by a rhetor for a specific audience.

Doxa is another related term and broadly means opinion or belief, as opposed to *episteme*, or knowledge. Prelli (1989) also provides a useful definition of *doxa*, saying that argumentation involves “exploring the *doxa*, or relevant body of opinion, for suitable materials and structures (p. 63). He further explains that *doxa* is important in constructing effective argumentation because it helps categorize information based on a specific, socially constructed audience:

The world of opinion—of humanely processed knowledge—is one in which data and conceptions are connected, associated, and dissociated. Peas are not just peas; they are *vegetables*. Atoms are not just structures; they are structures of *matter*.

To inquire into what may be said about something is to inquire into the prevailing and possible modes of connection, association, and dissociation known to a culture, a society, a community of scholars, a particular audience. (pp. 63-64)

That is, in Prelli’s view, *doxa* is key in how a “particular audience” organizes information in scientific argumentation. Pierre Bourdieu (1977) also considers *doxa* within sociology and anthropology and discusses the role it has in the structure of institutions. Bourdieu’s concept of *doxa*

broadly refers to the misrecognition of forms of social arbitrariness that engenders the unformulated, non-discursive, but internalized and practical recognition of that same social arbitrariness. It contributes to its reproduction in the social institutions, structures, and relations as well as in minds and bodies, expectations and behavior. (Deer, 2014, pp. 119-120)

Doxa, in Bourdieu’s perspective, contributes to the “reproduction” of institutions (including medicine) that can reduce those institutions down to “social arbitrariness.” In

discussing how *doxa* can hide “expectations and behavior,” the term seems closely related to that of Crowley’s usage of “commonplace.”

However, despite the close association between *topoi*, *doxa*, and commonplace, I have opted to use commonplace partly because of Crowley’s elucidation about how difference can render commonplaces visible. She articulates how difference can highlight the use of commonplaces, which are usually obscured and hidden in discourse:

Commonplaces are part of the discursive machinery that hides the flow of difference, that firms up identity and sameness within a community[...]

Commonplaces generally become available for discussion only when (a) believers wish to solidify identity and community or (b) they encounter unbelief—that is, they become aware of counterclaims. ... That is to say, commonplaces can be made available for scrutiny by encounters with differences. (p. 73)

Encounters with differences are important to challenge pervasive and damaging beliefs that can run unchecked through narratives. In Crowley’s work on fundamentalism and religion, she examines how commonplaces both infiltrate public life in the U.S. through shared ideological beliefs.

In the case of narratives about healthcare, unchallenged beliefs and assumptions can be a matter of life and death. Crowley’s contention that difference can reveal commonplaces in discourse serves as a basis for my analysis of healthcare-specific commonplaces, using rare disease experiences as that “difference” that broadly highlights the gaps and limitations of healthcare.

Healthcare-Specific Commonplaces

In this project, I first identify three healthcare-specific commonplaces that I use to analyze narratives about the rare disease experience by analyzing rare disease representations in TV medical dramas. Then I use those commonplaces in subsequent chapters to examine arguments within the narratives told by rare disease advocates and people within patient communities:

Illness is visible. The first healthcare-specific commonplace I identified in Chapter 2 is that *illness is visible*. The idea that illness must be visually identifiable is a longstanding belief in medicine. This commonplace assumes that illness is rooted in biomedical evidence easily seen in abnormal scans, blood work, or other visible symptoms. Biomedical evidence is then used by medical providers to identify a diagnosis for a patient. Diagnosis is often delayed or denied entirely when this evidence is not visible. The more complex the disease, the more difficult it may potentially be to establish a diagnosis. For example, when one first has a medical encounter for a symptom, the healthcare worker may check for specific visible signs—whether that is an examination, imaging, or bloodwork to identify the problem. These diagnostic procedures can be as simple as an X-ray to confirm a broken arm or as complex as a multi-stage collection of blood tests, imaging, and others to diagnose rheumatoid arthritis. Other diseases, though, are only diagnosed by exclusion, where other potential diseases are systemically eliminated from consideration. Effectively, these diseases are “invisible” to healthcare workers despite symptoms experienced by patients. The duality of visible and invisible illness is more complex outside healthcare settings, where potential visible signs of illness are not immediately legible on the body. Because of the pervading assumption that illness needs to be visible to be “real,” people with “invisible” illnesses struggle

significantly to legitimize their illness inside and outside the medical system and get support and treatment.

RHM scholars, such as Scott Graham (2009) and Vyshali Manivannan (2017), consider invisible and visible illnesses through medical technologies and how they render diseases readable on the body. Graham discusses the role of the PET scan in diagnosing fibromyalgia—a contested illness that causes diffuse pain—and how it has allowed new biomedical treatments. Manivannan challenges the role of visible proof of disease in her own felt sense of illness, arguing that by rendering pain as needing visual proof to be considered “real,” a patient’s experiential knowledge of illness will continue to be discounted. While much has been written about the delayed diagnosis of “invisible illness,” *illness is visible* becomes an important commonplace in rare disease narratives—whether the illness is visible to medical providers but still lacks a firm diagnosis or truly lacks biomedical evidence.

Medical expertise validates patient agency. The second commonplace is *medical expertise validates patient agency*. Essentially, while “patient agency” may seem to be valued and placed at the forefront of the patient experience and medical decision-making (through documents such as the birth plan or patient preferences worksheet), medical expertise is needed to legitimize that agency (Keränen, 2007; Owens, 2008). Agency and expertise have been written about extensively within RHM, where they have noted the complex ways that medical expertise is intertwined with that of patient agency. Ellen Barton (2000) writes about medical expertise in patient referrals, noting that “medical expertise is generally defined not only in terms of a body of specialized knowledge but also in terms of its power and authority within social and cultural

structures” (p. 261). Agency is further defined in Lora Arduser’s (2017) work on diabetes care, where she notes that agency, while often defined as an act of resistance, might actually *disempower* people because medicine remains a highly authoritarian structure (p.10). Instead, she writes, “agency as a whole ... is a form of rhetorical work attached to performances of expertise and enacted within a set of relations” (p.11). Further, RHM scholars also write about documents such as DNRs, patient preference worksheets, and birth plans as “boundary objects,” defined by Susan Leigh Star and James Griesemer (1989) as an artifact that “[develops] and [maintains] coherence across intersecting social worlds” (p. 393). Lisa Keränen (2007) and Kim Hensley Owens (2008) use the term for patient preference worksheets and birth plans and demonstrate how both documents seem to give agency to the patient to navigate difficult medication situations, even if that agency is falsely constructed.

RHM scholars also write about patient agency and expertise within e-health. Segal (2009a) and Kopelson (2009) both look at the internet-informed patient and how access to information changes their relationship with doctors. Segal considers that, for the patient, “the Internet can do no more than provide information with little direction about how to use it” and that the patient’s input is still secondary to the doctor (p. 359). These themes are reiterated by Kopelson (2009), who argues that online health information has reshaped “the status and subjectivity of patienthood” (p. 354) and can allow for patient expertise to develop—although such expertise still is framed around traditional medical hierarchies that continues to “marginalize alternative subjectivities and serves dominant interests” of medicine (p. 357). More recent scholarship on e-health (including health information literacy, online patient communities, and health activism conducted online)

moves beyond patients simply looking up symptoms and printing out material to take to the doctor to social media that allows sophisticated interactions between people with chronic and rare diseases (Hooker, 2022; Arduser, 2017, pp. 59-60; Opel, 2018; Willis, 2018).

Compliance leads to health. The last commonplace I use is *compliance leads to health*. The role of compliance is a complex one in medicine, and many healthcare workers are concerned with patient compliance and noncompliance. Compliance usually refers to a patient's ability to follow doctor's orders by taking medication, changing lifestyle habits, or being vigilant about testing (Segal, 2007; Gouge, 2018). Thousands of articles are published in medical journals about compliance and adherence. These articles include topics like how to persuade patients to be compliant and the effects of being either compliant or noncompliant on health. While the term "compliance" is still used in medical literature, some call for the use of other terms like "adherence" or "concordance" instead (Ahmed & Aslani, 2014; Martin et al., 2005; Chakrabarti, 2014). The move toward "adherence" and "concordance" suggests that being noncompliant may be an intentional choice on the part of the patient; despite this, most researchers still assume that all medical interventions are beneficial, and failure to comply only hurts the patient's health.

RHM scholars have long considered the role of compliance, adherence, and concordance in medicine. Segal (2005) argues that "compliance" represents the rhetorical processes between patient and doctor. She writes, "patients do in most cases make their decisions about their own care, and it is best if they are persuaded to make good ones" (Segal, 2005, p. 134). Segal is not alone in her opinion that health communications by

doctors play an essential role in persuading patients to be compliant—most medical literature argues the same. As for noncompliance, Gouge (2018) summarizes the medical opinion of noncompliant patients as “inconvenient at best and either intentional or accidental villains, at worst, in their own care,” although noncompliance can be generative and highlight gaps and limitations in healthcare services (p. 114). Research outside RHM has also examined the motivations behind medical noncompliance or nonadherence by patients. Huyard (2017) looks at the motivations of temporary “nonadherence” with medications for people with chronic conditions such as hypertension or chronic myeloid leukemia. She finds that patients would temporarily change or discontinue medications to either “exert control over the treatments and their effects on their body” or “to control the hold of the treatment on their daily life” (p. 1215). These findings reveal a more complex picture of why someone may discontinue or modify medical treatment, especially considering the many negative ways medications can interact with someone’s daily life. As a result, “compliance” and “noncompliance” becomes a more complex, rhetorically nuanced action by patients.

My Positionality and a Note on Terms

I come to this project as a researcher with a complex, rare, and chronic disease that causes physical disability. My first-hand experience with rare disease led me to pursue this project, and my positionality allowed me quick access to events and groups I would not otherwise have had. These include the Rare Disease Week events through the Everylife Foundation for Rare Diseases Legislative Advocates program, which provided much of the material for Chapter 3, and access to patient support groups and The

Myositis Association Patient Conference, where I interviewed research participants for Chapter 4.

It is worth taking a moment to discuss the role of the researcher in this study. In examining a community I am part of, I recognize that I am not taking the traditional researcher role. My decision to subvert this expectation is intentional, as I draw from rhetorical scholarship that has incorporated personal experience, including Beverly Moss' research on African American Churches or Brenda Jo Brueggemann's writing on Deafness and autobiography. These two texts position the researcher within the research project and talk frankly about potential bias and insights that the researcher's positionality affords. These models for my research impacted how I designed my methods, constructed my research objectives and questions, and talked about this illness with others in the rare illness community.

Additionally, I was attentive to the use of terms when referring to people and their experiences. As someone with a disability who works in disability studies, the use of language, especially when referring to disabilities, can be contentious. Personally, when referring to myself or disability in general, I opt for identity-first language (that is, "disabled researcher") as opposed to person-first language (like "researcher with a disability"). However, terms like "disability" or "disabled" can be very personal, and decisions around usage vary from person to person. Complicating this was an early decision I made not to use "patient" when referring to people with illness. However, further reading and anecdotal experiences with my research participants found that many people with illnesses do not want to use the term "disabled" to refer to themselves. They often referred to themselves as a "patient" and generally preferred that term. Because I

did not have the time to investigate the relationship between rare disease, patients, and the term disability for this project, I opted to refer to people with illness, generally, as “patients” throughout. Similarly, throughout the dissertation I tend to use “disease” as opposed to “illness” when discussing patients and the healthcare system, and when I use “illness,” it is not necessarily defined separately from “disease.” This, too, is an intentional choice, although one that goes against some scholarship in bioethics, RHM, and other fields that position “illness” as the patient’s experience, thoughts, and feelings regarding disease, and disease is the biological problem treated by a doctor (Cassell, 1976; Boyd, 2000). The reason I do not make the same distinction between illness and disease is due to the common usage of the phrase “rare disease experience” in rare disease research and patient advocacy groups (Huyard, 2009). Since “rare disease experience” as a term encompasses the definition of “illness,” I felt that using both “rare disease experience” and “illness” would be overly confusing. I opted to use “rare disease experience” when referring to the lived experience of patients.

Overview of Chapters

The first section of my dissertation (Chapters 2 and 3) considers how rare illness is broadly represented to a general and more specialized audience. To determine what shared themes exist in rare disease narratives, I identified commonplaces that highlight ideological assumptions made within them (Crowley & Hawhee, 2003, p. 96). Much like Segal's (2007) questions about breast cancer narratives, I am interested in what rare illness narratives “do for us and what do they do *to us*” (p. 6). Such rhetorical analysis attempts to make visible invisible assumptions about health and illness that impact people with rare diseases and shape the experiences of people who are ill. My methodological

intervention for the rhetorical analysis includes a close reading of specific themes and commonplaces in TV medical dramas and rare disease patient testimonials.

The second section is a qualitative study with patients from one rare disease community (Chapter 4). Qualitative researchers are concerned with “understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences” (Merriam, 2009, p. 15). This project seeks to understand the ways that narrative is used by particular people within specific contexts, and I use narrative inquiry to further collect and then make explicit the “beliefs, values, and assumptions” of illness experiences (Merriam, 2009, p. 12; p. 34).

The chapters of this dissertation are as follows: In Chapter 2, “This Means It’s Real”: Rare Diseases and Commonplaces of Healthcare in Medical Dramas,” I examine two TV shows, *House* and *Grey’s Anatomy*, in part to look at the legacy of rare disease representation after *Quincy, ME* in the 1970s and 80s. By examining two episodes (and the pilot) of each show that feature the rare disease experience, I identify three healthcare-specific commonplaces used to shape the narratives and representation of each fictional patient. I can do this because the rare disease experience, as an outlier in healthcare, contrasts with the expected experience in healthcare settings. Once I identify each commonplace, I examine how they operate in each TV show and communicate the rare disease experience to a primarily general audience.

Then, in Chapter 3, “The Expert Patient: Critical Compliance, Hypercompliance, and Rare Disease Advocacy,” I turn my attention to rare disease advocacy by analyzing the role of healthcare-specific commonplaces in rare disease testimonials given at the Rare Disease Congressional Caucus on Capitol Hill. Using the previously identified

commonplaces, I examine how advocates use them to initially engage their audience and then subvert those commonplaces to make a point about rare disease and call for specific legislation or political action.

Chapter 4, "Living Well with Illness: Transforming Commonplaces and Illness Narratives within the Rare Disease Community," examines one rare disease patient community. I interview people with a type of rare, idiopathic inflammatory muscle disease, myositis. I selected this community because only about 50,000 people in the United States are diagnosed with this cluster of diseases (Johns Hopkins Myositis Center, 2023). I also selected this community because I identify as part of it: I was diagnosed with dermatomyositis in 2010 and have been part of these online support communities since then. Through interviews with eight patients, I examine how commonplaces transform in patient communities and potentially become generative sites of empowerment.

Lastly, in Chapter 5, the conclusion, I consider the implications of commonplaces and rare disease narratives in RHM, disability studies, and narrative. I argue that the rare disease experience reveals the gaps and limitations of healthcare, making healthcare-specific commonplaces visible. Once these are identified, one can trace how the commonplaces shape how we interact with healthcare. The implications of such research include understanding and potentially intervening in systemic healthcare problems, such as rising costs, artificial intelligence, medical worker burnout, and bureaucracy creep that infiltrates all sectors of medicine. I close by highlighting the importance of RHM scholars to take up rare disease research to understand this particular illness community, chronic

and complex disease more broadly, and ways to reimagine the role of researcher in this field.

CHAPTER TWO

“THIS MEANS IT’S REAL”: RARE DISEASES AND COMMONPLACES OF HEALTHCARE IN MEDICAL DRAMAS

Susannah Cahalan’s memoir *Brain on fire: My month of madness* (2012) details her diagnosis and difficult recovery from a rare neurological condition, anti-NMDA receptor encephalitis, which causes seizures, erratic behavior, and psychosis (Center for Autoimmune Neurology, N.D.). While she had no memory of most of her illness, her memoir pieces together her experiences through interviews with her family, friends, and medical teams. At a turning point in the narrative, a specialist comes in to discuss options with Susannah’s parents. He authoritatively talks through his recommendation for a brain biopsy, and as he leaves, her mother whispers to her father, “He’s a real-life Dr. House” (p. 136), invoking their favorite TV show, *House* (2004-2012), starring Hugh Laurie. Later, in her acknowledgments, Cahalan writes, “How do I thank my brilliant and selfless Drs. House: Dr. Souhel Najjar and Dr. Josep Dalmau?” (p. 250). This fictional medical drama (and House, a character based on Sir Arthur Conan Doyle’s Sherlock Holmes) shapes Cahalan and her family’s expectations of what good medical care for a rare disease looks like. In fact, when discussing the long and arduous process of diagnosing a rare disease, Cahalan invokes House as the type of doctor one wants on their case. He seemingly represents the doctor who will not pass on an impossible medical

case, nor take other doctors' previous tests and diagnoses at face value, but will instead work obsessively to figure out the medical mystery at hand

What is so compelling about medical dramas such as *House* or *Grey's Anatomy* for both the broader public and people with rare illnesses? These shows, and other medical dramas like them, have a durable popularity and are familiar to much of the TV-watching public, even if audiences haven't viewed these specific shows. This is especially true in the case of *House*, a TV show that, even as it has been off the air for a decade, has had a lasting impact on the way the broader public understands rare illnesses. One way medical dramas are compelling is how they take on controversial yet universal topics surrounding health, illness, and death. Medical dramas continually draw large audiences because they craft stories around familiar commonplaces of health and illness—even as these commonplaces aren't entirely visible to the audience.

I use *commonplaces* as the intervention through which I examine rare disease narratives in various texts, including popular culture. Commonplaces are often considered synonymous with *topoi*, but I differentiate between the two terms by utilizing Sharan Crowley's (2006) definition of commonplaces, which focuses on how they operate as ideologically constructed beliefs that underpin arguments within a specific community (p. 70-75). Additionally, Julie Lindquist writes in the 2020 Conference for Composition and Communication call for papers that commonplaces can reveal the "borders" of a discipline by identifying the assumptions of that discipline. For composition studies, she writes that commonplaces may include that "some students must fail so that others may succeed" or that "our primary activity is 'teaching,' rather than creating learning opportunities for students." In a later introduction for a CCC special issue on the

conference, conference organizers further describe how commonplaces are “*unproductively durable*” (Lindquist, 2019; Lindquist, Straayer, and Halbritter, 2023, p. 5). Using commonplaces can help reveal durable ideological that can lead to barriers, potential bias, and a lack of creativity in addressing problems.

Identifying *healthcare-specific* commonplaces is important work of Rhetoric of Health and Medicine (RHM) scholars because such commonplaces can help us understand how beliefs, and thus arguments, operate in illness and health. For example, Elizabeth Britt (2001) uses commonplaces as a framework to construct her rhetorical analysis of infertility. She identifies “the expectations that success will be rewarded,” that “life proceeds predictably,” and that “individuals more or less control their fate” as major controlling ideas in infertility rhetoric (p. 15). She then examines the tacit arguments those commonplaces provide in policies, legislation, and first-person accounts. Margaret Price (2011) also uses commonplaces (which she also refers to as *topoi*) as the framework in *Mad at school: Rhetorics of mental disability and academic life*, using them to examine how the academy “intersects problematically” with mental disability (p. 5).

Commonplaces are invisible, yet ever-present components of rhetorical portrayals of illness and disability in medical dramas. However, I not only focus on the way that commonplaces generally operate in narratives of health and illness but also how the rare disease experience specifically renders commonplaces of health and medicine visible because of the ways that rare disease patients encounter medicine. I use the rare disease experience to reveal healthcare-specific commonplaces that operate in highly public narratives. Then, I look at how such commonplaces argue for certain values within medicine—often running counter to the rare disease experience.

Healthcare-specific commonplaces (like all commonplaces) are deeply entrenched in texts, but they are rendered visible by the rare disease experience. As a result, rare disease narratives, like those in medical dramas, can help identify the “borders” of healthcare and illness through its use of commonplaces. The rest of this chapter outlines the three commonplaces I have identified in popular medical dramas and how they operate in specific episodes of TV that focus on the rare disease experience. Then, in subsequent chapters, I analyze how rare disease advocates and rare disease communities strategically deploy these three commonplaces. These commonplaces are:

1. *Illness is visible*
2. *Medical expertise validates patient agency*
3. *Compliance leads to health*

The above commonplaces influence the public’s perception of healthcare, the interactions between patients and doctors, and how patients navigate finding care. Each of these commonplaces exemplifies stories of rare illness in TV shows like *House* and *Grey’s Anatomy* and shapes a viewer’s expectation of healthcare. The commonplace *illness is visible* is rooted in the biomedical model of medicine, which depends on illness being visible in the medical encounter through abnormal scans, blood tests, or biopsies. These visible signs of illness are considered “unbiased” and “objective” forms of evidence that an illness exists. This commonplace often governs clinical encounters between a patient and healthcare worker. Next is *medical expertise validates patient agency*, which refers to the role of patient agency in medical encounters and the ways that patients are denied control within a paternalistic model of care despite moves by the medical field to “empower” patients. While patient agency may seem to matter a great deal in medicine,

this agency is often not granted to a patient unless they present a sufficient display of medical knowledge. Finally, *compliance leads to health* refers to how patients are persuaded to be compliant in medical encounters in order to achieve good health.

I have selected two well-known medical dramas for my analysis. At their most popular, both *House* and *Grey's Anatomy* were included in yearly lists of the 10 most viewed TV shows. The TV show *House* aired on FOX, running from 2004-2012, and *Grey's Anatomy*, on ABC, began in 2005 and is currently the longest-running scripted prime time TV show. Consistently on the top 10 or top 20 highest-rated shows on Nielson's TV Rankings over its 19 seasons, *Grey's Anatomy* also has been on Netflix's top 10 streaming shows for 144 weeks (Porter, 2023).² *House*, while also popular, is more critically acclaimed and has won various awards for writing, directing, and acting, including the 2005 Peabody award for its new take on the Sherlock Holmes story. While *House* has been off the air for nearly a decade, and *Grey's Anatomy's* popularity has waned, both shows influence on the public's general understanding of the rare disease experience persists—especially as they reach new audiences through streaming platforms such as Netflix, Amazon Prime, and Hulu.

For both *House* and *Grey's Anatomy*, I analyzed the pilot episode to identify important themes. Then, I selected two representative episodes from each series that highlight the rare disease experience. To do this, I reviewed and tracked each episode of both shows to find those that highlight a medical mystery that results in a rare disease diagnosis. I also selected episodes where the patient or close caregiver substantially interacts with the doctors in the show. The episodes analyzed here also represented

² *Grey's Anatomy* has completed its 19th season and has been renewed for a 20th.

somewhat typical episodes of each show, that featured interactions between doctors and patients. Selecting such episodes is important to this analysis because the narrative structures of both *House* and *Grey's Anatomy* are formulaic and depend on assumptions of health and medicine made by the audience to tell stories. For example, both *House* and *Grey's Anatomy* typically utilize a “case of the week” structure, where most episodes center their plots on a patient or caregiver seeking medical care, which furthers a doctor’s character arc. Usually, by the end of the episode, the patient has the diagnosis, treatment plan, or surgery they need (or they have died in the process). The dramatic tension of both shows rests on the resolution of the patient’s narrative arc occurring within the 42 minutes of a single episode.³ The familiar stories that appear in both shows flatten the narrative into a predictable, formulaic structure and, in doing so, certain ideas and themes are rendered invisible. For example, most typical *House* episodes include several misdiagnoses, with inappropriate treatments, before finding the correct diagnosis.⁴ *Grey's Anatomy*, while more focused on the drama surrounding the doctors, utilizes similar narrative strategies episode to episode that are familiar and predictable (such as the voiceover that begins and ends each episode).⁵ The result of such typical plots and narrative devices is that the patient characters are also flattened and formulaic. While this

³ Of course, there are episodes outside of these basic plots, most often during multiple episode storylines.

⁴ *House* episodes, in particular, have such a familiar formula that its fandom has created memes and gifs to point it out. This includes the phrase “it’s never lupus” (used humorously as House often opposes any suggestion that a patient has lupus). The predictable nature of the show is somewhat ironic given the show’s premise about rare and uncommon diseases and medical situations.

⁵ *Grey's Anatomy*, like *House*, has inspired fandoms and memes about the formulaic nature of the show. *Grey's Anatomy* uses familiar tropes that are recognizable to its fan base—particularly the running jokes of the show ultimately killing off all of its main characters.

is not surprising since each TV show's main characters are doctors, it does mean that nuance and truthful experiences of people with illness are sacrificed in order to fit them into plotlines of the doctors, and those plotlines depend on a familiar narrative formula that allows commonplaces to flourish.

Narrative choices in *House* and *Grey's Anatomy* are so ingrained in viewers that the storytelling arc can obscure the values and assumptions of medicine and medical care that each show communicates. However, because rare disease experiences contrast healthcare-based commonplaces, they allow such commonplaces to be made more visible. In this chapter, I argue that medical dramas like *House* and *Grey's Anatomy* depend on healthcare-specific commonplaces to create their stories. In doing so, these TV medical dramas may seem to subvert commonplaces of health and medicine through narratives of the rare disease experience, but ultimately reinforce hegemonic perceptions of medical encounters.

Healthcare Narratives and Representation of Patients

The representation of health and medicine in media shapes our cultural imagination surrounding illness. Television shows, and specifically the medical drama, have provided depictions of illness since the latter half of the 20th century through programs like *M*A*S*H* and *ER*. Medical dramas specifically place the patients' bodies as the site of storytelling in ways that further the plots about doctors and medical professional at the heart of these shows, a storytelling strategy termed "narrative prosthesis," identified by Mitchell & Snyder (2001). The role of the patient is to reveal more information about the other, able-bodied characters. The body of the patient offers seemingly unlimited potential for dramatic storylines, even if those stories negatively

represent patient communities (Jacobs, 2003, p.2; Makoul and Peer, 2004). Many medical dramas, from the earliest iterations to shows currently airing, use patients and illness more broadly to develop recurring characters, impart lessons, and dramatize medical ethics in practice. Medical dramas, then, often create a specific (and false) lens through which to review illness stories (Jacobs, 2003; Cambra-Badii et al., 2021). This continues into the new generation of medical dramas, including *House* and *Grey's Anatomy*. Both of these shows create public awareness of medical issues in ways that leave lasting impressions on viewers. In fact, two separate studies focusing on entertainment television (and *Grey's Anatomy* in particular) show that audiences have an overall negative attitude towards organ donation after watching storylines focusing on the topic (Morgan, Movius, & Cody, 2009; Quick, et al., 2014). While medical dramas are obviously not representative of real life, research demonstrates how such TV shows can impact medical practice, patient experience, and the public's perception of health and wellness.

Disability studies offer useful examples of representations of health and illness in fiction and media, providing a critical lens to view the patient's body in the medical drama. G. Thomas Couser (2009) examines the role of narrative and disability throughout history, especially in what he terms "autosomatography," or first person writing about illness and disability, and how it can challenge stigmatizing experiences (p. 2-6). David T. Mitchell and Sharon L. Snyder (2001) also write about the use of disability as a "prosthesis" in narrative, which allows disability to both be a shorthand for larger societal issues and a lens through which to describe other, abled characters (p. 6). Jay Dolmage (2014) offers a list of disability myths and tropes that are "routinized and easily consumed" by audiences because such myths "[borrow] from and [shape] cultural beliefs

about disability in the everyday” (pp. 31-32). He details popular representations of disability, including the “kill-or-cure” myth, where disabled people must be dead or cured by the end of the story (*Million Dollar Baby* is an example of such a narrative) or the “disability drop” myth, where a disabled character is revealed to be faking (such as in *Usual Suspects*). Couser, Mitchell and Snyder, and Dolmage reveal how life writing, literature, and film have utilized disability and/or illness to communicate broader societal beliefs about “normalcy” and disability. Their analysis of disability representation affirms how narrative, whether first person or representative, conveys these beliefs to audiences.

Representation of health and illness is also a topic of concern for RHM scholars. For example, Segal (2007) uses first-person breast cancer narratives from Betty Rollins to Barbara Ehrenreich, arguing that these popular texts teach how someone “shall” be ill with cancer (p. 16). Other RHM scholarship on online patient narratives (Arduser, 2017) or medical testing technologies (Herndl, 2014) reveal the importance of seeing other people’s experiences in order to create patient agency. While most of these narratives are from the first person (that is, the perspective of the person with illness), TV shows such as *House* and *Grey’s Anatomy* provide additional representation of illness and health through their depictions of patients in the healthcare system, from the point of view of the doctor.

“Everyone Lies”: *House* and Visible Evidence of Illness

The premise of *House* is that a misanthropic, genius doctor and his team of fellows work to diagnose patients with mysterious symptoms that cannot be solved by other doctors. The main conflict is between Dr. House, who has unorthodox methods of diagnosing patients, and his boss, Dr. Lisa Cuddy (Lisa Edelstein), the dean of the

hospital. The show focuses on House's own health as well, most notably on an infarction in his thigh that caused loss of mobility and chronic pain in his leg. Subsequently, House uses a cane and grapples with addiction to pain medication throughout the series. Despite his cynical attitude and dubious ethical practices, fans reacted positively to his character. In fact, Dr. Lisa Sanders, the medical advisor to *House*, shares her surprise at the character's popularity in her 2010 book, saying that she "didn't think [the show] would last long" (p. 10). A clip from *House* appears in the first five minutes in Dr. Sanders' 2019 Netflix show, *Diagnosis*, which features people with rare and uncommon diseases, marking House's continued popularity despite the show ending in 2012. For this analysis, I identified episodes where there is a rare disease diagnosis, and the diagnosis is made over the course of one episode. I also included the pilot episode for *House* because it presents the show's initial arguments about healthcare in general. The two additional episodes I analyze ("DNR" and "House, Divided") highlight the rare disease experience because not only do the patients have a "medical mystery," but they also consider facets of living life with an illness—"DNR" includes a patient signing a "do not resuscitate" form and "House, Divided" strongly features the patient's relationship to his family and friends. I use these three episodes to specifically illustrate *illness is invisible* and *medical expertise validates patient agency*.

The pilot episode of *House* introduces the main structure of the show and outlines the main conflicts between House and other doctors. The show, particularly in the first few seasons, emphasizes the idea that "everyone lies," and House embodies (and instills in the other doctors) a belief that everyone—but particularly patients he treats—is incapable of telling the truth, even if their life is on the line. Diagnoses often rest on

House's ability to ignore patients and their stories, instead focusing on the "facts" of the case.⁶ The show demonstrates its ethos in the pilot, when House and his current fellows (Dr. Foreman and Dr. Cameron, played by Omar Epps and Jennifer Morrison, respectively) start a differential diagnosis on a patient:

Foreman: Shouldn't we be speaking to the patient before we start diagnosing?

House: Is she a doctor?

Foreman: No, but...

House: Everybody lies.

Cameron: Dr. House doesn't like dealing with patients.

Foreman: Isn't treating patients why we became doctors?

House: No, treating illnesses is why we became doctors, treating patients is what makes most doctors miserable.

Foreman: So you're trying to eliminate the humanity from the practice of medicine.

House: If we don't talk to them, they can't lie to us, and we can't lie to them.

Humanity is overrated. (Shore et al., 2004).

Even through a seemingly hyperbolic and satirical exchange, the show establishes its core belief that "everyone lies." House prides himself in finding out what the patients are

⁶ In her book, Dr. Sanders disagrees with the key belief in *House* that he ignores the patient's stories in order to gather information for his diagnosis. She argues that he actually fails at getting a diagnosis for patients "until the rest of the story is revealed"—either through a patient "revealing hidden truths" or through evidence gathered from the patient's home (p.11). She posits that House's distrust of patients and inability to establish relationships actually hinders gathering a patient's full history and finding a diagnosis. In this, she emphasizes both the doctor-patient relationship and the importance of the patient's illness story, even if they need a mediator to put the pieces together.

hiding from him, and will disbelieve the patient, other doctors, and even medical testing done in other hospitals. This drive to find out all he can about a patient also leads to him frequently ask his medical team to break into patient's homes to find clues that the patient may be hiding from them, alongside other unethical acts. This deep disbelief of patients and other doctors, paired with an intense, obsessive commitment to find a diagnosis, drives most of the action of the show. The narrative action while creating a compelling, nearly mythic character in the rare disease world, also establishes troubling relationships between patients and doctors in the show.

The pilot episode of *House* establishes two commonplaces: that *illness is visible* and that *medical expertise validates patient agency*. The show's theme that "everyone lies" reveals the belief that patients are unreliable and untrustworthy communicators of their bodies or their stories. Here, *House* buys into the overarching belief that biomedical evidence of illness is the only type of medical evidence that matters. That is, *illness is visible* to the objective observer, but one needs to know where to look. The pilot also reveals House's fundamental belief that patients do not have the medical expertise to validate their own agency.

An illustrative episode of *House* that details these themes is S1E9, "DNR." John Henry Giles (Harry Lennix), a famous jazz trumpet player, is admitted into the hospital with pneumonia under the care of one of House's fellows. John Henry is also experiencing progressive paralysis due to (what they all believe is) amyotrophic lateral sclerosis (ALS). However, House doubts this diagnosis. In the meantime, the patient signs a "do not resuscitate" (DNR) directive, believing his quality of life is too low for further care. When House, without consulting the doctors assigned the case, changes the

treatment plan to test for potential illnesses, the patient goes into respiratory failure. House illegally resuscitates the patient, and is charged with battery and receives a restraining order. Despite this, House continues treatments and medical testing. The team ultimately finds a clot, and when they remove it, John Henry's paralysis starts to resolve. He ultimately does not have ALS but an arteriovenous malformation, a rare, abnormal knot of blood vessels that can block blood or oxygen from circulating in the body, that was hidden in scans (Mayo Clinic Staff, 2023).

Throughout the diagnostic process and treatment of John Henry, House does not receive consent, and even hides medications he uses from another doctor in charge of his care. Despite this, the patient improves after being correctly diagnosed. John Henry recovers his ability to walk, and at the end of the episode, runs into House and says, "thanks for sticking with me" and gives House his trumpet. In any actual medical practice House's actions would be considered highly unethical. However, in the narrative of this show, this otherwise unethical behavior is not only justified but also glamorized because House and his team were able to provide a definitive diagnosis.

The healthcare-specific commonplaces that underpin this episode are that *illness is visible* (if the doctor is enough of an expert), and that *medical expertise validates patient agency*. The first commonplace is challenged initially because John Henry is diagnosed with ALS, a diagnosis of exclusion—that is, a diagnosis only given to a patient if more affirmative tests for other diseases are negative. House continually rejects ALS because it cannot be definitely diagnosed and instead wants to do tests to check for visible signs of disease that could diagnose (and potentially cure) John Henry. The commonplace that *illness is visible* is reinforced because, despite the incredible breach of

ethics in the episode, the illness is visibly identified and the patient is cured. John Henry is thankful and describes House's behavior as "sticking with me."

The second commonplace revealed here is that *medical expertise validates patient agency*. This commonplace is more explicitly acknowledged through the show as the idea of "patient agency" is routinely challenged. Here, doctors compromise patient agency in order to find a diagnosis. House specifically ignores the DNR order in order to save John Henry's life. The show justifies these ethical violations by the fact that John Henry is walking out of the hospital at the end of the episode—his life saved through House's tenacity in diagnostics. The trauma John Henry undergoes is essentially erased as he ultimately recovers his health. Even though the rhetoric of patient agency pervades medicine, this show routinely articulates an assumption that people cannot have agency over healthcare decisions because they are not medical experts. More often than not, House prevails and the patient is thankful that he took action without their consent.

"DNR" ultimately communicates a belief that the biomedical model of illness should be valued above the patient's agency. House insists throughout the episode that he needs visible proof of illness in order to accept a diagnosis. He did not believe that John Henry had ALS, insisting on retesting him for more "provable" illnesses. John Henry, on the other hand, had accepted his diagnosis and believed in his doctor and treatment plan. Since House ends up being right, and John Henry had a treatable disease that was both affirmatively diagnosed and reversible, the episode argues that House's actions are correct and to be rewarded (and indeed they are at the end of the episode when John Henry gives House his trumpet) no matter the impact on the patient. But, despite the ethical misconduct, and dubious medical practice in "DNR," this episode also highlights

the persistent belief House exhibits in diagnostics. He does not take at face value a diagnosis or test of another doctor. This trait could be part of how House is constructed as the ideal doctor in the rare disease community—he questions what we think we know about a diagnosis or set of symptoms.

The complicated relationship between objective medical evidence and the agency of the person with illness continues in S5E22 “House, Divided.” In this episode, a 14-year-old wrestler, Seth (Ryan Lane), is deaf, and suffers from “hearing” imagined explosions during a wrestling match. He is admitted to the hospital with exploding head syndrome, a phenomenon where someone hears loud explosions, usually right before falling asleep (Cleveland Clinic, 2021). Immediately House and the other doctors question why Seth hasn’t gotten a cochlear implant and rejects the “deaf pride” that Seth and his mom (Clare Carey) display. There is this exchange between two doctors (Dr. Remi Hadley (Olivia Wilde), referred to by her nickname “Thirteen,” and Foreman) while conducting a test on Seth that highlights the skepticism of the show on disability as an identity and the agency that implies:

Thirteen: The patient doesn’t want an implant because he’s comfortable with who he is. It’s admirable.

Foreman: He’s deaf. It’s not an identity. It’s a disability.

Thirteen: It’s also a culture. The deaf have their own schools. Their own language.

Foreman: Anything I can simulate with a three-dollar pair of earplugs is not a culture. (Shore et al., 2009)

The agency of the patient is contrasted with the potential perceived affordances of medical technology, and Seth and his mom are constantly represented as acting against his best interests. This animus culminates when the patient is under anesthesia for a brain biopsy, and House tells the surgeon to place a cochlear implant, despite the patient and his mom refusing one. When confronted by the dean of medicine and the patient's mother about why he ordered the cochlear implant, House argues it is because the patient and his mother are ill informed and "opting into a handicap" (Shore et al., 2009). Seth and his mom's opinions about how they should live in the world are contrasted from the "facts" of medicine, highlighting the belief that biomedical medicine is objective.

Like "DNR," "House, Divided" communicates shared ideas about healthcare through the use of commonplaces. This episode frames patient agency as not only a potential hindrance to Seth's health, but also as uninformed and potentially exploitative. Seth clearly values and identifies with the deaf community and has several scenes where he laughs and signs with friends—friends he later refuses to see when he gets the implant because he no longer feels like he belongs with them. Seth ultimately does not get the healthcare he wants. While he is a minor, and so his mother is in charge of medical decisions, the show implies that Seth is manipulating his mother so he can stay deaf, and that she should take charge and give permission for an implant. He is not allowed agency over his body, which is ultimately given over to the medical team.

The narrative arc of "House, Divided" argues for the biomedical model of medicine because of the belief that illness is visible (and also, in Seth's case, easily "fixable"). House's decision to place a cochlear implant is internally justified by the show when doctors want to test for a heart arrhythmia. Before they can do any additional

testing, Seth rips out his implant, stressing his body enough to reveal a heart arrhythmia—exactly what House wanted. If the implant had not been placed, the show argues, the arrhythmia would not be found. Ultimately, House does not diagnose Seth. His team realizes he has sarcoidosis, a disease that causes inflammation all over the body (American Lung Association, 2023). However, House’s decisions throughout this episode lead the other doctors to this diagnosis. Seth’s deafness is also treated within the biomedical model of disability and illness as he unsuccessfully argues that his deafness is a valuable and important part of his identity. Even as he refuses the implant, the episode closes with Seth’s mother deciding to ask doctors to fix it, saying, “I’m your mother. This is my call. And I don’t know if I’m making the right one, but it’s mine to make” (Shore et al., 2009). Seth’s mother is ultimately persuaded that a cochlear implant would improve his quality of life, even if it is against Seth’s wishes. The episode seems to end happily, as Seth receives treatment for sarcoidosis and his mother “takes charge” of his care. However, just like “DNR,” the happy resolution in the episode is at the sacrifice of patient agency and highlights the primacy of medical expertise.

The lack of consent in “DNR” and “House, Divided” illuminates a tension between patient agency and medical expertise that exemplifies the relationship between the patient and doctor in reality. Throughout *House*, patients are routinely and explicitly told they do not have patient agency, since they do not have adequate medical expertise. Instead, House controls the clinical encounter. In this, *House* exemplifies the faults of our current medical system, specifically in his paternalistic approach to treating patients. His insistence in ignoring a DNR, for example, very directly takes away a patient’s agency to end treatment. He behaves similarly when placing a cochlear implant, again

against the patient's wishes. However, in each instance, the story concludes with the patient receiving a correct diagnosis, making the diagnostic process seem successful to the audience. In *House*, the idea of a DNR or a patient consent form—both documents that seemingly give patients control over the medical encounter—are ignored. Yet, *House* is exalted by the rare disease community as the representation of what biomedicine can do if the resources are available. This conflict between medical expertise and patient agency seems insurmountable, and in ignoring treatment plans or DNRs, *House* highlights the false comfort that these “boundary objects” can give to patients.

The relationship between the institution of medicine, medical expertise, and patient agency is typically not so explicit in medicine. However, certain “boundary objects” (such as patient preferences worksheets, DNRs, and birth plans) do attempt to give control over to the patient, even if that comfort is often false. A boundary object, coined by Susan Leigh Star and James Griesemer (1989), is an artifact that “[develops] and [maintains] coherence across intersecting social worlds” (p. 393). Lisa Keränen (2007) takes up this term when discussing patient agency in end-of life care through the patient preferences worksheet (a document similar to a DNR). She specifies that the patient preferences worksheet is a boundary object because it represents the “intersecting world of patients, health care practitioners, and the institution” (p. 190). She identifies how the rhetoric of patient agency is used within documents such as the patient preferences form that then acts as a boundary object between the patient's autonomy over end-of-life care and the institution of the hospital that creates such a document. Kim Hensley Owens (2008) brings in another document—the birth plan—and how it also seemingly provides agency over the perceived inability of women and birthing people to

communicate their preferred care plan while giving birth. She examines the rhetorical moves that pregnant people demonstrate in their birth plans in an attempt to control the medical encounter of giving birth. While the birth plan can help mitigate a loss of control where pregnant people “seek to triumph over this loss of rhetorical power,” such documents do not operate the way that most people intend, although the act of writing them can empower patients (p. 266). Similarly, Keränen argues that the patient preferences worksheet ultimately is a document that exemplifies institutional control over personal decision-making. She highlights how medical institutions co-opt the language of patient agency by creating institutional documents such as the patient preferences form that allow patients to make decisions on end-of-life care, even as many patients lack the expertise to make informed decisions on the topic. Owens, too, highlights how part of the persuasive appeal of the patient-created birth plan is that it acknowledges the authority of the doctor even as the document itself is attempting to assert the patient’s wishes. That is, while the birth plan lacks the legal authority of the DNR, it is still an attempt by the patient to mediate their wishes against the authority of the doctor (p. 248).

While documents such as the patient preferences sheet or a birth plan seemingly give patients agency, both Keränen and Owens reveal the false sense of autonomy these institutionalized documents provide. “House, Divided” and “DNR” highlight the lack of patient agency and how the denial of agency is rewarded and celebrated by both John Henry and Seth recovering. The explicit lack of agency is potentially part of the show’s appeal—House’s intentions and motivations are visible to an audience that might view documents like the patient preferences sheet or birth plan, as provided by hospitals, as only offering a sense of pseudo-agency over medical events in which they would feel

helpless. Audiences instead might recognize and value the way that House does not offer such falsely agential moves to the patient.

People with rare diseases need medical intervention and their lives are often saved by such intervention; however, *House* aligns the patient/doctor relationship with the idea that the patient can actually be a *detriment* to their own care—because of their inability to tell a truthful, accurate, “objective” story of their illness and bodies. Despite this, an audience that recognizes the fallacy of “patient agency” in medical spaces can see the show as potentially cathartic. *House* clearly has had an impact on the rare disease community, as represented in the references to him in *Brain on fire: My month of madness* and *Diagnosis*. The character of House reinforces the idea that the rare disease patient needs not only a biomedical intervention but also the *right* doctor to make the medical intervention.

Both “DNR” and “House, Divided” demonstrate the rare disease experience within the world of *House*. In doing so, the show communicates commonplaces about healthcare through the rare disease experience. These commonplaces include believing in the biomedical model above all else (within the framework that *illness is visible* and that *medical expertise validates patient agency*). The tension between patient agency and medical expertise is highlighted through documents such as the DNR and patient consent. The reaffirmation of these commonplaces becomes more troubling when considering how House has been nearly mythologized as the epitome of the rare disease doctor. These commonplaces are picked up in *Grey’s Anatomy* as well, although they approach to the role of patient agency (through that of compliance) differently than *House*.

“Welcome to the Game”: The Myth of Patient Agency and Noncompliance in *Grey’s Anatomy*

Grey’s Anatomy, while also a medical drama, does not focus so minutely on rare diseases and solving medical puzzles as *House*. However, *Grey’s Anatomy* still engages with the same healthcare-specific commonplaces to tell stories. *Grey’s Anatomy* centers a group of interns (and later, doctors), led by Meredith Grey (Ellen Pompeo). The ethos of this show is different from that of *House*, despite their similar settings. In *Grey’s Anatomy*, episode storylines are grouped by common themes rather than by a medical mystery. In the early seasons, the driving conflict is the competition between interns and residents within a prestigious surgical residency program. Later, competition still motivates doctors as they compete for major, cutting-edge medical innovations and awards. Patients serve as both the major conflict and inspiration for such competition, as the doctors realize how their medical educations run counter to the lived experience of treating patients. The central tension of the show is that patients are more complicated and human than competition allows. However, the idea of patient agency *Grey’s Anatomy* purports to advocate for is not consistent with the values it ultimately communicates.

In this section, I first examine the pilot episode and how it sets up the main conflicts of the series, and then I analyze two representative episodes from the current run of *Grey’s Anatomy* that feature rare disease storylines. Like *House*, I reviewed episodes of *Grey’s Anatomy* to identify ones that featured the rare disease experience—not only someone needing a diagnosis, but storylines that show elements of the patient’s lives, reasoning for medical decisions, and relationships to others. The episodes I selected include the S9E19 episode, “Can’t Fight this Feeling,” featuring Kawasaki’s disease (a

childhood illness that causes inflammation in the arteries, which can cause permanent heart damage if not treated within the first two weeks of symptoms), and the S13E4 “Falling Slowly,” with Ehlers-Danlos Syndrome (a genetic disorder that causes problems in the connective joints) (Centers for Disease Control, 2020; Mayo Clinic Staff, 2022). Both episodes also feature noncompliant patient or caregiver. Through these episodes, I examine the ways that patient agency seems to be valued through noncompliance but ultimately the diagnosis and treatment of patients hinge on biomedical evidence of illness.

The tension between doctors and patients, and the role of patient agency in the medical encounter, is articulated in the pilot episode, which positions medicine as a game. *Grey's Anatomy's* narrative structure is not as predictable as *House*, but it has similar features in each episode that are established in the pilot. This includes narration at the beginning and end of each episode, most often delivered by the main character, Meredith Grey. This voiceover work allows for themes to emerge in each episode, and storylines that seem disparate unite. For example, Meredith's voiceover in the pilot sets up the tension between medicine, the competition between doctors, and the role of patients. She says, “The game. They say a person either has what it takes to play, or they don't...there comes a moment when it's more than just a game. And you either take that step forward or turn around and walk away. I could quit, but here's the thing... I love the playing field” (Rhimes et al., 2005). Here, the idea of medical education as a game is heavily emphasized, even as patient care is a new element for most of the interns experiencing their first 48 hours of work. While later episodes more overtly critique the

idea of medicine as a game, the pilot argues that competition can allow for diagnosis and medical innovation in unusual presentations of illness.

The theme of competition as a catalyst for medical innovation is introduced in the pilot, and highlights both the role of visible illness and diagnosis. Dr. Shepherd (Patrick Dempsey), the head of neurosurgery, asks for the interns' help to diagnose a patient that is having unexplained seizures. He explains the situation like this:

I've got this kid, Katie Bryce. Right now, she's a mystery. She doesn't respond to her meds. Labs are clean, scans are pure, but she's having seizures... She's going to die if I don't make a diagnosis. Which is where you come in. I can't do it alone.... So, I'm going to give you an incentive. Whoever finds the answer rides with me. Katie needs surgery. You get to do what no interns get to do. Scrub in to assist on an advanced procedure. (Rhimes et al., 2005).

Here, patient care is explicitly set up as a game, and the reward is assisting with a major surgery. Predictably, each intern works frantically to come up with a diagnosis.

Ultimately, two of the interns, Meredith and Cristina Yang (Sandra Oh), work together to figure out Katie's (Skylar Shaye) diagnosis. They are able to diagnose her when all others can't because Meredith talks to Katie while transporting her to a CT scan and learns that she fell a few weeks prior—leading to a diagnosis of a head aneurysm. Here, competition among doctors is seen as integral in the diagnosis of Katie, even while Meredith and Christina collaborate to diagnose her. However, it is listening to Katie and knowing a specific detail about her that was not in her chart that led to her being diagnosed. While still dependent on biomedical proof of illness (the diagnosis was confirmed through a CT scan), the pilot argues that patients are collaborators in their care, even if they can't quite

put together the diagnosis themselves. This show seems to demonstrate successful models of healthcare as a partnership between the patient and doctor, both of whom are willing to listen to each other. Throughout the show's run, medical innovation and treatment of rare diseases are used as motivation and competition between doctors, even as the show attempts to simultaneously listen and value the patient's agency in medical encounters. The show does not always succeed in valuing the patient's input in their own care, though, and often seems to fall apart when considering compliance on the part of the patient.

"Can't Fight This Feeling" (2013) (S9E19) focuses on the diagnosis of a rare disease in a young boy, Parker (Kaine, Hunter, and Raedin Reid) and seemingly allows for agency on the part of his mother, Casey (Sarah Chalke). In the episode, Casey returns to the ER after getting a diagnosis and treatment for Parker, because of her concern that he has something worse than the virus he was initially diagnosed with. At the second ER visit, Parker receives a positive test for strep throat and is discharged, but Casey returns with Parker for a third time because she is still worried that her son has a much more rare, deadly disease. Casey brings out a list (to the intern's dismay) of diseases she found by searching for symptoms online. She insists that while she is "just a waitress," she can't "fight the feeling" that something is wrong with him (Rhimes et al., 2013). Meredith, now co-owner of the hospital, overhears the exchange and admits Parker to the hospital. When the doctors realize that the strep test was a false positive, they rush back to the boy and start him on the treatment for Kawasaki's disease—a potentially deadly rare childhood illness—and one of the potential diseases on his mother's list. The doctors

ultimately intervene in time to prevent any complications in Parker. The story concludes with this exchange:

Meredith: Parker has Kawasaki's disease. You fought for your son. You didn't give up. You saved his life today. You were right.

Casey: [crying] I was right?

Meredith: You were right. (Rhimes et al., 2013)

The episode reaffirms the gut feeling that Casey has about her son's condition, and that her impulse to come back to the ER to push against the strep diagnosis was correct. In effect, the Internet research she does is also reaffirmed. This episode seems to support Casey's intuition and that Meredith was demonstrating valuable medical care by listening to Casey even if the biomedical evidence of illness originally did not support Casey's belief that something else was wrong. The closing lines in Meredith's voiceover in the episode are: "Try as you might, you can't ignore your instincts...It's like they say, always follow your intuition." The "moral" of the episode is that instincts are powerful and, if something is wrong, follow through and fight for yourself and your loved ones. That message is carried through to all the characters of the episode and attempts to communicate to the audience that intuition is as valuable as medical evidence, even when it leads to noncompliance on the part of the patient.

While "Can't Fight this Feeling" seemingly argues for patient agency and the importance of noncompliance on the part of the caregiver, it ultimately reaffirms the role of the patient as secondary to visible proof of illness and a doctor's interpretation of those signs. While Meredith validates Casey's intuition that her son is seriously ill, it is finding out that testing supported Casey's belief that led to a correct diagnosis. Ultimately,

Casey's noncompliance is less important than the results of those tests. Scholarship within RHM has examined the role of non/compliance in medical settings, from Segal's (2005) argument that medical care is inherently persuasive and, if a patient is noncompliant, the medical system failed its persuasive appeal,⁷ to Catherine Gouge's (2018) assessment of noncompliance as an opportunity to reevaluate the role of care in the clinical encounter. Related to non/compliance is the conflict between the patient's experience of their own body as a source of knowledge and a doctor's clinical understanding—even as Meredith exemplifies a doctor going above and beyond in listening to her patient. Despite moves to empower the patient through medical knowledge (such as that of e-health spaces like online support groups), a biomedical understanding of illness is still affirmed.

Unlike *House*, *Grey's Anatomy's* ethos elevates the patient's experiences and their self-reporting of symptoms, but in doing so, more insidiously communicates that patient agency is dependent on circumstances outside of the patient's control. In "Can't Fight this Feeling," Casey is in the ER arguing with an intern that the strep test is a false positive. The only reason her son is admitted is because Meredith, a co-owner of the hospital, decides to go against hospital policy and admit Parker (and presumably is offering the hospital room and medical tests for free to Casey, a waitress with little resources to pay out of pocket for medical care). Then, when going through potential diagnoses with Casey, Meredith reiterates that she thinks the diagnosis is strep. However, when Parker is about to be discharged, Meredith finds that the strep test was a false positive. While the episode ends with this notion that the correct diagnosis was based on

⁷ A position that Dr. Lisa Sanders reiterates in her book, *Every Patient has a Story*.

Casey's willingness to be noncompliant and push against testing, it is really another test (the negative strep test) that proves to the doctors that Casey is right. Again, they need the visual proof of disease (or the lack thereof) in order to make a change in the diagnosis, coupled with extraordinary access to resources that Casey receives when Meredith becomes involved in her case. The dependence on both visible signs of illness and a doctor's expertise can end up invalidating a person with illness's experience and knowledge of their own body.

Another episode that highlights the role of patient agency and noncompliance in a rare disease narrative is "Falling Slowly" (S13E4), which focuses on a patient, Emma (Taylour Paige), in the urgent care clinic. Alex (Justin Chambers), a pediatric surgeon, is suspended from his department and is instead working in the clinic. A patient, who comes in "once a month" (according to the nurse that runs the clinic), requests intravenous fluids. The hospital staff talks with her about drinking and addiction, thinking she is an underage binge drinker. Emma refuses to listen to this advice, though, and insists that she is simply doing what she has figured out to relieve her symptoms, which include a headache, dizziness, and chills. She requests fluids and directs Alex about how to push the IV, what arm to do the IV in because she bruises— all the signals of someone who spends a lot of time in hospital settings. Tellingly, when another doctor grabs her arm as she rips the IV out of her arm and tries to leave, her shoulder goes out of joint and she pops it back in as "she always does." Alex realizes that her symptoms are consistent with Ehlers-Danlos Syndrome (EDS), a group of connective tissue disorders that can cause hypermobility, subluxation (or joints frequently dislocating) and general dehydration, all symptoms Emma experiences (Mayo Clinic Staff, 2022). She is told she has EDS and

complimented for “listening to her body and knowing how to treat it.” She reacts emotionally, saying, “This means it’s real. I’m not crazy.” The episode ends with vague references to how Emma will need to “get tested” but that her symptoms are “real” and can be treated. While Emma sought treatment for her symptoms but not a diagnosis, because Alex was paying attention to what her body was “saying” through her symptoms, she still could be diagnosed appropriately and receive needed care.

This episode seems to value how Emma listens to her body and treats her illness on her own by going to the urgent care and insisting on fluids. She has essentially worked the medical system to give her the care she needs and advocated for herself to the extent she could. While the episode celebrates the idea that this rare disease was diagnosed, it also focuses on visible evidence of illness. It isn’t until the doctors try to stop her from leaving, grabbing her arm, that her shoulder dislocates and the doctors realize something more serious is going on. Emma’s dislocation, witnessed by everyone in the urgent care, is actually the key to getting her a diagnosis. Thus, while the episode proclaims that a doctor who listens to her and that her behavior helps them determine her illness, this doesn’t get underway until they have visible evidence that she has a physical illness.

Grey’s Anatomy, generally, is not as distrustful of patients and their stories as *House* is. This medical drama, on its face, seems to allow for patient agency in ways that *House* does not, but argues that it must be specifically constructed and align with visual proof of illness. While “Can’t Fight this Feeling” and “Falling Slowly” clearly value the input of the patient and/or their advocate, these episodes still depend on intervention on the part of the doctors and their willingness to care for a patient beyond what is expected of them. While it may be believable that a patient can get diagnosed with a rare disease in

an urgent care, the idea that a surgeon—and part owner of the hospital— would take an interest in a case with a positive strep test enough to admit Parker and keep him in the hospital to continue testing is incredibly unlikely. There is conflict between what *Grey's Anatomy* argues explicitly about patient agency (that following one's "gut" is good) and how patient agency is played out (it is only rewarded if it leads to biomedical diagnosis like Kawasaki's or Ehlers-Danlos Syndrome). *Grey's Anatomy* considers non/compliance on the part of the patient as an agential move—a move that differs from *House's* perception of patient agency as almost always detrimental to health. However, the commonplace that *compliance leads to health* is both challenged and reaffirmed by *Grey's Anatomy*. Noncompliant acts in these episodes underlie visible illness that doctors are able to find through extraordinary acts of diagnostics. In most cases, these patients would have been discharged, labeled as "doctor shopping"⁸ or unable to get care until much more serious signs of illness present themselves. Just like the myth of patient agency this show presents, the idea that "compliance leads to health" is also not *quite* subverted. While both Casey and Emma are guided by the felt-sense of the body (or, a loved one's body) as opposed to a clinical understanding of it, each episode still resolves with a doctor noticing visible proof of illness and taking extraordinary steps to help that patient. Without that doctor's validation, Casey would remain the noncompliant mother

⁸ "Doctor-shopping" refers to a patient going from doctor to doctor in order to receive a desired outcome, whether that is a specific diagnosis or prescription (Sansone & Sansone, 2012). The term is most frequently associated with the opioid misuse crisis and often describes people attempting to receive pain medications. Aside from the consumerist language "doctor-shopping" implies, this phrase has troubling implications for those changing doctors to seek answers to unexplained symptoms (as those with rare diseases must do frequently) especially as state and federal legislation is working to "crack down" on the perceived "doctor-shopping" phenomenon.

refusing to leave the ER, and Emma would remain the patient who walked out of the urgent care against medical advice.

While *Grey's Anatomy* is generally less valued in the rare illness community (it is not cited, like *House* is, as representative of the medical care they desire), it still communicates a very specific type of medical care that is provided in a top-tier hospital with specialists who are the best in their field. Rare illness care requires doctors who are willing to think creatively and find solutions to medical problems that are individual and tailored to the patient. In this, *Grey's Anatomy* does speak to a certain part of the rare disease experience that requires more individual and innovative care that's "outside the box." Both *House* and *Grey's Anatomy* depend on visual proof of illness and biomedical tests in order to diagnose patients, and often treat moments of patient agency or noncompliance as a detriment to receiving appropriate healthcare. In doing so, they utilize commonplaces that implicitly argue that the biomedical model of medicine is superior and most able to find answers for patients with rare diseases. This attitude can be detrimental to those with rare diseases, who can take on average 7.6 years to receive a diagnosis in the United States (Engel, et al., 2013). In the time between onset of symptoms and diagnosis to post-diagnostic care, there are years of trial and error. The certainty of diagnosis and treatment of rare diseases in both TV shows are deeply unfounded, problematic, and can communicate to this community incorrect ideas of what the rare disease experience is like.

Impact of Rare Disease Representation in the Medical Drama

The depiction of commonplaces such as *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health* set up expectations of the type

of care a patient might receive in a medical encounter. While these expectations may not be as important to the general public dealing with common illnesses, they deeply affect those who have rare diseases. Each TV episode described here seems to definitively diagnose the patient and offer a treatment plan, but this representation is wholly unsupported by the reality of the rare disease experience. In fact, statistically, 95% of the 10,000 rare diseases identified do not have FDA-approved treatments available (Levine, 2019, p.7). Rare diseases exemplify the limits of our current medical knowledge, and so each commonplace identified here illustrates a boundary that the rare disease patient disrupts. Ultimately, people with rare diseases must learn how to strategically use or reject these commonplaces in clinical encounters to receive necessary care.

The commonplace *illness is visible* shapes much of the medical encounter, specifically in the role of diagnosis, and rests on the assumption that good medicine is observable and objective. Medical diagnoses in both *Grey's Anatomy* and *House* are framed around the idea that visible proof of illness is available and a doctor only need find it. Both shows trust testing and “objective” proof of illness above all, including a patient’s self-reporting of symptoms. The depictions of diagnosis in both shows are significant because they shape expectations of the medical encounter that good medicine is reliant only on the biomedical model of medicine, and that, in the nick of time, visible proof of illness will “speak for” the person with illness in time to save them. However, visible proof of illness often does not exist (or does not exist yet) for rare diseases. In fact, most rare diseases have no testing available and no real sense of how a disease progresses over time without intervention (called the “natural history” of a disease). This problem is so significant that the FDA partnered with the National Organization of Rare

Diseases (NORD) in 2016 to fund a “toolkit” that patient organizations can use to document the natural history of a disease. According to NORD’s press release, “natural history studies can yield vital information that is essential to clinical trial design such as biomarkers, demographics, genetic and environmental variables, disease progression, and patient perspectives on the challenges of living with the disease.” This statement reveals the sheer lack of certainty and information about rare diseases—something that is not captured in representations in medical dramas. If so much of medicine depends on visible proof of illness, but that visible proof is not documented as part of a disease history, then the process to receive a diagnosis will be complex.

People with rare diseases also must exercise an immense amount of agency in order to get a diagnosis, and that agency is often coupled with noncompliant acts. While patients in these TV shows are usually informed about treatments or tests they receive, their contributions to such conversations are usually limited, and noncompliance on the part of the patient is typically punished if not backed by visual evidence of illness or appropriate levels of medical expertise. Particularly in the case of *House*, House often argues that patients cannot have agency in medical situations because they are incapable of understanding the disease at the level he can. This is in contrast to the rare disease experience, where one needs to see multiple doctors to receive a diagnosis (Engel et al., 2013). The ability of a person with illness to reject the treatments, give suggestions, and ask for diagnostic testing is a fundamental part of having a rare disease, and these are often life-saving actions. While such actions might be seen as actively hurting one’s health (in the case of discontinuing treatments) or “doctor-shopping” for a specific diagnosis (in the case of asking for multiple opinions), these noncompliant acts can be an

effective form of patient agency that is beneficial to health—a topic considered in my next chapter about rare disease advocacy.

Lastly, healthcare-specific commonplaces in the medical drama reveal an assumption of certainty in medical encounters that does not exist for people with rare diseases. Crista Teston (2016) outlines the un/certainty of biomedical medical evidence in cancer care, arguing that such evidence is always in flux despite attempts to create concrete evidence with actionable results (pp. 1-2). The complex process of developing medical expertise she outlines is—necessarily—flattened in the medical drama, and the result is a sense that illness is discrete, objective, and visible. The medical certainty that *Grey's Anatomy* and *House* offer in diagnosing rare diseases is not representative of lived experiences. While one would hope that a rare disease can be diagnosed quickly and with ease, this is often not the case. In fact, the NIH refers to the lengthy process to get diagnosed with a rare disease as a “diagnostic odyssey” because of the length of time and number of doctors one needs to see before getting a diagnosis. This statistic is further complicated when considering factors like race, gender, class, and access to insurance. When these shows focus on the extraordinary actions of doctors, they do not necessarily represent the lived experience of those seeking a diagnosis with a rare disease.

Conclusion

TV medical dramas may have obvious limitations in telling illness stories, but they are incredibly important to analyze because of the reach they have with the general public. Both *Grey's Anatomy* and *House* include rare disease narratives, and in each episode examined here the fictional doctors find a diagnosis. By highlighting rare disease stories, these shows offer remarkable visibility to rare and uncommon diseases and

patient care. They provide people with rare illness stories of unrealistic hope that they may be able to find a diagnosis and treatment. Perhaps most importantly is that they offer people with illness the expectation that they will encounter a doctor that has a novel approach to medicine and a different way of thinking through symptoms that can find a rare disease diagnosis and treat the patient when all other, more typical avenues have failed (much like Cahalan's experience with her "Drs. House"). Just naming the illness itself can be beneficial as it can lead to awareness and even increased diagnosis of a rare disease.⁹ It can also provide a touchstone to family and friends who may not understand or grasp the seriousness of an illness that is not well known.

However, these shows still end up communicating troubling ideological beliefs about rare diseases, healthcare, and the role of people with illness in the medical encounter. The patient stories in *House* and *Grey's Anatomy*, especially when put up to heightened scrutiny, do not resist the damaging ideologies that discourses of healthcare often reside in— John Henry in *House* must have a visible illness and not ALS, or Casey's son must have a negative strep test to justify her noncompliance. Through the narratives of these TV shows, I identify three healthcare-specific commonplaces (*Illness is visible, medical expertise validates patient agency, and compliance leads to health*) that guide both stories of illness and the experience of accessing medical care.

House calls on specific commonplaces, and in doing so, implies that patient agency is antithetical to diagnosis. Then, rare disease experiences that are depicted in *Grey's*

⁹ As mentioned in the introduction, the 1970s TV show *Quincy, M.E.* highlighted a rare condition, Tourette's syndrome, in one of its episodes. After it aired, many people were diagnosed with Tourette Syndrome and thousands of letters were sent to the Tourette's Society of America asking for more information about rare diseases, conditions, and medications to treat them (Meyers, 2016, p. 64).

Anatomy argue for a certain *type* of patient agency that may seem to allow for noncompliance as long as it is supported by medical testing. Rare diseases, in highlighting experiences outside of normal expectations of medicine, provide insight as to how ideologically constructed commonplaces are overwhelmingly pervasive. These narratives effectively teach people what rare illness looks like, especially when such rare illnesses are not highly visible in other contexts. Through these shows, a picture of healthcare in the 21st century emerges, as inaccurate as these representations may be.

In the next chapter, I examine the ways that real-life rare disease experiences differ from the commonplaces outlined in representation on television. To do this, I examine the narratives shared in rare disease advocate testimonials. Much like narratives of rare disease in television shows, healthcare-specific commonplaces are visible in narratives rare disease advocates share in Rare Disease Congressional Caucus meetings. Advocates deploy these commonplaces (*illness is visible*, *patient agency is validated by medical expertise*, and *compliance lead to health*) strategically in order to connect to various stakeholders and gain resources from the federal government. In addition to these three commonplaces, advocates also engage in a rhetorical strategy I term as “critical compliance,” where a rare disease patient or advocate actively engages in compliant decision-making in order to gain leverage in clinical encounters and access medical institutions. While the commonplace *compliance leads to health* suggests a passive engagement with health decisions, critical compliance provides a method through which people with illness (and rare disease specifically) can have more agency in the medical encounter.

CHAPTER THREE
THE EXPERT PATIENT: CRITICAL COMPLIANCE, HYPERCOMPLIANCE, AND
RARE DISEASE ADVOCACY

On February 28, 2018, the Rare Disease Congressional Caucus met at the Russell Senate building in Washington D.C. This particular session was held during Rare Disease Week, a specific period of advocacy for rare disease patients and caregivers held in the last week of February. Patients and caregivers, along with patient advocacy organizations, highlighted concerns of the rare disease community on Capitol Hill. While the Caucus meets four times a year, the sessions held during Rare Disease Week are specifically attended by rare disease patients and advocates¹⁰ from across the United States.¹¹ At the Caucus meeting on an unseasonably warm day, six speakers waited—seated at the front of the room—to present. The audience was comprised of people with rare diseases, their loved ones (including service animals), doctors, other health professionals, and staffers who work in rare disease research and policy. Everyone in the room had interest in improving the “diagnostic odyssey” that a rare disease patient goes

¹⁰ Throughout this chapter, I use the term “patient advocate” to refer to people speaking at the Caucus briefing, to encompass both patients, caregivers, and patient organization representatives who speak to the specific experience of people with rare disease.

¹¹ I attended the Caucus described here in-person as part of the Rare Disease Legislative Advocates program through the Everylife Foundation for Rare Disease.

through (the theme of the Caucus that day) and each speaker pushed for specific policy and legislation to further their cause. After this meeting, many would go back to report to their patient advocacy groups, health policy leaders, and other stakeholders in rare disease research.

As established in Chapter Two “‘This Means It’s Real’: Rare Diseases and Commonplaces of Healthcare in Medical Drama,” stories and representations of rare diseases (like those in TV medical dramas) impact both the rare disease community and the general public. Commonplaces within medical dramas can powerfully communicate harmful ideologies about health and illness. In the Russell Senate Building, the audience was much different than the TV-viewing public. Rare disease advocates at the Rare Disease Congressional Caucus were focused on the legislative and regulatory representatives in attendance who shape health policy. However, despite the difference in audiences, rare disease advocates still drew on healthcare-specific commonplaces in their testimonials through compelling, embodied stories.

In this chapter, I examine testimonials by rare disease advocates at the Rare Disease Congressional Caucus in order to understand how patient activists utilize commonplaces about healthcare to reach their audience and craft the persona of the “expert patient.” I focus on these testimonials because they provide brief examples of the rare disease experience in highly public and visible moments of advocacy. These testimonials exemplify the “expert patient;” that is, someone who is able to negotiate the rhetorical difficulty of occupying the role of “patient”—a traditionally passive role—and that of “expert,” where one is knowledgeable and actively engaged in the subject matter at hand. The tricky rhetorical positioning of the “expert patient” depends on developing

credibility and engaging in the institutional discourse of medicine. While the in-person audience includes legislative staffers, policymakers, and lobbyists, because these briefings are recorded and uploaded onto the Rare Disease Legislative Advocates YouTube page, they also circulate among a public audience who did not need to be in attendance to see them.

I specifically analyze four testimonials by rare disease patient advocates given in Caucus meetings from 2018-19. Three of the speakers are rare disease patients, or parents of children with rare diseases, and all three tell a personal narrative about their experiences. The fourth speaker is the executive director of a rare disease patient organization who represents the patients in that organization. I selected these four speakers because of their close proximity to patients with rare diseases and/or personal experience with the difficulty in getting a diagnosis or treatment for the diseases they represent. Testimonials by speakers are approximately 5-10 minutes and follow similar organizational structures, including first informing the audience about rare diseases, then describing their affective experiences with a specific rare disease, and finally arguing for a policy or initiative that would help the rare disease community. After selecting each testimonial, I transcribed them from the Rare Disease Legislative Advocates' YouTube page, where each testimonial is archived. From there, I identified the three commonplaces in each testimonial for my analysis through close reading.

I aim to build on the healthcare-specific commonplaces identified in the previous chapter, which include *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health*. Through each testimonial, I further investigate how these three commonplaces create persuasive appeals to a variety of stakeholders and create the

persona of the “expert patient” for the speakers. However, as opposed to creating compelling representations of illness through commonplaces (as television shows do), these testimonials instead invoke commonplaces in order to gain access to partnerships and resources to build networks. In crafting their testimonials, rare disease patient advocates challenge their audience to understand healthcare in new ways. I first examine how illness is made visible by advocates, and how medical expertise creates credibility within patient testimonies. Through these commonplaces, “expert patients” testifying here become compelling witnesses of healthcare systems and the rare disease experience. Then, I specifically focus on the strategic use of compliance by rare disease advocates — a rhetorical strategy I call “critical compliance.” “Critical compliance” is not just a patient “following” doctor’s orders, but is instead the series of actions and negotiations by the patient within the medical system in order to gain resources and necessary care. The purposeful engagement by patients with “compliance” and “noncompliance” allows access into the complex system of medicine. Further, I argue that *hypercompliance* by these expert patients—that is, the use of medicalized discourse and the institutional setting of medicine to bring about change— contributes to their ability to construct authoritative, “expert” personas.

Rare Disease Patient Advocacy Overview

In order to understand how rare disease patient testimonials utilize commonplaces to embody the “expert patient,” it is useful to outline some of the history of the term “rare disease” and resulting rare disease advocacy. The term “rare disease” is primarily used in activist and coalitional advocacy work and not in clinical medicine (Huyard, 2008). In fact, many rare disease organizations and advocates do not focus on one disease but

instead locate their activism in rare diseases more broadly. Creating a rare disease “coalition” is an intentional move by rare disease advocates to not only argue for the economics of rare disease research (that if approximately 1 in 10 people in the US have a rare disease, it is a relatively common experience and therefore worth investing money) but also because people with rare diseases often share similar experiences, such as a delay in diagnosis, seeing multiple doctors, and limited treatment options, even if they don’t have the same disease. Caroline Huyard (2008) examines the term “rare disease” and how the term came to be used primarily by health activists (as opposed to clinical encounters with doctors). She finds that the experiential understanding of having a rare disease is significant for patients. As a result, “rare” has become a useful organizing term because of three characteristics of the rare disease experience: that having a rare disease fosters a feeling of injustice, that rare diseases are invisible to the broader public, and that a rare disease patient’s experience is shared within the community. Huyard sums up the rare disease experience with, “thus, in the patient’s view, [rare disease] has nothing to do with the refinement of diagnostic techniques or of medical descriptions, but rather with a political weakness” (p. 468). Both the experience of rare disease and a perceived political weakness—the belief that issues of importance to the rare disease community are deprioritized in both the public and private sector—drive activists to bring rare disease groups together and advocate for policies that will be mutually beneficial.

The history of rare disease is coupled with advocacy. Rare disease advocates, in the 1970s and 80s, championed the Orphan Drug Act, which provided needed access to research and defined the term “rare disease.” The Orphan Drug Act provides incentives for pharmaceutical companies to do research on “orphan” drugs that may have stalled

because the cost of completing pharmaceutical drug trials. These are medications that the cost of research and development would not be recouped by the small market of patients those drugs could help (Huyard, 2009). As reviewed in the introduction, while the Orphan Drug Act defined “rare disease” for the purpose of pharmaceutical research, the term was taken up by people with rare diseases in order to build coalitions and advocate for common goals. Then, in 2002, the Rare Diseases Act further refined the definition of “rare disease” and funded federal agencies to spearhead research. Rare disease activism has since extended to two basic areas: the federal level through organizations like the National Organization for Rare Diseases (NORD), Global Genes, and the Everylife Foundation for Rare Diseases; and the grassroots level within specific patient organizations that work to provide resources to people with rare diseases. Individual advocates often circulate in both federal organizations and specific patient groups and speak publicly about their own rare disease experiences. As a result of advocates at all levels, rare disease activism has developed institutional support such as the Rare Disease Congressional Caucus, the FDA’s “Rare Disease Program” under the Center for Drug Evaluation and Research office, and the NIH’s Office of Rare Disease Research.

Coalition building is key in the advocacy work of rare disease activists and patient organizations. Through their efforts, they have built a lobbying arm that works in Washington D.C., helping establish the Rare Disease Congressional Caucus alongside Members of Congress. Deanna Portero, testifying at the February 2018 Rare Disease Congressional Caucus, articulated the need for coalitions in rare disease advocacy:¹²

¹² Please note that the use of ellipsis in quotations here and throughout indicate removed material. The full videos are available on the Rare Disease Legislative Advocate’s YouTube page.

The definition of rare disease in America is any disease that has 200,000 or fewer people in the United States. And that is a practical number. That's a pragmatic number. Because it's the number that...serves as a delineating line at which it is unprofitable for companies to develop treatments to help that community. So, while each rare disease community is small, and therefore unservable, or unprofitable...altogether, the 7,000 rare diseases recognized by the NIH, cumulatively, represent over 30 million Americans. (Everylife Foundation for Rare Diseases, 2018a)

Portero argued that one rare disease community may be too small to be the focus for research, but when those communities are combined, they represent a much larger share of people in the U.S. These communities are then worthy of study, even from the perspective of profit-motivated pharmaceutical companies. Further, clinicians and researchers at agencies at the FDA and NIH call for research development help from patients and patient communities representing rare diseases. In his presentation at the 2018 Rare Disease Day at the NIH, Dr. Marshall Summar (the NORD Board of Directors Chair) argued for collaboration between doctors, researchers, and patient communities. He stated that collaboration is not just "nice" but is "key to the survival of patients." He added, "Given the genetic variation even within a single disease group, each family in many ways becomes the expert, the world expert on their version of that disease. If we don't listen to them, we do so at our own peril" (NIH Center for Information Technology, 2018). Summar highlighted how people with rare diseases (and their advocates) are often expert patients, by necessity. Both Portero and Summar identify the role of rare disease

patient advocates and the need for the patient's voice to move policy and medical innovation forward.

Rare disease patient advocacy was not created in a vacuum, however. It joins the legacy of other embodied health activism that emphasizes the patient's experience and story to change policy and medical research methods. Embodied health activism, or health social movements more broadly, emphasizes the patient and the patient's voice in medical research and was the result of women's health activists, LGBTQ+ activists, and other groups. Embodied forms of activism include lobbying to remove the term "homosexuality" from the DSM, changing the biomedical approach to treating intersex people, and increasing focus on community input in clinical trials and research from the NIH and FDA (McCarthy & Gerring, 1994; Karkazis 2008; Mangianello & Anderson, 2011; Dusenbery 2018). Embodied health activism has demonstrated how people from a variety of backgrounds can work together to enact change. For example, bioethicist Katrina Karkazis, writing about the intersex community, argues that social and cultural attitudes are integral in embodied activism. The patient advocacy movement in the intersex community brought together a variety of stakeholders including clinicians, patients, parents, patient advocacy groups, and others, and they were able to change clinical guidelines surrounding diagnosis and treatment (p. 237).

Additionally, Mangianello and Anderson investigates how HIV/AIDs activism led to changes at the FDA and NIH, and what lessons that community can offer rare disease activists now. Specifically, activists approached their work with two primary strategies: highly public scenes of protest (such as having a "die-in" on the New York Stock Exchange or paper-bombing leaflets on the NIH campus in Bethesda, MD) and deeply

researched criticisms and policy proposals that demonstrated a high level of understanding about regulatory agencies (p. 5). Dr. Anthony Fauci, National Institute of Allergy and Infectious Diseases Director, recalls picking up one of the pamphlets and thinking, “If you take away the theatrics and look at what they were talking about...they asked reasonable questions, such as ‘why have we accepted for decades that the regulatory process excludes this and says you must do that?’” (Mangianello & Anderson, 2011, p. 14). Over the course of activist demands, the FDA created the Parallel Track policy, which allows drugs in clinical trials (that are not yet FDA approved) to be available to the public and removed obsolete restrictions for participating in drug trials. FDA and NIH scientists also began including patient advocates in scientific meetings. This deep understanding of policy and healthcare practice highlights the need to talk in an informed, practical manner after bringing attention to a cause.

Rare disease organizations have, for the most part, followed the model of HIV/AIDS activists by placing the patient advocate testimonies at the center of highly public events in addition to partnering with legislators and speakers from regulatory agencies and offices. One of the most visible spaces for policy discussions and its impacts on people with rare diseases is the Rare Disease Congressional Caucus.

Rare Disease Advocates and the Congressional Caucus

Congressional caucuses are formed by Members of Congress on shared topics of interest for the purpose of finding common legislative objectives. These caucuses are voluntary and include the high profile Congressional Black Caucus or the Congressional Freedom Caucus, or more niche interests, like the Congressional Bourbon Caucus or the Congressional Bike Caucus. These caucuses are governed by the rules of the House of

Representatives.¹³ Caucuses provide an avenue for Members of Congress to find legislative solutions to problems in specific interests or communities as well as draw awareness around a topic. Briefings held by congressional caucuses are separate from Congressional hearings, which are called by House, Senate, or Joint committees (U.S. Government Publishing Office, N.D.).

The Rare Disease Congressional Caucus is considered an interest-based caucus group, which is primarily “used to gain media attention and raise public awareness” (EveryLife Foundation for Rare Diseases, N.D.a). This bipartisan Caucus was founded in 2009 by Rep. Fred Upton (R-MI) and now includes members from both the House and Senate. As of 2023, the Caucus was co-chaired by Sen. Roger Wicker (R-MS), Sen. Amy Klobuchar (D-MN), Rep. Doris Matsui (D-CA), and Rep. Gus Bilirakis (R-FL). The Caucus’s mission is to:

[Represent] constituent concerns about disease and health related issues. It also works toward collaboration on ideas and solutions for those affected by rare or uncommon diseases, and to facilitate conversations between the medical and patient community. The Caucus works to influence legislation to assist citizens and families affected by rare diseases. (EveryLife Foundation for Rare Diseases, N.D.a)

In practice, the Congressional Caucus meetings occur quarterly and offer opportunities for various stakeholders to testify on specific themes concerning rare diseases (for a list

¹³ The House of Representatives has a formal structure through which to create caucuses, and often are able to get funding. The Senate does not have this formal structure but still form groups around common interests (“What’s the point of congressional caucuses,” N.D.).

of Caucus topics, see table 1). For example, the February 2018 Congressional Caucus theme was “The Rare Disease Lifecycle: Diagnosis to Treatment,” and testimonials were given by rare disease advocates, researchers working in biotech companies and clinical trials, and Members of Congress offering commentary.

February 28, 2014¹⁴	Science Behind Rare Disease Policy, feat. Special guest Jonny Lee Miller
May 7, 2014	Access to Care & Therapies in the New Healthcare System: A Rare Disease Perspective
September 17, 2014	Implementation of Rare Disease Provisions in FDASIA
November 13th, 2014	Creating Economic Incentives to Spur the Development of Treatments for Ebola and Other Life-Threatening Rare Diseases
February 26, 2015	Urgent Healthcare Policy Needs of the Rare Disease Community
May 21st, 2015	21 st Century Cures Initiative: Priorities for the Rare Disease Community
November 5, 2015	Precision Medicine: New Frontiers for Rare Diseases
March 3rd, 2016	The Rare Disease Ecosystem: Fostering Patient Engagement & Driving Biomedical Innovation
May 18, 2016	The NIH and FDA: Vital Agencies in the Fight Against Rare Diseases
September 14, 2016	Strengthening Medical Innovation in America for Rare Disease Patients
November 15, 2016	Driving Innovation for Lifesaving Therapies through PDUFA Reauthorization in 2017
March 2, 2017	Advancing Rare Disease Treatments in the Era of Cures and Health Care Reform
May 18, 2017	Incentivizing Innovation for Rare Disease Treatment Development
September 13th, 2017	Curing Rare Disease: Policy and Regulation Needed for Emerging Technology

¹⁴ RDLA Archives only go back to 2014, although the caucuses have been meeting since 2009.

November 15, 2017	Diagnostic Challenges for Rare Disease Patients
February 28, 2018	The Rare Disease Lifecycle: Diagnosis to Treatment
September 12, 2018	35 Years Later: The Orphan Drug Act
December 4, 2018	The Diagnostic Odyssey
February 27, 2019	Rare Disease 101
May 15, 2019	New Technologies and Treatments for Rare Diseases

Many caucus testimonials offer narratives of one’s own rare disease experience, paired with a call for a specific action or policy initiative that fits the theme of the day.¹⁵ These testimonials are rhetorically savvy and engage with specific commonplaces of health and illness to argue strategically towards policy. What is remarkable about these testimonials is the use of story and the embodied experience of illness. Through these stories, patient advocates strategically use the three healthcare-specific commonplaces I have identified in previous chapters to connect to their audience and communicate their rare disease experience: *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health*.

Visible Illness and Patient Agency in Congressional Testimony

As established in Chapter Two, commonplaces about healthcare are illuminated through rare disease narratives that appear publicly, like in popular television shows. In the following testimonials, I examine how these commonplaces are taken up and used as persuasive appeals by people with rare diseases and their caregivers. These advocates

¹⁵ Initiatives currently advocated by the rare disease community include appropriately funding federal agencies like the FDA and NIH, a Federal Newborn Screening bill that would expand genetic testing covered by Medicaid, and the OPEN act, which would extend patent exclusivity for six months to pharmaceutical companies who develop products for rare diseases (Everylife Foundation for Rare Diseases, N.D.b).

include Tesha Samuels, who has sickle cell anemia;¹⁶ Deanna Portero, from the Fibrosis Dysplasia Foundation;¹⁷ Gina Szajduk, part of the Rare and Undiagnosed Network; and Christina Frigo, a caregiver for her daughter with late-onset Pompe disease.¹⁸ Each testimonial included personal experience to frame their presentation, and those stories depended on commonplaces of healthcare to find common ground with their high-stakes audiences. Through these commonplaces, advocates (whether they were patients, primary caregivers, or patient organization representatives) were able to construct themselves as experts and give compelling testimonials.

Illness is visible

Illness is visible is a commonplace I identified earlier through analyses of rare disease narratives in *House* and *Grey's Anatomy*. As outlined in the introduction, RHM scholarship has addressed how illness is rendered visible in a variety of ways, including medical wearables, diagnostic tests, and other biomedical evidence (Gouge & Jones' 2016 *Rhetoric Society Quarterly* issue; Graham, 2009; Manivannan, 2017). *Illness is visible* often leads to the false assumption that if an illness is not readily visible, either by the eye or by other means of testing, it must not exist. Complicating this false assumption is when "invisible illnesses" have no biomarkers but instead rely entirely on excluding other diagnoses or clinical symptoms, like pain and fatigue, where healthcare workers

¹⁶ Sickle Cell Anemia is a condition where red blood cells change shape and can no longer carry oxygen throughout the body (Centers for Disease Control, 2023).

¹⁷ Fibrous Dysplasia is a disease that causes bone to be replaced by fibrous tissue, leading to frequent fractures (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2023).

¹⁸ A disorder where the body cannot break down complex sugars, affecting the muscles. Symptoms can include muscle weakness, feeding problems, and difficulty breathing (Cleveland Clinic, 2023).

must take the patient's word over the seeming lack of evidence. Additionally, for many diseases, there *are* visible signs of illness—but they are not easily recognized and therefore also not frequently diagnosed. This is also the case for many rare diseases. *Illness is visible* becomes an important organizing theme of testimonials—whether the illness is visible to medical providers but still lacks a firm diagnosis, or truly lacks specific biomarkers.

Several patient advocates examined here highlight how their illness is visible to outside observers, even as those visible symptoms are not easily legible to medical providers. Other advocates push back against the visibility of illness by highlighting a disease's *invisibility*, especially when considering factors like genetics. By depending on the commonplace that *illness is visible*, all speakers argue that their illness experience is legitimate and needs support. One compelling example was the testimony from Portero, a representative from the Fibrous Dysplasia Foundation. She described in detail how the disease is made visible by placing the audience in the patient's perspective through the use of second person:

[Fibrous Dysplasia] is a runaway train. When you are diagnosed with this disease, if that's when you... fell in the supermarket at the age of two and had [your] femur break in half because the cells that are mutants... travel to the skeletal system [and] develop these massive bone tumors that are weak and...susceptible to chronic fractures, chronic pain, deformity... Maybe that's your story. Or maybe your diagnosis came when you were four and your parents noticed that your eyeballs [started] to bulge out of the back of your head because the bone around your optic nerve had [begun] to encase the optic nerve and threaten blindness. Or

perhaps it's when you start to limp. Because if this bone tumor is in your hip it [will] ultimately...not be able to maintain integrity and you're going to potentially lose mobility. (Everylife Foundation for Rare Diseases, 2018a)

Portero's use of second person, combined with descriptions of physical signs of illness in the first part of each vignette (like falling in a grocery store or developing a gradual limp) allowed for two effects. First, for the audience who was most likely unfamiliar with the disease, this description allowed them to identify with the experience of having mysterious symptoms that lead to a diagnosis with a rare disease like fibrous dysplasia. This is an effective persuasive strategy for those in the audience who might not be sick themselves. Second, for those in the audience who were personally connected to rare diseases, this description was familiar because many diagnosis stories start with mundane symptoms that progressively get worse. By describing the initial onset of symptoms this way, Portero uses the audience's familiarity with the commonplace *illness is visible* (no matter if they've experienced this illness first-hand) to articulate the affective experience of rare disease and fibrous dysplasia. Portero's testimony is able to draw in a variety of stakeholders into a coalition of those who care about rare disease and subsequent treatments and cures. Building familiarity works for Portero as an effective rhetorical device, inviting attendees to imagine the world she describes. Additionally, Portero effectively talked to dual audiences in her brief testimony by highlighting the visibility of illness, and while she does not disclose in her testimony whether she has a personal connection to the disease, she still exhibits the role of the expert patient in how she advocates for patients and how her rhetorical techniques operate for a visible, rare disease.

While many advocates focused on the visible signs of illness, others use the *lack* of such obvious signs to make persuasive points about rare diseases. By highlighting the seemingly “normal” appearance of someone with a rare disease, these presenters often ended up arguing for the importance of programs like the Federal Newborn Screening bill, which would require Medicaid to pay for newborn screening for a variety of genetic diseases and standardize testing across the country.¹⁹ One testimonial was from Christina Frigo, whose daughter was diagnosed with late-onset Pompe Disease at her newborn screening test in Illinois. Frigo described the experience: “Ada was 10 days old when I was called by the Illinois Health Department for something called Pompe disease. She had a normal heart and lung function.” The emphasis of Ada’s “normal” appearance was a recurring theme in her testimony. Frigo repeated how her daughter had typical features of a healthy child, and that she “runs and climbs and is healthy” despite having this diagnosis. She added, however, “When Ada was 6 months old, she was seen at...Duke University where mercifully her heart, lungs, and CPK numbers were normal.²⁰ But she did show other gross motor delays consistent with other late onset patients who had been diagnosed at birth” (Everylife Foundation for Rare Diseases, 2018c). Frigo’s testimony emphasized the need for medical intervention to see the signs of illness. Despite Ada’s functions being described as “normal,” because she was diagnosed early and had heightened screening (at some of the most preeminent medical facilities in the country), she can start physical therapy. Frigo then transitioned into a broader argument for the

¹⁹ Currently, the diseases tested for during newborn screening vary from state to state (Everylife Foundation for Rare Diseases, N.D.b).

²⁰ CPK, or creatine phosphokinase, is a type of enzyme in the body that is observable through a blood draw. High levels of CPK in the blood can show muscle, heart, or brain/lung damage (Pietrangelo, 2023).

Federal Newborn Screening bill. Frigo argued here that knowing a child has an illness before they show visible signs allows for more time to treat and monitor them.

Frigo's descriptions of Ada's care and the early interventions also worked to connect to the dual patient and non-patient audience that would access her testimony, and the invisibility of illness described here creates the powerful narrative (and argument for the Federal Newborn Screening bill). For those who are patients or primary caregivers, Frigo's description of a seemingly "normal" child is familiar, as many illnesses and genetic diseases are not readily apparent at birth. They may have received similar screening results in themselves or in their children; or they did not receive such results and had to go through a grueling diagnostic process when symptoms appear. For those who are not in the rare disease community, Frigo placed them in the position of receiving the news (as she and her husband did) and also to imagine how Ada would be impacted if she had not received the diagnosis, and what resources are now available because she was born in the right state at the right time. From there, Frigo broadened her story to appeal for legislative action—to support the Federal Newborn Screening bill. Her description of Ada's visible and invisible symptoms, and her positive diagnosis when no symptoms were apparent, make a persuasive appeal.

Finally, in a third testimonial, Gina Szajnuik spoke on behalf of people with undiagnosed diseases, who have visible symptoms that require medical intervention but do not fit any existing diagnosis. In her testimonial, she showed images of herself and her three children as they tried to find a diagnosis for the myriad symptoms they experience. Like many of the advocates, Szajnuik used visual aids, such as a PowerPoint presentation with photos, to emphasize the visible signs of illness their diseases cause. These visual

aids often were either photographs of people—mostly children—with visible symptoms or more general medical illustrations of physiological abnormalities. Szajnuik introduced her children one by one, showing a slide of pictures of each child and their symptoms. She began with, “this is Eva,” and showed six images of a little blonde girl reclining in a hospital bed, holding out her hands with rashes, and showing a head scar with stitches. Szajnuik then described Eva’s health problems, including how “Eva ended up having a subdural hygroma and went through four cranial surgeries and is now shunt dependent.” She then moved on to her son: “This is Oscar,” she said, showing an image of a brown-haired boy in a hospital bed and getting blood drawn. She added, “Oscar lives in pain every single day [and] we have accepted Oscar’s new normal.” She then talked about her youngest child: “This is Lucy,” and showed another set of images of her youngest daughter, primarily asleep in hospital beds. She added, “Lucy pushes through every single day but comes home and crashes and cries.” Szajnuik ended on a slide of herself, saying: “this is me.” The photos on her slide highlighted herself getting blood draws, doing nebulizer treatments, as well as displaying images of x-rayed hands. She emphasized that for herself and her three children, there was “no magic pill” as they were all still undiagnosed despite participating in the Undiagnosed Diseases Network—a program through the NIH.²¹ The focus on images demonstrating visible signs of

²¹ The Undiagnosed Diseases Network (UDN) is a program through the NIH to “bring together clinical and research experts from across the United States to solve the most challenging medical mysteries using advanced technologies” (Undiagnosed Diseases Network, N.D.). Prospective undiagnosed patients apply to this program and are evaluated. Then, if selected, they undergo further testing at a UDN site location. Approximately 30% of people accepted are ultimately diagnosed.

illness—shunts, rashes, IVs going into arms—was particularly key in Szajnuk’s presentation, perhaps because the lack of a definitive diagnosis meant that she must work against not only an unfamiliar diagnosis (like many in the room) but *no* diagnosis. Her testimony highlighted how visible symptoms can exist and remain unexplained despite going to the highest profile hospitals in the country.

The commonplace that *illness is visible* is used by rare disease advocates to build arguments for research and policies. Narratives about the first signs of illness describe the affective experience of being diagnosed (as Portero skillfully demonstrated), the seemingly invisibility of illness that means one must depend on access to genetic testing (as is the case with Frigo’s daughter), or the use of images to show that even with visible signs of illness, a family may be “about twenty years behind” scientific advancement (as is the case with Szajnuk’s family). The commonplace *illness is visible*, then, broadly represents the experience of rare disease and helps patient advocates position themselves as expert patients and make persuasive appeals.

Medical Expertise Validates Patient Agency

The second healthcare-specific commonplace I identify is *medical expertise validates patient agency*. Agency, autonomy, and expertise have been written about extensively within health and medicine to better understand the relationship between patients, healthcare workers, and disease.²² Patient autonomy (and later, patient agency)

²² *Agency* and *autonomy* have close definitions, and each has been considered within RHM literature. Patient autonomy, within bioethics specifically, represents a shift in medical treatment and care for patients from a beneficence model—that is, the doctor is in charge and patients do what they are told—to an autonomy model, where patients must consent to care. The autonomy model reflects the advent of “informed consent” in clinical medicine, and the belief that patients should know and understand their diagnosis, treatment options, potential risks, and make decisions *without undue influence* (Ubel,

was taken up as a “patient right” by the American Medical Association in 1972 as medical research increased and the atrocities of WWII medical experimentation were litigated in the Nuremberg trials. While the U.S. was late to take up changes to consent in research involving human subjects compared to Europe, the development of informed consent in medical research and practice eventually made its way through the broader American medical system (Will, 2011). Previously, I have defined “patient agency” as the way that people with illness are able to control the choices they make about their bodies and their health. This agency, while often seemingly valued by medicine, often must be paired with a certain level of medical knowledge (see Chapter Two). “Agency” is a fraught topic in the history of health and medicine. As Graham (2009) and Arduser (2017) note, agency suggests both a resistance from ascribed authority and a position of power through which to speak. However, patients working within the medical system do not necessarily have the ability to resist authority (often, represented by their doctors) nor the power to challenge common medical practice. As a result, *patient* agency looks different than theoretical definitions of agency alone—in part due to the unequal power between patient and health care worker.

Scherr, & Fagerlin, 2018; Chubak, 2009, emphasis mine). Several fundamental works of RHM literature have discussed the fiction of autonomy in medical care (Keränen, 2007; Owens, 2008). This is contrasted with patient agency, generally defined as patients *taking control* over the care, management, and treatment of disease and other healthcare decisions (Hunter, Franken & Palmer, 2015; O’Hair, et al., 2003, emphasis mine). As Arduser (2017) writes, “agency” highlights how patients are “doing the work rather than people being cared for” (p. 7). “Doing the work” suggests that “agency” is a long-term undertaking and goal for a patient to achieve, as opposed to “autonomy,” which suggests a set of conditions crafted by health professionals to ensure patients are free from influence.

Effective patient advocates who become “expert patients” have found that they need to know, understand, and strategically utilize medicalized language to convey expertise, even if they do not have formal medical training. Within rhetoric of health and medicine, medical expertise, along with patient agency, has long been a point of interest. For example, Ellen Barton (2000) considers patient referrals (when a doctor requests a patient go to another doctor or department to get further care, or complete certain testing) in doctor’s offices. Her key questions centered around the role of power and authority in the doctor’s office and how that authority connects to broader social and cultural structures (p. 261). She argues that “asymmetry emerges when a family’s expertise and compliance are seen to be problematic within the interaction in this institutional context” (p. 263). That is, when a family does not follow-up on patient referrals, it leads to conflict in the doctor’s appointment. However, Barton also highlights how medical expertise provides access to “social resources” if patients prove to their doctor they have expertise.

Lora Arduser (2017) is also concerned with the role of patient agency and expertise in her work on patients and diabetes care. Diabetes, as a complex chronic illness, often depends on patients to do considerable work to manage the disease outside the doctor’s office. Through this study, Arduser offers a revised definition of patient agency that considers the complex power relationship between patients and the institution of medicine. To embrace this revised definition of agency, Arduser argues that there need to be more flexible ways to become “expert” in health that do not require traditional medical education, such as how diabetes patients use “episteme, techne, and bodily knowledge” to understand, create, and share knowledge (p. 93). Medical expertise may validate patient agency, but what we accept as “expertise” often still rests on Western

biomedical traditions, which continually creates tension between patients and healthcare workers. One way to understand the complex relationship between patients, medical expertise, and agency is through e-health.

E-health, or electronic health information available to patients without a doctor mediating such information, has further complicated the doctor-patient relationship. Much has been written about whether access to the internet empowers or simply emboldens the patient. Segal (2009a), who defined the “internet-health user” as someone who “[visits] health-information websites in aid of making decisions about one’s own and one’s family care” (p. 352), challenges the assumption that access to the internet in itself “empowers” the patient. Additionally, Karen Kopelson (2009) writes about how doctors construct the e-health patient. By examining a variety of medical texts where doctors vacillate between dreading the e-health patient with their “sheaf of papers” of medical information and heralding the e-health patient as an expert and a “new way” of doing medicine, she reveals how each idea reinforces the boundaries of medical expertise as defined by doctors. With the increased access to medical information online, scholarship on related e-health topics, such as health activism, patient communities, and online health information has increased considerably. The easy access to both medical information and patient communities online has allowed many advocates to learn about specific issues within chronic and rare diseases outside of the authorization of medical doctors. However, this access is not always a net positive—online misinformation about health topics (like vaccines, infectious diseases, and non-pharmaceutical interventions such as masking) is an ongoing problem.

Rare disease advocacy has historically depended on activists having an above average understanding of not only the medical terminology and research about illness, but also the medical research process and the agencies that guide that research. Rare disease patients have crafted their own relationship to patient agency and medical expertise rooted in the unique clinical encounters they experience, although resulting in similar tensions as the empowered/emboldened e-health patient. Several studies have examined the clinical experience of rare disease patients and found that there is often a tension between the patient and doctor, stemming from the fact that the patient typically has more expertise than the doctor on the disease experience (Budysh, Helms, & Schultz 2012; Garrino et. al, 2015). Some of these “expert” patients not only challenge individual doctors or clinics, but entire hospital and research ecosystems by leading initiatives that result in change. For this reason, it is necessary to discuss how medical expertise for the rare disease patient is shaped by the role of advocacy.

The Rare Disease Congressional Caucus advocates used medical evidence to support their affective experience and demonstrate medical expertise. They then connected their medical expertise with their affective experience to advocate for specific policies. Tesha Samuel’s testimony is one illustrative example of the use of medical expertise in testimony. She spoke about her experience with sickle cell anemia and NIH clinical trials, but rather than utilizing accessible, plain language used by other advocates, she instead used highly technical language to describe her experience. By foregrounding her testimony with this medicalized language and *then* speaking to how the experience affected her, she highlighted her own expertise:

At the age of two, after many doctor's appointments...I finally got the diagnosis of sickle cell anemia... My entire life I have gone through many debilitating crises. At the age of seven I went through aplastic anemia where I actually flat lined... At the age of 13 the disease caused me to have a transient ischemic attack and which caused me to lose feeling and sensation on the left side and I had to go to [physical therapy]... At 17 I went through an acute chest crisis that affected my ability to breathe properly. The pain literally took my breath away and I was put into a drug-induced coma. When I awoke, it was with the realization that I had to learn how to do everything all over again. (Everylife Foundation for Rare Diseases, 2019)

Samuels described the sickle cell crises she went through as a child, but instead of describing the affective experience and then the medical cause, she inserted the technical language for her experience first. For instance, she had a "transient ischemic attack" that caused her to lose sensation in her left side. In doing so, she demonstrated a high level of technical knowledge about her medical condition, and the awareness that her primary audience was comprised of doctors and medical professionals. In this case, the rare disease audience was secondary.

Additionally, the use of technical language to describe Samuel's illness gave her credibility and justified decisions she and her family have made about her care, specifically to trust the NIH's services. This testimony purposefully highlighted how originally, she had a lack of medical knowledge, which she argued limited her ability to find and connect to clinical research earlier. She attributed this lack of knowledge to a

lack of agency and pointed out the importance of researchers and doctors connecting to communities that may be distrustful of medical research:

It's important that patients and parents and caregivers know that help is out here. If I had known 25 years ago that the NIH was doing research to try and get to where we are today with the therapies I have received, we'd have known what to fight for. My family and I searched high and low to find a place for respite... my hematologist suggested that I contact NIH once again. I chuckled to myself because I was feeling like, this? Again? I didn't feel that I was being taken care of, not by NIH, but I just felt like sickle cell was a community that was not thought about. I had no idea that they had these new research options on the horizon...Here I am, still standing, and I would do it all over again. (Everylife Foundation for Rare Diseases, 2019)

Samuels ended her testimony reiterating how if she knew then what she knows now about NIH clinical trials, she would have sought them out earlier. She highlighted how this lack of awareness can disenfranchise the sickle cell community, a community that is disproportionately Black and has historically been excluded from research. As a result of implicit bias by doctors and researchers, sickle cell disease is underresourced and those with the disease face significant barriers in accessing appropriate care. Research has only begun to catch up on one of the most diagnosed rare diseases in the United States (Power-Hays & McGann, 2020). In her case, Samuels argued that it wasn't until she found out about the robust research being done by the NIH that she felt that she had agency in institutions of medicine and could share her story.

Each caucus testimonial uses medicalized language in order to make points about the rare disease experience or to argue for policy change. While these testimonials might attempt to engage dual audiences (as discussed in the *illness is visible* section), the language choices of advocates connect most strongly to those with medical backgrounds. By describing the illness experience in specifically technical ways, advocates can connect to both legislators and medical experts in the room. Samuels used her credibility for those with rare diseases, who may not be familiar with the specific science behind each illness described, but will be familiar with the need to describe an illness in such specific, scientific terms. Her demonstration of medical expertise and connections to patient agency all contribute to her credibility to both Congress and other rare disease patients who view her testimony.

Illness is visible and *medical expertise validates patient agency* are two commonplaces taken up by rare disease advocates on the high-profile stage of the Congressional Caucus. However, another strategic way advocates subvert those commonplaces is in the way they take up compliance. The third commonplace, *compliance leads to health* is demonstrated in several ways in these testimonials, and patient advocates featured here articulate how they are both strategically compliant and noncompliant. This commonplace, like *medical expertise validates patient agency*, requires patients to convey their knowledge within an institutionally sanctioned, medicalized discourse. I call these set of actions, and the rhetorical moves that accompany them, “critical compliance.” I examine next how compliance, noncompliance, and even *hypercompliance*— when patients intentionally use medicalized discourse and their deep understanding of the institution of medicine and related research,

programmatic, and regulatory knowledge to create change—helps expert patients communicate.

Critical Compliance, Noncompliance, and Hypercompliance

Compliance leads to health is another commonplace of healthcare that is visible in Rare Disease Congressional Caucus testimonies given by expert patients. As described earlier, compliance considers a patient's ability to follow a doctor's instructions to manage a disease, such as changing lifestyle habits, taking medication, and consistently coming back to the doctor for follow-up appointments (Segal, 2007; Gouge 2018). While this is a topic of concern for RHM scholars, concerns and proposed alternate strategies (such as using terms like “adherence” or “concordance”) to manage patients exist everywhere in the healthcare industry (Ahmed & Aslani 2014; Martin et al. 2005; Chakrabarti 2014).

Compliance, though, is largely a rhetorical process, functioning as a way to negotiate care between patient and doctor. For patients with chronic illness, compliance is often necessary to access care, and the perception by doctors that patients are “noncompliant” can be detrimental. However, it isn't just useful to think of a patient as “compliant” or “noncompliant.” Instead, we must consider how compliance is a collection of actions and negotiations between patients and the broader medical system. In many ways, compliance is a strategy where patients demonstrate control and expertise over their bodies by taking complex actions and inactions. Each action/inaction taken by a patient exists on a spectrum I term “critical compliance” (figure 1). Critical compliance is the *intentional* use of compliance, noncompliance, and/or hypercompliance to access resources from healthcare professionals and the institution of medicine more broadly, as a

form of control over the medical encounter, and as a way to demonstrate medical knowledge.



Figure 1: Depiction of the critical compliance spectrum used by complex, chronic, and rare disease patients and advocates.

The rhetorical nature of compliance has led to it being considered RHM scholarship. Generally, compliance still places doctors as the rhetors and patients as the audience who needs persuasion. Segal (2005) explains that “patients do in most cases make their decisions about their own care, and it is best if they are persuaded to make good ones” (p. 134). She explains that while there are alternate models of compliance (such as “concordance”—where doctors and patients are “collaborators in their care”), doctors and patients cannot have “equally valid health beliefs” because patients are not educated in medicine the same way as doctors. Fundamentally, Segal writes, doctors and patients have a different set of goals and beliefs that can impede ideas of “compliance.” However, the assumption that patients are best served by passively complying with medical guidance limits how we understand patients with chronic, complex, and/or rare diseases. For example, Segal draws on several patient interviews as examples of compliance or noncompliance:

[One patient] said he planned to go off his prescribed painkillers before his next doctor’s appointment ‘so I can get my pains in my joints, so when I go to the...arthritis specialist then he could [suss] out what my joints are like.’

[Another] unfolded a plan to take a prescribed treatment for indigestion, only

because ‘if I turn round and go back to the [doctor] and say well the problem’s not cleared up and then he turns round and says them tablets didn’t work, I can’t turn round and say I didn’t take them.’ (Stevenson, et al., qtd. in Segal, p. 146)

These patients demonstrate how they interpret being “compliant” and how they strategically prepare for doctor’s appointments—whether that is taking prescribed medications (so they can argue for a different course of care should it not work) or discontinuing medications (to demonstrate untreated medical conditions to the doctor). While Segal provides these examples as ways patients exercise compliance, the scenes described here are also remarkable in the rhetorical savvy the patients display in order to get what they need out of a medical encounter, such as a change in medications.

The issue of compliance and noncompliance can be considered a simple communication breakdown between patient and provider, but it can also indicate larger systemic barriers that patients face. Catherine Gouge (2018) looks at noncompliance as more of a symptom of a systemic problem:

Noncompliance... can disclose to those paying attention to it something more than just the character of the individual patients (their so-called deviance, errant willfulness, and failures as individuals). The divergence of healthcare participants can disclose something about systems and contexts of care, care practices, resources, and ways of knowing. (p. 127).

That is, noncompliance is complex and often reveals gaps and problems within our healthcare system. The medical system’s limited view of compliance also does not capture the difficulty in managing complex, chronic, and rare illnesses. Gouge’s (2018) study describes how different models of compliance help reveal how compliance operates

differently depending on the illness. She details the history of compliance through two iterations (compliance 1.0 and compliance 2.0), where compliance 1.0 is based on the idea that illness is a deviance from “normalcy” and that, when sick, patients passively accept help from medical professionals. Gouge writes, “in this model, there is no space for someone who is noncompliant, except that they wish to remain sick” (p. 119).

Unfortunately, this attitude still shapes many medical encounters. Gouge argues that the next model, compliance 2.0, allows for more flexibility and knowledge on the part of the patient, as people may live with illness for longer, indefinite periods of time. Compliance 2.0 grows out of the “remission society,”²³ where the boundaries between health and illness are blurred by those with chronic illness or with a “predisposition” for such illnesses (like positive genetic testing) (Gouge, 2018, p.120). Compliance in our current “remission society” is much more complex than what medical attitudes reveal, and those with complicated, chronic health conditions push against medical and general understanding of medical expertise.

The motivations behind medical noncompliance or nonadherence by patients is important to examine as well. Interestingly, Caroline Huyard (2017) found that motivations for temporary nonadherence by patients were often efforts to bring back a sense of control, either in the medication’s effects over the body or the control treatments had on daily life (p. 1215). This suggests that compliance isn’t just a matter of not being “persuaded” to continue treatment, or that patients are either complying or not complying with treatment. Instead, of the “all or nothing” attitude, patients instead had nuanced and

²³ Arthur Frank (1995) coined the term “remission society,” arguing that when we develop treatments for a once fatal disease, people will live instead with a chronic illness as a result of treatment.

complex reasons for “noncompliance.” However, Huyard’s study doesn’t take into account how non/compliance may be used intentionally to shape encounters with doctors. One way to understand the complex relationship between patients, medical providers, and non/compliance is, again, through e-health.

As I outlined earlier, e-health is one way that RHM has considered tensions between patient agency and medical authority. The relationship between patient agency, medical expertise, and compliance is also interrogated through the advent of e-health. Both Segal and Kopelson describe the anxieties the medical community has of e-health patients and empowerment: specifically, that the “empowered” e-health patient will no longer be a compliant one. The worry that the e-health patient will rebel in the doctors’ offices, or will verbally assault the doctor for imagined injustices, is actually a fear that a patient will no longer easily follow “doctor’s orders.” While certainly exaggerated, these fears as outlined in Kopelson’s analysis are about compliance. The scholarship of both types of e-health patients, the compliant or empowered, still assume that patients cannot have the medical expertise necessary to make decisions about healthcare, including whether to be compliant to medical directions.

RHM scholars broadly argue that compliance is dependent on a patient engaging in specific activities that a doctor advises them to do to keep well, which is ultimately a passive engagement with healthcare. However, the paradigm of critical compliance offered here suggests active engagement is needed by those with rare diseases, whose knowledge often can exceed the understanding of medical professionals. Rare disease patients demonstrate remarkable rhetorical savvy in engaging with compliance in a variety of ways. This includes noncompliance, or finding care and support outside of

medical institutions, and hypercompliance, or the act of being in agreement with the institutional discourse of medicine in ways that exceed simple, passive compliance—to the point of becoming experts in medical and institutional discourse themselves. How people with rare diseases engage with compliance, noncompliance, and hypercompliance reveal the complexities of the term, and their strategic use of critical compliance demonstrates further how they embody the “expert patient” within congressional testimony.

Critical Compliance and Rare Disease Patient Advocacy

Critical compliance is the act of patients intentionally performing compliance, noncompliance, and/or hypercompliance to access medical institutions and healthcare more broadly. The strategy of compliance is not only used in the clinical encounter between patient and doctor, but also in rare disease activism. Rare Disease Congressional Caucus testimonies provide examples of critical compliance by patient advocates. Additionally, critical compliance offers rare disease advocates, and patients more broadly, strategies to demonstrate their credibility as an “expert patient” to connect with institutions like the NIH, FDA, and Congress to tell their stories.

Patient advocates have historically used the appearance of compliance to their advantage, including all presenters invited to present at the Rare Disease Congressional Caucus. Rare disease advocates providing testimony deliver their remarks within the rules of civil engagement in the halls of Congress. The very act of using this forum to communicate shapes the testimony in itself, and is an example of compliance. Daniel

Brouwer (2001), writing about ACT UP²⁴ activists and their testimonies in congressional hearings, notes that ACT UP speakers not only testify to the “immediate audience comprised of other witnesses or federal officials” but they also use this platform to reach a wider public. Brouwer highlights how activists utilize public hearings, as opposed to refusing to participate: “of equal significance to the particular ways [ACT UP activists] use the forum is the basic fact *that* they use the forum” (Brouwer, 2001, p. 176, emphasis his). Brouwer continues to argue that while ACT UP participated in the hearings, their testimonies were far from “grateful supplication” but instead they approached their testimonials as “critics and reformers” (p.179). Activists demonstrate that they know they need to partner with people in institutions in order to create action (Brouwer, 2001, p. 171). Participation in public hearings is a strategy that the participants in the Rare Disease Congressional Caucus also use to their advantage. Each presenter is courteous and no one becomes irate at the people in the room. Primarily, each presenter discussed their experience calmly—even if they get emotional during testimony. This civil engagement with stakeholders at the Rare Disease Congressional Caucus is often in contrast to the criticisms that patients are irrational and illogical. Critical compliance is visible in each Caucus testimony examined here, and I focus on examples that Christina Frigo, Gina Szajnuik, and Tesha Samuels provide, since they specifically include first person experiences of rare disease. Much like *medical expertise validates patient agency*,

²⁴ AIDS Coalition to Unleash Power, or ACT UP, was founded in 1987 and is “committed to non-violent direct action to end the AIDS crisis.” They coordinate large-scale actions, including dropping leaflets on the NIH headquarters in Bethesda, MD, to draw attention to the AIDS crisis and hold elected leaders accountable (ACTUP NY, N.D.).

compliance is framed as a way for patients to be allowed into discussions and collaborations with medical institutions.

Frigo (whose daughter, Ada, was diagnosed with late-stage Pompe disease) described her compliance in getting medical care for her daughter after receiving the results from the Illinois Newborn Screening. These compliant acts include monitoring Ada closely, which would mean adhering to testing, frequent doctor's appointments, and documentation. Frigo argued that such monitoring (and resulting compliance) would allow Ada to receive treatment "as soon as she needs it" (Everylife Foundation for Rare Diseases, 2018c). Additionally, she has sought out excellent healthcare for Ada, at medical centers considered "centers of excellence" for specific diseases (like Duke University) rather than local medical centers that might not be able to offer specialized care for her rare disease. Frigo's testimony also recounted advice that she received from a genetic counselor, when discussing her worry that "every stumble and fall" might mean the beginning of the disease. The counselor responded, "every parent worries, regardless of a diagnosis. The benefit of catching this early is that your daughter can be monitored [and] you can leave the worrying to the experts" (Everylife Foundation for Rare Diseases, 2018c). In this case, performing compliance before the disease is truly visible and active allowed Frigo to feel prepared and supported. Compliance in this example is straightforward—it is an example of passive agreement with medical decision-makers in the tradition of compliance 1.0—she "doesn't have to worry" because doctors and medical tests can do the worrying for her.

Noncompliance was recounted by Szajnuik's testimony about her and her children's experience being undiagnosed. Being undiagnosed means that there is less

certainty about the boundaries surrounding compliance and noncompliance. Without the certainty of a diagnosis, what one doctor recommends may be wholly different from another. Szajnuik discussed the multitude of doctors she and her children have seen: “We have been to 8 hospitals, in five different states, in the past 6 years, and have seen 50 specialists” (Everylife Foundation for Rare Diseases, 2018b). Szajnuik’s description of multiple doctor’s visits speaks to her unwillingness to take one doctor’s word and her commitment to get an appropriate diagnosis for her and her children. In fact, highlighting the many medical specialists she has seen was less about working alongside medical institutions to find answers and more about challenging those institutions to help those who are undiagnosed. Because Szajnuik is highlighting a gap in current medical knowledge and support, noncompliance is featured more prominently. For instance, she described the first medical emergency she had with her oldest daughter:

In 2013, we nearly lost our oldest daughter Ava. I was the crazy mom in the ER that refused to leave. If we left when they told us to leave, she would most definitely be blind, and most likely be dead. She suffered in pain for over 6 weeks, a pain that I wouldn’t wish on my biggest enemy. Ava ended up...being shunt-dependent. (Everylife Foundation for Rare Diseases, 2018b)

Szajnuik described herself as the “crazy mom” in the ER, both undercutting the stereotype about parents who refuse to leave the ER and eliciting a laugh from the audience.

However, her actions prevented her daughter from becoming blind or potentially dying. She, in this scenario, was the noncompliant mother. However, later in her testimony, she worked to validate this noncompliance by demonstrating her expertise in medical and legislative initiatives that would help her and her family, specifically highlighting

statistics about the economic burden of undiagnosed diseases. She broadened from her own experience and advocated for legislation that allowed for global data sharing and mandatory genetic testing for newborns. The rhetorical strategy of noncompliance allowed her to reiterate the healthcare and legislative gaps that currently exist.

Last, there are several examples of hypercompliance. As a reminder, hypercompliance is when advocates connect to the institutional discourse by deeply researching, understanding, and intentionally using medical ideas, concepts, and language. Like the ACT UP activists who demonstrated their knowledge of the clinical trial and regulatory processes that were holding up the development of HIV treatments, rare disease patient advocates also use their deep knowledge of the rare disease they experience to connect to scientists, doctors, funders, and policymakers that may be able to facilitate research and make change for those with rare disease. In the case of these testimonials, these advocates could be characterized as “speaking like a doctor” and demonstrate a sophisticated understanding of institutional discourse of medicine. In many ways, hypercompliance connects medical expertise and compliance together, and demonstrates the role of medical expertise in the critical compliance spectrum. In fact, writing about the rhetorical role of ostomies,²⁵ RHM scholar Molly Margaret Kessler (2020) argues that “[for] patient’ perspectives, to be authorized or validated, often need to be matched with an external biomedical reality considered more objective, such as a physician’s perspective, blood tests, or MRI scans” (p. 297). In the case of these rare

²⁵ An ostomy is a surgery that changes how urine or stool exits the body into a prosthesis through a stoma, or opening in the abdomen. This procedure can be temporary or permanent (MedlinePlus, 2021).

disease advocates, they are demonstrating their medical expertise and “validating” biomedical reality through hypercompliance. Frigo showed this briefly as she described Pompe disease briefly as: “late-onset Pompe disease...or glycogen storage disease type 2, is a metabolic disorder that causes progressive muscle and nerve damage often fatally resulting in respiratory failure. [The disease] has variable symptoms depending on the patient's specific genetic mutation” (Everylife Foundation for Rare Diseases, 2018c). Frigo demonstrated her knowledge of the disease through her ease in using highly technical jargon, but the fact that she, and other rare diseases advocates at these briefings, provides testimonials in the Russell Senate building, confers to her an institutional compliance that goes beyond simply “talking like a doctor.” Including such highly technical language shows a deference and an understanding of the medical institutions she needs to access, and a willingness to work within the system to affect change.

Another example of hypercompliance is Samuels, who went through a clinical trial at the NIH for sickle cell anemia. Samuels also used highly technical language throughout her testimony, although she first described her initial reluctance to go to the NIH. Throughout her talk, she reiterated that she wished she “had come to [the NIH] earlier” and that “she’d do it again in a heartbeat” (Everylife Foundation for Rare Diseases, 2019). She used her role as an advocate to make clear that while she had her doubts, the institution of the NIH, and the National Heart, Lung, and Blood Institute in particular, can be trusted:

I had no idea that they had these new options on the horizon. But Dr. John F. Tisdale and his staff at the NIH [National Heart, Lung, and Blood Institute] were recruiting a small number of patients for a gene therapy transplant. Once I made it

through the much-needed testing to see if my body would even be able to withstand all that it would have to go through, I was ready. I was ready because the illness I thought I had robbed me of a full life was not going to take me from it any longer. I always have faith that I would be cured, or at least be ... in remission, but I just didn't know how. (Everylife Foundation for Rare Diseases, 2019)

In this excerpt, Samuels connected to her mindset and attitude to the medical field as opposed to her physical body and experiences. She says above that she is “ready” because she didn’t want her illness to “rob” her anymore. Or later in her testimony, when she says, “trust me, I am excited to be here on the gene therapy transplant [panel]. Like I said, I would do it again and I would say that because for 35 years I went through so many debilitating illnesses and times where I felt like I wasn't going to make it.” Her persuasive case is not only to support the NIH, but also to convince other people with rare illnesses to trust these institutions as well. She leverages her connections to both her patient community (Centers for Disease Control, 2023) and to the NIH in order to effectively communicate the benefits of enrolling in clinical trials.

Conclusion

As health activists have shown, while patients do not always have access to *institutions* of medicine, nor years of medical training, they are capable of understanding the profession and science of medicine. Critical compliance offers rare disease advocates and patients more broadly a strategy to demonstrate their credibility as an “expert patient,” as well as the ability to gain access to institutional spaces, such as Congress, to tell their stories. However, it is worth considering the social factors that contribute to the

idea of critical compliance. Research shows that healthcare still holds extraordinary bias against certain groups of people, including Black and Indigenous People of Color, LGBTQ+ communities, and other marginalized groups. This has a huge impact on how engaged patients or patient advocates can be in the discourse of the clinic. Sickle cell disease is an example of a community that has been systemically marginalized by medicine, both in research and patient care. Robvais (2019) discusses the systems of care created outside medical institutions to help this patient community. While this patient community may *seem* to be noncompliant (that is, operating outside the confines of the clinic and medical discourse) because they lack initial access to medicine, these actions are far more care-oriented and significant than the term suggests. This highlights a major failing of rare disease activism, which tends to focus on access to institutions as opposed to challenging systemic bias inherent in the system. While such access allows for people with rare diseases to advocate for themselves, this access sacrifices the ability for health activists to challenge these institutions at a more fundamental and ethical level. What good, for instance, is advocating for the OPEN Act when drug prices are skyrocketing? What is the value of advocating for more patient access to drugs in clinical trials (such as the Right to Try Act) when pharmaceutical companies do not allow those drugs to go to patients?²⁶ Critical compliance is a necessary step to working within the systems of healthcare as they currently stand, but what does that mean for the patient who cannot

²⁶ The Right to Try Act was signed into law in 2018 and allows people with life-threatening diseases to work with doctors and pharmaceutical companies in order to try drugs that passed through phase 1 clinical trials without consulting the FDA (U.S. Food and Drug Administration, 2023). Lisa DeTora (2018) discusses the rhetorical pitfalls and limitations of the Act in “The dangers of magical thinking: Situating Right to Try laws, patient rights, and the language of advocacy.”

demonstrate such medical expertise and does not have the ability or desire to advocate for highly technical policies to get the care they need?

The commonplaces *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health* are utilized strategically by rare disease advocates to tell stories about illness that are persuasive and compelling to an audience that is not familiar with them. By doing so, rare disease advocates fill the role of the “expert patient”—a rhetorically persuasive persona that speaks to several levels of medical discourse. While healthcare-specific commonplaces guide how we talk about health and illness, they are specifically highlighted in rare disease rhetoric where the limits of medical knowledge and expertise are challenged. Through their testimony, advocates give voice to an experience that may not be visible otherwise. Rare disease patients also take up non/compliance in strategic ways. This strategy is often tied to the need for them to access institutions with significant gatekeeping mechanisms. In fact, advocacy organizations work hard to train and prepare people with rare diseases for rhetorical negotiation between doctors and patients. An article from the nonprofit organization Patients Rising details the strategies people living with rare diseases ought to use to “advocate” for themselves. They write:

Do your research. Read the literature. Know your drug/device/surgical options and potential outcomes. Investigate what the latest research is in the field. Really try to understand your disease, its history, and its future. Also, familiarize yourself with the terms you’ll need to know to have a smart talk with your doctor. Nothing will empower you more than knowledge. (Patients Rising, 2017)

This advice is echoed in the many patient support groups online, advocacy groups, literature for patients to give their doctor, share at patient-centered conferences, and facilitate research led (often financially) by patient organizations. Developing the agency and expertise to “advocate for yourself” is a complex process for those with rare diseases—for all the reasons outlined above. Not only must people with rare diseases become experts in their disease, but they might also need to become healthcare experts navigating private health insurance, Medicaid, or Medicare; policy experts in legislative and regulatory processes; medical researchers; fundraising experts; and community organizers.

In the next chapter, I examine interviews with rare disease patients from one community and how they take up healthcare-specific commonplaces to discuss their illness stories and advocate for themselves. Through narrative interviews, I elicit the strategic ways people with rare diseases (who don’t necessarily consider themselves experts or advocates) use and ultimately transform commonplaces.

CHAPTER FOUR

LIVING WELL WITH ILLNESS: TRANSFORMING COMMONPLACES AND ILLNESS NARRATIVES WITHIN THE RARE DISEASE COMMUNITY

In September 2018, I attended The Myositis Association (TMA)'s Annual Patient Conference in downtown Louisville, Kentucky. Myositis is a rare, systemic autoimmune disease characterized by inflammation and weakness in muscle groups throughout the body (Lunberg et al., 2021). The conference convened patients, doctors, and health science researchers to gather information, share research, and understand the disease better. Many session presentations were about the science and medicine of myositis, but others focused on how patients can "live well" with this rare disease—including how to find good doctors, manage medications, enroll in clinical trials, and even participate in gentle yoga or nutritional classes. I interviewed several attendees about their experience living with myositis at the conference. It was also the first time I met a large group of people with this disease—I was diagnosed with dermatomyositis in 2010.

Commonplaces, as I outline in Chapter 2 ("This Means It's Real": Rare Diseases and Commonplaces of Healthcare in Medical Drama") and Chapter 3 ("The Expert Patient: Critical Compliance, Hypercompliance, and Rare Disease Advocacy"), are ideologically constructed beliefs that underpin arguments within a specific community (Crowley, 2006, pp. 70-75). While often invisible, commonplaces can pervade texts

created and shared among groups, contributing to dominant narratives. I anticipated that the three healthcare-specific commonplaces (*illness is visible, medical expertise validates patient agency, and compliance leads to health*) would appear in the illness narratives I collected because, I hypothesized, patients create illness narratives to make sense of experiences in healthcare settings. However, because I had similar clinical *and nonclinical* experiences as participants, and connected with them as a patient rather than simply as a researcher, the illness narratives I collected instead focused on issues outside medical research and practice. As a result, the narratives discussed here challenge expected norms of the illness experience and instead highlight community and interdependence as key to “living well” with a rare, complex, and chronic illness like myositis. The original three commonplaces were transformed and emphasized how patients identify with illness and connect to others in that illness community. The transformed commonplaces are: *illness is visible through narrative, medical expertise from community engenders patient agency, and community leads to living well*. Each commonplace reveals how community and interdependence are necessary for those with rare diseases.

Overview: Illness Narratives

As stated, I collected illness narratives from participants through interviews for this part of the study. Narratives help us make sense of significant events in our lives, and illness is no exception. Illness narratives, or first-person accounts about disease, allow the teller to make personal meaning of their experiences (Frank, 1995; Kleinman, 1988; Journet, 1990). As opposed to scientific, quantitative writing on illness by doctors (as illustrated by articles in most medical journals), narrative reveals details of “an individual

story” and personalized context to emerge about a patient (Journet, 1990). Illness narratives also allow others to examine sickness and wellness in an individual person’s life as well as within medical systems, revealing how illness affects activities of daily living (ADLs), quality of life, and the affordances and limitations of systems like healthcare access and social supports. As a result, many people in clinical and social sciences collect and use illness narratives for scholarship and teaching material.

Illness narratives are increasingly used in healthcare settings to either research topics of interest or teach students about the patient experience, ethics, and difficult problems that may arise in medical practice. Rita Charon (2007) founded the first academic narrative medicine program, defining narrative medicine as a “clinical practice fortified by narrative competence—the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness” (p. 4). Many medical clinicians and social science researchers have studied the potential therapeutic power of illness narratives for patients: psychiatrist Arthur Kleinman, family practitioner and philosopher Howard Brody, and neurologist and author Oliver Sacks, among others. While narrative medicine is important in the field of medicine by providing healthcare workers with patient experiences and perspectives on complex ethical situations, these stories still tend to center the role of clinicians, often featuring their point of view rather than that of the patient. There is, however, a growing body of medical and social science studies on chronic, rare, and/or complex illnesses and their impact on patients, particularly as medicine continues to consider the role of social determinants of health on health and wellness.

One particularly useful narrative medicine text in analyzing the experience of chronic and/or rare illness is *The wounded storyteller: Body, illness, and ethics* by sociologist Arthur Frank (1995). Using narrative theory and narratology, Frank categorizes stories of illness, arguing that narrative can help patients make sense of their lives amid uncertainty (p. 53). He describes serious illness as a type of "narrative wreckage" that patients attempt to repair through storytelling (p. 54). Organizing illness narratives into three specific types, the "restitution narrative," "the chaos narrative," and "the quest narrative," Frank argues that illness is an isolating experience for people, especially if the disease does not follow a typical restitution narrative structure (which is: "Yesterday I was well, today I am sick, but tomorrow I will be well again") (p. 77). Most people with chronic illness fall outside that restitution narrative. Having experiences that resist easy resolution can lead to both the chaos narratives—"where the teller is simply experiencing illness and not filtering those events into a 'story'"— and quest narratives—a type of journey story where the speaker "accepts illness" and uses the experience to help others (p. 99; p. 115). This text, along with those by other narrative medicine scholars, considers how narrative can contribute to medical practice. Narrative medicine scholars use primary texts in an attempt to build a universal theory of the illness narrative, which, while helpful, can be limiting to the intricate and very personal stories of people with illness (Kessler, 2022, pp. 10-12). Frank writes about concerns over his typology of illness and its application in his recent blog post "Illness Narrative 2022, Unconcluded" (2022). There, he reflects that in organizing first-person illness narratives into categories for "professional accessibility" in *The Wounded Storyteller*, he "academically distanced" them, as opposed to allowing those voices to be "uncontained,

unframed, unfiltered.” Such messy, “unfiltered” narratives are employed in fields like disability studies, where first-person writing is often used to generate scholarship.

Disability scholars have long considered the role of illness narrative, life writing, and representation, often specifically focusing on the messy and deeply personal stories that other theorists do not. Disability scholarship often uses first-person writing, autobiography, or autoethnography—examples include Audre Lorde’s *The Cancer Journals* or Susan Wendell’s *The Rejected Body: Feminist Philosophical Reflections on Disability*. By using personal experiences in these texts, Lorde and Wendell offer critical reflection and insight into the experiential nature of disability. Critical reflection, in disability studies, allows the rhetor to reach their audience by creating new and compelling connections that intersect policy, systemic problems, and their lived experiences.

Rhetoric of Health and Medicine (RHM) also uses illness narratives to analyze medicine, illness, and conceptions of wellness. Debra Journet (2012), writing about the use of narrative broadly in composition studies, states that “narratives are complex, mediated, and rhetorical,” thus offering rich sites of analysis (p. 20). Additionally, narratives—whether about literacy, composition studies, or illness—can powerfully communicate perspectives that have been historically excluded from the mainstream. However, RHM, perhaps due to its disciplinary history as a branch of Rhetoric of Science, tends to be more concerned with healthcare workers, medical perspectives, and the clinic generally—those typically in power, rather than patients' viewpoints. Recently, though, a narrative focus in RHM scholarship has allowed more diverse perspectives from the patient (such as in Arduser, 2017; Kessler, 2022; and Molloy, 2020). Despite

moves to foreground patient voices in RHM, these stories and experiences of specific patient communities are still primarily analyzed within a biomedical, clinical context, often commenting on the interactions between patients and doctors (such as Berkenkotter, 2008; Teston, 2017; Keränen, 2014). While essential work, this perspective can leave out huge swaths of healthcare experiences from people with chronic and/ or rare illnesses.

Illness narratives have various uses ranging from medical education to informing a lay audience of the illness experience. Because narratives are rhetorically deployed, they include commonplaces that help the rhetor connect to the audience. Chapters 2 and 3 reveal that representations of illness and advocacy testimonials use healthcare-specific commonplaces. However, to what degree are commonplaces used by participants when sharing stories to other patients? Or a patient-researcher, like myself? The scholarship on the role of illness narratives within communities and how they build agency and expertise for patients to live a good life is limited. In order to determine the role of commonplaces in illness narratives, and to better understand the function of the illness narrative within a specific rare disease community, I conducted a qualitative study that sought to elicit stories from participants.

Methods:

Overview

This qualitative research study, IRB-approved through the University of Louisville, uses narrative inquiry to structure data collection and analysis. This project connects to previous research into how we “construct our stories in some relation—conforming or transgressive—to other stories we have heard or read” (Journet, 2012, p. 17). Stories shape us and our understanding of the world, and by using stories as my

primary mode of collecting data within the myositis community, I hoped to make new meaning of the illness experience and healthcare more broadly. To achieve this, I used narrative inquiry to clarify the "beliefs, values, and assumptions" of the rare disease illness experience (Merriam, 2009, p. 34). I utilized methodologies outlined by qualitative methods scholars like John Creswell, Sharan Merriam, and Patricia Leavy. Both Creswell (2012) and Merriam (2009) detail how narrative inquiry, as a subset of qualitative methods, identifies how stories are important to the human experience and outlines strategies to collect and interpret narrative data. My methodology is also informed by my disability studies background. While arguments about illness are present in texts and documents, it is important to me to talk to people with illness who are impacted by the narratives that circulate. A guiding principle in disability studies is "nothing about me without me," and this idea prompted me to study something so close to myself and to center those with rare illnesses.

Participants and Research Sites

All participants I met with were diagnosed with the rare disease, myositis, which is divided into several disease subtypes depending on symptoms and diagnostic testing: dermatomyositis (DM), polymyositis (PM), inclusion body myositis (IBM), immune-mediated necrotizing myopathy (IMNM), and juvenile dermatomyositis (JDM).²⁷ These diseases can be quite different from one another, but they are all systemic and cause muscle inflammation that results in progressive muscle weakness.²⁸ IBM is also

²⁷ There are other subtypes of myositis diseases outside of these five. Most share the characteristic muscle weakness and systemic complications.

²⁸ One dermatomyositis variation includes amyopathic dermatomyositis, with only skin rashes and no muscle weakness (Johns Hopkins Myositis Center, 2023).

considered a type of myositis, but unlike DM, PM, or IMNM, where muscle weakness begins in large muscle groups such as the quadriceps and deltoids, muscle weakness instead begins in the hands and feet. And, unlike the other types of myositis, there are no effective treatments for IBM. Myositis is both a chronic illness, primarily considered an autoimmune disease, and a rare disease because it is diagnosed in less than 1 out of 200,000 people in the United States.²⁹ There is no cure for any type of myositis.

In order to conduct interviews with qualified research participants, I created an interest survey that could circulate online so that I could connect to people, collect demographic information, and determine a diverse representation of participants willing to be interviewed. To circulate the survey, I asked for and received permission to post in the facebook group "Dermatomyositis" and several Myositis Support and Understanding groups, including the general "Myositis Support" group and the more specific "IBM support" group.³⁰ Because each patient group is private (I only have access because I am diagnosed with DM), I limited my use of these groups to advertise interest surveys and set up interviews with interested members.

After circulating the interest survey and receiving 129 responses, I selected interview participants to get a diverse age range and disease representation.³¹ I conducted eight interviews either in-person at the 2018 TMA Patient Conference or over the phone.

²⁹ The Rare Diseases Act of 2002 defines a rare disease as one that affects less than 200,000 people in the United States.

³⁰ Myositis Support and Understanding is a patient advocacy nonprofit that runs multiple patient support facebook groups. I served on their Board of Directors from 2018-2022.

³¹ My results were limited in gender and racial diversity, with 87.5% White respondents and 75% women respondents. However, statistically, more Black people are diagnosed with myositis than White people (Nevares, 2022). This demonstrates limitations with my participant-gathering techniques that must be mitigated in future studies (see Chapter 5).

These interviews were semi-structured and attempted to elicit stories from participants where possible. By doing semi-structured interviews that focused on narratives, I sought to understand how healthcare-specific commonplaces that guide stories of illness in pop culture representation and advocacy are apparent in narratives told by patient communities. Thus, my questions centered on how patients communicate to people without a rare illness and whether existing narratives (such as books, television shows, or social media posts) helped them better understand their experience.

Data Collection

During interviews, I asked each participant several questions to gain insight into their experience of illness and the role of narrative in their understanding of myositis. I most specifically focused on their diagnosis experience, their connections to other people with myositis, and how they explain myositis to people unfamiliar with it. The questions I began with were:

1. Tell me about yourself and your experience with myositis?
2. How did you get diagnosed?
3. Do you explain this illness to others without the illness? If so, how and why?
4. Have you ever met anyone with myositis? What were the circumstances?
5. Are there any stories that help you understand your experience of illness? Tell me about them.

Each interview was recorded through an audio recorder, with my iPhone as a backup.

After each interview, I saved the audio files to a USB drive, transcribed them, and then anonymized the transcripts. I then read through each interview and analyzed each for common themes, paying particular attention to how they address my previously identified

healthcare-specific commonplaces, *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health*.

Researcher Positionality

As someone who shares the same diagnosis as my research participants, it is important to discuss my research positionality and the complex role I occupied. I thought I would have a more traditional “objective” researcher role when conducting interviews. However, once I arrived at the TMA conference venue in Louisville, I found that I could not maintain an "objective" researcher positionality. I was unsure how to approach interviewing participants, collecting data from those interviews, and analyzing the results when I could not extricate myself from the experiences my participants discussed. In the eight interviews I conducted, I ended up responding to participants with my own emotions and stories. The interviews then diverged and covered many more topics than I had predicted. As a result, the interviews, which I had estimated would be about a half hour, lasted much longer. We discussed my initial interview questions, but we also shared experiences with treatments, difficulties, and challenges communicating with friends, family, and total strangers. Many interviews lasted over an hour, and several, over two. I was emotionally and physically exhausted thinking of holding onto these stories and finding ways to represent them here.

Thus, I found I had to change, or "crip," my research methodologies. Price & Kerschbaum (2017) write about how disability changes research methods and methodology, particularly when "disability is assumed to be an important part of the qualitative interview situation (rather than something external that ‘enters’ the situation and then must be accommodated or compensated for)” (p. 20). They focus on how

disability research methods reorient the researcher and participant's relationship to "time, gaze, and emotion" (p. 30). By carefully considering my relationship with all three—each primarily assumed as neutral in most research methods literature—I was able to better understand my relationship with my participants as a disabled researcher. As someone with the same rare, chronic illness as those I interviewed, I had to consider how I physically challenged traditional notions of the "researcher." For example, because I have a physical disability and a chronic illness that can lead to fatigue, pain, and brain fog, I found interviews physically and emotionally taxing for me in ways I did not expect. Price & Kerschbaum address the challenges disabled researchers face when conducting research:

Additional time pressures exist for disabled researchers. Like our participants, we may be operating on a thin margin (of energy, resources, or options). Seemingly minor issues such as the chemicals present in a room, a high doorway threshold, or poor resolution on a video might make or break someone's access to the interview. (p. 32)

When conducting interviews, either by phone or in-person, seemingly innocuous things, like the height of the chairs, distance between myself and the participant, vocal projection, and proximity to windows (UV rays from the sun can trigger dermatomyositis rashes), affected my energy level, just as Price & Kerschbaum caution. Additionally, the emotional engagement with participants, who shared experiences very close to mine, and the length of interviews, left my brain fried and my body exhausted. I had immense guilt over my limitations as I wanted to be mentally present, write reflective responses after each interview, and facilitate transcription as soon as possible. But, because I had limited

energy, I had to accept that each facet of the research process would simply take longer for me.

Initially, I thought I made a mistake by engaging in meandering, dialogic conversations with participants because I was concerned that I biased the sample by not allowing connections to commonplaces to appear organically. However, when I reread the transcripts, I found that the healthcare-specific commonplaces still emerged. Unlike in Chapter 2 where I collected representations of rare disease, or Chapter 3, where I analyzed advocacy stories of rare disease patients, interviews in this chapter were with me, an “insider” to the patient community. And, because these interviews were dialogic, my voice and experiences appear in transcripts and in data included here. I came to these interviews as a patient myself who was also a researcher, and not as a researcher who represented an extension of the medical clinic. Commonplaces, then, presented differently than expected when research participants talked with me. Unconventional research relationships can lead to new and novel findings. Jessica Restaino (2019) elaborates on the "messy" experience of conducting research when the boundary between participant and researcher is blurred. Writing with her friend and collaborator, Susan Lundy Maute, who was dying of cancer, Restaino discusses atypical research partnerships. She and Maute initially undertook a research project about athleticism and the body, but ultimately challenged feminist research methods and the role of relationality, intimacy, and knowledge as Maute grappled with stage IV breast cancer. Necessarily, Restaino's book pushes against the boundaries of traditional qualitative research methodologies and calls for "critical attunement, attention, and openness so that we might recognize those unique collaborations that have the capacity for overpowering

and destabilizing *us*, for teaching us new rhetorical limits” (p. 25, emphasis hers). This text, valuable for disability research methods, challenges traditional interview practices and urges researchers to connect to one's humanity and embrace the uncertainty of illness and bodies.

I found that many of the interviews I conducted for this chapter shared similar characteristics in how participants discussed their illness experiences. Specifically, each interview demonstrated transformed commonplaces that highlight the role of community and interdependence among patients. I selected three representative interviews where the transformed commonplaces emerged clearly. These interviews also had a diversity of age, gender, and diagnosis. They include: "John," in his fifties and diagnosed with PM; "Lorraine," in her seventies and diagnosed with IBM; and "Carrie," in her twenties and diagnosed with JDM.

Narrative Interviews and Commonplaces

This study collected illness narratives from participants through co-constructed, semi-structured narrative inquiry. The narratives here differ from previous texts I used to analyze commonplaces—their form was mediated through conversations between each participant and myself. As a result, there was more reflection and deliberation when we talked together, including sharing stories to understand our experiences better.

Participants also told their illness narrative and connected to the experiences of other people who are ill, thus embracing a communal aspect of illness. Sharing narratives helps participants build formal and informal patient communities, discuss experiences and expertise that allow for more patient agency, and teach others to live well with a chronic, complex, and rare disease. Because each healthcare-specific commonplace identified

earlier was through clinical and medical contexts, each “transforms” when outside of the confines of the clinic. Each commonplace now centers on community and how connections are built among patients. The new commonplaces are: *illness is visible through narrative*, *medical expertise from community engenders patient agency*, and *community leads to living well*.

Illness is Visible through Narrative

In previous chapters, I identified *illness is visible* as a healthcare-specific commonplace that guides how we understand illness and health. This commonplace often shapes healthcare practice and how patients receive clinical care—especially when an illness seems “invisible” in medical tests and imaging. In Chapters 2 and 3, I focused on how *illness is visible* manifests in the clinical encounter through diagnostic tests and signs, such as blood tests, imaging, and other physical changes like a fever or rash. While clinical tests can confirm a myositis diagnosis, leading to treatment and other medical resources, doctors must recognize symptoms enough to run myositis-specific tests and avoid common misdiagnoses. When people with myositis experience delays in diagnosis, their care can be impacted and result in worsening outcomes like organ damage, cancer, and an increased risk of death (Namsrai, 2022). Other studies have examined the diagnostic delay in rare diseases broadly, and its impact on the rare disease community, including medical clinicians being unfamiliar with rare diseases (Isono, 2022), patients doubting their perception of their symptoms as a result of physician condescension (Le Hénaff, Héas, & Joly, 2019), and misdiagnoses (Jessop, 2014). The complex process for a rare disease diagnosis is such a common, shared experience among patients that it is

called the “diagnostic odyssey.” These experiences often shape the diagnosis story shared by patients within communities.

However, through my interviews, I noted how the commonplace *illness is visible* changed when considering the patient experience within illness communities and outside of clinical encounters. Instead of blood draws, imaging, and other diagnostic tests that render illness visible to healthcare workers, the way illness is made visible in patient communities is through sharing stories. Thus, *illness is visible* needed to change to *illness is visible through narrative*. Patients use many cues, including narratives, to disclose their belonging in an illness community. Disclosure is a fraught topic that can encompass many actions to publicly mark disability. For example, Tobin Siebers (2004) discusses in “Disability as Masquerade,” that he exaggerated his existing limp at an airline gate to prevent questions as to whether he “deserves” to board early. Kerschbaum (2022) argues that many direct and indirect signs make disability itself “perceptible...through all kinds of cues” (p. 12). These cues can include road signs, hearing aids, and others—and each contribute to the perception and relationality of disability. Bringing in materialist theory and cultural rhetorics, Kerschbaum threads together how “disability is always shifting, contingent on circumstances, contexts, and particular experiences, relationships, and bodily arrangements” and that “narratives...materialize disability” (p. 10). She also moves the concept of “disclosure” away from the more traditionally understood act of telling someone about a disability and/or illness and instead to the “intra-actions” and “dis-attentions” that shape the material perceptibility of disability. Others, such as Ellen Samuels (2017), overviews disability disclosure and the role of “passing” as abled when

having disability. She notes how speech acts, such as a diagnosis story, are a performance that can make disability visible to others:

Thus, some scholars have argued that “performed” disability identities are frequently displayed in the visual field (Davis 1995; Garland-Thomson 1997); others point out that disability identification also makes use of speech acts such as impairment narratives (i.e., the story one tells about how one “became” disabled) and forms of medical certification (Brune and Wilson 2013; Siebers 2004). (p. 385)

While Samuels is referring to performance, including speech acts, as a way to make disability visible to the broader, nondisabled community, each can also apply to disclosing belonging to a patient community. Here, I consider the more traditional speech act of someone with an illness telling someone else about their experience through the diagnosis story, as opposed to unintentional, incidental, or subversive cues.

Participants in this study disclose their myositis diagnosis to others in the same community to access relationships. Sharing the diagnosis story is important because while myositis can cause significant visible disability, not all with the illness are physically disabled. And, even if one is visibly disabled, because myositis patient communities are primarily found online, disclosure to signify one is part of the myositis community must still occur in order to be approved to join the primarily private online support groups. The design of this study allowed for disclosure strategies to become apparent, because participants disclosed their illness narrative to me, a person who shares the same diagnosis as they do. Finding a shared community, and witnessing other

people's stories and sharing their own, is significant and a major theme in many of the interviews.

All participants in this study discussed their diagnosis experience, prompted by my question, "How are you connected to the myositis community?" Through each story, patients share their personal experiences of being diagnosed with myositis, allowing them to connect to a broader community of myositis patients who recognize that story in their own and make that connection visible to me through the diagnosis story speech act. My first participant, John (50s, diagnosed with PM), offered a typical diagnosis story for those with myositis. He described to me his initial symptoms and diagnosis, highlighting both the moment he noticed he had some sort of physical issue and decided to see his general practitioner (GP):

I kind of noticed [muscle weakness]... on our 15th anniversary. And we were out in the ocean and I was starting to tire and stiffen up a little bit just swimming. So then I mentioned it to my GP when we got back; this was in September. And then, by December, she's like, "There's something wrong with you." She knew already my [creatine kinase] numbers were out of whack, and she said, "Hey, you gotta go see a rheumatologist." So we went to one fairly quickly, and she, of course, did the full gauntlet of blood work and went, "Hmm, I'm not sure what this is. What we really need you to do is get you to see a neurologist and get a muscle biopsy done." First, the main tests were the MRI, all the bloodwork, and the different scans, and then, of course, the muscle biopsy came. Yeah, very much polymyositis. She showed us the slides, and they were very textbook. With all the different stains and it was exactly what it was. That may have taken four months

total. So I was very fortunate that it went that quick. I've heard a lot of horror stories.

John's diagnosis story followed a familiar pattern that several interview participants shared. First, he described the affective experience of feeling like something was wrong and that he needed to see a doctor. He started seeking a diagnosis by going to his GP and then was referred to a rheumatologist and a neurologist. He underwent several diagnostic tests, including bloodwork, to check his creatine kinase (CK) levels (which can be significantly elevated in people with myositis) and others. Imaging and biopsies followed, which showed abnormal results. During this process, John was able to connect with the right doctors and find treatment quickly.

John's story, while about his "diagnostic odyssey," also indicated how he valued community and the importance of disclosing his story with others who have myositis and making his illness visible to other going through similar experiences. He noted that he had "heard" horror stories about the length of time it can take to get a diagnosis, acknowledging that he had discussed other people's diagnosis stories and knew his experience was an outlier. John also connected to the patient community quickly, potentially because he was diagnosed right away. He discussed finding his first support group because he and the leader of that group shared the same neurologist. The ability to get diagnosed quickly allowed him to get access to patient support communities, and later in the interview, he discussed the value of the patient conference we were attending and provided advice to me to get the most out of the experience—what sessions to attend, and that I was "in the right place." For John, his diagnosis story was one he told others to make his illness visible to other patients so he could get connected to the patient

community and then become a resource for others. Throughout the interview, he continually returns to the role of community in his experiences having PM and how valuable he found that community in feeling less isolated.

My next interview was with Lorraine, 70s, who was diagnosed with IBM. Like John, she had an incident that indicated “something was wrong”—a fall— that led her to seek medical care and a diagnosis. This experience is the beginning of her diagnosis story that ultimately also disclosed her relationship to the myositis community:

I had been at the dental school for some periodontal work. Walked out on this perfectly flat shiny floor and stubbed my toe and fell and skinned my knee and couldn't get up. And the head of that department, who had just seen me... he and his wife were going out the lunch and they came along and helped me get up. So I had this big nice story to go back and tell. I went to see my primary care doctor that week. Anyway, my knee was skinned, and he says, “How'd you do that?” And I told him this great story. And he said, “Well, stand up.” Walked along. He had never seen me stand up. I had always sat in the examining room. And I'd been complaining about getting up from chairs and things like that and it's like “How old are you now?” But that got his attention, and he sent me for tests and set up an appointment with neurosurgeon. Which it should have been the neurologist. When I showed up at the neurosurgeon's office, he said, “Well, you really are supposed to see a neurologist first. We'll get you an appointment across the hall. Just [take] another left here.” And that neurologist had me do tests, tests, tests. He looked at everything. He says, “I don't know what you have.” Maybe you would like to try some Prednisone? Well, he was putting it up to me. He said,

and I've heard this from other people, with a 10% chance that it might do some good, and 40% chance, there's interesting side effects. And we decided that wasn't good thing, so we didn't do anything. But then I had the follow-up appointment with the neurosurgeon. He looked at it [the EMG], which my primary care doctor had [sent]. And he said, "I'm gonna send you up to the guy that did this." And that's who made that diagnosis. And my suspicion is that when he was doing the test, that he had a good idea of what I had. Because right away, I had a biopsy... And then, once I found out what I had, I read about it. I found The Myositis Association. I found the Johns Hopkins Myositis Clinic and made myself an appointment over there and got the biopsy sample sent over there, which confirmed it, which is a good thing. They redid some of the tests, most of the EMG... And then I came to a myositis conference; the first one I went to was in Charlotte, which was in 2009.

The beginning of Lorraine's "diagnostic odyssey," like John's, also began with an experience that indicated "something is wrong." Myositis, which induces gradual muscle weakness, can cause unexpected falls and many patient diagnosis stories start in the same way. Lorraine also shared several common experiences with other participants, including having her symptoms discounted, which resulted in a delayed diagnosis. At first, her symptoms were blamed on getting older, and she had difficulty getting to the right specialist. Lorraine also discussed, as part of her diagnosis story, the personal research she did to find out more about myositis, including going to the Johns Hopkins Myositis Clinic, the foremost research center for myositis in the United States. She also shared her experience finding support through the TMA patient conference and making

social connections to others. She ended her diagnosis story with the experience of attending a patient conference in 2009, where she met other people with IBM and learned more about the scientific advances for the disease from medical experts and other patients. Lorraine, like John, included finding others in the myositis patient community in her diagnosis story because finding community was a significant moment. In disclosing her IBM diagnosis and making that diagnosis experience visible to others in the same patient community, she found resources, friends, and relationships she wouldn't have found otherwise.

My third research participant highlighted here, Carrie, was diagnosed with JDM at seventeen. She also had a similar trajectory as John in getting a diagnosis. Once Carrie began experiencing symptoms at softball practice, she had appropriate testing and could access the right doctors relatively quickly. However, in her interview, she focused more on the role of diagnosis on her sense of self. Unlike John and Lorraine, who discussed connecting to the myositis patient community and making their illness experience visible through their diagnosis story, Carrie highlighted the *loss* of her local community, specifically her friends at school. Here she discussed the initial symptoms that led to her diagnosis:

I was diagnosed when I was 17. And I was diagnosed pretty quickly, which was a blessing. Since then, I [was] pretty sick. I would say like two years with a lot of issues. And [I] have been fairly stable since then. I've had some flares and some other health issues, but mostly since then it's been mostly stable. I've been able to do a lot of traveling; I went back to grad school; I've been working. So, things have been fairly smooth, with a couple bumps. I was a very normal high schooler,

was really active in sports, and really athletic. And that had always been something that was really important to me and part of my personality and identity. I think the first memory I have of noticing something was wrong was that I was at softball practice and doing the sprints where you go backwards and forwards, sort of like doing these quick turns. I was noticing on the turns that my thighs and knees would give out when I stopped and pushed against them. I thought that was really weird, and trying to figure out what was happening. Yeah. And so then, I think, I got sick fairly quickly after that. I started having flu-like symptoms and muscle weakness. I think it was pretty scary for me and also for my family. In some ways, I think, probably because of the medication, I just seemed really sick for the first year or so. I actually don't have that many memories of being sick and of that time. Partially that is also, I think, that just being a really upsetting, difficult time of being a teenager. I can remember parts of it, but not all of it.

Carrie's identity as an athlete was impacted by the diagnosis and the limitations created by the illness and medication. Both the diagnosis and medications separated her from her peers and made her illness visible in a way that she felt she could not control. Unlike John and Lorraine's connection to community, Carrie focused on the loss of social experiences and how that impacted her. For Carrie, the realities of the disease (how it is rare, chronic, and needed to be managed with serious, potentially life-long medications) meant that getting a diagnosis resulted in her losing her community, and she did not feel that she gained connections with other patients like John and Lorraine.

John, Lorraine, and Carrie all disclosed their belonging to the myositis community to me when telling their diagnosis story, whether through the familiarity of

the “diagnostic odyssey” each went through or the role of family and community connections after diagnosis. Several other research participants I interviewed also commented on communities when discussing diagnosis. One participant noted that after being released from a lengthy hospital stay, she was afraid to be alone. Her family and friends made sure someone was by her bed at all times. She noted that after being sick, “all my relationships were different.” Another, reflecting on his hesitation to share his diagnosis with friends, expressed frustration at their lack of understanding of his experiences and how illness changed his physical abilities. Several also spoke of becoming leaders of a patient support group after diagnosis and then the experience of transitioning out of that leadership position when needed.

John, Lorraine, and Carrie revealed how they make meaning of their myositis diagnosis through how they told their stories to the broader patient community. John and Lorraine quickly disclosed their experiences to other myositis patients. Through his description of getting diagnosed, John mediated his experience through what he had heard others going through. He had considered his experience alongside others with myositis and incorporated that into his understanding of being diagnosed and having the disease. Lorraine, who struggled more to get an initial diagnosis, quickly started to do her own research by connecting to patient communities. Lastly, Carrie, who did not seek out and disclose her diagnosis with a broader patient community, discussed the chaotic understanding of the disease when first diagnosed and how she does not have many memories of being sick. Instead, she noted that it was a “scary time” for her, in part because of the loss of her social world. For some patients, a diagnosis and diagnosis story

can allow them to connect to patient communities and begin to make sense of the experience of illness and what having a chronic and/or rare disease means for one's life.

Medical Expertise from Community Engenders Patient Agency

The healthcare-specific commonplace *medical expertise validates patient agency* was identified in earlier chapters. As discussed in Chapters 2 and 3, the relationship between medical expertise and patient agency is complex. However, medical expertise generally needs to be legitimized by the medical establishment for patients to be afforded "agency" to make medical decisions. Patients, then, need to present expertise in specific ways for clinicians to accept the patient's knowledge. For rare diseases such as myositis, it can be difficult to navigate how to present medical expertise to healthcare providers because it is common for patients to possess knowledge that exceeds clinical understanding of these diseases. Thus, these interviews reveal how this commonplace transforms into *medical expertise from community engenders patient agency*—that is, patient communities impart important medical expertise, and that expertise can provide patients agency in making healthcare decisions around issues like pain, mobility devices, and accommodations, particularly if those topics are stigmatized in the doctor's office. By connecting with community as opposed to the clinic, patients can develop agency over their rare disease and advocate for themselves more effectively.

One example of medical expertise and patient agency in the experience of myositis can be seen in this excerpt from John's interview discussing pain—a difficult topic for people with myositis. While recent research has shown that over 80% of myositis patients self-report pain, many doctors still believe that myositis does not cause pain at all, only muscle weakness (Bhashyam et al., 2022). As a result, pain is often

dismissed in the doctor's office and is instead discussed in depth among patients, where others affirm they experience it, describe what it feels like, and share potential treatments. While I had not intended to ask about pain specifically in this interview, during the course of John's narrative, I interjected to ask him to clarify a mention of pain:

Caitlin: So what does the pain feel like to you? Like how do you describe it?

John: I would have to say it's sort of like when you haven't used your muscle groups in a long time and say, "Okay, I'm going go and do some heavy hiking." And then the next day, or two days later, walking is difficult. It hurts. That muscle stiffness is what I-

Caitlin: Yeah, I actually described it almost the same way to doctors that didn't believe me.

John: That's exactly what it feels like, and it just doesn't go away.

Caitlin: Yeah, I'd describe it as like I ran a marathon and lifted weights, and that feeling has not gone away.

John: Yeah, it's not like you're fatigued from it. It's just that the pain is there.

John and I connected here on the discussion of pain. In fact, I remembered this interview specifically because it was the first one I conducted. I was shocked when John used the same description for muscle pain—like after going on a long hike—that I did. In my excitement, I accidentally cut him off to affirm what he had just said, and the following

few exchanges were a series of agreements, starting with "yeah," to highlight that shared experience of not only the muscle weakness and pain, but also in how we discussed it with others. This excerpt demonstrates how a conversation between two people with a similar experience can affirm and validate the experience of pain, even if doctors often discount it. Both of us experiencing pain and describing it similarly reaffirms that pain is “real” despite the insistence by medical professionals that pain is not a symptom of myositis. The affirmation that we both experience this symptom can help destigmatize the discussion of pain, start to find treatments, and potentially even bring the topic up to our doctors.

Lorraine also brings up another often stigmatized topic in our conversation. We discussed using assistive devices and household modifications, revealing how each relates to medical expertise and patient agency. Myositis, specifically IBM, causes progressive muscle weakness and wasting that often necessitates assistive devices, such as canes, rollators, and wheelchairs. In fact, during our interview, Lorraine was sitting in her powerchair, and I was using my cane. We discussed the decision to get and use assistive devices and how she gathered expertise from other patients rather than her doctors, partly because doctors would only say to get assistive devices "when she really needed it." The importance she found in the connections she made with people she met at the conference and online was strongly communicated in the following exchange:

Lorraine: I've just started using this [powerchair], mostly in the past year, although I've had it about three or four years, because I came to conferences where they would say get these before you think you'll need them. Well, there was somebody in the [Myositis Support and Understanding] group, I think

they said, "My doctor said not to get a chair until I really needed it, and now, how long is it gonna take?" And they were saying like six months. And it sat in the kitchen for a long time, and I would take it out to go to Walmart because I couldn't walk as far as I wanted to in Walmart with my rollator.

Caitlin: Sure. Yeah. Yeah. So you had the rollator, then.

Lorraine: And that's been for several years. I had gotten [the rollator], and I don't know [if I got it] before I got my diagnosis or not. I was doing taxes for the AARP program at the senior center and sitting in folding chairs, and it was getting hard to get up from. Not impossible, it was getting [to be a] a challenge. And this little old lady came in with a rollator, and I looked at it, and it had a seat higher than the one I was sitting on, and I said, "Where did you get it?" And I think I ended up buying one from Best Buy.

Lorraine highlighted the importance of connecting to social support groups with the same diagnosis and gathering information in these communities. Specifically in getting assistive devices, she discussed how she learned from people in the myositis or disability community more broadly, rather than her doctor or medical team, about when to buy and use them. That allowed Lorraine to demonstrate agency over her decision-making and to get and use her powerchair when she felt ready.³²

³² Unfortunately, many people must wait until a doctor's referral for assistive devices as the cost can be significant, and they may need insurance coverage. These patients are forced to wait until their doctor or insurance says they qualify, as opposed to patients determining if they are ready for them.

Lastly, Carrie, diagnosed at 17, discussed a few of her frustrating daily experiences when first diagnosed and how they impacted her familial relationships and friendships. She also talked about how she had difficulty asking for help, whether in her social circles or through “official” channels, such as disability services at her university, and how asking for help felt stigmatizing to her. Carrie did not seek out patient-specific community support groups, limiting her ability to develop expertise and resulting patient agency:

I have a very clear memory of needing to do my laundry, and the laundry was in the basement, like two floors down from my room. I was asking [my siblings] to help me because I couldn't lift laundry baskets. Then them saying, "No. Do it yourself." I was just crying and crying because I was like, "I can't do my laundry. [I also have] very clear memories of, I had a really solid group of girlfriends before I got sick, and after I got sick, they kind of dropped away and stopped visiting me, and stopped saying hi, and I missed a bunch of school. So, memories of just being really confused and upset about that. Of them visiting one time, and kind of like making a mess of my house and just hanging out with me, and then leaving. It was just really messy. I was like, “What happened, and how do you expect me to clean up?”

Carrie highlighted how the symptoms of JDM impacted her relationships with her siblings and friends and how they had difficulty understanding her experiences with illness—even making fun of her when she asked for help. Later, when asked how myositis impacts her currently, and her decisions about her future (such as going to

college and her career aspirations), Carrie talked about moving to college even as she was still sick:

I think I still struggle to this day with asking for help from people and realizing that I don't need to do everything on my own and that for sure happened when I got to [college]. I remember my dad and I having a meeting with the disability office, and they just really didn't know what to do with me. They were like, "What do you need?" I was like, "I don't really know. I feel fine today." And they were like, "Well, we can send the golf cart to take you to classes when you can't walk." I was just like, "No. There is absolutely no way I am going to ride to class in a golf cart." I don't think I used their services at all. Other than like, my teachers got a letter saying, "If she's missing class then excuse her."

Carrie highlighted feeling disconnected from her community, such as her friends who "made a mess" in her house and didn't help her clean. She also discussed feeling ostracized due to her illness and avoidance of stigmatizing experiences that will mark her as different (like how she refuses campus transportation: "No. There is absolutely no way I am going to ride to class in a golf cart"). Unlike John and Lorraine, who connected to patient communities and found affirmation in pain and the use of assistive devices, Carrie did not find these supportive voices and tools to help, potentially due to her lack of patient community connections. The logistical impacts on Carrie's day-to-day life, and her understanding of her options, demonstrate how a lack of strong community connections can make things like asking for accommodations or brainstorming college accommodation requests more difficult.

Each of the three representative participants shared their experiences with medical expertise and patient agency as it manifested in the day-to-day management of myositis symptoms. Other interviews also highlight the importance of finding community to gain expertise not found in the clinic. One discussed the loneliness of being first diagnosed with DM, that "it was a big psychological adjustment," and that she had "never heard of the disease" and "didn't know what was going on." She then described joining one of the facebook support groups, and a "lightbulb went off." She realized, "okay, you are really living with something serious." Others spoke about being "lurkers" in facebook groups, getting a sense of community and taking comfort in that despite not interacting directly with others: "I do like [the facebook groups]. Just naturally you don't want to be the only one in the world. So, there are others. There are very few of us, but worldwide there seems to be quite a pack." However, there were others who hesitated to find and engage in community, especially with friends and family who may not understand the experience of having myositis, saying things like, "You're not going to get any sympathy, and so there's no sense in even talking about it." Overall, patient-specific communities play an important role in understanding and learning more about the disease—specifically, a rare one without much publicly understood information.

Patients share expertise in strategic ways, including through telling stories to one another, and in talking to one another, they support one another's agency. Specifically, knowledge of the illness experience can help one manage day-to-day symptoms that impact ADLs and/or quality of life. The expertise John, Lorraine, and Carrie discussed surrounding stigmatizing issues of pain, assistive devices, and requests for help are all ways to manage daily symptoms. Often patients recounted the discussions around these

issues with other patients as key in their decision to take action and express their own agency.

Community Leads to Living Well

Previously, I discussed the healthcare-specific commonplace, *compliance leads to health*, and how it shapes patient clinical encounters. This commonplace focuses on the perception that patients must follow doctor's orders is necessary to be healthy. For those with chronic, complex, or rare diseases, "compliance" is often a fraught process, typically defined through the lens of clinical healthcare professionals who are often concerned by the "noncompliance" of patients. The assumption of research on "compliance" is that patients who are compliant with medical orders return to good health—and those who are not do not want to become healthy again. This limited view of compliance doesn't leave room for patients using non/compliance intentionally to access resources and medical care, nor how those with incurable conditions manage daily symptoms.

However, interviews with participants reveal the role of community in managing and maintaining good health within the context of chronic, complex, and/or rare illness, leading to the transformed commonplace *community leads to living well*. This transformed commonplace highlights how a patient's goal is not necessarily returning to good health (which may not be possible). Instead, within patient communities, *community leads to living well* considers the strategies undertaken by patients to understand, manage, and lead good lives with chronic illness. For myositis patients, much of the day-to-day experience of illness is outside of a medical setting, related to issues beyond the scope of a clinical encounter with a medical professional. Many patients work to understand the complete picture of illness as part of their lives—not merely something that is managed

only by compliantly taking daily medications and going to doctor appointments. Negotiating the decisions made in one's daily life as a rare disease patient can be overwhelming for many and is often the topic of conversation in patient communities.

Each interview I collected included examples of knowledge gained through first-person experiences or discussions with other community members about living well with a serious, rare disease. John, Carrie, and Lorraine discuss these topics in their interviews, specifically the experience of finding patient support groups, changes in appearance, and insights into grief. John discussed in his interview connecting to support groups and how important finding patient communities was to him:

John: [T]here was lots of times I wasn't sleeping, so you're on the support groups chatting, just seeing people's posts. And then the support groups at home, just talking to others. The conference is a good one. There's so many here that will ... It's like, wow, there's this many people. You're not by yourself.

Caitlin: Yeah, that's what I really like about them, especially online support groups... It's one of the first things I found when I got diagnosed. You put it into Google, and you're like, "What is this thing? How do you spell it?"

John: We all do the same thing. It's just easy to be in the same trend. Like, "What is this disease? Who else is out there?" As you're digging, you start coming across different words.

Caitlin: Yeah, and did you find those groups right away, in the 2006 timeframe?

John: The TMA I was on that almost right away, and they had a little chat area [for] people...And that was pre-facebook. Out there, it was a message board, and people would ask questions, and you would respond. Say your experiences, and you just see what they're doing. Same thing. You're swapping stories. I think though, being here, you're in the right place. I think you're going to come away going, "Wow." Tomorrow [at the conference], they break out into your own groups. And prior to that, there's for first-timers. It's good to go to that one, but when you go to your own groups, they'll have a round table where everybody gets to talk a little bit about themselves, and you'll get to know others in the group. You're like, "Hey, I gotta go talk to that person because they've got something that they don't know about, or they know something that I don't."

Finding patient communities can connect newly diagnosed people to disease education and others with similar experiences. Patient communities can be support or advocacy nonprofits or foundations, with access to medical doctors and researchers in addition to patient support. Or, patient communities can also be more informal—a group on facebook or an in-person/online weekly meeting. John discusses finding TMA, a nonprofit foundation that funds medical research and provides infrastructure for in-person support groups and the annual patient conference. Here, John found comfort in the early days of his diagnosis by finding online and in-person support networks. Connecting to other patients outside of the clinic can help manage illness on a daily basis.

Carrie and I had a more direct conversation about living well—even if it goes against a doctor's orders— over the shared experience of appearance changes. She was diagnosed with JDM in her teens, and she talked about being diagnosed with myositis as a young adult (the average age of diagnosis for JDM is 5 to 15, and adult myositis is 45 to 60) (Oldroyd, Lilleker, and Chinoy, 2017). Carrie and I were both diagnosed as young adults (she was in her late teens, and I was in my early twenties). As outliers in the community, navigating social and interpersonal connections can be difficult as we are at different points of our lives than the typical myositis patient. In the following excerpt, we discussed how the disease and treatments changed our appearance and how devastating we found that. As mentioned in the previous section, Carrie generally did not seek out shared community experiences. However, she and I had a long conversation about having myositis as a young person and the particular challenges we face. The following exchange was about having a changed appearance and, consequently, not being compliant with doctors' requests to stop wearing makeup to help manage facial rashes:

Carrie: I think by the time I got to college; I was beginning to improve. I didn't want to show up and be like the sick person. I didn't really tell people what was going on. I still had the prednisone face. That was a big transition for me when I finally got my face back.

Caitlin: Yeah. I remember that very distinctly, actually. I see pictures of myself when I was on the high doses of prednisone.

Carrie: Oh my gosh.

Caitlin: I don't recognize myself, and people didn't recognize me. So, getting my face back was a huge, huge deal.

Carrie: Yeah. Absolutely huge. Especially as a teenager, an 18-year-old, obviously.

Caitlin: Right. Yeah. I had a doctor that told me not to wear makeup because my rashes on my face were so bad. I was like, "Whatever, I'm going to get the green makeup and make it work."

Carrie: I know. Totally. It's kind of [a] missed understanding of doctors talking to a teenage girl or a young adult woman. There were a lot of things that I was just like, "Are you joking?"

Caitlin: Right.

Carrie: I never said that. I think I definitely grew up; I think, as most of us do, with the understanding that you don't really talk back to doctors, and when they tell you to do something or suggest something, even if you know that, that's wrong, you just do it or say that you are going to.

Caitlin: Right. Exactly. Yeah. I'll wear makeup later, but I'll just tell you that I'm not.

Carrie: Yeah. Sure. I don't wear makeup.

I recalled the moment when Carrie mentioned being on prednisone and having "prednisone face." This was a moment where I interjected and added my own

experiences because it was a moment I recognized. Prednisone, a corticosteroid, works as an anti-inflammatory and is well-known for its side effects. In long-term use, prednisone can cause osteoporosis; high blood sugar; and fatty deposits in the abdomen, face, and back of the neck; among other side effects (Mayo Clinic Staff, 2022). The signature round face caused by prednisone is called "moon face" and can come on suddenly and significantly change one's appearance. Despite its side effects, high-dose, long-term prednisone is often the first line of treatment for many autoimmune disorders, including myositis. After the exchange we had about prednisone, we then discussed the shared experience of how symptoms of JDM/ DM affected us and how doctors have a limited understanding of what that can mean for young adults. In this excerpt, I talked about a conversation I had with a doctor who told me not to wear makeup because I had deep red rashes on my face, and my decision to still wear makeup, tinted green to cover the red. Carrie interjected to affirm this experience and added that doctors do not always understand or are sympathetic to our experiences living with chronic illness. At the end of this exchange, she said sarcastically, "Sure. I don't wear makeup." Our conversation captured how we each shared the feeling that doctors did not understand us and our experiences (due to our age), how being told not to wear makeup represented doctors not listening to us, and how the disease affected our sense of self. Our shared understanding in this passage highlights how community can clarify this experience and help us navigate our feelings around it. While makeup does not "lead to health," the conversation Carrie and I have about dismissive doctors and feeling out of place with our peers can provide support and a sense of belonging.

In her interview, Lorraine also discussed how she processes her illness and her role within community. IBM has significantly different outcomes than other types of myositis. There are no effective treatments for IBM, and once muscle weakness has developed, the only thing that can be done is to mitigate symptoms through physical/occupational therapy and assistive devices. Lorraine also considered herself an elder in the community, often taking on a teaching role in her interview with me. Here, she framed her experience of IBM as offering advice to others newly diagnosed. The advice and knowledge she wanted to share with others began with her recommending finding ways to engage in hobbies but ended up being a commentary on grief over losses from this disease:

Caitlin: If somebody that was just diagnosed with IBM, what advice would you give that person?

Lorraine: Well, don't get spooked. Figure out how you can get things done, what you want to do. I have not figured out how to continue with my daffodils. I've been in the Daffodil Society...since, well, before 1999...It was the first time I had seen a daffodil show, and of course, it was huge. Lots and lots of flowers. And I was just blown away....Then I read about the American Daffodil Society, and eventually, I took classes and was qualified to be a judge. And just in daffodils, now. Not of flower arrangements or anything like that. That's a whole different category. But I had planted in my yard over 600 different kinds.

Caitlin: Oh, wow. Oh, that must be beautiful.

Lorraine: Now, the ones that are left. I can't take care of them anymore. And a couple of the beds are just about gone. There's a bulb there. And a lot of them, I had just bought one bulb of. And expecting to have two, three years, or at least several blooms from that. And some of them did very nicely. But generally, daffodils, you plant them and don't worry about them. Now, for showing, you were digging every year or every other year, your plant. Which I never did, but I occasionally considered it. When I planted the daffodils [it] would have been in '98 or something. I can remember it being difficult to figure out how to get back up and figure out how to get my feet braced to get back up off the ground.

This exchange highlighted the loss of a hobby that gave Lorraine great satisfaction and meaning in her life. She framed it as an educational lesson for others with IBM—to not get "spooked" and figure out how to do what you love. Interestingly, she immediately goes into how she “doesn't know” what to do about her daffodils, despite advising a hypothetical new patient to continue with hobbies. In the scope of my interviews, this conversation with Lorraine stuck out to me as an expression of grief that is more difficult to discuss and how the loss of a beloved hobby cannot necessarily be overcome. The loss of Lorraine's hobby may never come up in doctor's offices but was something meaningful and important to her. Despite her desire to come up with strategies to continue her hobbies, she has yet to figure out appropriate accommodations. Changes to one's quality of life are hard and unavoidable with myositis (and many other chronic and complex illnesses). Potential modifications to daily activities could potentially help her, but if those cannot be found, having an empathetic patient community that understands

the loss of hobbies is invaluable. In such a community, Lorraine can share her frustration with others and potentially make the impact of this life change less painful. Lorraine's advice to keep connected to hobbies is how she transforms her challenges into productive advice for others.

Each interview in this section transforms the healthcare-specific commonplace *compliance leads to health to community leads to living well*. My other interviewees had similar insights that they wanted to share: "In [the doctor's mind], the way to [manage] the disease is take this medication, show up to PT, which in my mind, I'm thinking I gotta read. I gotta research. I gotta talk to people." Others shared simple strategies to complete daily activities, such as purchasing a steam mop or using the counter to balance your arm when brushing your teeth. Many participants also discussed how they keep engaging in community activities—one participant joined a "slow hike" group for disabled people, and another used golf as a benchmark for his strength—tracking his decrease in strength by how far he could hit with a four iron.

The way people speak and understand illness is often beyond the clinical and biomedical understanding of illness, treatment, prognosis, or any other medicalized term about our lives. Through the commonplace *community leads to living well*, John talked about finding patient groups, Carrie reflected on ignoring medical advice as a young person, and Lorraine discussed the importance of continuing hobbies after diagnosis and, through that discussion, also communicated her role as a leader in the community. Each topic would not necessarily be discussed in medical settings, and we are not formally “taught” how to navigate the broader, nonmedical world as someone with illness—but doing so is key in living well with a life-changing diagnosis.

Research participants in this study discussed their experiences in finding belonging in patient communities and focused on their illness experiences outside of clinical medicine. As a result of these interviews, healthcare-specific commonplaces I identified in earlier chapters (*illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health*) are transformed to acknowledge the significant role of community and how patients outside of clinical settings discuss a rare disease like myositis. Each transformed commonplace, *illness is visible through narrative*, *medical expertise from community engenders patient agency*, and *community leads to living well*, provides avenues for patients to disclose their belonging into the patient community through their diagnosis story, develop patient agency by discussing stigmatizing issues with others with myositis, and, ultimately, find strategies to “live well” with the disease.

Implications: Interdependence

For this chapter, I conducted narrative interviews to gather stories about the experience of rare diseases within one specific rare disease group, myositis. My positioning as an “insider” to the community allowed participants to share their experiences with me informally—which produced different commonplaces from the publicly circulating commonplaces discussed in previous chapters. I originally hypothesized that each participant's narrative would demonstrate the healthcare-specific commonplaces I identified and discussed in Chapters 2 and 3. However, as participants shared their experiences with me, commonplaces instead transformed in ways that highlighted community and interdependence. Each transformed commonplace illustrates how an illness narrative makes the illness experience visible, allows patients to share medical expertise, and helps facilitate shared strategies to live well with illness.

As myositis patients share their stories with one another, they also allow *interdependence*—or strategic, empowering relationships within an online or in-person community—to develop. While illness narratives have typically been considered individual stories shared by one person to an audience of primarily clinicians or family/friends, the narratives in this study instead connect people within a specific patient community. Each narrative reveals how patients are connected together, and this analysis of commonplaces highlights how patient communities, through narrative, create interdependent networks with one another.

Community and interdependence are essential for those with rare diseases and disabilities, as noted by disability theorists and activists. Sins Invalid, a disability justice and arts advocacy organization, defines interdependence simply as “the state of being dependent upon one another” (p.160). They expand the definition in their "10 Principles of Disability Justice" that "we work to meet each other's needs as we build toward liberation, without always reaching for state solutions which inevitably extends state control further into our lives" (p. 25). Activist and author Leah Laskhmi Piepzna-Samarasinha (2018) further considers interdependence as a “care web” of collective access, highlighting how those who do not fit into a narrow definition of disability can create informal and rich collective access communities (p. 41). Disability theorists, such as Dolmage (2016), also broadly consider the history and resistance to interdependence while acknowledging its importance to the disability community in accessing resources. Dolmage writes that “available means—discursive and material—are negotiated socially. We are intercorporeal and concorporeal. Language is one of the key vectors of this contact and touch and exchange between bodies” (p. 114). Dolmage emphasizes that

while society generally has a “fear of interdependence” as opposed to independence (p. 111), social connections facilitated through language, such as storytelling, are necessary and inherent in the disability community. The necessity of interdependence to living well with disability and illness is also discussed by Opel (2018), writing about caregiver experiences, health literacy, and aging. She contends that interdependence allows for networked caregiving and a "new rhetoric of care" (p.148), moving away from a deficit model that only considers what aging patients are “lacking” to a more “humanistic” approach to caregiving practice (p. 137). Further, Keyes, Clarke, and Gibb (2018) discuss the care of patients with dementia, coming to similar findings that interdependence fits into an Ethic of Care framework that allows for a sense of belonging and agency for patients (p. 314).

The role of interdependence in the experiences of people with rare diseases is underscored throughout all interviews in this study, particularly in people who value finding patient communities. Often, these connections helped participants make sense of their illness experience, get valuable advice, and empathize with one another. John and Lorraine valued finding and interacting with the patient community, whether it was with me as the patient-researcher, as John and I demonstrated when discussing describing pain to others, or as a collective, like when Lorraine talked about using the facebook groups to learn more about myositis and ways to manage symptoms. However, not all participants sought out community, as highlighted by Carrie. Instead, Carrie shared with me a sense of alienation from her peers, saying she “had a really solid group of girlfriends” before she got sick, and then after she was diagnosed, she described them as having “kind of dropped away.” Then, when describing going to college, she highlighted her difficulty in

asking for help from people around her: “I think I still struggle to this day with asking for help from people, and realizing that I don't need to do everything on my own.” The lack of connection and ability to ask for help reflected her alienation from others, including the myositis patient community. While those who connect with other patients and cultivate interdependent relationships might also struggle with being alienated from others or have difficulty asking for help, these interviews reveal that connections can benefit one's understanding of illness. Such connections can be facilitated with social media and online support groups, depending on consistent access to the internet and the digital literacy to make such connections.

The intersection of online communities and illness narratives reveals how interdependence plays an important role in the myositis community and how we learn and make decisions about our health. Online patient communities for people with rare diseases allow interdependence to emerge—helping people understand the disease, make medical decisions, and live well with this illness. Online patient communities can facilitate sharing stories easily with other patients, *and* other patients can easily comment and share their own stories. RHM scholars note the role of “web 2.0” (websites that allow easy interaction between users, whether a comments section to an article or social media platforms) in illness narratives and patient communities. Web 2.0 allows for more interdependence to emerge among patient communities. Both Wallace (2019) and Hinson & Sword (2019) describe how as websites became more interactive between users, illness narratives can be collaboratively shared among communities. Wallace, diagnosed with Multiple Sclerosis (MS) in the early 2000s, writes that

changes in cultural-discursive responses to illness have made facing MS now an entirely more communal experience for me than living through cancer in 1992 was. Today, expanding roles available to me as an audience and as a patient make a living through a difficult diagnosis less isolating, and my sense of community comes from the ability to share my experiences online. (p. 26)

Wallace describes how sharing experiences online allows for a more communal experience as a patient, creating interdependent relationships with others through sharing and co-constructing narratives online. Additionally, Hinson & Sword, writing about facebook illness groups, note that patient communities “allow for a somewhat constant dialogue between multiple tellers telling not just their own story, but shaping and developing the stories of others” (p. 2). Wallace and Hinson & Sword argue that the interactive nature of social media means that illness narratives can be shared and built on one another. As a result, sharing narratives can build community and reiterate the importance of interdependence among those with shared illness experiences.

Conclusion

As demonstrated throughout this chapter, patients are compelled to tell illness narratives in a variety of circumstances. Clinicians can use narratives to understand patient experiences and medical ethics better, the general public can more fully understand someone's life that is unlike their own, and academics can see and identify gaps and systemic problems with healthcare and healthcare delivery broadly. Depending on the audience, these narratives can shift to emphasize or explore different themes, commonalities, and disparities. As this chapter demonstrates, commonplaces are not used in the same way when shared within a community as those shared for a public audience

or advocacy, like in Chapters 2 and 3. Commonplaces in this chapter reveal how patient communities use illness narratives to create relationships and make decisions about their healthcare. Such interdependence is important for the disability community and for those with rare diseases who often must lean on other patients to learn about the disease.

Each participant in this study shared stories with me about being diagnosed with a rare disease and how they came to understand the experience of illness in their lives. As a result of these narratives, I specifically identified how healthcare-specific commonplaces transform in patient communities in chronic, complex, and rare disease experiences. It is worth considering, however, that this analysis only captures the importance of interdependence and patient communities for those who find patient communities helpful. I had several participants, including Carrie, who felt alienated from support groups and did not consider themselves part of patient communities. While outside the scope of this study, it would be worth finding more outliers and investigating how people who are not part of patient communities, or who cannot afford to travel to a big annual conference every year, navigate similar questions of diagnosis, medical expertise and agency, and living well with illness.

Further, this study highlights the need for increased training and support for more RHM researchers with illness and disability who may share the experiential knowledge of those they are researching. Much of the findings in this chapter were only possible with my own experiential knowledge and access to people in the myositis community. While certainly there are researchers who have personal experience with the communities they are studying, being clear about one's research positionality to participants and readers is necessary. Further, clearly articulating how positionality shapes research practice can be

beneficial for future researchers who may struggle—like I did—with undertaking research methods and methodologies for the first time.

Lastly, while these commonplaces are “transformed” when in conversation with patient communities, each narrative I collected here is still haunted by the clinic. Many of the conversations between patients are about managing the clinical side of myositis, including how to talk to doctors, when to take medical advice and how to do so, and whether symptoms “fit” the diagnosis. As a result, those who have typical presentations of myositis, or fit a specific patient profile, often take leadership roles in patient communities. Gatekeeping can happen in patient communities, just as in the doctor's office. In this chapter, Carrie most obviously represents the alienation caused by gatekeeping, as her age and JDM diagnosis place her outside the typical experience of those with myositis, who are often much older. Nevertheless, understanding how interdependence is key for rare disease communities can benefit patients by providing a sense of belonging, sharing experiences with one another, and finding community to “live well” with myositis.

CHAPTER FIVE
SEARCHING FOR A RHETORIC OF RARE DISEASE

The story of rare disease is also the story of healthcare in the United States. High costs, complicated bureaucratic processes, lawmaker and regulatory agency input, pharmaceutical research and development, insurance benefits, and access to knowledgeable doctors are all challenges that patients face in the healthcare system. However, the rare disease experience further highlights the gaps, limitations, and barriers of each healthcare sector. As one illustrative example, a 2019 episode on the *New York Times* television documentary series *The Weekly*, called "The Six Million Dollar Claim," describes a typical rare disease story. A mother and two children have a rare disease, and the drug needed to treat their condition exceeds 2 million dollars per year per person. Ultimately, the episode described the role of the Orphan Drug Act in establishing high drug prices, resulting in higher insurance payouts and, therefore, higher premiums for everyone on an insurance plan. The sympathetic but pragmatic insurance representative assured the family that while they are on their employer plan, they will always be covered, but added, "the money has to come from somewhere," underlining the relationship between the bureaucratic systems that often guide medical care decisions and the rare disease patient, and how the rare disease patient is often on the hook for the additional costs (Yang et al., 2022). Other media portrayals also highlight rare diseases

in a medical system constantly pushing towards automation, higher profit margins, and less human interaction between patients and decision-makers. Ann Curry's TV show *Chasing a Cure* and Lisa Sanders' *Diagnosis*, both airing in 2019, consider people with severe symptoms but no diagnosis, who are seeking answers and a way back to their old life and health. In *Diagnosis*, Dr. Sanders, *New York Times* contributor and author (as well as the medical advisor on *House*), used her *New York Times* platform to share stories about patients with mysterious symptoms and to crowdsource potential diagnoses from readers. The responses were open to anyone, including doctors and scientists worldwide, as well as patients and family members who have lived experience with similar symptoms. In each episode, patients come from a variety of circumstances but share the same challenges: medical debt from continual appointments that result in no diagnosis, a severe decline in quality of life, isolation from friends and loved ones, and a fear of the unknown. While many episodes connect patients to the medical community, just as important are connections made to patients and families who are going through similar experiences. In several episodes, the patients put equal weight on getting a diagnosis as finding others with similar experiences. As one parent with a daughter with a rare genetic disease puts it, she wants to know "what the future looks like for us." The major themes throughout this show were all familiar to me, as the story in each episode wrestled with the three healthcare-specific commonplaces that appear within the pages of this dissertation.

However, the role commonplaces play in healthcare are not limited to the representations in media, such as *Diagnosis*, *House*, or *Grey's Anatomy*. Commonplaces shape real-life access to healthcare. The rare disease experience hit me materially in

2020-2023. Upon changing doctors, my insurance denied the primary treatment I used for dermatomyositis, rituximab, which they had previously covered. A monoclonal antibody that depletes B-cells (thought to be one of the mechanisms that cause an inappropriate autoimmune response for those with dermatomyositis), rituximab is a treatment that has worked to keep my disease under control. Without it, my muscle weakness and atrophy worsen significantly, resulting in the loss of the ability to walk, raise my hands over my head, or even open doors. Under the contention that rituximab is now "investigative," my insurance's denial of this medication highlights the difficulty of "fitting" rare disease treatments, research, and cost into existing bureaucratic processes. I had to prove that I had a confirmed diagnosis for my condition by submitting my muscle biopsy results from 12 years ago, thus demonstrating to the doctors my insurance company hired, who have never met me, that my disease was "visible." The appeal I wrote included my lived experiences with the disease but also incorporated quotes, findings, and recommendations from medical experts through journal articles and compendia recommendations. Even if I am not a medical expert, I used medical expertise to demonstrate that the drug should be covered. Finally, I had to demonstrate compliance with previous medical treatments in order to provide evidence that other treatments failed for my condition. Despite providing this information to my insurance company, and adhering to the commonplaces in the process, my appeal was denied again because they do not include my diagnosis on an internal list of "approved off-label" conditions they will cover for rituximab. Because my disease is rare, I do not expect it to be listed as an approved condition (like rheumatoid arthritis or lupus). Additionally, while there is evidence this treatment is safe and

effective, it is still not FDA-approved for my condition because studies are difficult to conduct due to the challenges in recruiting people with rare diseases.

As I worked on this appeal, I noted again how the three commonplaces are assumptions that guide healthcare decisions and how the rare disease experience lays bare the limitations of such commonplaces. My contention throughout this dissertation is that rare disease does not fit into typical medical systems and, therefore, reveals gaps in all areas of healthcare (including the limits of medical knowledge, difficulty in running standard clinical trials on drugs that can lead to FDA approval, and getting pharmaceutical companies to conduct further research and manufacture drugs). Patients must often become experts in all aspects of medical research, drug development, and regulatory agencies, as well as expert navigators of hospital systems to find and access knowledgeable healthcare workers and appropriate treatment.

My initial interest in the rhetoric of rare disease stemmed from the relationship between rare disease and medical care, legislative processes, and regulatory agencies, in addition to the perception of rare disease with different audiences. To further understand how healthcare workers talk about those who have rare diseases and how patients advocate within such a complex rhetorical system, I identified three commonplaces that generally run through all healthcare rhetoric, especially when there are disparate power relationships (like that between patient and doctor, patient and insurer, and/or doctor and legislator, to name a few). These three commonplaces are featured in each previous chapter within different genres and audiences, including TV medical dramas watched by a general audience, testimonials to the rare disease congressional caucus to a legislative

and regulatory agency audience, and rare disease patient communities who communicate with fellow rare disease patients. These commonplaces are:

- *Illness is visible*, which considers how illness needs to be visible to healthcare workers for patients to gain care, treatment, and resources within the medical system.
- *Medical expertise validates patient agency*, which looks at how medical knowledge and agency demonstrated by patients need to be sanctioned by medical research, experts, and other "official" purveyors of this knowledge.
- *Compliance leads to health*, which considers the perception that a patient should do all that a doctor prescribes (including medications, physical therapy, specialist visits, and further testing and imaging) to get well. If patients do not comply, then they do not want to get better.

An analysis of commonplaces in each chapter also revealed additional takeaways. These include how commonplaces play a crucial role in communicating to the general public stories about healthcare (Chapter 2), how non/compliance is a rhetorical process used by people with illness (Chapter 3), how community connections transform commonplaces (Chapter 4), and how we should incentivize research led by people with disabilities and illness (Chapter 4).

Each chapter focused on a different rhetor and audience, revealing nuances of each healthcare-based commonplace through rare disease narratives. Chapter 2, "This Means It's Real": Rare Diseases and Commonplaces of Healthcare in Medical Dramas," examined the role of two popular medical dramas in communicating the experience of rare disease to a general audience. By analyzing several episodes of *House* and *Grey's*

Anatomy that highlight the rare disease experience, I identified how the three commonplaces *illness is visible*, *medical expertise validates patient agency*, and *compliance leads to health* manifested in rare disease patient representation. While the visibility of rare disease in these popular medical dramas is important, commonplaces communicate pervasive, misleading, and potentially dangerous narratives about the relationship between doctors, healthcare systems, and patients. In *House*, the importance placed on the visibility of illness and medical expertise undermines any potential patient agency. The show often argues that patients cannot have their own agency due to their inability to be truthful communicators of their experiences. In *Grey's Anatomy*, patient agency is seemingly valued and embraced throughout the show, especially in storylines of noncompliance. However, by looking deeper, diagnosis still depended on visibility and validation through medical expertise. While medical testing and the expertise of healthcare workers are critical to a diagnosis, these TV shows elided the lived experience of rare disease patients, who often go to (on average) seven doctors to get a diagnosis (Engel et al., 2013).

Chapter 3, “The Expert Patient: Critical Compliance, Hypercompliance, and Rare Disease Advocacy,” moved to a different genre and audience—that of the rare disease caucus testimonials by patients and advocates. The audience for these testimonials included congressional and regulatory agency staffers, medical researchers, and other patient advocates. Again, each commonplace appeared in the testimonials, where they were used to initially bridge a connection between rhetor and audience about the rare disease experience. Once that connection is established, these expert patients “turned” the three commonplaces to make a point about rare diseases, including the seemingly

invisibility of rare disease, the limits of medical expertise and patient agency, the utilization of critical compliance, the limits of rare disease research, and the need for legislative and regulatory support. The commonplace *illness is visible* became an important initial organizing theme of testimonials—whether an illness is visible to medical providers but still lacks a firm diagnosis (like in undiagnosed patients) or seems genuinely invisible to others (such as in patients with genetic disease). Then, in the commonplace *medical expertise validates patient agency*, rare disease advocates demonstrated their medical expertise through knowledge of medical terminology and specific names of doctors and organizations. They then connected medical expertise with their affective experience to explain their decisions and advocate for action. Lastly, in the commonplace *compliance leads to health*, advocates strategically engaged in both compliance and noncompliance rhetorically. I call this *critical compliance*, where patients intentionally use compliance or noncompliance to achieve an end, like stopping medications to demonstrate ongoing symptoms to a doctor. Further, patients may even use *hypercompliance*, or strategies to connect their expertise to the institutional discourse of medicine. Engagement with commonplaces can provide rare disease advocates access to medical and legislative institutions. However, one must be cautious of existing bias and discrimination that limits marginalized groups from having access to the same strategies.

Chapter 4, “Living Well with Illness: Transforming Commonplaces and Illness Narratives within the Rare Disease Community,” is a qualitative study within one rare disease patient community, those with idiopathic inflammatory myopathy or myositis. Unlike the previous two chapters, which focused on representations of rare disease and

creating connections between the rare disease experience and an audience who does not experience rare disease, the interviews in this chapter were between myself and research participants who all experience the same rare disease. I identified three revised commonplaces by collecting illness narrative experiences through semi-structured interviews. While still connected to the previous three commonplaces in Chapters 2 and 3, these new commonplaces, *illness is visible through narrative*, *medical expertise from community engenders patient agency*, and *community leads to living well* highlighted the role of patient community (as opposed to medical clinics) in how patients approach living life with a rare, complex, and chronic illness. Interviews revealed not only a patient's experience in the medical system but also how they manage the disease and improve quality of life on a daily basis—outside the doctor's office. I close by offering how interdependence, or close relationships to in-person or online communities, are key in creating connections through shared experiences, developing agency and getting information, and generally, developing strategies to “live well.”

Each chapter considered the role of commonplaces as a method of analysis and as a way to identify the gaps and problems of healthcare highlighted by rare disease. Commonplaces generally can be a useful organizing tool to uncover ideologically hidden beliefs shared by groups, and identifying healthcare-specific commonplaces can interrogate how multiple stakeholders can impact a patient's health and experience.

Limitations of the study

I set out to examine how the rhetoric of rare disease manifests in different rhetorical situations and how the experience of rare disease often contrasts with the values and expectations of healthcare. The most significant limitation of this study was

time. Because this dissertation has a natural time limit, I had limited time to design and collect data for the qualitative study. As a result, I was unable to adjust my small interview cohort to bring in more voices that vary by age, disease type, and race. Additionally, I could not do follow-up interviews with study participants to allow for more insights and clarifications of my data. This might leave some conclusions or points of analysis out that otherwise could have been interrogated. The study also had a somewhat flawed gathering technique to recruit participants. Because rare disease patients in one community are difficult to find, I relied heavily on online support groups and The Myositis Association's Annual Patient Conference to find people to complete my interest survey and conduct interviews. Initially, I circulated the survey in several Facebook groups and one Reddit community. Only people who regularly use certain online patient support groups would see and complete the survey. Additionally, I used the patient conference to conduct several interviews. While I did conduct phone interviews as well, preferencing in-person interviews limited my participants to those who could afford to travel and pay conference registration fees and lodging. Like Carrie, who found my survey unconventionally, there are participants who would have needed to be identified through additional gathering techniques if they did not regularly participate in patient support groups. This could bias my results and limit the diversity of study participants.

Implications

At the outset of this project, I wanted to understand better how rare disease is represented and how those with rare disease communicate to others about their experience. Research into rare disease requires an interdisciplinary approach, as little is

written about rare disease as a group within Rhetoric of Health and Medicine (RHM), disability studies, or scholarship on illness narratives and narrative medicine.

Rhetoric of Health and Medicine

As stated earlier, the story of rare disease is the story of healthcare. As a subfield, RHM is constantly defining and positioning itself within the healthcare system and stakeholders in medicine. RHM is inherently interdisciplinary and benefits when bringing together people with different perspectives on healthcare topics. Further, the subfield has articulated a commitment to diversity, justice, and accessibility as part of the social justice turn in technical and professional communications (Shelton, 2019; Rhetoric of Health and Medicine Symposium CFP, 2023). The field can advance in these areas through rare disease, which can identify gaps in medicine and systemic power structures in healthcare. Additionally, by prioritizing the study of patient experiences, RHM can get a cross-sectional look at how different healthcare sectors interact, such as clinical care, insurance, and/or medical research.

Currently, rare disease research in RHM seems limited to analyses of patient support groups and community building online. While some articles examine rare disease patients as a unique community (Hooker, 2023), often researchers analyze an online rare disease community and draw implications for all patients—rare or not (Cameron, 2023; Hinson & Sword, 2019). While such research is important to online communities and patients, new iterations of such scholarship should consider the nuances and unique relationship between rare disease patients and healthcare. As the research in this dissertation reveals, rare disease patients often have goals and concerns that are unique to

that community. By foregrounding rare disease more prominently in such research, we can ensure we are not potentially conflating patient communities.

Disability Studies

This project also has implications for disability studies research within composition and rhetoric. First, this project is informed by a disability studies methodology that prioritized "nothing about us without us," meaning that I specifically sought out rare disease patient experiences. The study's findings in Chapter 4 would not be possible without my background in disability studies methodology, reinforcing the need for more disabled researchers to contribute to all fields of study. This project also sought to value the lived experience of patients as a valid source of information and empowerment—whether from my research participants, testimonials from rare disease advocates, or even myself as a disabled researcher. I brought new insight into these topics through my angle of vision as someone who experiences rare disease firsthand. Nontraditional research methods that embrace different participant/researcher relationships should be further considered, theorized, and discussed among disability studies researchers.

Additionally, understanding how commonplaces operate in narrative can reveal unequal power relationships and ableism in the healthcare system—all issues that are not new but constantly impacting the disability community and of interest to disability studies. By identifying and naming specific commonplaces, especially ones that affect people with medical conditions that can cause disability, those commonplaces can be made visible and challenged.

Illness Narrative and Narrative Medicine

Analysis of narrative was foundational to this project, and examples included medical drama narratives, illness narratives, and narrative medicine. Generally, healthcare-specific commonplaces were found in narratives throughout each chapter—TV shows, testimonials, and narrative-based interviews. Research in this project challenged the role of illness narrative. Typically, both illness narratives connect the patient experience to others outside the disease experience, such as medical professionals, lawmakers, and loved ones. When narratives reach those external audiences, they often are polished, articulate experiences of illness. However, as Frank writes in his blog as a reflection on the COVID-19 pandemic, the strict narrative categories he outlined (the restitution narrative, the chaos narrative, and the quest narrative) in *The Wounded Storyteller* may limit the usefulness of such stories. He writes that these categories can "sanitize" patients' messy and unfiltered stories. Instead, while I sought to make meaning out of patient stories collected throughout chapters 3 and 4, I attempted to embrace these stories and include my own as a rare disease patient, which complicates the data I gathered—but hopefully generated new insight and conclusions.

I also was interested in contributing to ongoing conversations about narrative medicine. The narratives that are used in medical education can be, in Frank's word, sanitized. They may include published accounts of illness or patients whom doctors invite to speak about their experience. Medical workers and others who engage in narrative medicine work can benefit from embracing messy, complicated, and unfinished stories that challenge how care is given. Additionally, medical researchers are also conducting more qualitative research, which often requires first-person accounts of the healthcare experience from patients. More qualitative research can be instrumental in uncovering

gaps and biases in medical care. However, as this project highlights, it is crucial to have a variety of gathering techniques to gather research participants, including in patient communities, and work to get a diversity of perspectives—including those that may be historically excluded from research. This charge is difficult and may seem impossible, but gathering narratives from these groups will allow a better view of this community's challenges and, therefore, better interventions.

Future Research

At an NIH Rare Disease Day event in 2018, I watched a panel conversation with three young people with rare diseases. They had received medical treatment from the NIH and participated in clinical trials as children. As they got older, they started patient support groups and now were advocating for support and more research for their diseases. Most rare diseases impact children and have historically been fatal, so parents usually take charge of rare disease advocacy. However, at this panel, we were presented with the "next generation" of rare disease activism—those who had previously fatal diseases and survived. These rare disease advocates were among the first to reach adulthood with their illnesses. What, then, will the next generation of rare disease advocacy and stories look like? I do not yet know the answer, but it is an exciting time to do rare disease research, as the advocacy landscape is changing and merits further dialogue and research for RHM scholars.

Further, the COVID-19 pandemic has changed U.S. healthcare. It remains to be seen how changes, like improved telehealth access, longer wait times to see specialists, and healthcare worker burnout, will impact healthcare. One result of the pandemic is the increased incidence of complex and chronic medical conditions, including cardiac

complications, autoimmune disease, and long covid. COVID-19 has also impacted already existing patient communities and created new ones. One emerging area of patient advocacy is the immunocompromised community. While some primary immunodeficiency diseases have existing patient communities that predate COVID-19, immunocompromised people have now created some coalitional patient communities with distinct political positions (such as increased masking, improved air quality, and funding support for better vaccines and treatments for COVID-19). Generally, immunocompromised people did not exist as a politically oriented group before the pandemic. However, in the years since March 2020, people connecting to one another based on their immunocompromised status have increased (such as the “Immunocompromised Collaborative” through the Immune Deficiency Foundation or the facebook group “Immunocompromised People Are Not Expendable”). Interestingly, increased advocacy among immunocompromised people has followed much of Caroline Huyard's (2008) definition of a “rare” disease: that being immunocompromised includes a feeling of injustice, that immunocompromised people are invisible to the broader public, and that an immunocompromised patient experience is shared within the community (p. 468). The overlaps between rare disease advocacy and the emerging immunocompromised community advocacy suggest that Huyard's definition has more utility in coalitional healthcare advocacy than just for rare disease.

Lastly, when I started this project, I was interested in rare disease counternarratives in the vein of Pezzullo's (2003) and Segal's (2008) work on breast cancer. However, I quickly realized that there needed to be more literature and research on rare disease narratives, making an analysis of counternarratives premature. Instead, I

undertook this project to examine what a "standard" narrative of rare disease looked like. In the future, I would like to consider what a rare disease counternarrative might look like. In a system where healthcare is often only afforded to those who are constructed as "good" patients, what does it mean for noncompliant patients who do not have medical expertise and healthcare experts validating their experiences? Or those who remain undiagnosed and so their experience and illness remain "invisible" to the medical bureaucracy? The landscape for rare disease research in composition and rhetoric is immense, and I hope to see projects related to these topics (and many more I cannot yet imagine) occur over the next few years.

At times, while writing this dissertation, I have felt overwhelmed by the sheer amount of potential research directions and implications of the rhetoric of rare disease. I have joked—and said seriously in job interviews—that this research could easily be a life's work. The role of representation, narrative, patient experience, the need for medical research to break new ground, and dedicated clinicians to bridge that research to patients will take the work of many people and disciplines. As my own experiences demonstrate, there is not a moment to lose to improve the lives of this community.

REFERENCES

- 2023 Rhetoric of Health and Medicine Symposium (N.D.). Call for proposals 2023
rhetoric of health and medicine symposium. *Rhetoricians of health and medicine: An un-organization of scholars of RHM*.
<https://medicalrhetoric.com/symposium2023/call-for-proposals/>
- ACTUP NY (N.D.) ACT UP Accomplishments 1987-2012. <https://actupny.com/actions>.
- Ahmed, R., & Aslani, P. (2014). What is patient adherence? A terminology overview.
International journal of clinical pharmacy, 36(1), 4–7.
<https://doi.org/10.1007/s11096-013-9856-y>
- American Lung Association (2023) Learn about sarcoidosis. <https://www.lung.org/lung-health-diseases/lung-disease-lookup/sarcoidosis/learn-about-sarcoidosis>
- Arduser, Lora (2017). *Living chronic: Agency and expertise in the rhetoric of diabetes*.
Ohio State University Press.
- Avrahami, Einat (2007). *The invading body: Reading illness autobiographies*. University
of Virginia Press.
- Barton, Ellen (2000). The interactional practices of referrals and accounts in medical
discourse: Expertise and compliance. *Discourse studies* 2(3), 259-281.
- Barker, Kristin K (2011). Listening to Lyrica: Contested illnesses and pharmaceutical
determinism. *Social science & medicine*, 73(6), 833-842.

doi:10.1016/j.socscimed.2011.05.055.

- Barker, Kristin K (2008). Electronic support groups, patient-consumers, and medicalization: The case of contested illness.” *Journal of health and social behavior*, vol. 49 (1), 20-36. DOI: 10.1177/002214650804900103.
- Berkenkotter, Carol (2008). *Patient tales: Case histories and the uses of narrative in psychiatry*. University of South Carolina Press.
- Bhashyam, A., Lubinus, M., Filmore, E., Wilson, L., Williams, J., Gonzalez Ramos, O., & Bhai, S. (2022). Pain profile and opioid medication use in patients with idiopathic inflammatory myopathies. *Rheumatology*, 62(1), 264–269. <https://doi.org/10.1093/rheumatology/keac271>
- Bourdieu, Pierre (1977). *A theory of practice*. Cambridge University Press.
- Boyd, Kenneth (2000). Disease, illness, sickness, health, healing and wholeness: Exploring some elusive concepts. *Medical humanities*. 26(1). 9-17. doi: 10.1136/mh.26.1.9. PMID: 12484312.
- Britt, Elizabeth. (2001). *Conceiving normalcy: Rhetoric, law and the double binds of infertility*. U of Alabama P.
- Brody, Howard (1987). *Stories of sickness*. Yale UP.
- Brouwer, Daniel C. (2001). ACT-ing UP in Congressional Hearings. In Robert Asan and Daniel C. Brouwer, *Counterpublics and the State*. SUNY P.
- Brueggemann, Brenda Jo and Debra A. Modellmog (2002). Coming out pedagogy: Risking identity in language and literature classrooms.” *Pedagogy: Approaches to Teaching Literature, Language, Composition, and Culture*. 2(3), p. 311-335.

- Brueggemann, Brenda Jo (2009). 'Writing insight': Deafness and autobiography. *The Norton Book of Composition Studies*. Susan Miller (Ed.) Norton.
- Budysh, K., Helms, T. M., & Schultz, C. (2012). How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient-physician interaction. *Health Policy*. 105(2-3), 54–164.
<https://doi.org/10.1016/j.healthpol.2012.02.018>
- Cahalan, Susannah. (2012). *Brain on fire: My month of madness*. Simon & Schuster.
- Cambra-Badii, I., Moyano, E., Ortega, I., Baños, J. E., & Sentí, M. (2021). TV medical dramas: health sciences students' viewing habits and potential for teaching issues related to bioethics and professionalism. *BMC medical education*, 21(1), 509.
<https://doi.org/10.1186/s12909-021-02947-7>
- Cameron, Shanna (2022). Agentive assemblages in online patient spaces. *Technical communication quarterly*. 32(4). 347-363.
- Cassell, Eric (1976). Illness and disease. *The Hastings center report*. 6(2). 27-37.
- Center for Autoimmune Neurology (N.D.). Anti-NMDAR encephalitis. Perelman School of Medicine, University of Pennsylvania.
<https://www.med.upenn.edu/autoimmuneneurology/nmdar-encephalitis.html>
- Centers for Disease Control (2020). Kawasaki disease. <https://www.cdc.gov/kawasaki>.
- Centers for Disease Control (2023). What is sickle cell disease?
<https://www.cdc.gov/ncbddd/sicklecell/facts.html>
- Chakrabarti S. (2014). What's in a name? Compliance, adherence and concordance in chronic psychiatric disorders. *World journal of psychiatry*, 4(2), 30–36.
<https://doi.org/10.5498/wjp.v4.i2.30>

- Charon, Rita (2006). *Narrative medicine: Honoring the stories of illness*. Oxford UP.
- Chinn, Jonathon (Executive Producer).(2019). *Diagnosis* [Television series]. Netflix.
www.netflix.com
- Chubak, B. (2009). Clinical responsibility in the age of patient autonomy. *The virtual mentor: VM*, 11(8), 567–570.
<https://doi.org/10.1001/virtualmentor.2009.11.8.fred1-0908>
- Cintrón, Ralph (2010). Democracy and its limitations. In John M. Ackerman and David J. Coogan (Eds.), *The Public Work of Rhetoric: Citizen Scholars and Civic Engagement* (pp. 98-116). University of South Carolina P. 98-116.
- Cleveland Clinic (2021). Exploding Head Syndrome.
<https://my.clevelandclinic.org/health/diseases/21907-exploding-head-syndrome-ehs>
- Cleveland Clinic (2023). Pompe Disease.
<https://my.clevelandclinic.org/health/diseases/15808-pompe-disease>
- Couser, G. Thomas (2009). *Signifying bodies: Disability in contemporary life writing*. University of Michigan Press.
- Creswell, John W (2012). *Qualitative inquiry and research design: Choosing among five approaches*. SAGE Pub.
- Crowley, Sharon and Debra Hawhee (2003). *Ancient rhetorics for contemporary students (3rd Ed)*. Longman.
- Crowley, Sharon. (2006). *Toward a civil discourse: Rhetoric and fundamentalism*. University of Pittsburg Press.
- Davis, Elizabeth (2008). Risky business: Medical discourse, breast cancer, and narrative.

Qualitative health research, 18 (1), 65-76.

<https://doi.org/10.1177/1049732307309002>

Deer, Cécile (2014). Doxa. In Michael Grenfell, (Ed.), *Key concepts: Pierre Bourdieu*.

(pp. 114-121). Routledge.

Derkatch, Colleen and Judy Z. Segal (2005). Realms of rhetoric in health and medicine.

University of Toronto medical journal, 82 (2), 138-142.

DeTora, Lisa (2018). The dangers of magical thinking: Situating right to try laws, patient

rights, and the language of advocacy. *Rhetoric of health & medicine* 1(1-2), 37-

57.

Dolmage, Jay (2016). *Disability rhetoric*. Syracuse University Press.

Dolmage, Jay and Cynthia Lewiecki-Wilson (2010). Refiguring rhetorica: Linking

feminist rhetoric and disability studies. In Eileen Schell (Ed.), *Rhetorica in*

Motion. University of Pittsburgh Press.

Dusenbery, Maya (2018). *Doing harm: The truth about how bad medicine and lazy*

science leave women dismissed, misdiagnosed, and sick. HarperOne.

Mayo Clinic Staff (2022). *Ehlers-Danlos Syndrome*. Mayo Clinic.

<https://www.mayoclinic.org/diseases-conditions/ehlers-danlos-syndrome>.

Engel PA, Gabal S, Broback M, Boice N (2013). Physician and patient perceptions

regarding physician training in rare diseases: The need for stronger educational

initiatives for physicians. *Journal of Rare Disease* 1(2). 1-15

Everylife Foundation for Rare Diseases (2018a). Deanna Portero: Incentives for rare

disease treatment development [Video]. YouTube.

<https://www.youtube.com/watch?v=VBpqzi9XrOU&list=PLDScWcpkQ5CywoF>

IdHjGguBOdOPnSQclZ&index=4&t=158s&ab_channel=EveryLifeFoundationforRareDiseases

--- (2018b). Gina Szajnik: Diagnostic challenges and policy solutions [Video]. YouTube.

https://www.youtube.com/watch?v=4kwv_f_7v5I&list=PLDScWcpkQ5CywoFIIdHjGguBOdOPnSQclZ&index=3&ab_channel=EveryLifeFoundationforRareDiseases

--- (2018c). Christna Frigo [Video]. YouTube.

https://www.youtube.com/watch?v=gH1UF7a1Gqc&list=PLDScWcpkQ5CwxRoUJmRSLsXILf_0mBOok&index=2&ab_channel=EveryLifeFoundationforRareDiseases

--- (2019). Tesha Samuels [Video]. YouTube.

https://www.youtube.com/watch?v=p3rhYoVmGmQ&t=342s&ab_channel=EveryLifeFoundationforRareDiseases

--- (N.D.a) Rare diseases congressional caucus. <https://everylifefoundation.org/rare-advocates/rarecaucus/>

--- (N.D.b). Support legislation. <https://everylifefoundation.org/newborn-screening-take-action/support-legislation/#federal-bills>.

Frank, Arthur (1995). *The wounded storyteller: Body, illness, and ethics* (2nd Ed.). U of Chicago P.

Frank, Arthur (2022). Illness Narrative 2022, Unconcluded. *Narrative, experience, and ethics*. <https://arthurwfrank.wordpress.com/2022/07/08/illness-narrative-2022-unconcluded/>

Foucault, Michel (1972). *The birth of the clinic: The archaeology of medical perception*.

Trans. Tavistock Publications, Ltd. Pantheon Books-Random House.

Gabay M. (2019). The Orphan Drug Act: An appropriate approval pathway for treatments of rare diseases? *Hospital pharmacy*, 54(5), 283–284.

<https://doi.org/10.1177/0018578719867665>

Garland-Thompson, Rosemarie (2014). Feminist disability studies. *Signs*. 14 (3), p. 1-32.

Garrino, L., Picco, E., Finiguerra, I., Rossi, D., Simone, P., & Roccatello, D. (2015).

Living with and treating rare diseases: Experiences of patients and professional health care providers. *Qualitative health research*, 25(5), 636–651.

<https://doi.org/10.1177/1049732315570116>

Genetic and Rare Diseases Center (N.D.). About GARD. *National center for advancing translational sciences*. www.rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases

Global Genes (2021). *Annual impact report, 2020*. https://globalgenes.org/wp-content/uploads/2021/03/Annual-Report-2020_FINAL.pdf.

Gouge, Catherine & John Jones (Eds.). (2016). Wearable rhetorics: Bodies, cities, collectives [Special issue]. *Rhetoric society quarterly* 46 (3).

Gouge, Catherine (2018). “The inconvenience of meeting you”: Rereading non/compliance, enabling care. In Booher, Amanda and Julie Jung (Eds.), *Feminist rhetorical science studies: Human bodies, posthumanist worlds* (pp. 114-140). Southern Illinois University Press.

Graham, S. Scott (2009). Agency and the rhetoric of medicine: Biomedical brain scans and the ontology of fibromyalgia. *Technical Communication Quarterly* 18(4), 376-404.

- Heale, R., & Twycross, A. (2018). What is a case study? *Evidence-based nursing*, 21(1), 7–8. <https://doi.org/10.1136/eb-2017-102845>
- Herndl, Diane Price (2013-2014). Virtual cancer: BRCA and posthuman narratives of deleterious mutation. *Tulsa studies in women's literature* 32-33(2-1). 25-45.
- Hillinger, Suzanne (Director). (2019). The six million dollar claim (Season 1, Episode 11). [TV Series Episode]. In S. Dolnick, *The Weekly*. Hulu. www.hulu.com.
- Hinson, Katrina & Ben Sword (2019). Illness narratives and facebook: Living illness well. *Humanities* 8 (106), 1-22.
- Hooker, Tristin Brynn (2022). Tweeting zebras: Social networking and relation in rare disease advocacy. *Rhetoric of health & medicine* 5(1), 93-121.
- Horvitz, Louis J. (Director).(2019). *Chasing the cure* [Television Series]. Lionsgate Entertainment.
- Hunter, Judy, Franken, Margaret, & Balmer, Deborah (2015). Constructions of patient agency in healthcare settings: Textual and patient perspectives. *Discourse, context and media* 7, 37-44.
- Huyard, Caroline (2008). How did uncommon disorders become 'rare diseases'? History of a boundary object. *Sociology of health & illness* 31(4), 463-477.
- Huyard, Caroline (2009). What, if anything, is specific about having a rare disorder? Patients' judgements on being ill and being rare. *Health expectations* 12, 361-370.
- Huyard, Caroline, Derijks, Luc, Haak, Harm, & Lieverse, Louis (2017). Intentional nonadherence as a means to exert control. *Qualitative health research* 27(8), 1215-1224.

- Isono, Moeko, Minori Kokado, and Kazuto Kato (2019). Why does it take so long for rare disease patients to get an accurate diagnosis? —A qualitative investigation of patient experiences of hereditary angioedema. *PLOS One* 17(3), e0265847.
<https://doi.org/10.1371/journal.pone.0265847>
- Jacobs, Jason (2003). *Body trauma TV: The new hospital dramas*. Bloomsbury Publishing.
- Jessop, Edmund (2014). The quest for diagnostics: A narrative analysis of patient journeys. *Rare diseases and orphan drugs: An international journal of public health* 1(4), 108-115.
- Johns Hopkins Myositis Center (2023) *About Myositis*. Johns Hopkins.
www.hopkinsmyositis.org/myositis/
- Journet, Debra (1990). Forms of discourse and the sciences of the mind: Luria, Sacks, and the role of narrative in neurological case histories. *Written communication* 7(2), 171-199.
- Journet, Debra (2012). Narrative turns in writing studies research.” In Lee Nickolson and Mary P. Sheridan (Eds.), *Writing studies research in practice: Methods and methodologies* (pp. 13-24). Southern University Press.
- Jutel, Annamarie & Ginny Russell (2021). Past, present and imaginary: Pathography in all its forms. *Health*. 27(5), 886–902.
<https://doi.org/10.1177/13634593211060759>
- Jurecic, Ann (2012). *Illness as narrative*. University Of Pittsburg Press.
- Karkazis, Katrina (2008). *Fixing sex: Intersex, medical authority, and lived experience*. Duke University Press.

- Kafer, Allison (2013). *Feminist, queer, crip*. Indiana University Press.
- Keränen, Lisa (2014). Public engagements with health and medicine. *Journal of medical humanities* 35, 103-109.
- (2007). “Cause someday we all die”: Rhetoric, agency, and the case of the “patient” preferences worksheet. *Quarterly journal of speech* 93(2), 179-210.
- Kerschbaum, Stephanie (2022) *Signs of Disability*. New York University Press.
- Kessler, Molly Margaret (2020). *Stigma stories: Rhetoric, lived experience, and chronic illness*. Ohio State University Press.
- Keyes, Sarah E., Clarke, Charlotte L., & Gibb, Catherine E. (2019). Living with dementia, interdependence and citizenship: Narratives of everyday decision-making. *Discourse & society* 34(2), 296-319.
- Kleinman, Arthur (1989) *The illness narratives: Suffering, healing, and the human condition*. Basic Books.
- Koerber, Amy and Brian Still (Eds.).(2008). Online health communication. [Special issue]. *Technical communication quarterly* 17(3).
- Kopelson, Karen (2009). Writing patients’ wrongs: The rhetoric and reality of information age medicine.” *Journal of advanced composition*, 29 (1-2), 353-404.
- (2013). Risky appeals: Recruiting to the environmental breast cancer movement in the age of pink fatigue. *Rhetoric society quarterly*, 43 (2), 107-133.
- Lanzkron, Sophie (2018). Race, funding, and access to high quality care. *CIOsler—Johns Hopkins Medicine*. <https://closler.org/lifelong-learning-in-clinical-excellence/race-funding-access-high-quality-care>.

- Le Henaff Y, Héas S, Joly P. Taking care of oneself and others: The emotion work of women suffering from a rare skin disease. *Health*. 2023;27(5):738-755.
doi:10.1177/13634593211064127
- Leavy, Patricia (2015). *Method meets art: Arts-based research practice* (2nd Ed). The Guilford Press.
- Levine, Daniel (2019). *NEXT: Imagining the future of rare disease*. Global Genes.
https://globalgenes.org/wp-content/uploads/2019/09/Global_Genes_NEXT_Report_2019.pdf
- Lindquist, Julie (N.D.). *Call for program proposals*. Conference on College Composition and Communication. www.cccc.ncte.org/cccc/call-2020.
- Lindquist, Julie, Bree Straayer, and Bump Halbritter, (2023). Introduction. In Julie Lindquist, Bree Straayer, and Bump Halbritter (Eds.), *Recollections from an uncommon time: 4C20 documentarian tales* (pp. 1-33). National Council of Teachers of English; The WAC Clearinghouse.
<https://wac.colostate.edu/books/swr/documentarian/>
- Linton, Simi (1998). *Claiming disability: Knowledge and identity*. New York University Press.
- Lorde, Audre (1997). *The Cancer journals: Special edition*. Aunt Lute Books.
- Lundberg, I. E., Fujimoto, M., Vencovsky, J., Aggarwal, R., Holmqvist, M., Christopher-Stine, L., Mammen, A. L., & Miller, F. W. (2021). Idiopathic inflammatory myopathies. *Nature reviews. Disease primers*, 7(1), 86.
<https://doi.org/10.1038/s41572-021-00321->

- Mairs, Nancy (1992). On being a cripple. *Plain text: Essays by Nancy Mairs*. University of Arizona Press.
- Makoul, Gregory and Limor Peer (2004). Dissecting the doctor shows: A content analysis of *ER* and *Chicago Hope*. In Lester D. Friedman, (Ed.), *Cultural sutures: Medicine and media* (pp. 244-262). Duke UP.
- Manganiello, Michael & Anderson, Margaret (2011). *Back to basics: HIV/AIDS advocacy as a model for catalyzing change*. Milken Institute.
- Manivannan, Vyshali (2017). What we see when we digitize pain: The risk of valorizing image-based representations of fibromyalgia over body and bodily experience. *Digital health*. 3, 1-15.
- Martin, L. R., Williams, S. L., Haskard, K. B., & Dimatteo, M. R. (2005). The challenge of patient adherence. *Therapeutics and clinical risk management*, 1(3), 189–199.
- Mayo Clinic Staff (2022). *Prednisone and other corticosteroids*. Mayo Clinic.
<https://www.mayoclinic.org/steroids>.
- Mayo Clinic Staff (2023). *Arteriovenous Malformation*. Mayo Clinic.
<https://www.mayoclinic.org/diseases-conditions/arteriovenous-malformation/symptoms-causes/syc-20350544>
- McCarthy, Lucille and Joan Gerring (1994). Revising psychiatry's charter document. *Written Communication* 11(2), 147-92.
- McCruer, Robert (2006). *Crip theory: Cultural signs of queerness and disability*. NYU P.
- MedlinePlus (2021). *Ostomy*. <https://medlineplus.gov/ostomy.html>
- Merriam, Sharan (2009). *Qualitative research: A guide to design and implementation*. Josey-Bass.

- Meyers, Abbey S. (2016). *Orphan drugs: A global crusade*. Printed by the author.
- Mitchell, David T. & Sharon L. Snyder (2001). *Narrative prosthesis: Disability and the dependencies of discourse*. University of Michigan Press.
- Molloy, Cathryn (2020). *Rhetorical ethos in health and medicine: Patient credibility, stigma, and misdiagnosis*. Taylor & Francis.
- Moss, Beverly (2003). *A Community Text Arises: A Literate Text and a Literate Tradition in African-American Churches*. Hampton Press.
- Morgan, Susan, Movius, Lauren & Cody, Michael (2009). The power of narratives: The effect of entertainment television organ donation storylines on the attitudes, knowledge, and behaviors of donors and nondonors. *Journal of communication*, 59, 135-151. doi:10.1111/j.1460-2466.2008.01408.x
- Namsrai, T., Parkinson, A., Chalmers, A., Lowe, C., Cook, M., Phillips, C., & Desborough, J. (2022). Diagnostic delay of myositis: An integrated systematic review. *Orphanet journal of rare diseases*, 17(1), 420.
<https://doi.org/10.1186/s13023-022-02570-9>
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (2023). Fibrous Dysplasia. <https://www.niams.nih.gov/health-topics/fibrous-dysplasia>.
- Nevarés, Alana M. (2022). Autoimmune myositis. *Merck Manual*.
<https://www.merckmanuals.com/professional/musculoskeletal-and-connective-tissue-disorders/autoimmune-rheumatic-disorders/autoimmune-myositis>
- NIH Center for Information Technology(2018). *NIH rare disease day 2018 [Video]*. National Center for Advancing Translational Science.
<https://videocast.nih.gov/watch=26851>.

- Hillinger, Suzanne (Director). (2019). The six-million-dollar claim (Season 1, Episode 11). [TV Series Episode]. In S. Dolnick, *The Weekly*. Hulu. www.hulu.com.
- National Organization of Rare Disease (2021). *Orphan drugs in the United States: An examination of patents and orphan drug exclusivity*. https://rarediseases.org/wp-content/uploads/2022/10/NORD-Avalere-Report-2021_FNL-1.pdf.
- O’Hair, D., Villagran, M.M., Wittenberg, E., Brown, K., Ferguson, M., Hall, H.T., et al. (2003). Cancer survivorship and agency model: Implications for patient choice, decision making, and influence. *Health communication*, 15(2), 193-202.
- Oldroyd, A., Lilleker, J., & Chinoy, H. (2017). Idiopathic inflammatory myopathies - a guide to subtypes, diagnostic approach and treatment. *Clinical medicine*, 17(4), <https://doi.org/10.7861/clinmedicine.17-4-322>
- Orphan Drug Act of 1983, Pub. L. No. 97-414, 96 Stat. 2049 (1983). <https://www.govinfo.gov/app/details/STATUTE-96/STATUTE-96-Pg2049#:~:text=L.,%2FSTATUTE%2D96%2DPg2049>.
- Opel, Dawn S. (2018). Challenging the rhetorical conception of health literacy: Aging, interdependence, and networked caregiving. *Literacy in composition studies* 6(2), 136-150.
- Owens, Kim Hensley (2009). Confronting rhetorical disability: A critical analysis of women’s birth plans. *Written communication* 26(3), 247-272. doi: 10.1177/0741088308329217.
- Patients Rising (2017). Rare Disease: The challenges and hopes of living with a rare disease. <https://www.patientsrising.org/living-with-a-rare-disease/>

- Pearson, Charlotte and Filippo Trevisan (2015). Disability activism in the new media ecology: Campaigning strategies in the digital era.” *Disability and society*, 30 (6), DOI: 10.1080/09687599.2015.1051516.
- Pezzullo, Phaedra (2003). Resisting ‘National Breast Cancer Awareness Month’: The rhetoric of counter-publics and their cultural performances.” *Quarterly journal of speech* 89(4), 345-65.
- Pietrangelo, Ann (2023). CPK isoenzymes test. *Healthline*.
<https://www.healthline.com/health/cpk-isoenzymes-test>
- Pfeiffer, David (2002). The philosophical foundations of disability studies. *Disability studies quarterly*. 22(2), 3-23. <http://dsq-sds.org/article/view/341/429>.
- Piepzna-Samarasinha, Leah Laskhmi (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.
- Porter, Rick (2023). Why three shows always dominate the streaming charts, even amid peak TV. *The Hollywood Reporter*. <https://www.hollywoodreporter.com/tv/tv-news/greys-anatomy-ncis-streaming-charts-rankings-history-1235580072/>
- Power-Hays, Alexandra and Patrick T. McGann (2020). When actions speak louder than words: Racism and sickle cell disease. *New England journal of medicine*, 383. 1902-1903.
- Prelli, Lawrence J. (1989). *A Rhetoric of science: Inventing scientific discourse*. University of South Carolina Press.
- Price, Margaret and Stephanie Kerschbaum (2016). Stories of methodology: Interviewing sideways, crooked and crip,” *Canadian journal of disability studies*, 5 (3), 18-56.

- Price, Margaret (2011). *Mad at school: Rhetorics of mental disability in academic life*. University of Michigan Press.
- Quick, Brian L., Morgan, Susan E., LaVoie, Nicole R., & Dave Bosch (2014). *Grey's Anatomy* viewing and organ donation attitude formation: Examining mediators bridging this relationship among African Americans, Caucasians, and Latinos. *Communication research* 41(5), 690-716.
- Rare Diseases Act of 2002. Pub. L. No. 107-280, 116 Stat. 1988.
<https://www.govinfo.gov/app/details/PLAW-107publ280>
- Restaino, Jessica (2019). *Surrender: Feminist rhetoric and ethics in love and illness*. Southern Illinois University Press.
- Rhimes, Shonda. (Writer), & Horton, Peter (Director). 2005. A Hard Day's Night (Season 1 Episode 1) [TV Series Episode]. In Betsy Beers (Executive Producer), *Grey's Anatomy*. Netflix. www.netflix.com.
- Rhimes, Shonda (Writer), Meg Marinis (Writer), & Jackson, Mark (Director). 2013. Can't Fight this Feeling (Season 9, Episode 19) [TV Series Episode]. In Betsy Beers (Executive Producer), *Grey's Anatomy*. Netflix. www.netflix.com.
- Rhimes, Shonda (Writer), Klein, Jen (Writer), Barnett, Lauren (Writer), & Mahoney, Victoria (Director). 2016. Falling Slowly (Season 13, Episode 4) [TV Series Episode]. In Debbie Allen (Executive Producer), *Grey's Anatomy*. Netflix. www.netflix.com.
- Robvais, Raquel McFarland (2019). *The rhetoric of sickle cell anemia* [Unpublished doctoral dissertation]. Louisiana State University and Agricultural and Mechanical College.

- Samuels, Ellen (2017). Six ways of looking at crip time. *Disability studies quarterly* 37(3). <https://doi.org/10.18061/dsq.v37i3.5824>
- Samuels, Ellen (2015). Passing. In Rachel Adams, Benjamin Reiss, and David Serllin, *Keywords in disability studies* (pp. 135-136). New York University Press.
- Sanders, Lisa (2009). *Every patient has a story: Medical mysteries and the art of diagnosis*. Harmony.
- Sansone, R. A., & Sansone, L. A. (2012). Doctor shopping: a phenomenon of many themes. *Innovations in clinical neuroscience*, 9(11-12), 42–46.
- Scott, J. Blake (2003). *Risky rhetoric: AIDS and the cultural practices of HIV testing*. Southern Illinois UP.
- Segal, Judy Z (2005). *Health and the rhetoric of medicine*. Southern Illinois UP.
- (2007). Breast cancer narratives as public rhetoric: Genre itself and the maintenance of ignorance. *Linguistics and human sciences* 3 (1), 3-23.
- (2009a). Internet health and the 21st-century patient: A rhetorical view. *Written communication* 26 (4). [page number] DOI: 10.1177/0741088309342362
- (2009b). Rhetoric of health and medicine. In Andrea Lundsford (ed.), *The Sage Handbook of rhetorical studies*. Sage, 227-45. DOI:10.1558/lhs.v3i1.3.
- (2011). What, in addition to drugs, do pharmaceutical ads sell?: The rhetoric of pleasure in direct-to-consumer advertising for prescription pharmaceuticals. In Joan Leach and Deborah Dysart Gale (Eds.), *Rhetorical questions of health and medicine* Lexington Books, 9-32.
- Siebers, Tobin (2004). Disability as masquerade. *Literature and medicine* 23(1). 1-22.

- Shakespeare, Tom (2006). The social model of disability. In Lennard J. Davis (Ed), *The disability studies reader*. Routledge, 197-204.
- Shelton, Cecilia (2020). Shifting out of neutral: Centering difference, bias, and social justice in a business writing course. *Technical communication quarterly* 29(1). 18-32.
- Shore, David (Writer) & Bryan Singer (Director). 2004. Everyone Lies (Season 1, Episode 1) [TV Series Episode]. In Paul Attanasio (Executive Producer), *House*, Amazon Prime. www.amazon.com
- Shore, David, David Foster (Writer); Keller, Frederick King (Director). 2005. DNR (Season 1, Episode 9) [TV Series Episode]. In Paul Attanasio (Executive Producer), *House*. Amazon Prime. www.amazon.com.
- Shore, David (Writer), Matthew V. Lewis (Writer), Liz Friedman (Writer) & Yaitanes, Greg. (Director). 2009. House, Divided (Season 5, Episode 22) [TV Series Episode]. In Paul Attanasio (Executive Producer), *House*. Amazon Prime. www.amazon.com
- Sins Invalid. (2019) *Skin, tooth, and bone: The basis of movement is our people* (2nd Ed). Sins Invalid.
- Solomon, Martha (1985). The rhetoric of dehumanization: An analysis of medical reports of the Tuskegee syphilis project." *Western journal of speech communication*, 49, 233-247.
- Star, Susan Lee and Griesemer, James R (1989). Institutional ecology, 'translations' and boundary objects: Amateurs and professionals Berkeley's museum of vertebrate zoology, 1907-1939. *Social studies of science* (19)3, 387-420.

- Teston, Christa (2017). *Bodies in flux: Scientific methods for negotiating medical uncertainty*. U of Chicago P.
- Laur, Janice M. (1996). Topics. In Enos, Theresa (Ed.), *Encyclopedia of Rhetoric and Composition: Communication from Ancient Times to the Information Age* (pp. 724-725). Garland Publishing, Inc.
- Ubel, P. A., Scherr, K. A., & Fagerlin, A. (2018). Autonomy: What's shared decision making have to do with it?. *The American journal of bioethics*. 18(2), W11–W12.
<https://doi.org/10.1080/15265161.2017.1409844>
- Undiagnosed Diseases Network (N.D.) About Us.
<https://undiagnosed.hms.harvard.edu/about-us/>
- U.S. Food and Drug Administration (2022). Rare diseases at FDA.
<https://www.fda.gov/patients/rare-diseases-fda>
- U.S. Food and Drug Administration (2023). Right to try.
<https://www.fda.gov/patients/learn-about-expanded-access-and-other-treatment-options/right-try>
- U.S. Government Publishing Office (N.D.) Congressional hearings.
<https://www.govinfo.gov/app/collection/chr/118/house>
- Wallace, Ann (2020). Temporal disruptions: Illness narratives before and after web 2.0. In Jamie White-Farnham, Bryna Siegal Finer, and Cathryn Molloy, *Women's health advocacy: Rhetorical ingenuity for the 21st Century* (pp. 25-33). Routledge.
- Wen, K.-Y., F. McTavish, G.L. Kreps, M. Wise and D. Gustafson (2011). From diagnosis to death: A narrative analysis of coping with breast cancer as seen

- through online discussion group messages.” *Journal of computer-mediated communication*, 16(2). 331-361.
- Wendell, Susan (1996). *The rejected body: Feminist philosophical reflections on disability*. Routledge.
- “What’s the point of congressional caucuses?”(N.D.). Chamber Hill.
<https://chamberhill.com/whats-the-point-of-congressional-caucuses/>
- Will, Jonathan F. (2011). A brief historical and theoretical perspective on patient autonomy and medical decision making, part II: The autonomy model. *Chest* 139(6), 1491-1497.
- Williams, Julie (2017). “Breaking Silences: Crip Theory.” *Wright State University*. Retrieved October 2017 from <https://www.wright.edu/event/sex-disability-conference/crip-theory>
- Willis E. (2018). Applying the health belief model to medication adherence: The role of online health communities and peer reviews. *Journal of health communication*, 23(8), 743–750. <https://doi.org/10.1080/10810730.2018.1523260>
- Wilson, James C. and Cynthia Lewiecki-Wilson (2001). *Embodied rhetorics: Disability in language and culture*. Southern Illinois University Press.
- Yang, G., Cintina, I., Pariser, A., Oehrlein, E., Sullivan, J., & Kennedy, A. (2022). The national economic burden of rare disease in the United States in 2019. *Orphanet journal of rare diseases*, 17(1), 163. <https://doi.org/10.1186/s13023-022-02299-5>

CURRICULUM VITAE

Caitlin E. Ray

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(402) 707-6615//raycaitlin@gmail.com

Education

Ph.D. in Rhetoric and Composition, University of Louisville (UofL) Dec. 2023
Dissertation: “From ‘Smart Talk’ to ‘Living Well’: Commonplaces of Healthcare and their Role in Narratives of Rare Disease”
Committee: Drs. Karen Kopelson (chair), Andrea Olinger, Kristi Maxwell, and M. Remi Yergeau.

M.A. in English, University of Nebraska at Omaha (UNO) May 2015
Thesis: ‘Calming These Nerves’: The Politics of Gender and Disability in Fibromyalgia Rhetoric
Committee: Drs. Tammie Kennedy (chair), Maggie Christensen, and Jay Irwin.

B.A. in English and Theatre, Hamline University, *cum laude* May 2009
Culminating Project: ‘To Die for Love’: Violence Against Women in Early Restoration Drama.
Advisors: Drs. Carolyn Levy and Marcela Kostihova

Employment

Grants and Scientific Writer, University of Nebraska Medical Center 2022-Current
Primary grant writer for CityMatCH, a professional membership organization for over 160+ city and county maternal and child health programs. Also consults on other writing projects with University of Nebraska Medical Center (UNMC) College of Public Health faculty, staff, and students.

Graduate Writing Consultant, UNO Writing Center Fall 2020-Present
Tutored and provided peer support to UNO and UNMC undergraduate and graduate students on writing projects. Worked primarily with multilingual writers with a variety of language backgrounds. Assisted in planning and developing new consultant training. Completed assessment reports that tracked usage of the UNMC Writing Center

Asst. Director of BizComm Coaching, UofL College of Business 2018-2019
Tutored College of Business students and staff on writing projects. Coordinated day-to-day operations of the BizComm Coaching lab. Managed schedule and trained new coaches. Created new initiatives to meet student need, including expanding remote and asynchronous appointment options for distance education students.

Asst. Director of Graduate Student and Faculty Writing, UofL 2017-2018
Responsibilities split between the main University Writing Center and the Health Sciences Campus. Tutored graduate students, postdocs, and faculty and coordinated the Mini-Dissertation Writing Retreat, the Health Sciences Grant and Manuscript Drop-In event, and the weekly Graduate Student and Faculty Writing Group. Conducted outreach to promote our services and collaborate with multiple academic units.

Writing Center Tutor, University of Nebraska at Omaha 2011-2012
Tutored clients in the main UNO Writing Center and provided guidance on a variety of assignments, spanning diverse disciplines and skill levels.

Selected Teaching Experience

Graduate Teaching Assistant (Instructor of Record), UofL 2015-2020
Business 301, Business Communications (2 sections)
English 310, Writing About Literature (1 section)
English 306, Business Writing (1 section)
English 101, Beginning College Writing (4 sections)
English 102, Intermediate College Writing (2 sections)

Graduate Teaching Assistant (Instructor of Record), UNO 2011-2015
English 1154, Composition I (4 sections)
English 1164, Composition II (6 sections)

Teacher and Curriculum Designer, UofL Digital Media Academy Summer 2016
Created and implemented curriculum for the 2-week Digital Media Academy program for at-risk middle school girls.

Institute of Reading Development Summers 2011-2013
Taught reading and study skills to Pre-K to adult students. Assessed each student's reading skills and offered guidance to parents.

Research Assistantships

Morton Endowment Research Asst., UofL 2016-2017
Worked for Dr. Deborah Lutz, Morton Endowed Chair, on research projects. Tasks included editing, contacting archives for materials, and creating a database of Brontë ephemera.

Shakespeare First Folio Project Graduate Asst., UofL 2016
Researched archival history of Shakespeare in Kentucky to add to a digital storyboard, in addition to developing materials for exhibits related to the touring First Folio's stop in Louisville.

Academic Service

Service to the Field of Writing Studies
Nebraska Writing Center Consortium 2021
Treasurer

Best of the Journals in Rhetoric and Composition 2021 (Parlor Press). 2020
Assistant Editor

University of Louisville
Commission on the Status of Women, Graduate Student Representative 2018-2020
Campus Climate Subcommittee

Graduate Student Council, English Dept. Representative 2016-2018
Diversity Subcommittee
Educational Outreach Subcommittee

English Dept. Graduate Student Equity Working Group 2016-2018
Chair, Graduate Handbook Review Subcommittee

English Graduate Organization (EGO), PhD Liaison 2017-2018

#KnowMoore Story Project, Co-director 2017-2018
Developed and coordinated a long-term partnership with a local high school to teach students interested in social justice digital filmmaking skills. A final documentary created in collaboration between the UofL English department and high school students.

University of Nebraska at Omaha
First Year Writing Committee, Graduate Student Representative 2013-2015
Library Instruction Subcommittee

Co-Coordinator, Int'l Pedagogy & Theatre of the Oppressed Conf. 2013-2014
Created the program and welcome packet for attendees. Scheduled meetings and maintained minutes for the planning committees. Developed and enacted new accessibility policies, including coordinating a "quiet room." Created materials on accessibility for presenters to use.

Service Outside the University

Myositis Support and Understanding, Board of Directors 2018-2022

Rare Disease Legislative Advocates, Team Leader February 2018

Rare Disease Leadership Summit, Representative July 2018

Selected Professional Development

Professional Writing Reading Group, Co-President, UofL 2016-2020

Rhetoric Reading Group, Facilitator, UofL 2018-2020

Pedagogy Fellows Program, UofL 2017-2020

Inclusive Teaching Circle, UofL 2016-2020

Editorial Experience

#MyositisLIFE Website, Managing Editor May 2019-Dec. 2019

University of Louisville's *Cardinal Compositions*, Co-Editor 2017

Red Line Editorial, Copyeditor and fact checker 2012-2015

From the Heartland: Critical Reading and Writing at UNO (2nd Ed.), Contributor 2014

Hamline University's *The Fulcrum*, Literary Editor 2008-2009

Awards + Honors

Teaching

Barbara Plattus Outstanding Graduate Student Teaching Award, UofL 2019

UofL Delphi Center Faculty Favorite Nominee, UofL 2017-2018

Red and Black Faculty Favorite, UofL 2016

Service

EGO Outstanding PhD Student, UofL 2019

Student Marshal, University of Nebraska at Omaha May 2015

Research

CCCC Disability in College Composition Travel Award 2019

Dr. M. Celeste Nichols Professional Development Award, UofL 2018

Anne Braden Social Justice Research Paper Award-Runner Up, UofL 2017

Thomas P. Beyer Prize, Hamline University 2009

Hamline University Bridgeman Award 2008

Grants + Scholarships

Outside Organizations

#RareIs Scholarship Fund, Everylife Foundation for Rare Disease (\$5,000)	2020
Travel Scholarship, The Myositis Association (\$1,000)	2018
Travel Scholarship, Rare Disease Legislative Advocate (\$800)	2018

University of Louisville

Graduate Student Council Travel Grant (\$350 ea.)	2015-2020
Graduate Network of Arts and Sciences Research Grant (\$250 ea.)	2016, 2017, 2019
Graduate Student Council Research Grant (\$500)	2018

University of Nebraska at Omaha

Graduate Research and Creative Activity Research Grant (\$5,000)	2013
Arts and Sciences Travel Grant (\$250 ea.)	2014, 2015
Graduate Studies Travel Grant (\$250)	2013
Writing Center Travel Grant (\$250)	2013

Hamline University

Hamline University Collaborative Research Grant (\$2,000)	2008
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Refereed Publications

Journal Articles

Ray, Caitlin. "A Year of Worry: A Collection of Advocacy Writings from 2020-2021." *Journal of Multimodal Rhetorics*. [Special Issue on Carework and Writing During Covid: Part II]. Fall 2022.

Golden, Tasha, Kuge, Maria, Magsamen, Susan, **Ray, Caitlin E.**, Tetreault, Elliot, Tiedemann, Alyssa. "The State of Music-Based Interventions for Mental Illness: Thought Leaders on Barriers, Opportunities, and the Value of Interdisciplinarity." *Community Mental Health Journal*. December 2020.

Ray, Caitlin E. "'On Your Feet!': Addressing Ableism in Theatre of the Oppressed Facilitation." *Pedagogy and Theatre of the Oppressed Journal*. September 2017.

Alvarez, Sara P., Michael Baumann, Michelle Day, Khirsten L. Echols, Layne M. P. Gordon, Ashanka Kumari, Laura Matravers, Jessica Newman, Amy McCleese Nichols, **Caitlin E. Ray**, Jon Udelson, Rick Wysocki, and Daniëlle Nicole DeVoss. "On Multimodal Composing." *Kairos: A Journal of Rhetoric, Technology, and Pedagogy*. January 2017

Book Chapters

Ray, Caitlin E. "Composing an Argument." *Dynamic Activities for First-Year Composition: 96 Ways to Immerse, Inspire, and Captivate Students*. Edited by

Michal Reznizki and David T. Coad. National Council of Teachers of English. 2023.

Ray, Caitlin E. “This is What Happy Feels Like”: The Crippled Narrative of *Crazy Ex-Girlfriend*.” *Perspectives on Crazy Ex-Girlfriend: Quality Postnetwork Television*. Edited by Amanda Konkle and Charles Burnetts. Syracuse UP, 2021.

Rick Wysocki, Jon Udelson, **Caitlin E. Ray**, Jessica Newman, Laura Sceniak Matravers, Ashanka Kumari, Layne M. P. Gordon, Khirsten L. Echols, Michelle Day, Michael Baumann, Sara P. Alvarez, and Dànielle Nicole DeVoss. “On Multimodality: A Multivocal Manifesto.” *Bridging the Gap: Multimodality in Theory and Practice*, Ed. Santosh Khadka and Jennifer Lee. Utah State UP, January 2019.

Ray, Caitlin E. “The ‘Shit’ That Haunts Us: Disability in Rhetoric and Composition Research.” *Making Future Matters*, edited by Rick Wysocki and Mary P. Sheridan. Computers and Composition Digital Press/Utah State UP, 2018.

Book Reviews

Ray, Caitlin E. “Review of *The Lady's Handbook of Her Mysterious Illness* by Sarah Ramey and *What Doesn't Kill You: A Life with Chronic Illness—Lessons from a Body in Revolt* by Tessa Miller.” *Disability Studies Quarterly*, 2022.

Ray, Caitlin E. “A Kairotic Moment for Women’s Pain and Illness: A Review of Three Books” *Dósis: Medical Humanities + Social Justice*. Vol.3, No. 1, 2018.

Books

Ray, Caitlin E. *Revenge: Essential Literary Themes*. Minneapolis: Essential Themes-Red Line Editorial, 2015.

Poetry

Ray, Caitlin E. “Coda.” *The Untidy Season: An Anthology of Nebraska Women Poets*. Backwaters Press, 2013.

Selected Presentations

Invited Presentations

“Journaling, blogging, and creative writing with Myositis” The Myositis Association Annual Patient Conference. Louisville, KY, September 2018.

“Working with Students with Disabilities” Digital Media Academy Training Boot Camp. April 2016.

“Teaching the Disability Unit in First Year Comp” University of Nebraska at Omaha Teaching Composition Class. Fall 2013, Fall 2014.

National Conference Presentations

- “Working Together: Engaging Multiple Audiences in STEM Graduate Student Writing.” Conference on College Composition and Communication. Online. March 2022.
- “The Subversive Bodymind: Disability “Life Hacks” and Acts of Care in the Writing Center.” National Conference on Peer Tutoring in Writing. Online, November 2021.
- “Commonplaces in Creative Writing and Composition: Reimagining Sites of Craft, Pedagogy, Identity, and Community.” Creative Writing Standing Group Workshop. Conference on College Composition and Communication. Online. March 2021.
- "Describing and Deconstructing Rhetoric of Health and Medicine’s Commonplaces." Medical Rhetoric Standing Group Panel. Conference on College Composition and Communication, Milwaukee, WI. March 2020. [Canceled due to COVID-19]
- “Scene Work in Multi-Major Professional Writing Classes: Using Writing Scenarios for Success.” Panel. Council for Programs in Technical and Scientific Communications Conference, West Chester, PA. October 2019.
- “Rhetorical Negotiations in the Performance of Health, Medicine, and Disability.” Roundtable. Conference on College Composition and Communication. Pittsburg, PA, March 2019.
- “‘How Shall One Be Ill’: The Pedagogy of Rare Illness.” Thomas R. Watson Conference. Louisville, KY, October 2018.
- “Inventing a Disease: Mapping Narratives onto Rare Illnesses.” Rhetorical Society of America. Minneapolis, MN, May 2018.
- “Designing and Teaching Professional and Technical Writing.” Webinar, WPA-GO. April 2018.
- “Empowering the Wounded Storyteller’: Arts Organizations, Health Policy, and the Healing Public.” College Composition and Communication Conference. Kansas City, MO, March 2018.
- “‘Crippled America’: The Mobilization of #CripTheVote.” Thomas R. Watson Conference. Louisville, KY, October 2016.
- “Being a Girl in Louisville: Identity Constructions through the Digital Media Academy.” Roundtable. Cultural Rhetorics. East Lansing, MI. September 2016.
- “A Forum of One’s Own: A Genre Analysis of the Fibromyalgia Blogosphere.”

Rhetorical Society of America. Atlanta, GA, May 2016.

“‘Transforming the Structure’: Universal Design in Conflict with Critical Pedagogy.”
Conference on College Composition and Communication, Tampa, FL, April
2015.

“‘On Your Feet!’: Navigating Disability in Theatre-based Teaching Pedagogies.” Thomas
R. Watson Conference, Louisville, KY, October 2014.

“‘Beyond ‘Criss-Cross Applesauce’: Ways to Encourage and Empower Youth through
Pedagogy and Theatre of the Oppressed.” International Pedagogy and Theatre of
the Oppressed Conference. Omaha, NE, June 2014.

“‘The Effect of Choice’: Relationships Redefined in Eliza Haywood’s *The British
Recluse*.” The British Women Writer’s Conference, Albuquerque, NM, April
2013.

Regional Conferences

“Patient Agency and Biomedicine within Rare Disease Narratives.” UofL Graduate
Student Conference, Louisville, KY 2019.

“‘The Unavailing Wretchedness of Witnessing’: Fanny Burney’s Mastectomy Letter and
Narrative Restitution.” UofL Graduate Student Conference, Louisville, KY,
2018.

“The Kairology of Lyrica: Influencing Public Perception of Fibromyalgia.” University of
Nebraska at Omaha Research and Creative Activity Fair, Omaha, NE, 2015.

“(dis)ability: Exploring the Mind and Body Through Creative Narrative” The Examined
Life Conference, Iowa City, IA, 2014.

“Creating Identity through Spectacular Performance: The Education of Evelina in Fanny
Burney’s Novel.” Kansas State University Regional Graduate Student
Conference, Manhattan, KS, 2013.

Selected Workshops, Symposia, + Institutes

Workshops (Led)

Invited Presenter. Grant Writing for Public Health. University of Nebraska Medical
Center, CityMatCH. August 2023.

Invited Presenter. Resumes and CVs for Public Health Professionals. University of
Nebraska Medical Center, CityMatCH. August. 2023.

Co-Facilitator. Creative Narrative. Pediatric Academic Workshop. Children’s Nebraska
and UNMC-Child Health Research Institute. (CME Credit)

Facilitator, Handling Difficult Scenarios in the Writing Center. New Writing Center Consultant Training. UNO. August 2021

Presenter, Setting Writing Goals. Dissertation and Thesis Boot Camp, UNO and UNMC. December 2020.

Presenter. "Critical Compliance and the Boundaries of Medical Expertise in Rare Disease Advocacy." Discourse and Semiotics Workshop Series. University of Louisville, February 2020.

Moderator. Business and Science/Tech Writing Pedagogy Workshop. Pedagogy Fellow Initiative. University of Louisville, April 2018.

Presenter. Disability Studies Pedagogy Workshop. Pedagogy Fellow Initiative. University of Louisville, November 2017.

Moderator. Building Successful Committees Workshop. English Graduate Organization. University of Louisville, October 2017.

Selected Workshops (Attended)

Participant, "Transforming Research into Policy." Scholars Strategy Network, April 2019.

Participant, "Write Winning NIH Grant Proposals." Grant Writers' Seminars and Workshops, January 2018.

Selected Symposia, Institutes, + Forums

Participant, Rhetorical Society of America (RSA) Institute, "Crip is a Verb." June 2019.

Participant, "Crippling Performance in the First-Year Writing Classroom." Conference on College Composition and Communication, March 2018.

Participant, Rhetoric of Health and Medicine Symposium. September 2017.

Participant, RSA Institute, "Disability at the Intersections." June 2017.

Participant, "Give Writing a Body that Moves: Embodied Performance in the Writing Classroom." Conference on College Composition and Communication, March 2015.

Participant, "Writing Democracy: Invisibility and Visibility." Conference on College Composition and Communication, March 2015.

Participant, Digital Composition Colloquium, University of Louisville. August 2015.

Participant, Research Network Forum. “‘On Your Feet!’: Navigating Disability in Theatre-based Teaching Pedagogies.” Conference on College Composition and Communication, March 2014.

Memberships

American Medical Writers Association
Nebraska Writing Center Consortium
Midwest Writing Center Association