Stigma Stories

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Warning: This preface begins with a story about Seven Charles, a young Black boy who died by suicide after bullying and stigmatization. This discussion does not go into specific or graphic details; nonetheless, it is disturbing. To avoid this content, please begin at the section break on page ix.

ON JANUARY 19, 2019, Seven Charles, a ten-year-old Black boy from Kentucky, killed himself. Left home alone for just an hour while his father, Donnie, was at church choir practice and his mother, Tami, left to run a few errands, Seven was tasked with completing a list of chores. The type of boy who followed the rules, Seven promptly finished his homework and left it for his mother’s review on the kitchen table. He then cleaned his room and began to fold and put away his laundry. But sometime in the middle of this last chore, Seven stopped, leaving laundry scattered on his bed. He then entered his closet, where his mother would later find him unresponsive. What started out as a normal day for the Charles family turned out to be one of their worst.

Although Seven’s death came as a complete shock to Tami and Donnie, they have worked to piece together an explanation in the days and months since his death. According to his parents, Seven had been verbally and physically bullied several times by classmates and his adult bus driver in the months preceding his death. As Tami described, Seven wasn’t just teased. He was the target of racist harassment, and he was ostracized for a medical condition. Born with an imperforate anus (a condition in which the anus is either

1. I do not mean to downplay the role that racism played in Seven’s experiences. My retelling of Seven’s story attempts to follow stories shared in the many of the interviews that Seven’s parents have given in the wake of Seven’s death, which emphasized the bullying Seven experienced because of his ostomy and GI conditions.
blocked or missing), Seven underwent twenty-six surgeries by the age of ten, an average of two surgeries each year of his life. Along with these surgeries, Seven lived most of his childhood with an ostomy—a surgically created opening on the abdomen that allowed Seven to excrete digestive waste into an ostomy bag affixed over the opening.

Seven didn't want his classmates to know about his conditions or the fact that he needed an ostomy to go to the bathroom, so he did his best to hide them and prevent any leaks at school. However, sometimes his ostomy bag leaked digestive waste when it wasn't fully sealed against his abdomen or when it needed to be emptied. According to his parents, Seven occasionally experienced these leaks at school, which his classmates noticed and teased him about. “Kids at school and on the bus would make fun of the smell that stemmed from his condition,” Tami explained (Wheatley, 2019).

Eventually, Seven was able to undergo ostomy-takedown surgery that closed the opening on his abdomen and enabled him to defecate anally. However, as his body adjusted to functioning without an ostomy, sometimes Seven struggled with fecal incontinence and subsequently continued to face bullying. Like the leaks of his ostomy bag, the leaks Seven experienced due to fecal incontinence were uncontrollable, though this didn't deter the bullies. Seven and his parents did their best to prevent and limit any accidents, but sometimes they still happened. And even when the leaks were managed, the bullies did not go away. Tami remembered, Seven “just wanted to be normal, that's all” (Kim, 2019).

Tami and Donnie eventually turned to school officials for help, asking them to open an investigation and reprimand the students who were harassing Seven. Though the school agreed to investigate, Seven's parents felt that the situation had escalated beyond repair and therefore found Seven a new school for the next academic year. Tami also secured different transportation to school so that Seven could avoid taking the bus after even his adult bus driver made comments to Seven about his conditions and related smells. Tami would later recall how she had told Seven he just needed to make it through the school year and he would be able to start over at a different school. Despite these interventions and the promise of a fresh start at a new school, Tami lamented, Seven “just couldn't take the bullying any longer” (Ross, 2019).

Though no one will ever know for sure, Seven's parents have publicly and repeatedly pointed to the bullying their son experienced as a powerful contributing factor in his death. It is difficult—impossible even—to imagine what Seven, at just ten years old, endured. A congenital chronic condition, an ostomy, leaks, fecal incontinence, over twenty surgeries—Seven overcame significant medical hurdles. A “miracle child,” his mother called him (Shanklin,
On top of his medical challenges, Seven went to school, a place where he should have been able to make friends, experience the wonders of baking soda volcanoes, and get lost in the pages of a chapter book, and was, instead, outcast. It’s obvious in listening to the stories that Tami and Donnie have shared since Seven’s death that many of the people Seven interacted with at school failed to see the miracle of his life. Instead, although Seven was among millions of people around the world who are born with or develop chronic conditions, particularly related to the gastrointestinal (GI) tract, others saw him as abnormal, and, worse, they made him feel unworthy of life. In other words, Seven was stigmatized.

Seven’s story demonstrates just how real and powerful stigmas are and just how urgently we need to resist them. Seven’s story also reminds that acknowledging the very existence of stigma, particularly related to GI conditions, is a critical first step in eradicating this kind of stigmatization and preventing the bullying and harm that Seven endured. This book is one attempt to inoculate against the fear, mystery, and consequent stigmatization of ostomies and chronic GI conditions by studying and sharing the lived experiences and stories of people like Seven. The stories and experiences of people like Seven, if we take the time to really listen to them, can help destigmatize chronic GI conditions by providing more nuanced pictures of what it is like to live with a GI condition and inviting others to embrace empathy over fear and stigmatization. Stigmas often emerge from ignorance or misunderstanding, and they maintain power in silence; thus, this book provides one platform where the stories and experiences with chronic GI conditions, and stigma, can be made visible and heard. In doing so, this book is a call to both listen and speak up.

I’m advocating for the kind of careful listening that Krista Ratcliffe (2005) has outlined: “a stance of openness that a person may choose to assume in relation to any person, text, or culture” (p. 17). Ratcliffe’s rhetorical listening is both relevant and instructive for the work I attempt to do throughout this book and that I invite readers to do along with me. Such listening is active; it takes cognitive, emotional, and intellectual work. Rhetorically listening to stories like Seven’s requires us not only to hear others’ experiences but to reflect on our own and our own potential participation in perpetuating stigmas, be it through silence, accident, or intention. We must rhetorically and reflectively listen if we want to ethically engage with each other’s lived experiences, particularly in the contexts of health and medicine, and, in turn, eradicate stigma. Just as Seven’s story demands that we rhetorically listen to his story and others
like it, it also demands that we reject stigmatization as a constant in the world or as somebody else’s problem. Stigma’s emergence isn’t isolated to interpersonal interactions; that is, we cannot assume that if we aren’t bullying others ourselves or if discriminatory comments aren’t coming from us, then we are off the hook. Stigma, as I’ll dive into in the coming pages, is at once personal, interpersonal, and societal. Therefore, it is the responsibility of each of us to acknowledge our own complicit and/or active roles in either perpetuating or eradicating stigma in all its manifestations.

We’ll never fully know the reasons for Seven’s death, but if stigma played even the smallest of roles, I hope this book can advance a critical conversation regarding the seriousness of stigmatization, why stigmas exist, how they are kept alive, how they can be relinquished, and how doing so is a shared, social project. In the coming pages, I set out to do the complex work of raising awareness, encouraging more nuanced understanding, and improving the lived experiences of those struggling under the rhetorical and experiential weight of stigma.

But what, exactly, is stigma? This is a question that has many answers and, yet, often no answer at all. Stigma is one of those odd things that is difficult to define, yet somehow easy to spot, feel, or know. Like other related forms of social and structural oppression, stigma can be overt and explicit, but most often it emerges in implicit and ambiguous ways that make it not only hard to define but difficult to identify, bound, and uproot. Stigma’s simultaneous obviousness and elusiveness initially piqued the curiosity that led to the research presented in this book, but it is the experiences and stories I have heard (and lived) regarding stigma that kept me coming back, digging deeper and harder to understand what exactly stigma is, what it does in the world, why and how it persists. Although many researchers have worked to answer these questions (and to such work this book is certainly indebted), stigma continues to harm its targets—disabled people, Black, Indigenous, and people of color (BIPOC), those who don’t fit current standards of beauty/thinness/fitness, the elderly, immigrants, neurodivergent people, the poor. Really, the list of stigmatized identities and embodiments is far too expansive for anyone to capture fully; any difference from countless norms can provoke stigma. Because it affects so many people for so many reasons, this book sets out to build and expand our understanding of stigma.

Given the difficulty in defining and studying stigma and its widespread nature, this book aims to chip away at this complex phenomenon by narrowing in on the stigmatization of chronic GI conditions. I am focused on ostomies and chronic GI conditions in this book for a variety of interrelated reasons. Conditions and experiences related to the digestive system are an
ideal case for rhetorically theorizing stigma because these conditions sit on the edge of several boundaries. They are invisible, until they become visible (visually, auditorily, or olfactorily). They occupy the junction of the natural (all living things excrete) and the taboo (but what they excrete is unacceptable). And they enable us to consider how some medical technologies, experiences, and interventions fall within the accepted realm of the normal (contact lenses, cardiac implants, appendectomies) while others (excreting waste into a pouch through an opening on the abdomen) are considered abject.

GI-related stigma is not necessarily the most important or far-reaching stigmatization (though some might argue that it is), but the stigma surrounding digestion and related entities, practices, and biomedicalized conditions is as pervasive as it is pernicious. Seven’s story provides an especially painful and severe example of GI-related stigmatization, but stigma is often micro and mundane. I don’t need to look far or try very hard to demonstrate this. Take, for example, how Western society has developed a range of mitigation euphemisms to avoid directly talking about GI-related things and practices. We say things like going to the bathroom, number two, the porcelain throne, doodo, potty, ladies'/men’s rooms. This is of course just a handful of examples. Most often, when GI topics must be discussed, we find ways to talk around them, buffering our discursive (and sometime material) proximity.

Don’t get me wrong: this book is not an attempt to dismantle stigma by advocating for a complete abandonment of our polite approach to bathroom topics. I imagine I’m not alone in my preference for saying “I have to go to the bathroom” during a meeting rather than getting any more specific or concrete. This book does look, however, at the practices that enable us to avoid, make invisible, and, in turn, stigmatize GI-related conditions. Specifically, I suggest that this inculcated aversion to all things GI evidences widespread fear, shame, and distaste that often leads to, if not precipitates, stigmatization. GI-related stigma no doubt exists, and it inflicts emotional, social, physical, and mental harm across the GI community. Indeed, it is far-reaching and deep-seated. Accordingly, GI conditions and the lived experiences that accompany them are an important and rich site for studying stigma. My hope in narrowing in on GI-related stigmatization is not only that I can deeply examine and theorize stigma in ways that will help address the specifics of GI-related stigma, but also that this specific contribution will motivate and inform additional research into stigma for other conditions, lived experiences, and identities.

Additionally, I focus on GI-related stigma because it is important to me and to the communities in which I live and that I hope to serve. I know Seven’s story because it was shared widely and mournfully within my personal IBD (inflammatory bowel disease) community. In particular, I live with
Crohn’s disease, a chronic autoimmune disease that affects the entire GI tract. As much as I write this book from my academic positionality, I write this book from my identity as a person living with Crohn’s disease and, relatedly, as a person who has faced bullying and stigmatization for it. My teenage years, in particular, are scored by experiences with bullying related to my Crohn’s. My own lived experiences and stories serve as compass, counterpoint (and mostly unwanted) companion as I captured, analyzed, and retold the stories you’ll hear in the coming pages. I work throughout this book to make this undeniable positionality present when it is relevant or has something meaningful to add to various discussions.

However, whether or not it’s explicitly presented on each page, my patient-researcher perspectives are there. As I conducted the research that guides this book and wrote each sentence you’ll read, I was repeatedly overwhelmed with flashbacks of strangers’ hurtful comments in public bathrooms as I dealt with my own uncontrollable symptoms. I relived instances when employers reprimanded me for having to run to the bathroom more frequently than my legally sanctioned fifteen minutes every four hours and when healthcare providers mercilessly told me that I would never be normal or live a normal life. Too, I researched, wrote, and edited this book from hospital beds, clinic exam rooms, and bathrooms as frequently as from my desk. My own experiences undoubtedly shape my arguments in ways I’ve accounted for and in ways I have yet to realize.

Perhaps most relevant among my own lived experiences with the stigmatization are those I’ve experienced within our own academic community, which have both motivated this work and nearly led me to quit several times. In anonymized reviews of my work, much of which has been revised for inclusion in this book, colleagues have scoffed at my academic interest in GI conditions and ostomies because they are “disgusting,” peer reviewers have made “poop jokes” in response to article drafts and conference proposals, and one reviewer even went as far as to close a review noting that all my project did “was make [them] think about diarrhea.” Such comments, both wildly unhelpful and mostly unsurprising, frequently left me upset and eager to give up on this research altogether. Often I’ve wondered whether these colleagues realized the impact their actions would have on me. But then I think about the stories I’ve heard from other people with GI conditions or ostomies, particularly those about the painful life-altering and life-ending implications of stigmatization, and I quickly fall short in mustering the empathy and interest required to ask questions about rhetorical intention. Stigma doesn’t require intent; it has rhetorical implications regardless.
My positionality and the experiences that come with it have impacted everything from the research questions I asked and the ways I collected data to the ways I analyzed, interpreted, and now share my findings. The coming chapters explore these methodological influences in much more detail, but what’s perhaps most important now is that I believe my personal perspective isn’t a bias I needed to overcome to do this research or a limitation I needed to continually suppress in order to do high-quality work. In contrast, it is the very reason I am well suited to conduct this research. My expertise as a rhetorician of health and medicine and my lived experiences as a person with Crohn’s disease complement and amplify each other. And they’ve motivated me to find ways that my trained and experiential insights can help theorize and challenge the stigma associated with these conditions.

To this end, I see this book as both a response to and an invitation for discomfort. Rhetorician Caroline Gottschalk Druschke (2017) has argued that rhetorical studies, particularly of science, technology, and medicine, “needs discomfort” to intervene in the spaces and issues that matter most to us (p. 3). “We need—now—to engage with people and things, potentially make fools of ourselves, and labor with others to do the work that most matters to us, our field, and our world” (p. 3). My rhetorical investigation into stigma thus takes up Druschke’s call. Facing the discomfort surrounding GI conditions and ostomies by tracing the rhetorical tendrils of stigma might be uncomfortable at first, but grappling with that discomfort is an act of care for people who have been stigmatized, as much as a step toward transformative and destigmatizing change. Therefore, I begin this book with an invitation to get uncomfortable, to lean in if and when you find yourself uncomfortable reading about poop, ostomies, and digestion. This work is important for those with ostomies and GI conditions, but, as is clear, the pervasiveness of stigma extends well beyond the contexts presented in this book. My work in the coming pages is therefore both specific and broad—grounded in ostomies and GI conditions but relevant and illuminating for a host of conditions affecting millions of people. My hope is that this book, as a starting place, will help uproot stigma and instill care, empathy, and justice in its place.

2. Here, I follow the lead of many feminist and disability studies scholars who have argued that research and knowledge are always situated and partial (see Haraway, 1988; Harding, 2009) and who have thus pointed to the value in being entangled as both insider and outsider (see Ginsburg & Rapp, 2013; Molloy et al., 2018).