Stigma Stories

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EACH OF THE CHAPTERS in this book tells a different story—many different stories, in fact—and each story illuminates what it is like to deal with stigma, live with chronic conditions, and navigate these experiences through and within stories. These stories bring to light not only the complexities of living with chronic conditions but also the myriad ways in which stigma is done and undone. From the outset, I aimed to listen to these stories and to theorize stigma as an act of care because, as others have argued, care can orient us toward what matters most to our participants and their embodied lived experiences (Dolmage, 2014; Scott & Gouge, 2019). In this book, acting in care has motivated me to listen and retell many stories. Yet, I know that I’ve told only a few of the many stories and experiences worth telling about ostomies, chronic gastrointestinal (GI) conditions, stigma, and lived experiences more broadly. As Johnson (2014) poignantly reminds me:

There is something missing . . . tens of thousands of stories that will never be told. Those stories, and the faces, voices, and lives behind them, haunt this story, as they haunt all histories. Histories are intrinsically rhetorical. They select and interpret a certain reality for their audiences and each time something is made present, something is made absent by default. (p. 178)
Johnson’s sentiment here speaks to a type of historical story that this book does not tell; however, the insight remains relevant. I’ve included many stigma stories in this book—stories of ostomy leaks and lifesaving stomas, stories of being stigmatized and fighting back, stories of bathroom stalls and selfies. In telling these stories, I’ve left many others untold; thus, the insights offered through a rhetorical investigation of stigma stories are incomplete but nevertheless important. In collaboration with the people I observed, interviewed, and listened to throughout this project, I aimed to make visible the rich possibilities for both disciplinary insight and intervention in the domains of chronic illness, stigma, disability, and embodiment through a study of stories and lived experiences.

Through a rhetorical praxiographic approach, I have argued that the stories people tell about experiences with stigma and conditions that are frequently stigmatized, like ostomies, have something important to teach us about stigma’s rhetoricity. I’ve also argued for a particular approach to listening to these stories—that is, to listen to the stories and the lived experiences that are shared within them as if they tell about the events of what it is like to live with stigma, an ostomy, or chronic GI conditions (see Mol, 2002). Practicing such listening has allowed me to consider how a variety of rhetorical forces—fear, ableism, social media, racism, medical institutions, beauty norms, disability stereotypes, television shows, histories, feces, and temporality—all participate in stigmatization; and, of course, this list is incomplete. Nonetheless, the praxiographic approach I’ve used to study stigma has demonstrated the material, discursive, affective, social, institutional, and individual actors and practices implicated in stigma. In closing this book, I reflect on the scholarly, interventional, and personal insights that emerge from in this analysis.

**The Value of a Praxiographic Approach to Stories**

I began this book by acknowledging the complex and diverse ways that stigma has been studied across disciplines. Specifically, I entered the scholarly arena of stigma by laying groundwork from previous research in rhetoric, disability studies, and sociology, and, in doing so, I positioned the rhetorical study of stigma undertaken in this book as something to add to these conversations. I advocated for a praxiographic approach to stigma through stories that (1) treats people as their own ethnographers, and (2) studies stigma as a set of practices rather than an inherent property of particular entities, individuals, or conditions. This move, I argued, is not just methodological but ethi-
cal, in that it attempts to theorize stigma while looking for ways to intervene in stigma, which requires first that we see stigma not as something that is given in the world but as something that is done through practices and made meaningful through those practices along with the systems and logics that orient us in the world. Accordingly, this praxiographic approach to stigma stories invites researchers to recognize the rhetorical processes, experiences, and practices in which stigma is enacted or countered, instead of placing stigma as a psychological phenomenon or as an attribute inherent in particular individuals, conditions, or bodies.

More broadly, such praxiographic listening enables rhetoric of health and medicine (RHM) to simultaneously capitalize on its commitments to rhetorical analysis, lived experience, and advocacy/intervention. Lived experiences are caught up in the stories we tell just as much as the stories are caught up in lived experience—the two richly inform each other, for better or worse. In advocating for a praxiographic approach, I have attempted to demonstrate how praxiography can complement critical and rhetorical analyses, particularly by orienting researchers, in RHM and beyond, to the embodied lived experiences that profoundly engage in meaning-making of bodies, disabilities, chronic conditions, and experiences. “The stories people tell,” as Mol (2002) put it, “do not just present grids of meaning. They also convey a lot about legs, shopping trolleys, or staircases. What people say in an interview doesn’t only reveal their perspective, but it also tells us about the events they have lived through” (p. 15).

Applying this praxiographic approach to stigma stories, I then spent chapters 3, 4, and 5 focusing on a variety of stories—public, personal, visual—in which stigma was enacted, resisted, and otherwise imbricated in the ways people spoke, moved through the world, acted toward others, and experienced chronic GI conditions and ostomies. I thus praxiographically listened to many stories as a means of following stigma. In doing so, I first listened to public stories about ostomies that consistently stage the ostomy as a leaky worst-case scenario. These stories, told by institutions perceived as credible, like the CDC, police officers, and a prized medical TV show, demonstrated that stigma emerges through the complex entanglement among key entities, including histories of ostomies, negative ostomy experiences, visceral publics, and systems of power (ableism, sexism, and racism) that steer audiences to participate in meaning-making about ostomies that stigmatizes through fear and rejection of particular bodies and experiences.

In recognition that a single public story of ostomies does not tell the whole story, in chapter 4 I listened to disruptive ostomy stories, stories, and experiences that do not align with the dominant public ostomy story. These disrup-
tive stories suggested that the experiences of many people living with ostomies are not solely defined by leaks, fear, isolation, and a compulsive desire for life before the ostomy. Instead, for many ostomates, the experiences that define their ostomies are positive: leaving the hospital, healing from debilitating disease, and returning to desired activities like exercise, dating, and traveling. Through these positive experiences, the ostomy is staged as lifesaving and empowering, not a worst-case last resort. And, in turn, these positive experiences enable many ostomates to fully embrace life with or after receiving their ostomies, rather than miss their before-ostomy life. In sharing these alternative experiences, these ostomates challenge the idea that the ostomy is a “single passive object” and show that what an ostomy is depends on how an ostomy is done (Mol, 2002, p. 5). These disruptive stories, and the experiences shared within them, further challenge ableist assumptions about what life with a disability should be; that is, they tell us that life with an ostomy can be and often is better than life without one.

Finally, chapter 5 asserted not only that stigma is caught up in ableism but that sexism and gendered expectations are also strongly at work within the experiences of ostomates and the de/stabilization of stigma. Through discussions of various visual practices within the ostomy and chronic GI conditions community, this chapter argued that such practices, though risky, operate as acts of resistance against stigma. Specifically, displaying ostomies and evidence of chronic GI conditions in public contexts provides one avenue for resisting norms of sexuality, beauty, ability, and gender while offering a way for individuals to bring their conditions and related experiences into the “normative public sphere” (Garland-Thomson, 2017, p. 376). This analysis of visual practices as complex acts of resistance interrogated the complexity of normalization as a solution to stigma.

Collectively, this praxiographic approach has revealed three key takeaways regarding stigma’s rhetoricity. The following sections summarize how the specific insights of this book might influence or motivate future work on stigma.

**Stigma as a rhetorical practice, not an inherent quality.** On its most basic level, this book argues that stigma is not an inherent quality, mark, or property of entities; instead, stigma is better understood as the product of rhetorical practices. In the context of this book, positioning stigma as a rhetorical practice has revealed that ostomies are not inherently scary, dehumanizing, or gross; instead, ostomies are made to mean in these negative ways through oppressive practices like staring and stereotyping and through focusing on solely negative experiences like experiences with leaks and social isolation. In other words, the stories in this book demonstrate that stigma is not inherent in ostomies but is instead a manifestation of rhetorical forces. Stories and the
lived experiences within them, in other words, operate like arguments that persuade others about what to think and feel about ostomies. The lived experiences with ostomies shared through stories stage the ostomy as a leaking bag or a surgery that enables freedom from debilitating disease while communicating to listeners what those experiences mean: positive, negative, demeaning, empowering, de/stigmatizing, or otherwise. Listening to stigma stories as if they “tell about events” and experiences with stigma, accordingly, (1) foregrounds practices that de/stabilize stigma, and (2) reminds us that there are multiple ways to live with and experience ostomies and thus multiple ostomies (e.g., worst-case scenarios and lifesaving technologies). These findings are obviously ostomy-specific; however, the foundational insight that stigma surfaces in rhetorical, material-discursive practices is applicable beyond ostomies and chronic GI conditions. Future rhetorical studies of stigma might extend and complicate my findings to develop richer understandings of how rhetorical practice participates in the stigmatization of any range of conditions or lived experiences. As chapter 1 pointed out, there is, unfortunately, no shortage of conditions that are stigmatized. Therefore, I offer the insights of my work as an invitation for RHM to apply and adapt my praxiographic approach to theorize and intervene in the stigmatization of other conditions.

**Stigma is imbricated in multiple, intersecting systems of power.** In addition to making an ethical argument about how to study stigma and, therefore, an argument about what stigma is, this book advocates for attuning to how stigmatization is enabled by a variety of norms rooted in ableism, sexism, racism, gendered expectations, medicalization, and ageism. And although the stories in this book and my analysis of them did not overtly address them, I’ve no doubt that the enactment of classism, homophobia, transphobia, and many other forces are enmeshed in stigmatization. Recognizing stigma as a product of these systems is key to not only understanding stigma but intervening in it. Thus, this book argued that disability studies, especially a political/relational model of disability, and RHM can mutually inform each other. The productive overlaps across disability studies and RHM are complex but nevertheless highly generative for understanding how power circulates and participates in the meaning-making of embodied experience and difference. Work in this area, of course, has been ongoing, but recently there have been calls for additional scholarship at the intersections of disability and RHM (Reed & Meredith, 2020; Scott & Melonçon, 2019). My hope is that this book contributes to these conversations and brings disability studies to the fore for other rhetoricians of health and medicine.

**Stigma acts across a spectrum of rhetorical activity.** In chapter 1, I proposed that stigma actively operates through individuals and individual inter-
actions, as well as across the public sphere including institutional, cultural, and social spaces. Various stigma stories in this book exemplified the enactment and resistance of stigma across this spectrum. For instance, my own story that opens chapter 2 showcased how stigma is enacted in interpersonal exchanges. In contrast, the highly public stories in chapter 3 illustrated how stigma moves from individual experiences to the institutional level and into the public culture; and the stories in Chapter 4 showed how individuals work independently and collectively to nuance and complicate singular public narratives that become dominant. The visual stories in chapter 5 further indicate how digital interactions and circulation can both resist and fortify stigmatization. Too, all these stories are in dialogue with each other as they circulate in the public sphere, collaboratively curating the meaning(s) of ostomies and chronic GI conditions. Accordingly, the stories across this book, while grounded in their commonality of ostomies and chronic GI conditions, can serve as examples for where future rhetorical examinations of stigmatization of other conditions, illness, and disabilities might look for stigma’s subtle and overt manifestations. Stigma stories as a concept and the praxiographic approach I took to investigate them also offer one set of tools for future work interested in exploring the webs of rhetorical activities in which stigma emerges, operates, and de/stabilizes.

Interventional Insights

While the insights of my investigation into the rhetoricity of stigma have pointed to a variety of conclusions for RHM and allied scholars, I’d like to also explicate the practical, interventional implications that might emerge from this book. In particular, this rhetorical investigation of stigma has the potential to intervene in the practices and experiences for people living with ostomies and chronic GI conditions, healthcare providers, and public institutions such as the CDC. I offer two interrelated strategies—thinking with stories and embodying empathy—that a variety of stakeholders, including scholars in RHM and allied fields, as well as healthcare providers, institutions like the CDC, or any individual person, might adopt to dismantle stigma. In these final sections, I define these strategies and elucidate how they might be helpful and just responses to stigma.

In the opening of his oft-cited book Wounded Storyteller, Arthur Frank (2013) advocated that we move away from thinking about stories and instead begin to think with stories. Clarifying this distinction, Frank outlined: “To think about a story is to reduce it to content and then analyze that content.
Thinking with stories . . . is to experience it affecting one’s own life” (p. 23; emphasis added). Frank (2010) further discerned that to think with stories is to get “caught up” in them, to allow them to “get under [our] skin” and “affect the terms in which [we] think, know, and perceive” (p. 28). These lines from Frank also evoke Candice Rai’s (2016) concept of rhetoric offered in the opening chapter, in which she argued that rhetoric too “gets under our skin” (p. 7). To bring Frank and Rai together, I advocate for thinking rhetorically with stories as a strategy that affords empathy and an opportunity for intervention motivated by reflection. With this book, I have attempted to think rhetorically with stories that at once tell us what it is like to live with an ostomy or chronic GI condition and how stigma is done and undone. Therefore, as a way of both concluding and generating future work, I’d like to think with the stigma stories presented throughout this book and consider how these stories can affect practices moving forward and shape the practices and experiences that matter most to people.

A perhaps obvious but nevertheless important conclusion of my investigation of stigma stories is that stories are profoundly important, especially when we think with them. Stories are not only descriptive; they can also be prescriptive. In other words, they can tell how others have lived or are living with disability or illness, which affords us the opportunity to reflect on how our own lived experiences might be changed. Specifically, for people living with ostomies and chronic GI conditions, listening to others’ stories can help others change and manage their own lives. Indeed, telling and sharing stories is as much for ourselves as it is for others; these practices enable us to bear witness to what others experience in their own day-to-day lives (Frank, 2013). As one interview participant told me:

People need to realize that we need to be real with each other and share our stories authentically with each other so we can learn to have a heart for people in our lives. I don’t always have to be happy about dealing with [my ostomy]. There are days that it breaks me down . . . it’s not fun. But I have this life, and I’m going to make it amazing and that’s fine. And, at least you know who I am, I don’t have to act anymore. That’s my message more than anything: we all have a story to tell. Tell the real one and people will love you for it . . . together we can empathize a lot more when we know each other’s stories.

Heeding this participant’s call, I am actively collaborating with an organization called Girls with Guts to help others think with stories and learn from others’ stories and experiences. The organization’s mission is to “support and
empower women with inflammatory bowel disease (Crohn’s disease & ulcerative colitis) and/or ostomies through the building of sisterhood and self-esteem” (Girls with Guts, 2020). Over the course of writing this book, I have worked with and talked to many women affiliated with Girls with Guts and thus turned to this organization with initial findings from my research in hopes of identifying useful interventions. As a result of these discussions, I am working with Girls with Guts and its current president, Alicia Aiello, to create a digital storytelling archive that highlights the stories of women with ostomies and chronic GI conditions. To date, we have recorded the stories that five women offered in response to this question: If you could tell other people one story about what it is like to live with your condition, what would that story be? These five initial videos feature stories from women living with permanent and temporary ostomies as well as Crohn’s disease, ulcerative colitis, and a j-pouch. The goal of this project is to create an archive that patients, providers, caregivers, family members, and the general public can use to learn more about lived experiences with these conditions. It is one way to add nuance to the public story/ies about ostomies and chronic GI conditions. Moving forward, we hope to incorporate additional stories from diverse perspectives (including but not limited to women) that can speak to the many ways to live with an ostomy or chronic GI conditions.

This digital storytelling archive not only provides access to stories; it further can serve as a repository for the ways that ostomates and people living with chronic GI conditions respond to stigmatizing experiences. Each of the first five videos we have collected addresses both triumphs and challenges of living with these conditions as well as how the storyteller responded to these experiences. In this way, these stories provide potential strategies and practices that others can learn from. Stories enable others “to construct new maps and new perceptions of their relationships to the world” (Frank, 2013, p. 3). Thus, this storytelling archive can support others living with, considering, or caring for ostomies and chronic GI conditions by providing a window into the ways people already living with these conditions navigate the world. Overall, the Girls with Guts video project is one practical way I am using this research to intervene in stigma and advocate for people living with these conditions. My hope is that this project will encourage others to think with these stories, allowing the stories and experiences shared within them to affect the ways ostomies and chronic GI conditions are understood and engaged.

Thinking with the stories I heard over the course of my research points to a variety of additional interventions. During interviews, I asked participants what they thought the best strategies for dismantling stigma are. In their responses, I was surprised to hear the same answers over and over: educate
and raise awareness. Participants consistently stressed that many of their stigmatizing experiences were the product of “ignorance.” People just “do not understand what an ostomy is,” one participant told me as she sighed, sounding both frustrated and exhausted. Another participant summarized, “So much of the fear about ostomies is just that people don’t know what they are or why people have them. People just know it’s a bag full of poop.” These comments and others like them indicate just how important ostomy stories are in the public sphere, as chapters 3 and 4 also argued. People learn from the stories told about living with an ostomy or chronic GI condition; thus, it is critical that those stories show the diversity of lived experiences, not just negative ones. In line with this suggestion, participants proposed a range of strategies to raise awareness of ostomies and chronic GI conditions specifically strategies that make them visible (literally and socially) and foreground ostomies’ lifesaving and empowering potential. One participant remarked that “being honest” about living with an ostomy, showing others her ostomy through pictures, and revealing it during interpersonal encounters have been strategies she has personally used to destigmatize:

I think the more honest I’ve been . . . posting pictures of my ostomy even just like a week after my [ostomy] surgery with my stomach all poofy and with some pretty intense incisions. It helped destigmatize it. The more I show people or people have seen it, the less afraid they get. So I think it’s really important and cool to do that. Everybody’s stomach looks different and I think it’s great to show that.

Like the displays in chapter 5, this participant felt that visual practices are one way individuals can intervene in stigma on both personal and public levels. Other people I spoke with also advocated for being open and honest in personal interactions and for telling others about living with a GI condition. These suggestions signal the importance of telling, listening to, and thinking with stories.

In addition to these strategies, many participants pointed out that destigmatization needs to occur not only in the public sphere but also within healthcare spaces. Several interview participants expressed frustration and disappointment with healthcare providers’ lack of education and awareness. Here we can also recall Hilary’s story from chapter 2 that detailed interactions with nurses as some of the “most stigmatizing” experience she had ever had. Adding to Hilary’s experiences, another interview participant, Keisha, lamented, “Most of my providers don’t know anything about ostomies. I’m their only patient with an ostomy so that’s been a little difficult . . . it’s very
stressful.” Elaborating on this stress, Keisha said that none of her local healthcare providers are able to help her when she has issues with skin breakdown, despite repeatedly reporting these as issues to her providers. Instead of her providers seeking the necessary information to properly care for Keisha, she said, she travels several hours to see an ostomy- and wound-care nurse and otherwise relies on other ostomates via social media groups and digital communities to help her manage her own ostomy.

Moreover, when I asked interview participants whether their providers had ever discussed stigma with them, not one of my twenty participants said yes. Every interview participant, instead, told me that their healthcare providers didn’t talk to them about stigma or what it might mean to live with an ostomy beyond medically related experiences. One participant said that when she brought up concerns related to stigmatizing experiences she had, a provider shrugged and casually offered to refer her to a therapist. To be fair, this provider may have been well intentioned and, by suggesting the referral, acknowledging the limitations of their own expertise. Nonetheless, it is alarming that any provider whose practice includes caring for current ostomates and helping patients contemplate decisions about whether to undergo ostomy surgery or not may not see stigmatizing experience as even somewhat within their purview. Another interview participant’s response echoes similar concerns:

My GI hasn’t ever brought up stigma. I don’t know. I guess we don’t have a ton of time to talk during appointments anyway. But what immediately popped into my head when you asked that question [has a provider ever talked to you about stigma?] was this time when my provider kept saying that my body failed me and that’s why I needed to get an ostomy. Like who says that? My body isn’t a failure. This stupid disease is and the fact that medicine has no cure is a failure. Ugh. That crushed me.

This participant’s story and experience confirm just how impactful healthcare providers and their practices are when it comes to stigma. Notably, this participant later explained that she was overall “pretty happy” with the care she has received from her medical team, but her comments about embodied failure showcase that stigma can creep up where it is least expected and perhaps most powerful.

Encouraging healthcare providers to listen to and think with stories is, therefore, another interventional pathway illuminated by this book. Indeed, this finding aligns well with work already underway across medicine, though, as I’ll explain, this finding also complicates this ongoing work. Empathy has
been identified as an important dimension of chronic illness care (Jerant et al., 2005; Weed, 2012). In acknowledgment of the key role that empathy plays in care, medical schools, nursing programs, and physical therapy programs, among others, have begun to integrate training designed to foster empathy in future healthcare providers. For instance, many medical school programs have incorporated “standardized patient programs,” which bring in trained individuals (often actors) to act as patients in live-action clinic simulations. Additionally, courses and programs in medical humanities' and narrative medicine have begun popping up across the country in response to an increased desire to provide insight into the lived experiences of patients. Such medical humanities and narrative medicine programs are grounded in the idea that stories are not only informative but interventional.

One concrete way these programs aim to foster empathy is through simulation experiences in which students physically engage in scenarios designed to emulate real clinical scenarios. In addition to providing students the opportunity to develop technical literacies in cognitive and embodied capacities, nursing simulation experiences have specifically been used to blend “kinaesthetic actions and deliberate reflection” (Díaz et al., 2015, p. 513) in order to “enhance empathy” and “create caring and empathetic nurses” (Maruca et al., 2015; see also Díaz et al., 2015). In other words, such simulations work to make empathy core to the identity of nursing professionals through embodied experiences.

One specific type of nursing simulation is especially relevant within the context of this book: the ostomy simulation—in which prospective nurses wear an ostomy pouch through their regular daily routines for a day. It is heartening that nursing schools have recognized both the likelihood that nurses will interact with an ostomate and the important role nurses play in the care of these patients. Often, nurses are the only people ostomates have to teach them how to live with this new, long-term condition and technology. However, Gemmill et al. (2011) found that although nurses are a primary educator and care provider for new patients with ostomies, many nurses are uncomfortable caring for ostomate patients. In response to these findings, nursing programs have begun to include ostomy simulation experiences to address what has been called “empathy gaps” as well as educational gaps in ostomy care (Weed, 2012). By requiring nursing students to physically wear an ostomy pouch (i.e., use adhesive or a belt to physically attach the ostomy pouch to their bodies), these simulation experiences attempt to teach

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1. See Campbell (2018) for a more thorough discussion of the role that medical humanities curriculum plays in medical education.
the embodied reality of living with a long-term condition and technology. Ostomy simulations therefore present a rich site for investigating empathy as an embodied healthy literacy.

Although ostomy simulations are geared toward fostering empathy, many of my interview participants questioned the effectiveness of such experiences. For instance, many were pleased that nursing programs were emphasizing ostomy education, and many responded positively to the idea of ostomy simulations, particularly for helping nurses understand the embodied dimensions of changing an ostomy bag—a skill often necessary when caring for an ostomate. However, several pointed out that a simulation experience cannot fully replicate the chronic and embodied challenges of ostomies, including leaks and stigma, as well as the often chronic nature of living with an ostomy. Indeed, interview participants expressed concern that these simulations had the potential to backfire, engendering apathy or callousness toward ostomates’ experiences and concerns if the simulations simplified the complexity of life with an ostomy. One interview participant reflected:

I think it’s really cool . . . I’ve seen a lot of people on social media who will have their partner wear an ostomy for World Ostomy Day. It’s really important . . . but I think it’s really hard to fully simulate the experience because they don’t get the experience of the bag filling up or walking around with a full bag on your stomach. Or like oh, I ate and then thirty minutes later it starts filling up . . . I think it’s a step in the right direction but it is by no means what it is actually like wearing an ostomy for a day.

Another participant provided similar feedback:

Well, obviously [nursing simulations] are not very accurate, I mean it’s good that they are doing it, but if you don’t wear it long term you don’t have the skin breakdown and if you don’t have the output you don’t have the concern for leakage, so I mean I guess it’s good that they learn how to put it on, but they don’t anything to work with what’s real . . . it’s kind of fake learning.

While wearing an ostomy for a day can begin to foster empathy, as this interview participant noted, a single-day simulation is not sufficient to capture what it is like to live with an ostomy long term. It’s clear from these comments that living with an ostomy is more than simply wearing an ostomy pouch for a day. According to my interview participants, a richer, deeper engagement with lived experiences of having an ostomy is necessary to understand and care for ostomates.
I followed up with participants who shared these cautions regarding ostomy simulations and encouraging empathy. What would be better? I asked, and in response I heard the same answer repeatedly: bring ostomates in and listen to the stories they share. One participant said, “Have actual ostomates be in the classroom with them for a day or have actual ostomates come in for hands-on, so they can see the different kinds of stomas and ostomies and hear about what it’s actually like to live with them.” Living with an ostomy is more than simply affixing a pouch to the abdomen. As many interview participants recommended, listening to the lived experiences of ostomates is more important than pretending to be an ostomate for a day. These reactions to ostomy simulations point to the value of listening to stories and engaging lived experiences. In particular, these responses clearly articulate that there is more living with an ostomy or any chronic condition than any simulation can attempt to recreate.

Moreover, it is not just healthcare providers who might benefit from listening to and thinking with stigma stories. Health-related institutions like the CDC or the National Center for Chronic Disease Prevention and Health Promotion may also learn from stories. For instance, the Julia controversy exposes a place where diverse and even disruptive stories and lived experiences might be especially informative. The insights garnered through listening to stigma stories help showcase the value in understanding the rhetorical ecology in which public stories circulate. In particular, the analysis presented in chapters 3 and 4 illustrates the continued need for health organizations and other authoritative voices to more effectively and comprehensively engage with diverse patients and their stories. The CDC clearly had a particular audience (current and potential smokers) and purpose (decrease smoking) in mind as they crafted the Tips from Former Smokers campaign, which obscured the complexity of communicating within the public sphere. The CDC’s reliance on the negative ostomy metanarrative failed to consider that ostomy experiences and stories might go beyond what any single person can offer.

Overall, thinking with these stories and the recommendations for intervention offered within them identifies at least some initial intervention pathways that include increasing public and institutional knowledge and awareness through micro-level and macro-level visibility, including visual displays, storytelling, and media representations, and expanding healthcare-provider education into ostomies and ostomy management by more fully collaborating with patients and engaging their stories and experiences. Listening to stories as informant accounts that tell about events (Mattingly, 1998; Mol, 2002, p. 20) can further enable us to listen with those stories and the events within them as a way of identifying ways to move forward. Indeed, Frank
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(2010) argued, “Stories do not simply report past events. Stories project possible futures” (p. 10). In these ways, a praxiographic approach to stigma stories further supplemented by thinking with those stories is akin to the kind of rhetorical listening that Krista Ratcliffe (2005) has called for. Following these calls, I advocate for thinking with stories as one way that a rhetorical investigation into stigma stories can shape possible futures and eradicate stigma.

Conducting Entangled Research

I want to end this book by briefly reflecting on what it was like to study the stigmatization of a condition that I live with. Specifically, I offer reflections regarding my patient/researcher identities throughout the research and writing of this book. These reflections speak to the complexities of conducting entangled research, and I hope my work draws attention to what I consider one of the key questions in rhetorical studies of health and medicine: how do we attend to our personal identities and entanglements? It is not uncommon for rhetoricians of health and medicine to study and theorize about conditions that scholars are personally connected to (see Molloy et al., 2018). Often in their work rhetoricians simultaneously occupy many roles, including patient, caretaker, spouse, parent, and even healthcare provider. Thus, our field must hold thorough and sustained methodological and theoretical conversations regarding how these positions specifically shape our work and our discipline (Molloy et al., 2018). As many other rhetoricians of health and medicine find themselves in similar entangled positions, I hope this project might add to the ongoing conversation about how we attend to our identities and how we manage the insights they foster.

Perhaps most importantly, my patient identity alerted me to how personal and sensitive living with chronic GI conditions can be, how difficult it is to deal with stigma, and how intimate it can feel to share stories about navigating illness and stigma. Though it may not seem like it, given that I disclosed my patient identity within the first few pages of this book and proceeded to share a deeply personal bathroom story in chapter 2, it feels difficult and risky to talk publicly about my experiences with Crohn’s. In fact, for the first two years after I was diagnosed, I actively hid my disease to the extent that I can count on one hand the number of people who knew about my diagnosis and the lived experiences that led to it. It wasn’t until I was hospitalized for the first time that I began to tell others about Crohn’s, and it took nearly three

years of studying chronic GI conditions before I publicly disclosed my patient identity as a researcher. I have found that it is often easier to pretend that I don’t have Crohn’s than to attempt to unpack all the intricate ways in which Crohn’s impacts my life.

That said, my own experiences are the very reason I began searching for a methodology that would allow me to study stigma and connect with people living with ostomies and chronic GI conditions on their own terms. My patient identity and personal lived experiences are also the very reason I so strongly disagree with classifying some stigma experiences as “perceived” and others as “enacted” (see chapter 2) and thus the reason I sought to determine how a nuanced rhetorical understanding of stigma might add something important to ongoing stigma research. Without my own patient experiences, I don’t know that I would have pursued stigma stories or a praxiographic approach that helped place stigma as done in practice. Even more, I don’t know that I would have ever studied chronic GI conditions and ostomies. I certainly would have been more inclined to consider other research topics after receiving harsh, stigmatizing reviewer feedback had I not been personally invested in acknowledging and countering such stigmatization. Undoubtedly, my patient experiences enabled me to recognize that people living with ostomies and chronic GI conditions have much to teach us about stigma and the rhetoricity of chronic illness and motivated me to find an approach that would allow me to respect, care for, and listen to participants in my research on their own terms.

Additionally, my patient identity significantly influenced my ability to recruit and work with many of my research participants. A few even disclosed that they had agreed to talk to me specifically because I am “one of them” and I “get it.” Being part of the IBD community helped at least some of my participants feel comfortable sharing their stories because I have demonstrated through my engagement online and in-person discussion, events, and community-building as a patient that I am committed to improving the lives of people living with ostomies, GI diseases, and chronic illnesses more generally, and to dismantling stigma. To be clear, I did not aim to use my patient identity to coerce participants into participating in my research efforts. Instead, I honestly disclosed my motivations for my research and attempted to articulate the ways in which my research was and is committed to caring for those living with chronic conditions. These practices, motivated by both my patient and my research identities, enabled me to build trust and connections within the ostomy and chronic GI communities.

That said, it’s also important to recognize that disclosing my patient identity to potential participants did come with some costs. Earlier in this con-
clusion, I described how important it can be for people living with chronic conditions to hear others’ stories. Along with the potential benefits I earlier described, it can also be challenging to hear others’ stories, especially when those stories describe side effects, surgical complications, or other experiences that materialize the risks and difficulties of living with chronic conditions. I experienced both these benefits and challenges as I conducted the research for this book. During one interview, in particular, a participant repeatedly insisted that he knew exactly what it was like for me to live with Crohn’s, even though what he described was dramatically different from my own actual experiences (which I never shared with him). This participant’s comments likely were an effort to connect with me, but I couldn’t help but think you have no idea what it is like to be me, and I not only struggled to finish the interview but found it incredibly difficult to listen to that recording as I worked to transcribe and analyze it. This experience illustrated for me that my patient and researcher identities are not only mine to navigate; participants were also faced with grappling (consciously or not) with my entanglements as they participated in my research. I’ve no doubt that my patient identity influenced how my participants spoke to me and the kinds of stories they were willing to tell. This doesn’t make the stories any less real or important; it did, however, require extra care during analysis and reporting. Moreover, this experience reminded me how, despite common diagnoses, lived experiences with chronic conditions are highly individualized, and while my patient identity helped me relate to many of my participants, it did not grant me full access to or total understanding of their experiences.

I was surprised, during both interviews and observations, to find myself struggling to listen to some of the stories I heard. When it comes to being a patient, sometimes it can honestly be easier to not know what a future with a chronic condition might look like. This is not to say that I buy into what Kafer (2013) called “a future of no futures” for people with illnesses and disabilities. Instead, this is a recognition that life with a chronic condition or disability can simultaneously be positive, worth living, and difficult. It would be dishonest for me to say that it was always empowering or uplifting to hear others’ stories about living with ostomies or chronic GI conditions. Sometimes it just reminded me of how unpredictable life with a chronic illness can be, a fact that I, as a patient, often try to forget. To help account for my own embodied and emotional responses, I began to take personal notes in addition to these notes I would write things like “Hm . . . that is not how I feel about X” or “I am feeling really anxious listening to this story. I think it’s because I’m nervous about my next scope.” I worked to consciously record my emotions and opinions so that I could later try to account for them.

In such notes I would write things like “Hm . . . that is not how I feel about X” or “I am feeling really anxious listening to this story. I think it’s because I’m nervous about my next scope.” I worked to consciously record my emotions and opinions so that I could later try to account for them.
tion to collecting data so that when I later worked on data analysis, I could recall how my personal responses might have impacted what I noticed and documented as a researcher. This, of course, is not a flawless strategy, but it provided one mechanism through which I could account for my patient identity. Hearing stories—both those that aligned with my personal patient experiences and those I had trouble relating to—ultimately showcased the resilience and strength that often emerges in chronic illness experiences, and I am immeasurably grateful for the many people who shared their stories with me in hopes that doing so would help dismantle stigma.

Ultimately, I have come to see my patient identity and the experiences that accompany it as a strength of my research, not a liability. Working from the intersections of my patient and research identities is not difficult because I lack objectivity. Doing this research is difficult because being a researcher is an *embodied experience.*

4 When I sit down at my desk to write, I do not flip off my patient identity or magically erase my lived experiences. I am always a patient and researcher, whether or not I study Crohn’s disease. As Jenell Johnson (2014) has argued, “We may not choose our emotions or our attachments, but once we recognize them, we can cultivate them in certain ways” (p. 177). I certainly did not choose to have Crohn’s disease; nevertheless, I have cultivated my patient identity and experiences in an effort to acknowledge, understand, and intervene in stigma. I hope that by engaging in entangled research and encouraging readers to listen to and think with stigma stories, we can all identify ways in our own daily practices and lived experiences to resist stigma.

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4. For another take on how research is embodied, see Johnson (2014, pp. 175–179).