SIX IN TEN ADULTS in the US live with at least one chronic condition, according to the Centers for Disease Control and Prevention (CDC, 2019a). In other words, over half the US population lives with at least one long-term, likely incurable, condition (CDC, 2021b; National Center for Chronic Disease Prevention & Health Promotion, 2012). Such conditions vary widely but include cancer, addiction, diabetes, obesity, Alzheimer’s disease, and autoimmune conditions, among many others. Despite research demonstrating an already staggering prevalence of chronic conditions in the US, the number of Americans affected by chronic conditions is only estimated to rise. According to one report, “between 2000 and 2030 the number of Americans with chronic conditions will increase by 37 percent, an increase of 46 million people” (Anderson, 2010, p. 7; see also Wu & Green, 2000). The prevalence of chronic conditions alone is startling; however, concerns don’t end there. As a category, chronic conditions disproportionately account for 75 to 90 percent of the overall healthcare costs in the US each year, an estimate that lands somewhere between two and three trillion dollars annually (Buttorff et al., 2017; CDC, 2019b; Wu & Green, 2000). More importantly, chronic diseases have consistently been the leading cause of both death and disability in the US (Kochanek et al., 2011, 2019; Murphy et al., 2017; Xu et al., 2010, 2018).
Concomitant with the rise of chronic conditions has been, unfortunately, a rise in those affected by stigma. The list of stigmatized conditions is extensive; thus, examples of stigmatization are abundant. In the time I have been writing this book, the morning news alone has featured several stories about “fighting stigma” for a range of conditions. Posttraumatic stress disorder, postpartum depression, anxiety, and obesity are just a few of the stigmatized health and medical topics that have recently made major headlines. With little exception, stigma persists for an expansive list of chronic conditions. Put simply, stigma is an all too common feature of lived experience for so many people.

According to social psychologists Valerie Earnshaw and Diane Quinn (2012), “approximately half of adults are living with a chronic illness, many of whom feel stigmatized” by their condition (p. 157). Stigma, most commonly defined as “an attribute that is deeply discrediting” (Goffman, 1963, p. 3), has been considered to have three main categories: physical deformities, character blemishes, and affiliations with racial or religious identities (Goffman, 1963). Most chronic conditions fall into the first type, so-called physical deformities, as chronic conditions transform healthy bodies into ill, often disabled, ones. However, many chronic conditions are also stigmatized because they are seen as character blemishes, such as those that are viewed as preventable and/or associated with deviant behavior like HIV and sexual promiscuity, diabetes and unhealthy eating, or lung cancer and smoking.

Stigma, in other words, is central to living with a chronic condition for many people. Indeed, stigma surrounding chronic conditions is nearly as pervasive as chronic conditions themselves, and its negative consequences are felt deeply by many living with them. Research has demonstrated that because of stigma, people living with a range of chronic conditions experience embarrassment (Conrad et al., 2006), shame (Malterud & Ulriksen, 2011; Rosman, 2004; Saunders, 2014), a sense of internalized dirtiness (Manderson, 2005; Simbayi et al., 2007), decreased sense of self-worth (Hamilton-West & Quine, 2009; Kato et al., 2016), and discrimination (Conrad et al., 2006; Kilinç & Campbell, 2009). Stigma not only leads to decreased quality of life for those with chronic conditions but also “worsen[s] preexisting health disparities” (Courtwright, 2009, p. 91) and “likely acts as [a barrier] to care access” (Earnshaw & Quinn, 2012).

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2. I include so-called here because I want to trouble and reject the language Goffman used to theorize stigma. Disability studies scholars have recognized the value of Goffman’s foundational work while also challenging the insensitive and often ableist language he used (see Brune et al., 2014).
Further, researchers have found that stigma commonly “disrupts” finances, food practices, familial and social relationships, and the sex lives of those with chronic conditions like diabetes and gastrointestinal diseases (Aikins, 2006; Manderson, 2005). As communication studies scholar Dennis Owen Frohlich (2016) summarized, stigma “may be more difficult to manage than the physical symptoms” for people with chronic conditions (p. 1413). What seems abundantly clear overall is that millions of people not only suffer from chronic conditions but also endure stigma and its far-reaching effects.

Given the significant and myriad impacts of stigma, research into lived experiences with stigma and chronic conditions is both necessary and urgent. Recognizing this, and following the work within my disciplinary home, rhetorical studies, that has addressed chronic conditions (Arduser, 2017; Bennett, 2019), I set out nearly a decade ago to investigate lived experiences with chronic conditions, particularly focusing on the stigma that pervades such experiences. As somebody who studies persuasion and who lives with a chronic condition, I wanted to understand how persuasive practices inform and complicate people’s experiences with chronic conditions and stigma. To prioritize a deep rather than broad examination of stigma, I narrowed my focus to chronic GI conditions for a variety of academic and personal reasons. Research-wise, GI diseases are among the less popular areas within health and medicine studied by rhetoricians. GI diseases understandably have a tough time competing for academic and public attention with public health crises like the COVID-19 pandemic or more prevalent conditions like cancer, diabetes, or mental health conditions. Studying GI conditions struck me as a way to address an understudied area and to build out the capacity and scope of my home field, the rhetoric of health and medicine (RHM), the specialized area within rhetorical studies that attends to the persuasive, meaning-making dimensions of health and medicine such as patienthood, clinical care, biomedical practice, public health policy, and embodied experiences (see Scott & Melonçon, 2018). At the same time, personal experience motivates my focus on GI conditions because I live with a chronic GI disease. I was diagnosed with Crohn’s disease in my late teens; therefore, I have firsthand experience with stigmatization related to chronic GI conditions in my own personal,
professional, and social interactions, relationships, and healthcare. For example, when faced with surgical decisions recommended by my healthcare team, I refused to undergo surgery at the age of nineteen because I was terrified that I would wake up with an ostomy bag on my abdomen. In the years since, I have often contemplated that decision and grappled with why I was so strongly motivated by my then fear of ostomies.

My complex firsthand experience with a chronic condition sparked my interest in why and how stigma is such a powerful force. However, in March 2015 my research was suddenly catalyzed when I opened my Facebook account to an overwhelming flurry of sad, confused, and angry posts about a woman named Julia who had cancer and an ostomy. Quickly, I discovered that Julia was a participant (effectively, a spokesperson) in the CDC’s Tips from Former Smokers campaign, a nationwide public health campaign designed to decrease smoking across the US. As a participant in this campaign, Julia joined over thirty other “real people” who were sharing “real stories” about “living with smoking-related diseases and disabilities” with national public audiences primarily through thirty-second television commercials (CDC, 2020a). One of these commercials featured Julia, a middle-aged Black woman who developed colorectal cancer after years of smoking. In her commercial, Julia detailed her experiences with colorectal cancer, chemotherapy, and surgeries. Of her experiences, she poignantly told viewers, “What I hated most was the colostomy bag” (CDC, 2015a).

Let me pause here to provide some necessary context. A colostomy bag is a small bag or pouch worn on the abdomen over a surgically created opening called an ostomy. Through this opening, an end of the small or large intestine (called a stoma) is exteriorized on the abdomen (see figure 1). People with ostomies—often referred to as ostomates—wear an ostomy bag to collect waste as it is excreted through this opening. The term ostomy is commonly used metonymically to refer to the ostomy, stoma, and ostomy bag, and I use this shorthand throughout this book.

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5. There are also two other common types of ostomies: urostomies and gastrostomies. Urostomies are surgically created openings in the abdomen through which urinary waste is excreted. Gastrostomies are surgically created openings in the stomach. My focus in this book, however, is on gastrointestinal ostomies for the lower GI tract: colostomies and ileostomies.

6. While the term ostomate is used within biomedicine to refer to anyone who has an ostomy, the term has also gained particular rhetorical traction as an activist identity for those living with ostomies. As I’ve described elsewhere (Kessler, 2016), many people living with ostomies choose to self-identify as ostomates as an activist and celebratory identification with their ostomies. Many others, however, create material and discursive distance between themselves and the ostomy by identifying as someone with an ostomy or as someone who wears an ostomy.
Ostomy surgery, as Julia learned firsthand, is necessary when all or part of the colon, rectum, and/or small intestine is removed because of injury, scarring, or disease like cancer or inflammatory bowel disease (IBD). An ostomy enables the evacuation of waste when these digestive organs have been damaged, removed, and need to heal after injury or surgery. About 100,000 new ostomies are created annually in the US, adding to the estimated 750,000 people who already have ostomies (United Ostomy Association of America [UOAA], 2016). For many people, ostomies are permanent, placing them in the category of chronic conditions. For others, ostomies are considered temporary, which means that after weeks, months, or even years, the ostomy can be surgically reversed, enabling the person to evacuate waste through the rectum and anus. That said, even when ostomies are temporary, research has suggested that many of the lived experiences are similar to those with chronic conditions (Follick et al., 1984). In Julia’s case, her doctors found a large cancerous tumor in her colon, so she underwent surgery to remove it. Along with that tumor, part of Julia’s colon needed to be removed, which meant that she needed an ostomy to excrete digestive waste.
Julia’s story for the Tips campaign mentioned that she underwent surgery but primarily emphasized the colostomy bag she “hated” (CDC, 2015a). Throughout her commercial, Julia explained that she hated her ostomy because she was constantly worried that her ostomy bag would come loose and leak (digestive waste). These fears led her to isolate herself at home where she could deal with her ostomy privately. By emphasizing her extremely negative experiences with her ostomy, Julia’s story served as a warning to viewers: if you don’t want to end up like Julia—that is, with an ostomy—then you must quit smoking.

Julia’s commercial itself offered important insight into the very lived experiences with chronic conditions that I was initially interested in investigating, but it’s the controversy that quickly surrounded Julia that serves as one key impetus for this book. Within just a few short days of the public release of Julia’s story, over 10,000 people had signed a petition calling for the CDC to remove Julia’s video from the national airwaves (Rund, 2015). In addition, several national health-related organizations sent public letters issuing the same call. The reason? Stigma. Thousands of people, many of whom live with chronic GI conditions and ostomies, argued that Julia’s story not only mischaracterized life with an ostomy; worse, it spread stigma.

I initially saw these responses and critiques on my own social media accounts but quickly discovered that the backlash against Julia’s story was much bigger than my own networks. Across the responses, people shared their own stories about life with ostomies and chronic GI conditions such as cancer, Crohn’s disease, ulcerative colitis, short bowel syndrome, and irritable bowel syndrome. Notably, these stories were drastically different from Julia’s. They praised ostomies as lifesaving surgeries and technologies. They celebrated the lives that were enabled and empowered through ostomies. And they resisted Julia’s stigmatizing depiction of ostomies that suggested ostomies always leak and are universally disabling (Burns et al., 2015).

As it unfolded, I followed this controversy closely and became increasingly captivated by the different ostomy stories being shared and the central role stigma played across them. Stigma seemed to be both perpetuated and challenged within these stories, so I began to hypothesize the role stories played both in sharing lived experiences with chronic conditions like ostomies and in de/stabilizing stigma. Julia’s story highlighted the negative shift she experienced in the meaning of her life, self, and body once she had an ostomy. For Julia, experiences with leaks and social isolation negatively influenced her sense of self and ostomy, so much so that she hated her ostomy more than any of her other cancer-related experiences. In contrast, the stories shared by people protesting Julia’s commercial focused on the experiences made possible
by ostomies like leaving the hospital after long stays or eating favorite foods again. These experiences, unlike Julia’s, positively shaped the meaning of ostomies. Across the stories, I noticed that as people develop, are diagnosed, and live with chronic conditions, the meanings of themselves, their bodies, and their conditions are often transformed in profound ways through a diverse mix of influences at work within individuals’ lived experiences including cultural expectations, norms, material forces, and structures (e.g., bathroom location and access, medical technologies, pharmaceuticals, feces), public and private stories, language used by healthcare providers, and many others. The preliminary insights I gleaned from this controversy steered my research into chronic conditions and stigma toward ostomies and chronic GI conditions as well as the stories people tell about their experiences with such conditions. Before Julia’s commercial aired, I was already invested in GI-related chronic conditions because of my own lived experiences with Crohn’s disease; however, Julia’s story and its responses confirmed chronic GI conditions as an important site for rhetorical study.\footnote{See also Vidali (2010, 2013).}

Consequently, I began trying to map the controversy surrounding Julia onto the research literature on stigma across fields including RHM. Previous research in sociology, nursing, and social psychology affirmed that ostomies and related GI conditions, like other chronic conditions, are highly stigmatized (see, e.g., Frohlich, 2014; Smith et al., 2007). Research within RHM has also indicated that the rhetorical theorization of stigma is both a priority of the field and an important area for future work, with research to date demonstrating that stigma is a highly rhetorical phenomenon, affecting a speaker’s credibility and agency.\footnote{See, for example, Johnson (2010) and Molloy (2019).} However, I was left wondering how exactly Julia’s story spread stigma. What about her story of her own experiences propelled stigma? How could ostomies, described by many as lifesaving, be so stigmatized and feared that the CDC thought they could persuade people to quit smoking? What could these stories tell us about stigma’s rhetoricity and life with chronic conditions? In attempting to answer these initial questions, I realized that stories like the ones shared by and in opposition to Julia’s have much to tell us about the nexus of stigma, chronic conditions, lived experiences, and persuasion. Therefore, this book begins with the idea that the stories people tell about their experiences with ostomies and chronic GI conditions are rich sites for exploring how stigma, specifically surrounding chronic conditions, is rhetorically perpetuated and challenged.
Rhetoric of Stories, Stigma, Lived Experiences

Stories in health and medicine are powerful. They help us navigate illness, build communities, and make sense of our lives and experiences with disease, death, and acute issues. Researchers from fields ranging from narrative medicine and medical sociology to literature and RHM have long been drawn to the power and role of health and medical stories. As Siddhartha Mukherjee (2010) wrote in *The Emperor of All Maladies*, “Medicine . . . begins with storytelling. Patients tell stories to describe illness; doctors tell stories to understand it” (p. 390). However, stories are more than a starting place; they are one way in which medicine is done and experienced. In one of my favorite lines about the importance of stories in health and medicine, Dr. Lewis Mehl-Madrona (2007) explained the rhetorical work stories do for healthcare providers: “When people don’t believe our stories, they won’t follow our treatments. Instead of using terms such as noncompliance or lack of adherence, we could just say the story we told didn’t go over very well” (p. 7). Listening to symptoms, reading CT scans and blood workups, diagnosing, treating: each of these culminates in a story for and about patients that drives how they interact with their bodies and with medicine. Indeed, stories are central to the practice and experience of disease, illness, and medicine, both within and beyond the sphere of Western biomedicine.

In the public sphere, stories do important, complex, value-laden work as they “document and catalogue experience” with illness so that it can be shared and reported to others (Segal, 2012, p. 298). Moreover, stories, particularly about embodied conditions, provide templates for understanding our own bodies and experiences. That is, they generate roadmaps that help us navigate what it is to be diagnosed and endure treatment for cancer, be a person with autism, take metformin or birth control, or undergo an MRI. When we’ve heard others’ stories, we can use them to frame our own health and medical encounters. As Arthur Frank (2010) put it, stories “work with people, for people, and always stories work on people, affecting what people are able to see as real, as possible, and as worth doing or best avoided” (p. 3; emphasis original).

Similarly, Jeff Bennett (2019) has pointed out that “narratives, anecdotes, and myths are decisive in their ability to energize a patient’s feelings, guide medical deliberations, and arrange classificatory hierarchies” (p. 9). In other words, stories are persuasive; they inscribe a “hierarchy of values” (Segal, 2012, 9. Here, I’m drawing on M. Remi Yergeau’s (2018) discussion of how narratives (in their case, narratives about autism) “structure” as they “mediate” experiences in the world (p. 9). I also am building on discussions within narrative medicine that, in particular, inform my thinking here. See Mehl-Madrona (2007), Frank (2010), and Charon (2006).
Julie-Ann Scott (2018) summarized that “telling, listening, and interpreting stories enables human beings to share experiences, to access how life is lived through bodies other than our own” (p. 4). Stories tell us how to make sense of and give order to a variety of conditions, diseases, and medical tests; how to define wellness, health, and sickness; what it is we might expect as we navigate our embodied selves and lives.

Accordingly, rhetoricians of health and medicine have been drawn to the persuasion and power of stories in health and medical contexts (see, e.g., Arduser, 2014; Bennett, 2019; Berkenkotter, 2008; Johnson, 2014; Segal, 2012; Yergeau, 2018). Stories are not only a valuable mode of rhetorical activity; they also enable us to engage with people, conditions, and experiences on the terms of the storytellers themselves (Frank, 2010; Jones, 2016; Mol, 2002). For these reasons, this book is focused on exploring what I call stigma stories—stories that rhetorically engage, promote, or resist stigma—in order to “access how life is lived” through bodies with chronic conditions (Scott, 2018, p. 4).

Understanding and studying stigma stories first requires some important definitional work regarding stories, stigma, and my approach for understanding and studying each individually and together. I’ve so far outlined the rhetorical work that stories do within the expert and public spheres of health and medicine, but that doesn’t entirely explain what exactly a story is. In the next sections, I take time to unpack stories and stigma, and then I situate those concepts within my own approach grounded in RHM and disability studies.

**Story**

Experts spanning many disciplines agree that stories are highly powerful and valuable; however, what counts as a story or how to identify one if you see or hear it is another matter altogether. In general, we have an intuitive sense of story; it’s a term we use in everyday life to describe a variety of discursive and sometimes material events. Because stories are everywhere, we categorize them into a variety of kinds and types (e.g., fictional, nonfictional, news, histories and herstories, and, of course, genres of stories like comedy, tragedy, quests). These categories help us set expectations and find our way through different kinds of stories. Too, we often read stories not only for content but

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10. The Tips from Former Smokers campaign was and continues to be highly successful in its smoking-cessation efforts. This campaign is why Julia’s story was shared.
also for stylistic and literary elements like allegory, tone, characters, diction, or metaphor.

While genre and stylistic categories provide one way to make sense of stories, I’m more interested in what stories do in the world. Therefore, I approach stories as rhetorical objects or entities that participate in meaning-making and that are entangled with contexts, practices, time, space, culture, matter, and power. Figuring stories as rhetorical objects is an important first step for delineating stories as data for my research into stigma; however, the parameters of (stigma) stories—that is, where a story starts and stops, how to know what a story is and isn’t—take additional consideration, as many fields have worked to concretize the characteristics of stories. Notably, in the interest of scope, my discussion of stories is limited to a handful of theorizations of stories specifically in the contexts of health and medicine.

Among these, the field of narrative medicine is perhaps most relevant beyond my own field of RHM. Narrative medicine is "defined as medicine with narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (Charon, 2006, p. vii). In other words, narrative medicine has emerged and taken residence as a field complementary to medicine itself: specifically, a partner field that situates narrative as a central part of medicine's knowledge, practice, and ethics. In part, narrative medicine developed in response to the acknowledgment that patients’ stories of what it is like to live with a condition had much to offer biomedicine’s understanding and practice of medical care. Placing patients’ stories within biomedicine has led narrative medicine to ground itself interdisciplinarily in fields like literary studies and methods like narratology in an effort to meaningfully engage with stories.

For those who employ narratology and literary frameworks to conduct narrative medicine work, stories are defined by core features, a mix of which needs be present for something to qualify as a story. For example, Frank (2010) delineated a basic structure or set of story features: abstract, orien-

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11. For more on rhetorical objects, and the ways in which they are not exclusively discursive, see David Grant (2017). In "Writing Wakan: The Lakota Pipe as Rhetorical Object," Grant examines the Lakota pipe as a rhetorical object and demonstrates the mix of agential forces that are at play within a rhetorical object—material, discursive, experiential, human, animal, social, historical.

12. In addition to the specific theories/approaches to stories I mention in the text, Natasha Jones's (2016) work on narrative inquiry for technical communication and human-centered design also broadly informed my thinking about stories. Properly and fully discussing Jones’s work is beyond the scope of what I could cover in this chapter; however, for those interested in a feminist and technical communication approach to stories and narrative, I highly recommend Jones's treatment of narrative inquiry.
tation, complicating event, resolution, evaluation, and coda. These features likely show up in the stories I collected and share throughout this book; however, these features did not guide my data collection or analysis as I engaged stigma stories. Frank further articulated several “capacities” or recognizable elements that enable the work of stories, what they do and how they do it; thus, these capacities provide another framework under which I may have delimited stigma stories. These capacities include trouble, character, point of view, suspense, inherent morality, resonance, symbiotic, shape-shifting, truth-telling, imagination. Noting that not all capacities need be present to qualify as a story, Frank clarified that several must be engaged in order for a story to, well, be a story. Again, while I find this characterizing helpful, I didn’t operationalize or limit my story-gathering by these capacities. In retrospect, I wouldn’t be surprised to find that these capacities define the stigma stories shared in these pages; however, in the selecting and studying of stigma stories, capacities or particular literary features did not drive my approach because my focus was on the lived experiences that were shared within stories and how those experiences animated how ostomies and chronic GI conditions were made to mean within specific life events and moments.

Much like Frank, Rita Charon (2006), considered a founder of narrative medicine, has focused on broad elements that characterize a story or narrative, including “a teller, a listener, a time course, a plot, and a point” (p. 3). Charon’s definition leaves the scope of “story” or “narrative” expansive, which matches her sense that stories and narratives are both discrete, with a clear scope (e.g., a patient’s story about how she broke her leg), and broad, meta, and layered over the course of many small stories, interactions, and experience (e.g., a patient’s story, usually presented over many interactions and stories, that explains their attitude toward medicine). In accordance with Charon’s definition of story, narrative medicine is frequently focused on clinical encounters and the treatment/care of patients within the bounds of biomedical relationships and stories shared between patients and healthcare providers. While certainly there are stories specific to patient–provider interactions and the physical bounds of clinics and hospitals, the stories shared in this book reach outside the parameters of biomedicine proper. This is in part because experiences with chronic illnesses, GI-related or otherwise, and stigma seep into

13. Across scholars who study stories in the contexts of health and medicine, the terms stories and narrative are used in a variety of ways. Sometimes the terms are interchangeable; sometimes they refer to distinct entities. In my case, I draw on Harrington’s distinction between story and narrative, which positions stories as “living, local, and specific” and narratives as “templates” or “resources from which people construct the stories they tell” (Harrington, 2008, pp. 24–25).
every corner of individuals’ lives, including but moving far beyond the boundaries of biomedicine and interactions with healthcare providers.

Accordingly, Mehl-Madrona’s (2007) work on narrative medicine is helpful for me in that it is expansive in its understanding of borders and contours of medicine. In particular, Mehl-Madrona’s Indigenous approach to stories and healing sees both stories and medicine as far-reaching, crossing cultures, spaces, time, experiences, and entities. Much like Charon, Mehl-Madrona is committed to the field of narrative medicine and its focus on stories as a way to expand the purview and practice of medicine so that it more fully considers the humanistic dimensions of medicine, treatment, and care. However, unlike Charon, Mehl-Madrona has not defined or confined stories by particular literary or textual features like plots or characters, though he does provide some characteristics that align with Charon’s and Frank’s focus on stories’ literary elements. Instead, Mehl-Madrona approached stories as a way to exceed the limitations of Western biomedicine and its focus on statistics, randomized controlled trials, pharmaceuticals, and Western ways of knowing. This isn’t to say that Mehl-Madrona outright rejected the philosophy and practices of Western biomedicine; rather, he saw it as one way of doing and knowing health and healing, not the only way. Stories, for Mehl-Madrona, united Western biomedicine with individuals’ lived experiences, cultures, language practices, knowledges, and belief systems and place Western medicine among a constellation of relevant entities that inform our understandings of health and medicine.

Thus, stories are a way to connect what often appears as disparate or conflicting approaches to bodies, afflictions, and healing. Mehl-Madrona (2007) explained that healthcare providers and healers “treat by telling a story” (p. 6). Narrative medicine has presented one pathway to avoid divorcing lived experiences from healthcare and to place biomedicine among agents within the experience and process of illness and care. Even when it comes to a medical fact, Mehl-Madrona “prefer[red] to call that an explanatory story rather than a fact, because it reminded [him] that there are other ways to put together the same observations and even better stories that could emerge over time” (p. 11). Stories, therefore, connect and describe experiences, embodiments, responses to treatment, dialogues about a condition or ailment, biomedicine’s diagnostic tools and procedures, and all other factors that give way to an illness’s presentation, symptoms, and cures. Mehl-Madrona’s approach to stories guides my own, particularly in its willingness to be open to the variability of stories, its commitment to lived experiences, and its acknowledgment that stories are among the most fundamental units of meaning-making within health and medicine.
The conceptions of stories presented by narrative medicine scholars serve as both foundation and context for my own work in stories. In particular, I agree that stories are central to health and medicine and that such stories often have consistent features (though I’m not focused on mapping those features). However, unlike these narratology and narrative medicine scholars, I approach stories from a rhetorical perspective, particularly one guided by praxiography and multiple ontologies theory (as I explain more later in this chapter and in chapter 2), which necessarily means that my definition of and approach to story departs from narrative medicine and narratology in important ways.

Stories, in my conception, are defined less by features and more by the work they do. As Frank (2010) has described, despite his taxonomies for stories, “stories are too lively and too wild to be tied up” (p. 1). Thus, treating stories as rhetorical objects allows flexibility in the boundaries and features that define a story and, in turn, orients me toward the events and experiences shared by storytellers through their stories. Experiences and meaning-making drive the boundaries of a given story, and, depending on the experience(s) shared, and the meaning made from that experience, stories can take many shapes, include diverse elements, and vary in length and scope. For example, some of the stories in this book take the form of several textual paragraphs in a blog post, while others are Instagram posts with a handful of photos, a few lines of text captioning, and a series of hashtags. Other stories show up in interviews with people living with ostomies and chronic GI conditions, in news articles, on TV shows, and in public health campaigns. To be clear, some of these stories are from actual patients’ lives while others are fictionalized stories told in public media. I chose to include this diverse mix of stories because they all influence the meaning-making that happens in the public sphere about ostomies and chronic GI conditions; thus, they all participate in the de/stigmatization of these conditions. In my search for stories, I explored any spaces and ways that shared lived experiences with ostomies, chronic GI conditions, and stigmatization.

Rather than get caught up in finding the beginning, middle, or end of stigma stories or identifying characters or plots, I focus more on understanding the lived experiences being shared and how those experiences worked to make meaning about ostomies and chronic GI conditions. This often meant that stories were bound by particular events (e.g., a hospital visit, an interaction at a grocery store, a first date), but sometimes stories expanded across multiple moments. In either case, I listened for how and where the storytellers drew boundaries around their own experiences and explained how particular event(s) were meaningful in their lives. This open approach to stories was,
of course, messy and perhaps sometimes inconsistent in the size or shape of data collected, but it allowed me to be both flexible and inclusive in my effort to understand how meaning is made about ostomies and chronic GI conditions, particularly how they were made to be stigmatized in space and time. In this way, the messiness was a strength rather than a limitation. It prevented me from layering preconceived ideas about where lived experiences and meaning-making started and stopped, and it allowed the storytellers to be actively involved in generating the data, findings, and insights presented throughout this book.

Too, stories, in my approach, are both material and discursive and include a variety of agential, rhetorical entities—human, nonhuman, social, political, discursive—at work within stories. That is, stories are always emergent through a range of entities that take shape as material, discursive, political, and social as they are practiced or experienced in space and time. What I’m getting at here is that although stories show up in this book as textual (by virtue of this book being textual itself), the stories are always more than text in that they present lived experiences that are fully material and always embodied. In taking this position toward stories, I’m also drawing on Cheryl Mattingly’s (1998) work on the narrative structure of experience. Stories, Mattingly has argued, are “informant accounts” that provide “access [to] events” and “a way to learn something new about [the storyteller’s] experiences and beliefs” (p. 7).

Treating stories as informant accounts and thus storytellers as informants helped me approach interview participants, writers of blog posts, or social media influencers, as present and active agents throughout my research and write-up, rather than as passive data points made invisible in the name of objectivity or rigor. This further contributes to my positioning of stories as rhetorical objects not only in data collection and analysis but in presentation as well. The informant storytellers and their stories show up throughout the book as fully as possible and in the storytellers’ own words as much as possible. In this way, I honor their lived experiences and stories on their own terms (which, as I explain later, is central to the work I do here) and continually position stigma as something done in practice, not inherent in ostomies or chronic GI conditions. As I show, this focus on events and stories as informant accounts is imperative to positioning stigma not as an inherent characteristic but as rhetorical itself.

Stories about life with a stigmatized condition or identity provide a way to unearth how, where, and why meanings, like stigmas, emerge and take hold. Indeed, stigma stories grant access to lived experiences and events that might otherwise be inaccessible or invisible; at the same time, they allow storytellers themselves to articulate how lived experiences were (made) meaningful. While perhaps mutable and messy as units of analysis, stories are poised for a rhetorical study of stigma because stigma too isn’t static or straightforward; the flexibility and openness of stories is conducive to studying a phenomenon as elusive as stigma. Stories, when approached as experiential and rhetorical, are a prime way to understand how stigma emerges and becomes powerful.

As rhetorical objects, stories are not just representations of lived experiences; they are themselves a piece of those experiences. Part of having an ostomy or chronic condition is having to tell people about it, to live through and with the stories that share experiences and make meaning. Paying attention to stories rhetorically means listening to them as accounts of how people navigate the material-discursive practices and norms that define and often exclude and oppress people and their embodied selves.

As Malea Powell (2012) has importantly shown, stories are both about us and of us; the stories we choose to tell, in turn, tell us who we are, what we are about, and where we are going (p. 389). Stories, Powell further reminded us, “constellate,” coming together in place and through time to make meaning among interconnected experiences and events (p. 388). In this way, stories are epistemological—they reveal our ways of knowing and the ideologies and entities rooted in those practices. And they are ontological—they drive our ways of being in the world and what we do both as individuals and in communities (Powell, 2012). Powell’s work is illustrative for my definition of stories in that it positions stories as essential spaces of meaning-making. Powell observed that stories “matter,” “have an effect,” and are “real” (p. 390). In these ways, stories are not only spaces to share events and experiences but spaces of potential transformation. They help illuminate practices and values that often become so engrained that they become invisible, and this illumination helps us track our present and more actively determine our future. Building on Powell, this approach to stories enables me to understand what it is like to live with an ostomy and chronic GI condition and face stigma, how stigma is done within specific practices, and how it is being countered. Those same stories, thus, point to the paths and practices that can transform stigmatizing

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15. I choose to use ambiguous collective personal pronouns here deliberately. The we is flexible and responsive. We might be people with ostomies and chronic GI conditions. It could be rhetoricians or scholars interested in health and medicine. We could be Americans or all of humanity. All these collectives fit the point I’m trying to make here.
experiences and the very rhetorical ecologies that enable those experiences to be possible and become powerful.

Consequently, theorizing stigma through stories is both explanatory and interventional. In other words, in theorizing stigma through stories, I am deliberately aligning with rhetoricians J. Blake Scott and Catherine Gouge's (2019) suggestion that theory-building, especially in RHM, is not only “inventional” but “an act of care.” Theorizing stigma through stories and lived experiences enables me to study how stigma shows up in the lives of people with chronic GI conditions and, in doing so, helps me find ways to “thoughtfully attend to and car[e] for” the embodied, lived experiences shared within those stories (Melonçon & Scott, 2018, p. 12). Thus, the kind of theory-building I aim to do through stigma stories is about finding ways to privilege and attend to what impacts “those with the most at stake” (Scott & Gouge, 2019, p. 191). This book undertakes such work by privileging the stories and experiences of the millions of people living with ostomies and chronic GI conditions and by drawing from those experiences and stories to theorize stigma in ways that will hopefully impact those living with chronic GI conditions by helping to destigmatize. In turn, I hope the theory-building and analysis reported in the coming pages is generative for future work that can privilege the millions more with other stigmatized chronic conditions.

Stigma

With this conception of stories in mind, my next step in foregrounding stigma stories is defining stigma itself, which, like stories, evades easy or clear definition. Of course, extensive research has investigated stigma, both within and beyond rhetorical studies, and, as I’ve already explained, my project is grounded in RHM but also guided by previous work in disability studies. However, to fully situate my rhetorical approach to stigma, I begin with sociologist Erving Goffman. Goffman’s (1963) seminal book *Stigma: Notes on the Management of a Spoiled Identity* occupies a central role in most contemporary conversations regarding stigma. As I’ve mentioned, stigma, according to Goffman, is “an attribute that is deeply discrediting” (p. 3). While this basic definition from Goffman is often operationalized in contemporary stigma research (a problem I elaborate on later), Goffman offered a more nuanced theorization of stigma, centered on the relational processes like conversational encounters that stage stigma (p. 13). Goffman argued that the emergence and management of stigma occur in interactions between what he called “normals” and “stigmatized.” With a focus on these interactions, Goff-
man suggested that stigmatization occurs when any attribute deviates from what has been socially deemed normal. ¹⁶ Difference and stigma become inter-changeable in Goffman’s theory; any difference from the normal naturally warrants and facilitates stigma.

Building on Goffman’s stigma theory, disability studies scholars have advanced the concept of stigma, particularly by resisting the idea that stigma is inherently synonymous with difference and by questioning how particular characteristics become stigmatized (see Coleman, 1986; Garland-Thomson, 1997). According to much work in disability studies, stigmatization is a relational and highly contextual process used to “categorize differences and impose some kind of meaningful order on experience” (Garland-Thomson, 1997, p. 31). More specifically, scholars have argued that stigma is a social process that “infuses negative value” by identifying particular objects, bodies, persons, identities, and characteristics as different and problematic (Garland-Thomson, 1997, p. 31; see also Coleman-Brown, 1986; Kafer, 2013; Wendell, 2001). Stigmatization, Rosemarie Garland-Thomson (1997) has summarized, “is an interactive social process in which particular human traits are deemed not only different, but deviant” and through which concepts like neutral, normal, and legitimate are defined, enforced, and calcified by dominant social groups and systems (p. 31; emphasis added). In essence, stigmatization deems some entities normal, and others undesirably different (Kafer, 2013). Thus, stigma is not inherent but a meaning-making activity that gives order and value, is enabled by power, and propels fear, repulsion, and avoidance (Coleman, 1986; Coleman-Brown, 2017; Garland-Thomson, 1997; Kafer, 2013; Wendell, 2001).

Consequently, rhetoric, as a study of meaning-making and power, has much to offer theorizations of stigma. In alignment with disability studies frameworks of stigma, rhetoricians have forwarded similar stigma theories that focus on the processes in which difference has been conflated with problematic deviance (Johnson, 2010; Rothfelder & Thornton, 2017). Jenell Johnson (2010) has argued that a rhetorical approach to stigma is one that examines “stigmatization as a dynamic social process rather than an individual attribute” (p. 462). Moreover, rhetoricians have positioned stigma as a “rhetorical phenomenon” (Rothfelder & Thornton, 2017, p. 362) and as “an object of rhetorical criticism” (Johnson, 2010, p. 462). Stigma, rhetorically understood, is a “social force enacted through language and rooted in culturally and historically contingent values” (Johnson, 2010, p. 462). Thus, a rhetorical study

¹⁶ Goffman (1963) argued that “normal” tends to mean White, healthy, heterosexual men (p. 128). For more discussion on this, see Garland-Thomson (1997, p. 3).
of stigma, informed by disability studies, searches for the processes by which stigma is made possible and powerful as well as the processes by which stigma is fought. This has predominantly led rhetoricians to focus on the relationship between stigma and credibility and to consider how being stigmatized impacts a stigmatized individual’s ability to be heard, valued, trusted (Johnson, 2010; Molloy, 2015). For example, Johnson studied the “rhetorically disabling” effect that stigma had when the public learned that Senator Thomas Eagleton (the running mate of 1972 US presidential candidate George McGovern) had previously been treated for depression, which was credited for McGovern’s loss to Richard Nixon. Cathryn Molloy (2015, 2019) has also illustrated how stigmatization works to discredit people with chronic mental illnesses. Molloy (2015) concluded that “stigma takes potential rhetors out of the polis altogether and renders them less-than-fully-human” (p. 159). Additionally, as M. Remi Yergeau (2018) demonstrated, neurodivergent individuals are frequently stigmatized and dehumanized because their words and actions are cast as unintentional and involuntary (p. 10). Yergeau showed that under such logics, the stigmatization of neurodivergence doesn’t simply negate credibility; it positions neurodivergent people outside the realm of rhetoricity or meaning-making altogether.

While I recognize stigma’s key rhetorical role in establishing or negating credibility for rhetors, I’m most interested in extending this previous rhetorical work on stigma by focusing more specifically on the “dynamic processes” and practices in which “differentness” is made to mean undesired, abject, disgraced, and deviant (Johnson, 2010). As the coming chapters demonstrate, for people living with ostomies and chronic GI conditions, stigma doesn’t always negatively affect a person’s ability to speak or to be considered credible or trustworthy. In fact, in some stories I explore in this book, stigma actually bolsters the ethos of people living with ostomies and their stories. Most often, though, stigma discredits the very existence of people living with ostomies and related conditions or, as Molloy (2015, 2019) described, renders these people “less-than-fully-human” (2015, p. 159). Examining the stories and lived experiences of those with ostomies and chronic GI conditions, I argue, productively expands our understandings of the rhetorical processes and power of stigma.

Accordingly, I advance a rhetorical approach that positions stigma as both part and result of meaning-making practices, especially stories about living with ostomies and chronic GI conditions. In this sense, stigma is enmeshed in material-discursive rhetorical systems composed of persuasive practices like the way people talk to each other, tell stories, experience bodies, and engage the world. Stigma is not just a look of disgust or condescending comment; it’s
the absence of a bathroom on every floor and the internal cringe that crawls up your spine reading about poop. Indeed, stigma is a complex, insidious force. Powerful, interlocking, and dominant systems, namely twenty-first-century Western biomedicine but also ableism, sexism, racism, ageism, colonialism, and classism, have led us to believe that there is an optimal, normal, way for our bodies to be. Under these logics, human bodies should perform, look, and exist in particular ways—we should have four limbs; we should grow tall, but not too tall; we should weigh enough, but not too much; we should be White, but if we aren’t, we should act White; we should eat through holes on our faces and shit through holes no one else should ever see. These expectations—what scholars across disciplines have called norms—drive the actions, thoughts, words, and expectations we use to order ourselves and others. When norms are not upheld, stigma emerges to make us toe the line. Stigma, in other words, is enacted when these complex and interlocking material-discursive rhetorical systems attempt to (re)assert stability, stability that privileges and demands the dominant norms and ideals.

RHM, Disability Studies, and Stigma Stories

As a rhetorical project, this book traces how ostomies and related chronic GI conditions are stigmatized. That is, how such conditions—through and within material-discursive systems—are made to mean discreditable, undesirable, disgusting, unworthy, subhuman. How does stigma operate rhetorically? What meaning-making practices de/stigmatize chronic conditions? What role do stories play in those meaning-making practices, and how can stories help in studying stigma? How might rhetoric help us trace, understand, and challenge stigmas surrounding ostomies and GI conditions, as well as other conditions, technologies, and experiences with health and medicine?

In attending to these questions, I study stigma through people’s lived experiences as shared within stories. Thus, I am also forwarding a particular

17. While I could cite any number of scholars here from across disciplines, I refer readers to Alison Kafer’s Feminist, Queer, Crip (2013) as a primer for considering the variety of scholarship that has interrogated the relationships between these systems and their effect on bodies.

18. Throughout the book, I capitalize both Black and White in reference to race. In doing so, I’m trying to give presence to these categories as rhetorically significant. I’m also trying to resist suggesting that White is the norm when, really, it is “a specific social category” that brings with it clear social and material privileges (Ewing, 2020). At the same time, I capitalize Black to honor and recognize the “personhood, culture, and history” of Blackness (Mack & Palfrey, 2020).
rhetorical approach for studying lived experiences in contexts of health and medicine, as well as chronic conditions, through stories. Although research, particularly in health communication, sociology, and nursing, has theorized and explored stigma, I argue that rhetoric, particularly RHM, can provide important insight regarding health-related stigmas and chronic GI conditions, including ostomies, because rhetoric is not just a diagnostic or critical tool. RHM is committed to both making and adapting knowledge, often in an effort to intervene or ameliorate (Scott & Melonçon, 2018, p. 6). Or, as Caroline Gottschalk Druschke (2017) put it, “rhetoric is our means of negotiating life in common” (p. 3). The tools of RHM can not only help acknowledge and understand stigma but also help (re)negotiate our life in common so that stigma can be overcome altogether.

As a way to “make sense of the world,” (Koerber, 2000, p. 61; see also Druschke & McGreavy, 2016), rhetoric is a rich tool for understanding the processes and practices by which both norms and stigmas materialize, circulate, change, and collapse. Specifically, rhetoric examines the persuasive practices that create meaning in the world, meaning that is in flux, highly contingent, and contextual (Bitzer, 1968; Johnson, 2014; Teston, 2017). For my research, rhetoric offers explanatory power for making sense of stigma, especially as stigma is established, documented, navigated, and shared within stories. As rhetorician Judy Segal (2005) has outlined, RHM “illuminat[es] and recast[s] problems in health and medicine” by mapping how meaning is made in health and medical contexts (p. 1). Moreover, rhetoric’s attunement to power (Dolmage, 2014; Johnson, 2014) is especially useful for understanding stigma in the contexts of chronic conditions. Rhetoricians recognize persuasion and power as intimately intertwined. In other words, RHM and rhetorical studies more broadly examine “power in action, particularly the power of meaning” (Johnson, 2014, p. 12). In line with this conception of rhetoric, the study of stigma that unfolds in this book focuses on the practices and processes in which particular conditions, identities, technologies, and bodies are staged and made to mean undesirably different through powerful, persuasive actions.

Importantly, though, when I say that stigmatization is enacted through rhetorical processes, I am not only referring to interactions between individuals, as Goffman might have it. Instead, drawing on both RHM and disability studies, I am committed to exploring how a variety of practices, systems, and logics (e.g., ableism, medicalization, sexism) enable stigmatization. Central to

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19. See, for example, Smith (2007, 2014).
20. See, for example, Kelly (1992) and Scambler (2004).
21. See, for example, Garcia et al. (2005) and Joachim and Acorn (2000).
distinguishing stigma as a rhetorical process is accounting for the distinctions and relationships among stigma, disease, disability, medicine, and systems of power. As I discussed at the outset of this section, disability and stigma have often been framed as interchangeable, in part because disabilities are so frequently and compulsively stigmatized. Conflating disability with stigma or assuming that being disabled automatically warrants stigmatization is highly problematic, and it highlights the complex nuances that must be recognized between disability, illness, stigma, and medicine. Untangling these relationships, especially in the context of chronic GI conditions, provides necessary groundwork and is essential to the theory-building project of this book. Therefore, in the next paragraphs, I take a step back to first explore tensions between disability studies and biomedicine by offering a short overview of the medical and social models of disability and, relatedly, by discussing the nuances between disability, impairment, and illness. Then, I elucidate how these models play out for a rhetorical study of stigma related to chronic GI conditions and ultimately position my theory-building work at the intersection between political/relational models of disability and RHM.

While there are many models for theorizing disability, the medical and social models of disability are especially relevant to my theorization of stigma. These two models provide an important foundation for understanding the relationship between disability and stigma, and they also help me tease out the nuances between chronic illness and disability. For starters, the medical model is perhaps the most pervasive understanding of disability. Despite its name, the medical model does not simply refer to the way medical providers and experts approach disability; instead, it is “the positioning of disability as an exclusively medical problem and, especially, the conceptualization of such positioning as both objective face and common sense” (Kafer, 2013, p. 5). In other words, the medical model positions embodied difference as abnormal, problematic, stigmatizing, and unequivocally in need of fixing. That is, it places disability and illnesses as problems within individuals that can and should be solved through Western medicine. Within a medical model, those with disabilities and illnesses are expected to perpetually attempt to (re)solve their embodied differences and to normalize because, ultimately, the goal of Western medicine is to prevent, minimize, invisibilize, overcome, and ideally eradicate disease/disability. As Susan Wendell (2001) explained, the “identification [of disability with illness] contributes to the medicalization of disability, in which disability is regarded as an individual misfortune, and people with disabilities are assumed to suffer primarily from physical and/or mental abnormalities that medicine can and should treat, cure, or at least prevent” (p. 17; see also Oliver, 1996). In this medicalized view, illness and disability
become definitional opposites of normal and, as Goffman (1963) reminded us, anyone or any body that is not “normal” is “deviant” and thus at risk of stigmatization. Bodies and minds that deviate from what has been deemed “normal” are cast as diseased, disabled, deficient, and in need of the remedies that medicine can provide (Kafer, 2013).

Importantly, disability studies scholars and disability activists have shown that the medical model can be an extremely harmful way to conceptualize disability. The idea that Western medicine itself can or should attempt to normalize bodies is a fraught endeavor that problematically figures those with embodied differences (read: most all of us) as undesirable, inadequate, and in need of fixing. This isn’t to say that all of Western medicine is inherently villainous; rather, its underlying ideologies help create a rhetorical environment conducive to the stigmatization of disabled and different bodies. When people with illness and/or disability refuse to or cannot be cured and consequently fail to normalize, stigmatization often results. All of this is to say that the relationship between illness, disability, and stigma is influenced extensively, and often negatively, by paradigms of Western medicine.

In response to the medical model of disability, disability studies has advanced the social model, which both argues that disability is not a medical condition to be treated or cured and focuses on the cultural, social, physical, political, and economic forces that oppress people with embodied differences. In other words, the social model of disability “names systems of oppression as the problem, not individual bodies” (Clare, 1999, p. 106). Similarly, Tom Shakespeare (2017) outlined that the social model “defines disability as a social creation—a relationship between people with impairment and a disabling society” (p. 196). The social model ultimately refutes the idea that disabilities are problems within individuals and further rejects the idea that normalization and Western medicine are the most impactful and legitimate ways to address the discrimination and marginalization of disabilities. The social model, alternatively, pivots the site of the problem and the site of intervention away from individuals and toward the ableist systems and structures that create the disability.22

This turn toward the social model, which centers the ableist systems and structures as the source of the marginalization, discrimination, and stigmati-

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22. Buildings that lack wheelchair ramps are a canonical example of structures that create disability. According to the social model, for people who use wheelchairs, it is not their wheelchair that prevents them from entering but the building itself. This is an obvious example. The social model extends in more complicated ways to disabling systems like policies and laws, social attitudes and dominant culture, and access to social services, employment, education, and healthcare.
zation of disability, has been highly useful for illuminating problems with the medicalization of disability. However, central to the social model of disability is the separation of disability and impairment—a distinction that becomes especially troublesome in the context of chronic conditions (Kafer, 2013; Wendell, 2001). Impairment refers to particular embodiments or conditions that affect a person (e.g., Crohn’s disease or paralysis), while disability is conceptualized as the result of systems (both discursive and material) and ideologies that construct some identities and embodiments as not only different but problematically different. As Kafer (2013) has explained, in the social model framework, “impairments aren’t disability, social and architectural barriers are” (p. 7). This distinction between impairment and disability has emerged, in part, in resistance to the idea that all disabled people are sick or diseased. Disability studies scholar and activist Eli Clare (1999) has argued specifically against the impulse “to think of disabled people as sick, diseased, or ill people” (p. 105). He further contended:

Of course, disability comes in many varieties. Some disabled people, depending on their disabilities, may indeed have pressing medical needs for a specific period of time or ongoing basis. But having particular medical needs differs from labeling a person with multiple sclerosis as sick, or thinking of quadriplegia as a disease. The disability rights movement, like other social change movements, names systems of oppression as the problem, not individual bodies. In short it is ableism that needs the cure, not our bodies. (pp. 105–106; emphasis added)

In short, advocates of the social model argue that disability is more than a diagnosis or impairment, and that disability itself does not require medical but rather social intervention.

Ultimately, while the social model has been productive in displacing individualized and medicalized understandings of disability, it has made the placing of chronic conditions, specifically, within or outside of disability studies a tricky task (Erevelles, 2014; Kafer, 2013; Wendell, 2001). The social model’s distinctions between disability and illness are rooted in the medical model’s medicalization of disability and the stigmatization and harm that medicaliza-

23. At the risk of being read here as arguing that disability is always perceived as a negative identity or embodiment, I want to clarify that many disabled people reclaim and embrace their disability identity as an act of resistance and empowerment. In such instances, disabled people often still recognize that their disabilities are created through social and structural systems, but they simultaneously celebrate their disabled identities as a means to highlight, resist, and deconstruct those systems.
tion has enabled, not in a desire to exclude those with medical conditions from the landscape of disability justice. Rejecting medicalization and normalization brought on by the social model of disability has been an important step in acknowledging social and structural ableism; however, it leaves those with chronic conditions at a precarious crossroads between medicine and social systems, between impairment and disability. Kafer (2013) has argued:

Asserting a sharp divide between impairment and disability fails to recognize that both impairment and disability are social; simply trying to determine what constitutes impairment makes clear that impairment doesn’t exist apart from social meanings and understandings . . . the social model with its impairment/disability distinction erases the lived realities of impairment; in its well-intentioned focus on the disabling effects of society, it overlooks the often-disabling effects of our bodies. (p. 7)

Further, Wendell (2001) suggested that the social model of disability is predicated on the “healthy disabled . . . whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future” (p. 19). Building the social model of disability on the experiences of healthy disabled people is problematic because it pits illness against disability and elides “those disabled people whose bodies are highly medicalized because of their suffering” (p. 18). These individuals, according to Wendell, evidence the limitations of a strictly social model of disability:

Some people with disabilities are sick, diseased, and ill. Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. (p. 18; emphasis added)

Although the social model has demonstrated that disability is not fully a diagnostic category, scholars like Kafer and Wendell have pushed back on the idea that disability, as an identity or embodied, is entirely socially constructed.
The tensions that emerge between disability and impairment raise important questions for my investigation into chronic GI conditions and stigma. Where do chronic GI conditions and ostomies fit within these models and tensions surrounding disabilities? And what does the answer mean for my study of chronic GI conditions and stigma? Under either the medical or the social models, chronic GI conditions are not neatly or easily categorized as disabled. Some with chronic GI conditions may find medical treatments that allow them to manage their conditions both medically and socially, while others are never fully able to control symptoms or disease, in which case both medical and social consequences typically emerge. Too, many chronic GI conditions are marked by periods of flares and remission, which essentially means that there are symptomatic periods (flares) and asymptomatic periods (remission). This ebb and flow defines living with most chronic conditions but has also prompted disability studies scholars to further question whether chronic conditions should be included under the umbrella of disability (Erevelles, 2014; Kafer, 2013; Wendell, 2001). Under the medical model, this ebb and flow does not readily poise chronic GI conditions to be considered disabilities socially, medically, or legally. The physical manifestation of disease is extremely significant when it comes to socially classifying chronically ill bodies. Those whose conditions are invisible to outsiders are perhaps least likely to be deemed disabled through social or structural means, which can protect them from stigmatization but also exclude them from the benefits of disability communities and activism. At the same time, ostomies’ relationship to disability is complicated in other ways. Unlike some chronic conditions, ostomies require daily management that is not always considered disabling but often is. Further, many people with ostomies also have comorbid chronic conditions such as IBD or cancer that, when compounded with managing an ostomy, can have a profoundly disabling effect. Under a medical model of disability, ostomies and most chronic GI conditions are considered a disability; however, the fluctuating nature of flares/remission as well as the individually specific experiences with ostomies trouble the idea that these those with ostomies are disabled under social models. And, regardless of these models, many people living with ostomies and chronic GI conditions do not identify as disabled, while perhaps just as many embrace disability identities.

24. In the US, Crohn’s disease, one of the two primary types of IBD, is included in the Social Security Administration’s list of qualifying conditions for disability protections and benefits. However, the qualifying criteria for Crohn’s disease are very narrow. Although it wasn’t a primary part of my research for this book, an unanticipated finding was that many people with IBD, while too sick to earn livable wages, struggle to receive disability benefits because they do not sufficiently meet one of the five strict criteria.
Ostomies and chronic GI conditions consequently occupy a liminal space between the medical and social models of disability, which has repercussions when considering stigma. Both social and medical systems participate in the meaning-making of ostomies and chronic GI conditions. For instance, contemporary medicine frequently frames ostomies as a “last resort” or final option in a long series of treatment options. Social systems pick up, extend, and exacerbate these medicalized understandings of ostomies as last resorts, and thus stigmatize and stage them, the rerouted digestive system that comes with an ostomy, and the alternative way of evacuating waste, as problems that need to be corrected or hidden. Additionally, some people with ostomies feel empowered to engage in activities that were impossible prior to receiving an ostomy, especially in cases where preostomy disease rendered a person hospitalized, while others find going out in public with an ostomy to be embarrassing or humiliating. In either of these cases, it is not simply the medicalized experience of having an ostomy that enables or prevents disability, nor is it solely social systems; instead, the entanglement of medicalization, socialization, and individual preferences, experiences, attitudes, and histories participates in the sense of dis/ability.

Acknowledging the complexities surrounding both the medical and the social models of disability, I follow Kafer (2013), who offers a third model, the political/relational model, a “friendly departure from the more common social model” (p. 7) that both contends that “the problem of disability no longer resides in the minds or bodies of individuals but in the built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being” (p. 6; emphasis added) and honors the embodied realities and impairments. To do so, the political/relational model “position[s] disability as a set of practices and associations that can be critiqued, contested, and transformed” (p. 9). I rely heavily on Kafer’s political/relational model because it attends to the social dimensions of disability while deliberately acknowledging the embodied, lived realities that become deeply intertwined with political and social spheres. Additionally, the political/relational model serves as a model for my theorization of the stigmatization of chronic GI condition, which works to move stigma outside individuals and into social, material, discursive, political spheres, while being careful to not lose sight of the physical, often medical, realities of living with chronic GI conditions.

The political/relational model of disability, when combined with RHM, offers a nuanced lens through which I can explore the lived experiences of and the stigmatization of chronic GI conditions and ostomies. Specifically, Kafer’s political/relational model of disability aligns with and facilitates my interest in the practices and embodied experiences of stigma. By situating disability itself
as “a set of practices,” this model helps me situate having an ostomy and living with a chronic GI condition as a set of practices that stage and give meaning to those conditions, the people who have them, and their experiences. Moreover, a political/relational model attends to the lived experiences of people living with embodied differences and recognizes the detriments of situating impairment/disability along the binary of physical/social. Kafer (2013) has suggested that “what we understand as impairing conditions—socially, physically, mentally, or otherwise—shifts across time and place, and presenting impairment as purely physical obscures the effects of such shifts” (p. 7). Thus, a political/relational model positions disability as a collective affinity (see Scott, 1989) that encompasses everyone from people with learning disabilities to those with chronic illness, from people with mobility impairments to those with HIV/AIDS, from people with sensory impairments to those with mental illness . . . because all have been labeled as disabled or sick and have faced discrimination as a result. (Kafer, 2013, p. 11; see also Linton, 1998)

Expanding disability to include this wide-ranging collective extends the reach of disability studies, potentially motivating more people to be extends in and committed to political and social change. Additionally, the more expansive approach to disability forwarded by a political/relational model enables me to sidestep the complex issue of whether ostomies and chronic GI conditions should or need to qualify as disabilities and instead recognizes that critical and activist possibility is opened by inclusivity and by being able to locate my work in this book within both RHM and disability studies. This is not to say that I am arguing that all ostomies and chronic GI conditions are always disabling, nor that all people living with ostomies or chronic GI conditions embrace a disability identity. Instead, I recognize that my examination of stigma through ostomies and chronic GI conditions is richly informed by a political/relational model of disability and, hopefully, has much to add to ongoing conversations at the intersections of RHM and disability studies. Finally, Kafer’s political/relational model is explicitly intersectional, which helps attune my study to the multifaceted ways that stigma is enacted at the compounding intersections of disability, gender, sexuality, race, and age. Together, these foundations catalyze my rhetorical investigation of stigma and my efforts to intervene in the stigmatization of ostomies and chronic GI conditions.

In the remainder of this chapter, I elucidate my approach for studying the rhetorical processes of stigma. Specifically, I introduce my praxiographic
methodology (Mol, 2002) for capturing and analyzing stigma stories (explored more fully in chapter 2). Then, in the spirit of methodological openness, I outline my data collection, which included participant observations, ethnographic interviews, and textual artifacts. In these discussions, I take special care to detail the methodological choices I made, particularly as I collected stigma stories online. Finally, I preview the forthcoming chapters.

**Studying Stigma Stories**

Throughout the coming chapters, I present analyses from a multiyear exploration of experiences with stigma, chronic GI conditions, and ostomies. This research included a variety of qualitative approaches, which I outline in this section, to gather stigma stories. These stories have much to say about what it is like to live with a chronic condition and about the complex processes and systems that de/stabilize stigma. Each chapter, then, shares stories about how living with an ostomy and/or chronic GI condition is done by people, and how a key part of life for these people is dealing with stigma. These stories have much to teach us rhetorically, medically, and socially, and I share them with caution and respect, in the hopes that sharing will empower ostomates and people living with chronic conditions to challenge stigma and provide more robust and ethical understandings of the rhetorical processes of stigma. I explore many stories that demonstrate stigma’s looming presence and impact, but I also explore how many people living with chronic GI conditions are fighting to change the public understanding of what it’s like to live with an ostomy or chronic GI condition. Through these stories, I trace how stigma is done in practice and, subsequently, how ostomies and chronic GI conditions are made meaningful, stigmatized or otherwise, and how these meanings become powerful.

While I’ve so far argued that stigmatization is a rhetorical process, I haven’t been clear about what ramifications that has for how I conducted the research that undergirds this book and my arguments. Importantly, when I argue that stigma is a rhetorical process, I do not mean to suggest that stigma is locked in discourse. Nor do I mean to imply that I explore the language about stigma, which places stigma as separate from language that describes or reports it. Thus, this book makes an argument about how we should study stigma and lived experiences rhetorically. Specifically, I outline and apply a

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25. Scholars within RHM, in particular, have called for more explicit and thorough discussions of method/ology in our publications. For one such example, see the introduction to *Methodologies in the Rhetoric of Health and Medicine* (Melonçon & Scott, 2018).
methodology for studying stigma through a rhetorical engagement with lived experiences (see chapter 2 for this full discussion). Accounting for the lived experiences or practices—terms I use interchangeably throughout this book—that are involved in stigmatization has two important consequences.

First, focusing on practices places stigma as active, something enacted in practices, rather than an inherent quality. Stigma, in this formulation, moves from potential to kinetic energy—from something held in, inherent in, or attributed to certain entities to rhetorical power in motion, emergent within practices and events. In other words, the rhetorical approach to stigma I advocate is one that highlights that stigma is not an ontological precondition of ostomies, GI diseases, feces, mental illness, obesity, disability, skin color, ethnicity, sexuality, or otherwise—a claim that persists across stigma research where stigma is defined as an inherent attribute. As rhetoricians know well, meaning is not fixed but is always in the process of being made. My work, therefore, is grounded in previous arguments that rhetoric is a “verb,” a “performance,” or a “becoming” (Teston, 2017, p. 2). This kind of rhetorical approach to stigma allows me to trace the “processes of becoming” in which stigma emerges, becomes powerful, and is countered (p. 2).

Second, foregrounding experiences shared within stories enables me to account for the range of rhetorical work that stages stigma, which includes but is often not limited to discursive practices. Stigma is not just experienced discursively. As stories throughout this book show, stigma’s meaning is made through embodied, material, psychological, social, and discursive practices. My emphasis here on rhetorical practices and lived experiences, as I elucidate in the coming chapters, is important. I suggest that RHM focus on the practices that enact stigmas, as well as the lived experiences and practices of those who are stigmatized—first as a means of identifying stigma’s sources, and then as a means of changing, intervening in, and upending stigmatizing practices. If our eye is on intervention, I argue, we must focus on the practices in which we see stigma being done and, just as importantly, being undone.

To capture experiences of stigma and other lived experiences with ostomies, I rely on the work of other RHM scholars who have centered rhetoric as embodied and lived in experience. Lisa Melonçon and Erin Frost (2015) remind us that meaning-making (as well as knowledge-making) emerges from diverse sources including traditional biomedical resources, online patient communities, and, I would add, embodied, lived practices (p. 9). After all, our embodiedness “is our means of making sense” of discourse and action (Fountain, 2014, p. 13). Indeed, Fountain (2014) argues (and I agree) that rhetoric and meaning are embodied: “bodies, objects, and discourses, mutually articulate each other through embodied rhetorical actions that give these
objects their meaning” (p. 194). Furthermore, as Candice Rai (2016) aptly summarized:

We might think of rhetoric—not simply as razzle-dazzle style or verbal bullshittery—but also as intimately tied to suasive public narratives and shared material conditions, as a force that not only orders our lives but also animates our bodies. Gets under our skin. Puts things into motion through and beyond human will. Emerging from and wedded to the coconstitutive interactions of language, people, things, matter, and all other presences and forces in the world . . . a theory of persuasion that (includes but also) extends beyond a concern for symbols, symbolic content, argument, language, rational logic, and human intention. (p. 7; emphasis added)

This version of rhetoric is especially apt for investigations of lived experience within the purview of health and medicine because, as RHM knows well, a diverse range of entities—bodies, fatigue, stethoscopes, stool samples, cells, pathology reports, cultural attitudes, patient–provider encounters, belly gurgles, medical charts, to name just a handful—make up the lived experience and meaning-making that occurs within “the networks, ecologies, and activity systems that shape health-related discourse and its effects” (Scott et al., 2013, p. 1). Accounting for rhetoric as embodied and material-discursive becomes especially important for studying lived experiences generally and lived experiences with stigma more specifically (a point I further explore in the next chapter).

Consequently, as I’ve mentioned, I collected and analyzed stigma stories as “informant accounts” (Mattingly, 1998) that “tell about events” and embodied experiences (Mol, 2002, p. 20). I treat stories as reports of how chronic conditions and stigma are experienced and done in practice (Mol, 2002, p. 15). That is, I study stigma praxiographically, as it is enacted or done in practices and shared through stories. Praxiography—an ethnography of practices—was developed by the anthropologist and philosopher Annemarie Mol to study how atherosclerosis, an arterial disease, “is enacted in multiple practices and how, on account of those practices, it has many realities, not one” (Pender, 2018, p. 14). Praxiographic work foregrounds practices because, as Mol argues, practices stage reality. Therefore, I adapt praxiography for my investigation into stigma stories as a way of attending to lived experiences and of situating stigma as a rhetorical process instead of a static object (my approach to praxiography was developed by the anthropologist and philosopher Annemarie Mol to study how atherosclerosis, an arterial disease, “is enacted in multiple practices and how, on account of those practices, it has many realities, not one.” (Pender, 2018, p. 14). Praxiographic work foregrounds practices because, as Mol argues, practices stage reality. Therefore, I adapt praxiography for my investigation into stigma stories as a way of attending to lived experiences and of situating stigma as a rhetorical process instead of a static object.

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26. Although I discuss my praxiographic approach in chapter 2, a brief overview of my methodology serves as framing at this point.
iography is detailed thoroughly in chapter 2). In other words, I listen to and analyze stigma stories for the practices presented within them and how those practices tell us something about how stigma is done or countered in the lives of those living with ostomies and chronic GI conditions.

RHM scholars have recognized praxiography’s utility and have adapted it for a variety of different projects. For example, praxiography, grounded in multiple ontologies theory, has been deployed to better understand pain medicine (Graham, 2015; Graham & Herndl, 2013), lived experiences with mental illness (Molloy, 2015), genetic risk (Pender, 2018), health policy deliberation (Card et al., 2018; Teston et al., 2014), and vaccines (Lawrence, 2020). Mol’s praxiography and related multiple ontologies theory have been particularly useful in helping rhetoricians of health and medicine move toward ontological inquiry that studies the practices that stage entities and realities. This move toward practices and ontology, as RHM scholars have illustrated, allows our work to examine “a constellation of diverse practices” (Teston et al., 2014, p. 162) in order to understand how “differently situated material activities . . . produce different objects” (Graham, 2015, p. 31). Within a praxiographic approach, stigma comes into being and disappears in practices; subsequently, ostomies and chronic GI conditions are also staged and made to mean undesirably different, through particular practices.

Put simply, praxiography and its RHM adaptations provide an important foundation for examining complex lived realities like chronic conditions and stigma. Stigma is enacted in a range of material-discursive and embodied practices, and praxiography provides a useful methodology not only for capturing these diverse practices but for understanding how these practices enact (or counter) stigma. Accordingly, throughout this book, I examine stigmatizing practices that enact ostomies and chronic GI conditions as undesirable or abject, as well those practices that stage these conditions and associated identities differently (i.e., not stigmatized) through stories about those practices. As later chapters show, stigma is not inherent in ostomies; instead, particular practices stage the ostomy as stigmatized, as deviant and different, and other practices stage the ostomy quite differently. In any case, I argue that practices enact both stigma as well as ostomies and chronic GI conditions in particular and meaningful ways.

In chapter 2, I detail and justify my praxiographic approach to stigma more fully; however, here I’d like to outline my approach to data collection. Praxiography, as an extension of ethnography, was initially developed and deployed through extensive physical observations of practices as they occurred in space and time. However, as I’ve made clear, the focus of my research has been on stories and the experiences shared within them. I gathered many stories for
this research through ethnographic means including participant observations and interviews. I conducted over 200 hours of participant observations at an annual event, which I attended twice, for women living with chronic GI conditions and ostomies. Approximately sixty women attended each of these three-day events, which gave me the opportunity to listen to many stigma stories. At these events, attendees spent time discussing various topics presented as important to living with these conditions, including diagnosis, treatments, exercise, work, dating, sex, relationships with caregivers, and mental health. In these discussions, many stories were shared about the day-to-day experiences and challenges of life with chronic GI conditions, and many stories were shared about experiencing and navigating stigma.

To follow up on the stories I heard during participant observations, between 2015 and 2020 I interviewed twenty people living with ostomies and/or chronic GI conditions. These sixty- to ninety-minute semistructured interviews asked participants about stigma, as well as day-to-day life, care, and treatment. Interviews were conducted using a mix of convenience, and then purposive and snowball, sampling to assemble a robust and diverse group of interview participants (Koerber & McMichael, 2008). That is, during the first wave of interviews ($n = 9$), which took place between 2015 and 2017, I deliberately recruited a convenience sample from attendees of the event at which I conducted my participant observations. During a second round of interviews, conducted between 2018 and 2020, I used purposive sampling to strengthen the diversity of my original interview sample ($n = 9$). I also used snowball sampling during this second wave of interviews to identify additional participants ($n = 2$).

Note that much of the data collected throughout my research and thus informing the claims I make throughout this book are from women. My ethnographic observations were at any event exclusively for women, and because I recruited half my interview participants from that event, many of them were women ($n = 15$). Therefore, as I incorporated my third data-collection method (outlined next), I was committed to collecting stories from as many identities as possible. The skewed representation of women in my data certainly impacts my findings in ways that I’ve worked to account for and no doubt in ways I’ve failed to see. That is not to say, however, that my findings are somehow less valid. They are situated and incomplete (Haraway, 1988); the claims in this book are not intended to be generalizable, anyway. In fact, listening to the stories of women with ostomies and IBD helps illuminate the intersectional ways that gender impacts stigmatization. Nonetheless, the gendered skew in my data reflects an important phenomenon within the ostomy and chronic GI communities. Women, at least from my view having studied
these communities for nearly a decade, tend to be more vocal, particularly in public, online spaces. This is not to say that men are absent; there are many men sharing their stories and experiences online (for two well-known examples, see Greenly, n.d.; Powers, 2020). But as one man I interviewed told me, “Women just seem to be far more willing to talk about their experiences.” Thus, throughout this book and especially in chapter 5, I work to account for the gendered dimensions of the stories and experiences shared.

Additionally, the stories in this book are skewed toward White perspectives. This is partly a result of the space in which I conducted my initial observations that then led to my interviews. That event at the time was mostly White. White individuals are also represented more in my research because of my own ignorance at the outset of this research nearly a decade ago. When I began this work, I thought I was focusing only on ostomies, chronic GI conditions, and stigma, leaving other identities and embodiments as outside the scope of my research. In fact, I thought I was conducting good work precisely because I isolated those particular phenomena. There was other research, after all, that looked at Black experiences with chronic GI diseases or how gender impacted quality of life for people with ostomies (as just two examples). I now know how privileged and uncritical that perspective was, and I worked through additional rounds of data collection to correct this harmful oversight. Specifically, in my second round of interviews, I recruited specifically to diversify the storytellers, perspectives, and lived experiences represented in my data set. I also took this more careful approach in collecting online stories, which I detail more in the next several paragraphs. Acknowledging the messiness and mistakes I made and worked to correct through my research process is important in enabling readers to situate my findings and in being accountable and ethical as a researcher.

Finally, I collected hundreds of stories online from a wide range of sources including blog posts, social media posts, news articles, and listicles. This third data-collection strategy, as I begin to explain here and elaborate in the next chapter, allowed me to engage with the rich stories that were being shared publicly about living with an ostomy or chronic GI condition and stigma. Because stigma is a social, relational, and rhetorical process, many of the practices that give meaning to ostomies—stigmatizing or otherwise—emerge in the public sphere. As Phaedra Pezzullo and Robert Cox (2017) defined it, the public sphere is

27 A listicle is a relatively new web genre of articles that are organized by list. For example, the following are listicle titles: “Top 10 Things You Should Know About Ostomies” or “5 Pictures That Show Wisconsin Is the Best State.”
the realm of influence that is created when individuals engage others in communication—through conversation, argument, debate, or questioning—about subjects of shared concern or topics that affect a wider community. The public comes into being in our everyday conversations as well in more formal interactions . . . and the public sphere is not just words: visual and nonverbal symbolic actions, such as marches, banners, and photographs. (p. 21)

Indeed, just as a range of practices stage stigma, a diverse array of public, rhetorical artifacts and spaces participate in those practices. In fact, stigma for ostomies and chronic GI conditions is so public and familiar that it is a fixture in popular culture, a reference that can be used off the cuff to evoke disgust or distaste. For example, in 2013 comedian Jim Carrey, frustrated by gun-legislation press coverage, called Fox News “a media colostomy bag that has begun to burst at the seams” (Huffpost, 2013). The popular lifestyle television channel TLC has even gone so far as to include ostomies in their UK series Too Ugly for Love?, a show that chronicles folks with conditions and medical experiences that have deemed them romantically unlovable. And, one evening in the middle of working on this book, I tuned in to a new episode of the Match Game remake, where the actor and show host Alec Baldwin randomly quipped: “I have a colostomy bag I could show you” in a sarcastic response to other celebrities on the show jokingly wearing body enhancers (e.g., padded bras and underwear). These are but a few quick examples. The pages of this book share many such public stories.

To find these public stories, I immersed myself in the public ostomy and chronic GI condition discourse through my existing network and quickly expanded that network as I discovered new websites, organizations, and communities pertaining to ostomies, chronic GI conditions, and stigma. In doing so, I was able to identify a variety of platforms and artifacts for inclusion in my research. This strategy, for example, was how I was first introduced to Julia’s commercial within the Tips from Former Smokers campaign. In the early years of this research (around 2016), I also set up a series of Google Alerts using terms like ostomy, stigma, IBD, colorectal cancer, chronic, and gastrointestinal disease. Ultimately, I collected and analyzed over 300 artifacts from a variety of spaces, including organizational websites like Uncover Ostomy, the UOAA, Ostomy Connection, and The Mighty; news articles from national and regional outlets; social media campaigns including #GetY ourBellyOut,

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#WorldOstomyDay, and #BagsOutForSeven;\(^{29}\) and blogs and posts by high-profile figures in the ostomy and GI communities such as Jessica Grossman, Gaylyn Henderson, Sam Cleasby, and OstomyGuy.

These online stories presented a way for me to reach a wider range of perspectives and stories and to more fully understand and calibrate the stories I observed and listened to firsthand through participant observations and interviews. However, online research, particularly about health and medical topics and experiences, requires special caution and ethical consideration. Too, a praxiographic approach in digital space presents unique challenges that have gone relatively unexplored. This is, in part, because a key tenet of Mol’s (2002) original praxiographic approach is physical place, as she argued that different places stage objects differently (p. 55). For example, the atherosclerosis staged at home tended to be different from the atherosclerosis staged in the pathology lab. However, S. Scott Graham and Carl Herndl have argued that Mol’s original emphasis on place can be adapted. Theorizing pain praxiographically, Graham and Herndl (2013) write:

Mol (2002) is quite physical in her sense of “site of practice” as a “where”—as a physical location of a set of practices—an understandable move considering her focus on atherosclerosis distributed through different spaces in a hospital. But the idea of specific physical sites of practice is less useful in our inquiry into pain medicine. We could easily say that the diagnosis occurs in the examination room, but that would be a somewhat myopic view. Diagnosis occurs equally in a variety of locations, for example, the examination room, the laboratory, the library, the Internet. Pain management is a spatially distributed practice . . . we will refer to “pragmatic regimes of engagement” or “pragmatic regimes,” an all-encompassing term, for example, action, practice, habit. In short, a **pragmatic regime of engagement is a way of interacting with the world from which emerges orders of value and agency attributed to people and objects.** (p. 114; emphasis added)

These pragmatic regimes are especially important for praxiographically accounting for language and meaning-making. As Graham (2015) later explains, regimes of practices “are sites of doing, and doing includes the practices of speaking, writing, visualizing, and representing” (p. 35). Consequently, I studied the practical regimes of stigmatization as well as the sharing of stigma stories publicly online to investigate “spatially distributed” stigmatizing experiences and practices. I collected and analyzed, for instance, several

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\(^{29}\) Capitalization of each word added for accessibility.
posts on a website called The Mighty, an online community where people share stories about chronic conditions and disabilities through written and video formats. Posts on The Mighty rhetorically operate as a regime of practice in that a particular web space is a “site of practice,” and they provide a particular “way of interacting with the world” through which meaning, value, and agency emerge and are attributed to the stories, experiences, and people that are shared through the site (Graham & Herndl, 2013).

However, conducting praxiography in digital regimes of practices opens the metaphorical floodgates for data. For instance, the social media campaign #GetYourBellyOut, which aims to fight stigma and empower people living with ostomies and chronic GI conditions, has hundreds of thousands of posts alone (I discuss this campaign more in chapter 5). If I wanted to treat patients as their own ethnographers, study the practices in which stigma is staged (or dismantled), and do so in the public digital domain, I needed to find ways to bound my study. Drawing on McKee and Porter’s (2012) heuristics for online research proved especially useful from my digital praxiographic work. Specifically, McKee and Porter suggest that researchers consider the following dimensions when conducting writing research online: public versus private, data identification, degree of interaction, topic sensitivity, and subject vulnerability. These metrics, they argue, should be used to guide researchers’ decision-making processes regarding online research and consent. Thus, I considered each of these dimensions as I collected digital artifacts.

- **Public versus Private.** I focused exclusively on digital posts that were expressly public. This included blog posts; news articles; social media posts that were participating in campaigns designed to reach broader, public audiences; and public advocacy sites that solicited and featured the stories of people living with ostomies and chronic GI conditions. None of the data analyzed for my research required a password or even an account to access; no data collected were protected by membership of a social media or advocacy group. I took special care to ensure that anything I treated as a praxiographic report of a person’s lived experiences was specifically meant for public viewing.

- **Data Identification.** Much of the data I collected is easily identifiable online. In fact, I deliberately included data that were identifiable because many of the blogs and websites I analyzed for this project explicitly state the goals of public education and awareness. Therefore, I chose to only include data where I felt identification was acceptable, if not promoted. Blogs or posts that seemed particularly private and sensitive, even though
they were posted publicly, were excluded from the data set. Such artifacts included those that discussed highly specific personal information (e.g., identifiable information about location, age, or health-related information) and artifacts that were posted publicly but that appeared to be intended for a smaller, more personal network of people (e.g., posts that discussed other people in an identifiable way).

- **Degree of Interaction.** Unlike digital research in forums and private groups, my research focused entirely on publicly published data such as blog posts, news articles, and social media posts that were part of public campaigns. Therefore, I did not interact with the vast majority of the authors who composed the stories I’ve included as data. That said, I do personally know a handful of the people whose writing or posts were included in the data set, because I am an active member of the chronic GI community as a patient and researcher. In these instances, the authors were already aware of my research, and none expressed a desire for their writing to be excluded.

- **Topic Sensitivity.** Stigma and other experiences with chronic conditions are often highly sensitive experiences. This actually served as a reason for me to turn to digital spaces for data collection (as I explained earlier in this chapter). Collecting artifacts posted publicly online offered me a way to engage lived experiences but to limit my research to the stories people wanted to share. Rather than asking people to expose every aspect of their lived experiences with me, I relied on what people had already decided was shareable information.

- **Subject Vulnerability.** Sharing personal health experiences and information, like experiences with chronic conditions and stigma, is a highly vulnerable act. Therefore, as I’ve repeated, I focused on the stories and experiences that people independently chose to share publicly. As McKee and Porter (2012) point out, technological knowledge should be considered when evaluating subject vulnerability (p. 253). That is, researchers should be mindful that some people may post publicly online but may not be fully aware of what “public” means in an online space. By limiting my data collection to spaces like blogs, news outlets, and social media campaigns, I worked to ensure that I collected artifacts written by people who were indeed aware of the extent to which their stories would be accessible by the public.

These principles guided my data collection as I worked to identify and select stories of people’s experiences and practices with ostomies, chronic GI conditions, and stigma.
Thus, I drew on multiple forms of data collection to crystallize30 lived experiences with ostomies, chronic GI conditions, and stigma in a meaningful and robust way. Calibrating the stigma stories shared across these spaces enabled me to develop a strong understanding of many lived experiences with ostomies, chronic GI conditions, and stigma.

**Preview of Chapters**

The chapters of this book trace the rhetorical practices taken up and embodied within stigmatization and its resistance by the diverse stakeholders involved. To lay the groundwork for my analysis, chapter 1 begins by exploring how stigma31 has been studied and by outlining what a rhetorically grounded approach adds to these conversations. In this chapter, I point to key tensions in contemporary stigma research and consequently carve out space for my own rhetorical theory and approach for studying stigma, which, as I’ve alluded to in this chapter, focuses directly on capturing lived experiences. Chapter 2 argues that a rhetorical praxiography approach to stigma stories enabled me to rhetorically listen to people as ethnographers of their own lives (Mattingly, 1998; Mol, 2002) while calibrating those experiences with others’ experiences, as well as my own experience as a person with Crohn’s disease. Thus, chapter 2 makes an ethical case for studying stigma stories praxiographically. To do so, the chapter details my praxiographic analysis of stigma stories articulating different stagings of stigma in the lived experiences of people having ostomies and chronic GI conditions. In doing so, chapter 2 sets the stage for the analyses that follow in chapters 3, 4, and 5 that examine how stigma is enacted and countered, as well as how ostomies and chronic GI conditions are staged through lived experiences shared in stories. Readers within RHM, in particular, will find the methodological discussions in chapter 2 useful, as I build on previous RHM scholarship to extend praxiography’s utility for RHM.

That said, I’ve written this book with this diverse readership in mind in hopes that each might find useful takeaways. Discussions in this book are

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30. Crystallization, as theorized by Laura Ellingson (2009), is akin to triangulation. Crystallization as a technique brings together multiple forms of data to crystallize phenomena. I use crystallization here instead of triangulation because crystallization explicitly recognizes that all data is partial and situated. Furthermore, crystallization values stories and lived experience, further making it apt for my study of stigma.

31. As readers will see, I discuss work on ostomy stigma in particular, but much of this work has been done from a biomedical perspective. Therefore, I also draw on and discuss research on health-related stigmas, more generally, that has been done within health communication, anthropology, health psychology, and nursing.
valuable for RHM but also for patients, healthcare providers, publics, and larger-scale institutions such as the CDC and the UOAA. Patients, healthcare providers, researchers, publics, and institutions—each of these broad groups is embroiled in the de/stigmatization of ostomies. In order to combat stigma, this wide range of diverse stakeholders must be involved. This work is already underway at organizations such as the UOAA and the Crohn’s & Colitis Foundation of America, each of which has content that focuses on recognizing and overcoming stigma. I hope to enrich these conversations through the addition of rhetorical research and insights.

In contrast to the antistigma and ostomy-positive goals of the aforementioned advocacy organizations, I show how other public institutions utilize stigma (deliberately or not) as a rhetorically powerful tool. For example, chapter 3 shows how one of our nation’s most trusted sources of health information—the Centers for Disease Control and Prevention—relied on stigma as part its most recent antismoking campaign, Tips from Former Smokers. More specifically, chapter 3 returns to Julia’s story to analyze how particular stigma stories do the very work of rhetorically staging stigma. Alongside Julia’s, I review several other public ostomy stories that have been accused of spreading stigma. I argue that one thing these stories share is the way they draw on experiences with leaks and disability to stage the ostomy as a worst-case scenario or last resort and, in so doing, precipitate a visceral public audience (Johnson, 2016; Winderman et al., 2019) and propagate stigma. Moreover, this chapter extends current RHM theorization of stigma by showing how stigma can actually enhance rhetorical credibility when stories and experiences align with pre-existing stigma.

Importantly, it is not only my analysis that contends that stigma is staged in these stories. Instead, as chapter 4 shows, thousands of people responded to the CDC’s stigmatizing ostomy message by highlighting how their ostomy experience diverges from what Julia described in her CDC materials. These responses, as I alluded to earlier in this chapter, told drastically different ostomy stories—stories that resisted stigma through sharing empowering experiences with the ostomy such as leaving the hospital, returning to “normal” life, and falling in love. Chapter 4 calibrates the responses to Julia with stories collected during interviews and participant observations to show that these and other stigmatizing public ostomy stories are indicative of common ostomy experiences. Central to these stories and the experiences shared in them is an ostomy that is enacted as lifesaving and positive. These more bright-sided stories illustrate that the stories we often hear in the public sphere about ostomies (presented in chapter 3) do not provide a full account of what living with an ostomy is or can be. Putting both negative and positive stories
(and those in between) in dialogue in chapter 4 also helps show how listening to stigma stories requires an attunement to the intersecting identities and experiences that inform ostomy experiences.

In addition, the analyses across chapters 3 and 4 trouble current best practices in health-messaging campaigns for relying on stigma, demonstrate the central to the divergence between Julia’s experience (as promoted by the CDC) and the experience of those who protested her, and highlight the value of stories in countering stigma. In other words, the analyses in chapters 3 and 4 show how different stories energize or dismantle stigma by sharing different experiences. The insight of these chapters is especially valuable for public institutions like the CDC, as I examine how, despite its admirable antismoking efforts, the organization could have benefited from more thoughtful consideration of multiple audiences and the risks of deploying scare-tactic strategies. Additionally, scholars focused on health writing, health communication, public health, and strategic communication will find value in this chapter’s discussion of empirically validated health-messaging strategies.

Chapter 5 examines the role of visual practices (e.g., displays) and norms regarding gender and sexuality in stories that stigmatize ostomies as well as those counter that stigma. In the same way that leaks and lack of control are cited as experiences that disable and stigmatize people with ostomies, as we’ve seen so far in Seven’s and Julia’s stories, visual displays or lack thereof are commonplace for enacting and countering ostomy stigma. In particular, chapter 5 reviews cases such as #GetYourBellyOut, an international antistigma ostomy-empowerment campaign where people posted pictures revealing their ostomies; television network TLC’s series Too Ugly for Love?, which included people with ostomies; Bethany Townsend, an aspiring model championed for posting pictures of herself in a bikini with her ostomy; and Sam Cleasby, a famous blogger in the ostomy and chronic GI communities, who posted boudoir-style photos on her blog and was criticized for “sexualizing disability.” Through a discussion of these diverse cases, chapter 5 argues that stigmatizing practices work to police who is allowed to reveal their ostomy, when, and how, which often disciplines people into concealing their ostomies. Further, this chapter examines how destigmatization is caught up in complex ways with the idea and process of normalization. Specifically, it suggests that certain people (i.e., those who fit particular societal standards for sexual attractiveness) are applauded as heroes for revealing their ostomies, while others (i.e., those who misfit such standards for sex appeal) are stigmatized even further for exposing their ostomies, attempting to sexualize disability, or otherwise existing with an ostomy.
Chapter 6 concludes the book by elucidating key takeaways of a rhetorical investigation of stigma for four primary stakeholders: (1) researchers in RHM, (2) people living with ostomies and other chronic conditions, (3) healthcare providers, and (4) public institutions such as the CDC. Primarily, I suggest that the careful tracing and analysis fostered by a rhetorical understanding of stigma illuminates pathways of intervention on many scales: from the micro level of day-to-day interpersonal encounters to nationwide communication stemming from institutions and organizations to the mundane, often implicit cultural biases we unconsciously agree to and propagate each day. I argue that this book not only provides a rationale for placing stigma within the bounds of caring for chronic conditions (including but not limited to ostomies and GI disease) but also might serve as an initial guide to the types of themes and lived experiences that warrant discussion within those care encounters. Specifically, this final chapter generates important takeaways for patient–provider interactions, as stories shared herein suggest that healthcare providers often play a critical role in shaping the lived experiences of people with ostomies and chronic GI conditions. This is significant because our current medical culture, at least as experienced by the ostomates voiced in this book, tends to position many lived experiences, including stigma, outside of health and medical care related to ostomies and GI conditions. In other words, healthcare providers typically treat disease and malfunctioning bodies instead of people. As one MD put it, “As doctors we’ve become more powerful at manipulating the manifestations of disease, but I don’t think we’ve become any better at understanding how to care for the people who have disease” (Spaeth, 2015). If (as has been one goal of the patient-centered care movement) healthcare providers treat people, then stigma falls squarely within the bounds of treatment and patient–provider encounters, not pushed to the periphery as secondary or separate treatment. To help make this argument, the chapter briefly discusses ways that healthcare providers are aiming to combat stigma through embodied simulations, wherein providers wear an ostomy bag for a day to gain embodied insight into ostomates’ lived experiences. In addition to takeaways, I take time, in chapter 6, to reflect on the experience of writing this book as both researcher and patient, outsider and insider. As a way of looking forward, chapter 6 summarizes how this book lays the groundwork for future work on stigma toward chronic, often unapparent, conditions, as well as future work on lived experience specifically in health and medical contexts.

Taken together, these chapters trace the diverse and complex rhetorical practices that stage ostomy stigma and the counterrhetorics that have emerged
to powerfully push back. Each chapter works to carefully unravel the ways that ostomies are made to mean in public discourse by considering the values, histories, cultures, and practices that have sustained stigma for decades. In doing so, each chapter tells many stories. Stories of pain, shame, and embarrassment. Stories of resistance and standing up to bullying. Stories of just trying to survive. These stories and the people who live and share them deserve our attention and our action. In sharing them throughout this book, I hope to foster empathy, awareness, and a chance for all of us to recognize our implicit and explicit participation in one of our most insidious cultural monsters: stigma.