

Stigma Stories: Rhetoric, Lived Experience, and Chronic Illness. Molly Margaret Kessler. Columbus, OH: Ohio State University Press, 2022. 240 pages, \$119.95 hardcover, \$29.95 paperback, \$37.95 ebook. <https://ohiostatepress.org/books/titles/9780814214916.html>

In *Stigma Stories: Rhetoric, Lived Experience, and Chronic Illness* (2022), Molly Margaret Kessler uses personal stories and lived experiences to theorize the stigma of chronic conditions, specifically gastrointestinal (GI) tract conditions and ostomies. An ostomy—a colostomy bag—is a small pouch attached to a stoma, a surgical opening in the abdomen. Ostomies collect waste externally rather than through the rectum, are necessary when all or part of the digestive tract has been removed, and can be permanent or temporary. Ostomates—people who use ostomies—are often subject to intense stigmatization, as the stories in Kessler’s book demonstrate. Kessler’s book is a valuable addition to scholarship that examines chronic conditions and is an exemplar of how rhetoric of health and medicine (RHM) and disability studies theory may be used in conversation with each other. RHM scholars will be particularly interested in Kessler’s use and expansion of Annemarie Mol’s (2002) praxiographic methodology, as well as her thoughtful discussions of race, sexuality, disability, and other intersectional approaches to studying chronic conditions, narratives, and stigma.

In the first chapter, Kessler provides an overview of her subject matter, major terminology, and methodology. Notably, she defines *stigma stories* as “stories that rhetorically engage, promote, or resist stigma—to “access how life is lived” through bodies with chronic conditions (Scott, 2018, p. 4)” (p. 9). Stories are integral to both the practice and experience of health and medicine: what story is a body telling? What story is a patient or doctor telling? How do we listen to or tell those stories to better understand health or persuade patients of certain treatments or actions? Stories, therefore, provide rich rhetorical material for understanding stigma. To theorize stigma through stories, Kessler situates stories within both the scholarship of RHM and disability studies. Ostomy bags and GI conditions present an interesting conundrum for disability studies: ostomy bags may be easily managed for some or completely disabling for others; thus, Kessler takes up Alison Kafer’s (2013) political/relational model of disability, which acknowledges the lived experiences of disabled people and the social/political dimension of disability.

Importantly, Kessler discusses her methodological approach in this first chapter and throughout the text. Kessler adopts Mol’s praxiographic methodology to capture and analyze stories as practices, allowing her to consider stigma as a series of practices. The stigma stories that Kessler collects include participant observations at an event for women living with chronic GI conditions and ostomies, ethnographic interviews, and text-based artifacts including blog posts, social media posts, news articles, and listicles. Kessler takes care to describe her approach to data collection, providing a helpful strategy for scholars who want to research patients with chronic conditions or other vulnerable populations. This collection of multiple narratives—from interviews, observations, and texts—allows for an expansive discussion of stigma stories and GI tract conditions.

In the second chapter, Kessler applies this praxiographic approach to lived experiences more fully. Building on previous work by RHM scholars who have worked with praxiography, Kessler outlines how this method allows her to understand how stigma emerges “in actions and

practices” (p. 62), rather than as a series of perspectives or opinions. She treats participants as their own ethnographers, which allows her to collect data ethically about a sensitive subject for so many people. Kessler uses this praxiographic approach to examine the interviews and observations she conducted as well as mediated and fictional stories, such as a Center for Disease Control (CDC) advertisement and episodes of the TV show *Grey’s Anatomy*. Including firsthand, mediated, and fictionalized accounts allows Kessler to examine public understandings and publicly circulated stories of ostomies and GI tract conditions. This chapter specifically features three different lived experiences: 1) a bathroom story shared publicly by a woman on her blog, 2) an interview with a woman who details her parents’ disapproval of her ostomy, and 3) an interview with another woman who discusses the stigma she has experienced at the hand of medical professionals, particularly relating to comments from nurses who could not successfully change her ostomy bag. These three stories illustrate the practices that make stigma visible in an ostomate's life.

The third chapter continues this work by introducing and discussing public stories about ostomies, including public health campaigns and episodes of *Grey’s Anatomy*. Public stories circulated about ostomies, as Kessler demonstrates, are nearly always negative and often used to serve another rhetorical purpose. For example, the public health campaigns Kessler examines are not campaigns *about* ostomies or GI tract conditions, but about smoking and gun safety. Rather, ostomies are used as “worst-case scenarios” (p. 73) that are not just bad outcomes but “the result of bad choices” (p. 77)—in these cases, smoking and unsafe use of a firearm. The ostomy is thus used as a scare tactic. Similarly, Kessler describes two episodes of *Grey’s Anatomy* that feature patients dealing with ostomies. In both episodes, ostomies are positioned as a worst-case scenario for both patients, worse than even death. The overwhelmingly negative association with ostomies in both the public health campaigns and episodes of *Greys Anatomy* sets up a single narrative of ostomies as always being bad. In these stories, there is no possibility for a good ostomy as stigma is rhetorically enacted through discussions of “fear, leaks, social isolation, and concerns about becoming disabled” (p. 96). Although each story is different and might seek to achieve a separate goal, they all rely on similar rhetorical strategies to make meaning of ostomies and situate them as something to be avoided at all costs. That is, ostomies as the worst-case scenario.

Kessler does take care to acknowledge that public health campaigns about smoking and firearm safety are important; perhaps fear as a tactic is a worthwhile endeavor to prevent smoking and gun violence. However, Kessler poses the question: “at what cost?” (p. 97). The continued stigma of a life-saving procedure and medical device? As such, the fourth chapter takes up those considerations by including positive stories about ostomies as “lifesavers” (p. 98) that protest stigma, stories that complicate ostomies across intersectional identities, and stories that are less easily defined in terms of being negative or positive. Kessler theorizes that these stories are disruptive ostomy stories that work to disrupt compulsory nostalgia—a term coined by Kafer’s (2013) work on crip futurities. Compulsory nostalgia describes the temporality that many disabled people find themselves operating in, which exists “before disability” and “after disability.” Before disability is a desirable state, while after disability is then thought to be worse, less desirable. Disruptive ostomy stories thus defy compulsory nostalgia by sharing the freedom and control offered by ostomies. In considering disruptive ostomy stories, Kessler suggests that ostomy stories should also consider the intersectional identities that may affect someone’s

experience with an ostomy. For example, the CDC campaign that Kessler discusses at length features the story of a Black woman, Julia. While Julia's story does stigmatize ostomies, Kessler notes that responses to Julia's story did not acknowledge her experience as a Black woman, how she may not have had access to care in the same way white ostomates do, and what support systems she may have had. While Julia's story does not challenge compulsory nostalgia or doom-filled ostomy stories, it does challenge the notion that white ostomy stories are the only ostomy stories.

Kessler continues the work of challenging dominant ostomy narratives in the fifth chapter, which focuses on visual practices of resistance in ostomy communities. Visibility, as Kessler notes, is "both central to empowerment and stigmatization" (p. 135). Looking and staring can be stigmatizing as ostomates decide whether to reveal their ostomies or stomas. However, many ostomates use visual practices to disrupt stigma, as Kessler demonstrates through the narratives she shares. In many online and social media campaigns, ostomates share pictures of themselves with their ostomies visible along with a caption or story that "coach[es]" (p. 148) viewers on how they should look or stare at their ostomy: as something positive and good rather than something negative or stigmatized. Visibility, Kessler argues, is "entangled" (p. 138) with normalcy and normalization, along with notions of sexuality, gender, disability, and beauty ideals. The goal of sharing pictures and visual displays of ostomies can be complex: Can an ostomy ever be truly "normalized"? The normalization of bodies is the process by which ostomies are made to stand out as abnormal. Sharing pictures of ostomies draws attention to their "abnormality" while also aiming to make ostomies ordinary and destigmatized. Kessler's careful examination of visual practices, intersectional identities, norms, and normalization explicate the complexities of such visual strategies and their goals.

Kessler concludes her book by offering thoughts on her praxiographic approach to working with stigma stories, key findings, and interventions with stigma, as well as conducting "entangled" research (p. 187). Thinking *with* stories rather than *about* them, Kessler argues, allows for a more ethical and empathetic understanding of resisting stigma. Kessler's account of her identity as a patient researcher to end the book is an important one: Kessler, as someone who lives with Crohn's Disease, came to this research because of her experiences. She is thoughtful about acknowledging her identity throughout the book, but this final commentary details the vulnerability in conducting this research, how her identity as a patient researcher guided her methodology and research process, and how she understands her positionality as an overall strength. Kessler's work as a patient-researcher is inspiring and hopeful as RHM scholars continue to examine the ways that disability, stigma, and intersectionality make meaning in health and medicine practices.

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