Stigma Stories

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DURING INTERVIEWS, I asked people living with ostomies and chronic gastrointestinal (GI) conditions what they thought of mainstream stories about these conditions and, specifically, Julia’s story in the Tips campaign. Often, participants knew about Julia’s story just by mere mention of her name; only a few had never heard of Julia or the campaign. Regardless of their familiarity, I read Julia’s story to each participant, and asked each to share reactions. While I’ll share the responses of several participants in this chapter, I’d like to begin with just one.

During this interview, like I did during all of them, I finished reading Julia’s story, waited a brief moment, and asked, “Hearing Julia’s story, what is your reaction? Can you describe how her story makes you feel?” Usually, participants had a lot to say about Julia’s story and were eager to say it. This time, though, there was a long, disquieting pause. At first I thought we might have been disconnected, but then, very softly, I heard what sounded like sniffles coming from the other end of the line. Eventually, Stella—my interview participant, who had been living with an ileostomy for about six months—replied:

1. Of my twenty interviews, two people admitted to having never heard of Julia’s story or the Tips from Former Smokers campaign.
It makes me really sad because I don’t feel that way at all. I really feel like my ostomy—sorry I’m getting really emotional—my ostomy did the exact opposite for me. It let me have my life back and it gave me freedom to like go about the world, like I don’t have to always worry about where the bathroom is anymore . . . and it just feels like her statements were out of fear . . . but I guess it was cancer and she probably didn’t have it for as long as somebody with [inflammatory bowel disease] IBD has . . . It just makes me really sad and wonder what kind of support she had from like her family and even from like medical staff if she felt like her ostomy wouldn’t stay on or wasn’t secured. It makes me sad that that’s what was shared with the public about what an ostomy is or what it’s like to have an ostomy.

Stella’s response poignantly illustrates that although the most widely circulated ostomy stories may be stigmatizing through an exclusive focus on negative experiences, they do not speak for all ostomy experiences. Further, listening to the experiences within Stella’s response is instructive. As she tries to understand Julia’s story, Stella compares her own experiences—not having “to worry about where the bathroom is anymore” and the “freedom” enabled by her ostomy—with Julia’s. Julia’s ostomy became a worst-case scenario, as it constrained her life, leaked, and left her isolated. Stella’s ostomy, on the other hand, improved her life, giving her the freedom to go out into the world and not always worry about being close to a bathroom. Put another way, Julia’s and Stella’s experiences with their respective ostomies are dramatically different, and, subsequently, so are their ostomies.

In this chapter, I explore alternative stories that both shed light on the diversity of ostomy experiences and trouble the dominant, public metanarrative that positions all ostomies and ostomy experiences as negative. In doing so, I follow Judy Segal’s (2012) call to identify diverse illness stories as a means to resist the “ubiquity” or “hegemony” of particular illness story (p. 307). Specifically, Segal argues:

Each of us, when we face a diagnosis of serious illness—heart disease, neurodegenerative disease, any cancer—need to get oriented to the new place in which we find ourselves. The stories we might tell of the experience, if we wish to tell a story at all, do need to be honored, even if they are—especially if they are—the ones no one really expected to hear. (p. 313; emphasis original)

Indeed, stories about illness, whether or not they align with cultural expectations, “need to be honored” and listened to carefully. I take up this task in this
chapter as I aim to listen to the ostomy stories that perhaps no one expects to hear—that is, stories in which ostomies and chronic GI conditions are staged through diverse practices that extend beyond leaking, smelling, and worst-case scenarios. In doing so, I work to disrupt the single, negative, and often stigmatizing ostomy story discussed in the previous chapter that circulates in the public sphere.

Listening to a range of stories and experiences is central to understanding how illnesses, conditions, and disabilities are made meaningful on individual, community, and cultural levels. Whether about cancer, addiction, bionic limbs, blindness, ostomies, or otherwise, stories are “prescriptive, or at least, advisory” as they “help the rest of us answer the question, ‘How shall I be ill?’” and, consequently, shape our cultural and experiential expectations about what it means to be ill or disabled (Segal, 2012, p. 295). As sociologist Arthur Frank (2013) has argued, “Published stories . . . have a particular influence: they affect how others tell their stories, creating the social rhetoric of illness” (p. 21). For these reasons, stories, such as those told about ostomies, need be “varied, complex, honest, and true” (Segal, 2012, p. 295). But of course this is not always the case, particularly when one narrative dominates and becomes the single story of an illness. For instance, many have argued that the cancer story is one of resilience and triumph that stages cancer as a didactic gift (Brenner, 2016; Ehrenreich, 2001, 2009; King, 2006; Nielsen, 2019; Segal, 2012). Or, as chapter 3 discussed, the ostomy story is negative, disabling, and tragic.

Dominant narratives may seem harmless at first, especially when they are positive and bring awareness of a particular condition. However, as I alluded to in chapter 3, rhetorical and lived tensions emerge when one kind of story dominates the “social rhetoric of illness” (Frank, 2013, p. 21). For people living with a variety of conditions, failure to adhere to the culturally prescribed expectations for illness or disability often results in disbelief, skepticism, alienation, and stigmatization (Nielsen, 2019; Segal, 2012). In the case of cancer, although bright-sided stories reflect the resilience and strength of many cancer patients, they can also encourage a bootstrap culture, telling people with cancer that the way to live with it is to prepare for a battle, dig deep, find strength, and pick themselves up to overcome an often debilitating and incurable disease. For many people experiencing cancer, living this bright-sided story is impossible and painfully conflicts with “the actual experience

2. For example, when people with cancer do not or cannot find the bright side of cancer, or, alternatively, when ostomates have positive experiences with their ostomies.
of disease” (Segal, 2012, p. 307). It is critical, then, to “expand the possibilities for what people with serious illness can say about their experience” (p. 307) for a range of reasons: to broaden cultural understandings of what it means to live with embodied difference, to allow people to share their authentic experiences, and to resist the idea that there is a universal illness or disability experience and thereby resist minoritizing and stigmatizing anyone whose experiences may buck the status quo.

Importantly, too, lived experiences and stories of health, medicine, and disability are entangled with live experiences of race, gender, sexuality, and class. Therefore, in addition to Segal’s call to expand the possibilities of illness stories, this chapter is motivated and guided by Aja Martinez’s (2014, 2020) advocacy of counterstory, which both aligns with and differs from Segal in important ways. Drawing on critical race theory, counterstory is a “method of telling stories by people whose experiences are not often told” (Martinez, 2014, p. 70). Counterstory is invested in untold stories, importantly, as it aims to “expose, analyze, and challenge stock stories of racial privilege to help strength traditions of social political and cultural survival and resistance” (p. 70; emphasis added). Counterstory also centers “the experiential and embodied knowledge of people of color” as a means of “understanding racism that is often well disguised in the rhetoric of normalized structural values and practices” (p. 69). In this way, counterstory aims to empower the minoritized through the “formation of stories that [ . . . ] disrupt erasures” (Martinez, 2020, p. 3). Thus, both Segal and Martinez insist on the importance of alternative stories that resist the hegemony of single or stock stories.

However, Segal (2012) argued for unexpected stories that complicate or altogether conflict with dominating stories of life with a particular illness, while Martinez’s (2014) counterstory is committed specifically to the stories of racially marginalized people whose voices and experiences are often otherwise silenced or invalidated by “ignorance,” “assumptions,” and “stock stories” (pp. 53). Counterstory further insists on an intersectional approach to stories that illuminates marginalization and privilege, particularly related to race, which are always at work in stories and lived experiences, especially those about illness, disability, or disease. Together, the work of Segal and Martinez facilitates a critical attunement that I bring to both identifying and analyzing the untold stories about chronic GI conditions as ostomies.

3. To read more about the complexities of bright-sided cancer narratives, see Moeller (2014).

4. In doing so, I also draw on Krista Ratcliffe’s (2005) rhetorical listening. For more discussion of rhetorical listening, see the preface to this book.
In particular, Segal (2012) argued that cancer narratives in the public sphere are overwhelmingly bright-sided and aimed to resist the hegemony of positive cancer stories; however, the familiar public ostomy story is “doom-filled” that insists on entirely negative ostomy experiences and consequently (re-)enforces ostomy stigma. As I searched for and traced a more expansive set of ostomy stories, it quickly became clear that doom-filled ostomy stories are certainly not the only, and perhaps not even the most common, ostomy stories, as Stella’s interview comments demonstrate. Responses to Julia’s video and the CDC, as well as to the Cincinnati PD and the *Grey’s Anatomy* episodes, show that several other ostomy stories also need to be told and honored. At the same time, dominant public ostomy stories, regardless of their doom-filled or bright-sided focus, effectively erase racialized experiences with ostomies and chronic GI conditions. That isn’t to say that Black, Indigenous, and people of color (BIPOC) with ostomies or chronic GI conditions aren’t represented, but their stories are often circulated as if their racial experiences don’t impact their health-related experiences.

Therefore, this chapter aims to disrupt simplified, stock stories about ostomies or GI conditions by taking into account the intersectional embodiments and identities that influence how ostomies and GI conditions are made to mean. At the same time, the chapter aims to “expand the possibilities” about ostomy stories and to trace the rhetoricity of different ostomy experiences by examining (and simultaneously amplifying) a broader set of ostomy stories, including what might be categorized as “bright-sided” ostomy stories as well as stories that grapple with experiences that fit less neatly into a binary of positive or negative experience.

In searching for ostomy stories that ostomates tell themselves, rather than stories told through an institution or secondhand source like the CDC or a TV show, I further advance Mol’s (2002) praxiographic call for allowing people to serve as their own ethnographers and to tell of the events and experiences of their own lives. The stories in this chapter are those shared in protests against mainstream doom-filled ostomy stories, as well as stories told through personal blogs, podcasts, and interviews with me. As we’ll see, these stories diverge from the negative ostomy metanarrative by resisting the idea that life *before* an ostomy is universally better than life after. On the contrary, the ostomy stories presented in this chapter—what I refer to as *disruptive ostomy stories* because they aim to disrupt the negative ostomy meta-

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6. As I explain more later in this chapter, I use the term *disruptive*, following the work of Emilia Nielsen (2019), who, like Segal, studied disruptive breast cancer stories.
narrative—illustrate that experiences after/with an ostomy are actually better for many people. In following such stories, I argue that disruptive ostomy stories resist the rhetorical system in which ostomies are staged as unequivocally disabling, negative, isolating, and always leaking.

Engaging disruptive ostomy stories, particularly as a means of complicating doom-filled ostomy stories, raises several questions: How are disruptive ostomy stories and the ostomy experiences shared within them different from stories like Julia’s? Is the ostomy staged differently, and if so, how? How are these stories used to complicate, challenge, or confirm stigma? Using these questions to guide my analysis of disruptive ostomy stories, I theorize that doom-filled ostomy stories have become the ubiquitous ostomy story because they enact what Alison Kafer (2013) has called “compulsory nostalgia,” or the presumed longing for the predisabled self and, in this case, preostomy self. At its core, compulsory nostalgia is marked by the acquisition or emergence of a condition, which creates before and after selves and experiences.

Tracing compulsory nostalgia in disruptive ostomy stories, then, becomes a temporal analysis that seeks both to explore differences in these before and after selves and experiences and to track the de/stabilization of stigma. In other words, I analyze disruptive ostomy stories to examine how the sequence of experiences meaningfully influences how ostomies are staged within the lives and stories of ostomates. Whether a story is bright-sided, doom-filled, or somewhere in between is shaped, at least in part, by the progression of experiences: specifically, those experiences that change over time as a person acquires and lives with a condition. As Kafer (2013) notes, people “are described (and often describe themselves) as if they were multiple, as if there were two of them existing in different but parallel planes, the ‘before disability’ and the ‘after disability’ self (as if the distinction were always so clear, always so binary)” (p. 42). For instance, notice how the ostomy marked a shift in Stella’s self and lived experiences (opening of this chapter) as well as Julia’s. Undergoing ostomy surgery represents a rupture in time for both Stella and Julia that shapes how these two women move forward in time and experience. In both stories, before-ostomy experiences are compared directly with after-ostomy experiences. Stella’s after-ostomy life is seemingly much improved, as Stella notes how her ostomy “let [her] have her life back.” Julia’s experiences through time, however, moved from normal to negative as she experienced her after-ostomy life, filled with leaks, isolation, and being stuck at home as much worse than her life before her ostomy.

Specifically, this chapter shows how compulsory nostalgia helps reveal stigma’s rhetorical viability and how the meaning of ostomies/ostomy experience relies at least partially on temporality and order of experience. Thus,
I forward the argument that stigma is contextual both culturally (Johnson, 2010) and temporally (Kafer, 2013). In what follows, I begin by exploring the relationship between temporality, disability, and lived experiences. Then, I examine disruptive ostomy stories and the role of compulsory nostalgia in staging or resisting stigma and argue that before-ostomy and after-ostomy experiences significantly shape the meaning-making of ostomies and the de/stabilizing of stigma.

**Temporality, Disability, and Progressions of Experience**

Scholars across disability, queer, and feminist studies have demonstrated the role of temporality in understanding embodiment, normality, and difference (see Edelman, 2004; Freeman, 2007, 2010, 2019; Halberstam, 2005; Kafer, 2013). Time and progressions of time, Halberstam (2005) argued, “form the basis of nearly every definition” of what it means to be human and normal (p. 152). That is, normalcy is deeply entangled with temporal expectations and milestones. A quick internet search for *childhood development timeline* will provide the age, down to the very month, at which “normal” children should be able to smile, lift their own head, respond to their name, be potty trained, express social desires, and much more.

At the same time, time and progressions of time also shape nearly every definition of what it means to be disabled or ill. In *Feminist, Queer, Crip*, Kafer (2013) theorizes temporality, particularly futurity, as central to defining and de/stigmatizing disability. She contends:

> Familiar categories of illness and disability—congenital and acquired, diagnosis and prognosis, remission and relapse, temporarily able-bodied, and “illness, age, or accident”—are temporal; they are orientation in and to time, even though we rarely recognize or discuss them as such. (p. 33)

Time is so deeply ingrained in our understanding of normalcy, and consequently disability, that it goes almost undetectable. When bodies or minds fall out of sync with “normal” temporal expectations, especially when they fall behind in time, they are typically deemed abnormal or disabled. In other words, when embodied practices operate out of, especially behind, time, they are frequently stigmatized as defective.

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7. See Jain (2007) as one example of theorizations of temporality and disease, what she calls “living in prognosis.”
Tracing temporality’s entanglement with disability, Kafer (2013) further argues that disability and living with illness “push time ‘out of joint’” (p. 36, citing Freeman, 2007). Disability and illness disrupt time—by accelerating bodily or cognitive breakdown, halting expected development, or challenging the progress of an individual or society—and are, consequently, often devalued and stigmatized. These embodied disruptions in time evidence human fragility; they expose and remind us that able-bodiedness/mindedness is temporary, which, in turn, rocks the stability of able-bodied/mindedness, creating discomfort and often stigma for those who disturb temporal normality.

“Failure to adhere to norms of bodies as unchanging, impermeable, long-lasting, and stable,” Kafer argues, leads to “the devaluation of disabled bodies” (p. 41). Disability and illness thus push people out of joint with cultural expectations of time and bodily progression. For a quick example of such out-of-jointed-ness, recall the *Grey’s Anatomy* episode in which the character Clara resists ostomy surgery because ostomies are for “old” people (see chapter 3). A young ostomized body is a body temporally out of joint, and a body thus worth rejecting. Disability and illness are resisted, devalued, and stigmatized because they serve as reminders that normality and able-bodiedness are temporary at best.

Kafer (2013) calls this temporal tension between normal and disabled a discrepancy between “curative time” and “crip time.” Curative time orients us toward the absolution of disability and illness. It is the temporal progression toward cure and the timeline on which ableist systems of power and stigma require disabled people to live. *How long until you are cured? When is the cure coming? How long have you been this way and when will it end? What is your prognosis?* These curative time questions are the often impossible bar against which disabled and chronically ill lives are measured. Undoubtedly, such questions are familiar to those living with ostomies, chronic GI conditions, and chronic conditions more generally. Crip time,\(^8\) as an alternative to

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8. Kafer (2013) theorizes the role of temporality through the case of Ashley X, whose case became famous when her parents, along with her healthcare providers, decided to stop her sexual and physical development (through hormonal and surgical intervention) to make Ashley easier to care for as she aged. Through Ashley’s case, Kafer theorizes that her parents and providers justified her treatment by arguing that it would restore temporal alignment between her mind (which, because of static encephalopathy, remained that of an infant) and her physically maturing body.

9. Drawing on queer theorists including Lee Edelman (2004), Lauren Berlant (1997), and Patrick McCreery (2008), Kafer (2013) argues that disability and queerness are framed within a “politics based in futurity” in which humanity’s progress is dependent on “able-bodied/able-minded heteronormativity” (p. 29). One obvious example of a politics of futurity is pro-eugenics arguments.

10. See also Zola (1993).
curative time, is “flex time not just expanded but exploded,” and it “requires reimagining our notions of what can and should happen in time” (p. 27). In crip time, there is no universal timeline, no milestones broadly marked on the chronology of human lives, bodies, or minds. Our timelines, instead, are our own, not constrained or evaluated by medical, historical, or cultural templates. Crip time, unlike curative time, has no predetermined destination or outcome (e.g., a cure, treatment, or timeline for embodied improvement).

Crip time and curative time are especially important to disability, Kafer (2013) argues, when placed on a continuum of past, present, and futures of disability. Engaging the past and present, Kafer articulates “compulsory nostalgia” to describe the experiential trajectory on which many people with acquired disabilities find themselves. Compulsory nostalgia creates two selves—a “before disability” self and an “after disability” self—in which the before-disability self is preferred and longed for. As Kafer explained:

Compulsory nostalgia is at work . . . with a cultural expectation that the relation between these two selves is always one of loss and of loss that moves in only one direction . . . The “after” self longs for the time “before” but not the other way around; we cannot imagine someone regaining the ability to walk, for example, only to miss the sensation of pushing a wheelchair. (p. 43)

This expectation of loss and nostalgia for a pre-disability time assumes that life with a disability is inherently worse than life without one. Such thinking is deeply entangled with the tragedy model discussed in chapter 3—that is, a disabled-self/after-disability life is compulsorily assumed to be accompanied by decreased quality of life, or perhaps no quality of life at all.

Compulsory nostalgia and curative time animate stigma, and we can see evidence in the rhetorical implications of ostomy stories. When audiences listen to stories about ostomies (or illness or disability), they come with expectations about order of events and progressions through time. That is, they are primed to listen “to normative narratives of time” (Halberstam, 2005, p. 152) in which the progression of events through time results in (a return to) normalcy through cure. Thus, experiences after undergoing ostomy surgery, acquiring a disability, or becoming ill are expected to be less positive than those prior, and ostomies, disabilities, and illnesses are expected to progress toward a cure so that the disabled and ill can return to the preferred,

11. Importantly, compulsory nostalgia is most evident in cases of acquired disability. Those with congenital disabilities, however, are often treated with the same compulsory nostalgic thinking; however, it usually assumes that those born with disabilities should want to be cured, treated, or otherwise fixed to rid themselves of their disability.
before-disability self. If and when these temporal expectations are not met, people with illness and disabilities are rendered less than human, and particular experiences and conditions are deemed undesirable and sometimes abject. When bodies and minds deviate from expected timelines—that is, the “natural, common-sense course of human development” (Kafer, 2013, p. 35)—stigma often emerges.

Kafer’s claims productively map onto mainstream understandings of ostomies and ostomy experience timelines. Stories, like those explored in chapter 3, in which compulsory nostalgia is evident and the after-ostomy self is undesirable, are rhetorically effective because they affirm cultural expectations about ostomies and ostomy experiences. Put another way, ostomy stigma emerges when (and demands that) after-ostomy selves are worse than before-ostomy selves, so ostomy stories that confirm this expectation are rhetorically successful. In contrast, stories in which after-ostomy selves are more desirable than preostomy selves are rhetorically untenable in an ableist culture (i.e., who could possibly prefer living with an ostomy? a disability?). Negative ostomy stories, like Julia’s, in which compulsory nostalgia is validated, are unsurprisingly the most persuasive and widely circulated.

Indeed, each of the negative ostomy stories presented in chapter 3 demonstrates compulsory nostalgia in action and provides a basis for which disruptive ostomy stories might be compared. Julia’s story and the Cincinnati PD story rely on a preostomy self as a silent referent within the stories. Rereading Julia’s story through the lens of temporality and compulsory nostalgia illuminates the rhetorical power of the “before disability self.” Through her story, Julia highlights the negativity, isolation, and leaking that can accompany an ostomy. These experiences and Julia’s story, positioned within the Tips campaign, tell the audience that Julia’s before-ostomy self (or the before-disability self, as Kafer might name it) is far better than her after-ostomy self. Put simply, Julia’s message is “change your habits now to prevent an after-ostomy self ever becoming possible.” Julia’s story is rhetorically contingent on her own compulsory nostalgia. Moreover, her story, positioned within the Tips campaign, assumes that viewers will also be motivated by a temporary, imagined experience with compulsory nostalgia and invites viewers to participate in that nostalgia by using second-person language, which helps viewers imagine their after-ostomy lives. Similarly, the Cincinnati PD story anticipates the audience’s ability to envision a future self filled with compulsory nostalgia.

12. I hope my sarcastic criticism and rejection of such thinking comes through clearly, but here’s clarity in case it doesn’t.

13. Though, in some cases, it is anticipated or imagined. For example, Clara fears what life will be like with an ostomy and pleads to prevent that life. This implies to viewers that no matter the risk, she prefers her current life and embodiment.
In this case, the lieutenant directly calls on his audience to imagine themselves as the after-ostomy self, “limping down Warsaw Avenue with a colostomy bag.” By forecasting this future for the audience, the lieutenant’s story leverages compulsory nostalgia for a life without an ostomy in his audience and thereby hopes to persuade them to prevent that very nostalgia from coming to fruition by avoiding gun violence in the present. The manipulation of temporal experience in these stories relies on compulsory nostalgia and ableist envisioning of ostomy experience. As Kafer (2013) might describe, a future with an ostomy in these stories is a “future of no futures”—that is, a future with an ostomy is not a future worth living (p. 33).

The order of experiential events in these stigmatizing ostomy stories enables compulsory nostalgia. In many stories and experiences, when life before the ostomy is considered “normal” and desirable and life after the ostomy worse, the overall experience of ostomy is negative, and the pre-ostomy self is longed for. However, many responded to the public circulation of compulsory nostalgia and the stigma it strengthens with anger, frustration, and protest. To complicate and disrupt this compulsory nostalgia, many people living with ostomies and related chronic GI conditions publicly told their own stories. In the following sections, I analyze these disruptive ostomy stories that were shared in protest as well as ostomy stories that were shared with me during interviews and publicly online that diverge from the ostomy stock story showcased in chapter 3. Specifically, I examine how experiences unfold temporally in these stories to engage compulsory nostalgia and attend to the meaningfulness of the before- and after-ostomy selves. In doing so, I consider the different ways in which ostomies are staged and made to mean through(out) these disruptive stories.

Rejecting Compulsory Nostalgia: Disruptive Ostomy Stories as Protest

Not long after the Cincinnati PD’s comments about ostomies during their antigun initiative, nor long after the airing of the Grey’s Anatomy episodes, people living with GI conditions and ostomies signed petitions, started social media campaigns, and wrote letters challenging the negative ostomy stories that were perpetuated in these highly public contexts. In response to the Cincinnati PD, a Cincinnati citizen with IBD told a local news station:

When this went out publicly it presented an image of a colostomy bag as unattractive, disgusting, and related to gangs. [The lieutenant’s depiction of
ostomies] created a negative image for those who have never heard about a colostomy. That image would be very difficult to change to a positive one. (Warren, 2013)

For this person with IBD, the lieutenant’s remarks were particularly persuasive and concerning because they reached an audience of “those who have never heard about a colostomy” (Warren, 2013). People with previous experience or knowledge of ostomies may have been able to be more critical of the lieutenant’s comments or, at the very least, may have had broader medicocultural contexts in which to situate the lieutenant’s story as one potential ostomy story, not the only one.

Similarly, a state chapter of the UOAA petitioned against the Grey’s Anatomy episodes, arguing, “We, as ostomates, are trying so hard to erase the stigma that goes with [having an ostomy] and that episode certainly didn’t help. I’m sure you are aware, in real life, that ostomies have saved 1000s of people’s lives who are now leading productive, healthy, and successful lives” (Hafner, 2009). Like the response to Julia’s story, this petition against the Grey’s Anatomy episodes called out the show writers for “obviously [giving] no thought whatsoever to the thousands of people who have colostomies.” Such criticisms oppose the ubiquity of doom-filled ostomy stories by suggesting that these stigmatizing stories do not represent the experiences of many living with ostomies. Further, this petition explicitly rejected compulsory nostalgia, temporal expectations, and stereotypes regarding ostomies, contending that

we [ostomates] are not all “old Grandpas” like depicted in the patient’s comments. We are mothers, spouses, children, young, old, sisters, brothers, coworkers, and employers . . . What about all the viewers out there that may be scheduled for an ostomy . . . and then to hear it “is the worst thing that could happen?” (n.p.)

This petition, in addition to other responses, specifically refuted the “stigmatizing” message put forward in the stories of the Cincinnati PD and Grey’s Anatomy episodes. Importantly, too, these responses, as we’ll see is also in the case in responses to Julia’s story, advocate for the ostomy as “lifesaving” rather than as a worst-case scenario. These responses, consequently, disrupt the dominant doom-filled ostomy narrative and outright reject compulsory nostalgia by arguing that life after receiving an ostomy is not only positive but only possible because of ostomies. Responses to Julia’s video not only expressed similar concerns but were significantly louder and broader in scale.
Almost immediately after Julia’s message aired nationally, a significant backlash emerged in the form of social media posts, petitions, phone calls, and letters aimed at the CDC. Together, thousands of people living with ostomies and GI conditions, especially those with IBD, and their allies rallied to demand that the CDC remove Julia’s materials. It wasn’t just individual people responding to the CDC and Julia, either. Major national organizations, including the United Ostomy Association of America (UOAA), the Crohn’s & Colitis Foundation of America (CCFA), and Fight Colorectal Cancer joined in the outcry against the CDC’s message about ostomies. So overwhelming was this response that within just a few days of Julia’s story release, the CDC’s Facebook page actually crashed from the number of posts that flooded it. Consistent across these calls and posts was a clear message: Julia’s materials should be removed from public circulation because the CDC, by including Julia’s video in the Tips from Former Smokers campaign, was perpetuating stigma by broadcasting Julia’s story as representative of all ostomy experiences.

The anger, distress, and disappointment at the core of these responses was palpable. At best, it seemed that people felt caught in some rhetorical crossfire. Many protesters of Julia’s video acknowledged that the Tips goal of encouraging people to quit smoking was well intentioned but still questioned whether accomplishing the goal needed to be at the expense of millions of people who are alive because of ostomies. At worst, it seemed that folks were outraged that the CDC (2019a), a premiere public health and medical organization, dedicated to “saving and protecting lives,” had either incidentally overlooked a significant portion of the ostomy community or simply didn’t care about them. A petition to remove the video argued that the video “sends the wrong message to the general public, at a time when those of us who have permanent ostomies are trying to educate others about this condition” (Rund, 2015). The petition further explained that the “fear of being stigmatized, including the extreme negative body image that our society has placed on those with ostomies, sometimes leads people to forego [sic] those lifesaving surgeries” (Rund, 2015).

Many who spoke out against the video did not reject Julia’s experience outright, suggest life with an ostomy is easy nor did they dispute the challenges of living with and wearing an ostomy pouch. Instead, much of the resistance to Julia rejected the idea that life with an ostomy is universally or inherently negative and argued that Julia’s story pictured life with an ostomy as exclusively negative, gross, constraining, which ignored that many find that an ostomy enables a life that would otherwise be impossible because of the disease or condition that preceded it. Even more, insofar as it reached a
nationwide audience, the CDC’s depiction of ostomies undercut the efforts of campaigns and advocacy work by organizations like CCFA and UOAA to dismantle the stigma surrounding ostomies. A joint letter to the CDC from the UOAA and the CCFA explained, “The situation is especially serious precisely because the CDC, a trusted source of important medical information, has spread the message. . . . We know that your ads are undermining what we have done to empower, educate, and reduce the stigma of ostomy surgery” (Burns et al., 2015). The UOAA and CCFA emphasize the rhetorical importance of the CDC here. The CDC, as a leading health organization, validated the story, granting it credibility in the public sphere. Had Julia posted this video on her personal YouTube channel, other ostomates might have left educational materials, resources, invitations to Facebook groups, or perhaps criticisms and angry comments, but it seems less likely that full-fledged petitions and public outcry would have ensued. The expansiveness of a public nationwide audience, the media through which this ad was made available—both TV and online—and the fact that this campaign emerged amid several ongoing ostomy-positive social media campaigns aligned to create the rhetorical opportunity for Julia’s ad and the response it received. Importantly, these activist responses are not the only discourse in which compulsory nostalgia is contradicted. Many other stories celebrate ostomies as lifesaving and champion after-ostomy life.

In addition to the petitions and letters rejecting these mainstream negative ostomy stories, many individual ostomates have shared their own stories to disrupt the hegemony of doom-filled ostomy stories. Jessica Grossman, a well-known ostomate and blogger, is one such individual. In a fiercely written blog post, entitled “Dear CDC” (2015), which she posted on her ostomy-positive site Uncover Ostomy, Jessica wrote:

Dear CDC,

My name is Jessica Grossman.
In my 25 years of life, I’ve tried to live as healthy as possible.
I watch my diet.
I exercise.
I take vitamins.
I don’t really drink.
And I certainly do not smoke.
BUT I HAVE AN OSTOMY.

I get it. You want people to quit smoking . . . But you’re doing it wrong. So. Very. Wrong. And I’m here to call you out. I’m here to enlighten you on something you really should already know. You are a major health organiza-
tion after all. Center for Disease Control, this video that you put out, featuring a woman named Julia, is what you think is the perfect way to scare people out of smoking.

From the outset, Grossman positioned her experience as at odds with Julia’s, specifically by highlighting her before-ostomy practices and with-ostomy practices as categorically healthy (e.g., exercising, taking vitamins, avoiding tobacco). In framing her experiences both before and with an ostomy as healthful, Grossman rhetorically resisted the idea implied in many publicized ostomy stories: that her ostomy was somehow a self-inflicted tragedy or the result of unhealthy choices. In other words, her story argued that many of her experiences, particularly those she can control (e.g., diet, exercise, drinking, and notably, smoking), remained unchanged (and healthy) as she transitioned from her before-ostomy self to her after-ostomy self.

In the next sections of her story, Grossman (2015) questioned how having an ostomy could be worse than chemotherapy and cancer, and addressed Julia directly:

I’m not entirely sure, but I assume that you, Julia, are a real person with this story. But, Julia, if this is your real story. I am saddened for you. You had colon cancer due to smoking and you needed an ostomy. But what you said in this video, Julia, to be honest, shocked me . . . Julia, the only time I’ve ever been stuck at home was during the time I was sick with my disease. My bag rarely ever comes loose, and thanks to my healthy diet, it doesn’t even smell . . . Julia maybe you didn’t know we were out there—others with ostomies who could help you. Others who live meaningful and enjoyable lives. Lives that, without an ostomy bag, would not exist. I can’t blame you though, Julia. It’s hard to find us. It’s hard to find the positive light hidden within our ostomy bags. You know why, Julia? Because of organizations like the CDC. Yes, CDC, because of you. (emphasis original)

Obvious in Grossman’s response is a significant conflict between her own ostomy experience (and seemingly what she feels is representative of others’ experiences) and the ostomy experience shared by Julia and the CDC. Grossman also countered compulsory nostalgia for her before-ostomy self when she explained that the “only time” she felt stuck at home like Julia was when she was sick with disease prior to her ostomy surgery. Grossman further rejected a longing for her before-ostomy self and simultaneously championed her after-ostomy self when she emphasized her “meaningful and enjoyable” life that “would not exist” without an ostomy.
Additionally, Grossman’s post complicated the idea that experiences with leaks, isolation, and smells define life with an ostomy, as she argued that such experiences are “rare” for her. Such negative experiences, in contrast, are central to the doom-filled stories challenged for perpetuating stigma. Echoing Grossman, a change.org petition that garnered nearly 11,000 signatures and received a public endorsement from the UOAA, argued that people with ostomies “are not necessarily ‘smelly’ nor do we hide in our homes to avoid leaks.” Similarly, Active Guts, another ostomy-positive site, wrote in a letter (2015) to the CDC that Julia’s video “vilifies ostomies” and “contributes to misunderstandings and fears about having an ostomy.” The Active Guts letter ended by calling for the media to “present ostomies realistically,” which suggested that the ostomy presented in the Tips campaign failed to do so. Collectively, the stories, petitions, tweets, and letters shared in response can be interpreted as an effort to expand the possibilities for what can be said about living with an ostomy and, thus, as an effort to resist compulsory nostalgia and the hege-
mony of doom-filled, stigmatizing ostomy stories. These responses forcefully insisted that public, doom-filled ostomy stories are both distressingly narrow and problematically ubiquitous.

Overall, responses to doom-filled ostomy stories (Julia’s and otherwise) hinge on the idea that despite the realities of some people living with ostomies, many other ostomates experience an after-ostomy life that is not always or only centered around leaks, uncontrollability, isolation, and fear. Instead, these responses emphasize repeatedly how the after-ostomy self and life is improved and desirable, and how the ostomy itself is lifesaving. These responses reveal significant differences across the lived experiences with ostomies. At the same time, they demonstrate how these different lived experiences can and do function as a way to resist stigma by highlighting alternative and more positive ostomy experiences. Further, compulsory nostalgia for preostomy life is countered across these stories as the after-ostomy self is framed as better, more desirable, than the before-ostomy self.

In addition to arguing that doom-filled stories are not representative of many ostomates’ experiences, responses repeatedly made two points: (1) doom-filled stories, especially those advanced by institutions (e.g., the CDC), not individuals, rely on stigma and perpetuate it; and (2) perpetuation of stigma is itself a pressing health threat insofar as ostomy stigma may prevent people from undergoing potentially lifesaving ostomy surgery, much in the way that the fictional Dr. Bailey from Grey’s Anatomy feared that Clara was refusing lifesaving surgery out of ostomy fear. For instance, the change.org petition pointed out that stigma was at the core of the CDC’s message in Julia’s video:
The negative stigma that is spread by this ad is itself a health threat. Fear of being stigmatized, including the extreme negative body image that our society has placed on those with ostomies, sometimes leads people to forego [sic] these life-saving surgeries, or to postpone them for so long that their health is irretrievably damaged.

Other responses made a similar argument, including a joint letter from the UOAA and CCFA:14

We write because the ads may lead individuals who need life-saving surgeries to delay or refuse those surgeries because of the stigma being reinforced through the campaign. While we understand that the CDC is promoting the benefits of not smoking in order to reduce the risk of cancer (thus saving lives), your message—funded by taxpayer dollars and splayed across national media—that having ostomy surgery is miserable and should be avoided/delayed at all costs is both offensive and dangerous. The ads may result in increased expense to the health systems as individuals needing those life-saving surgeries delay or refuse them due to misconceptions and the stigma the ads are reinforcing. (emphasis added)

Understanding the sentiment offered in the above quotes requires some additional understanding of ostomies themselves. For many, undergoing ostomy surgery is a lifesaving effort for people who have exhausted many other options and/or whose disease or condition has irreparably damaged their GI tract. After months, sometimes years, of dealing with uncontrollable symptoms, hospital visits, and side-effect-riddled treatments, patients often consider ostomy surgery as a viable (and sometimes the only) treatment option. As Grossman explained in her post to the CDC, “For reasons completely out of my control, due to Crohn’s disease, at the age of 13 years-old, I was told that my disease was going to kill me unless I had life-saving ostomy surgery. 12 years later, I’m alive.” Similarly, in reflecting back on Julia’s video, one interview participant pointed out that “the life-saving piece [of ostomies] is what [the CDC & Julia] weren’t showing.”

What becomes clear in comparing doom-filled stories with these responses is that lived experiences before and after receiving an ostomy are drastically different, and consequently the ostomies themselves are drastically different. For example, in their letters to the CDC, both Grossman and Active Guts

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14. This joint letter has since been removed from the UOAA and CCFA websites. The analysis presented here is based on copies of the letters I downloaded before their removal from public circulation.
describe their ostomy and ostomy experience as lifesaving. Similarly, as the change.org petition explained, “There are thousands and thousands of people living active lives with colostomies, urostomies and ileostomies every day.” The ostomy as lifesaving and ostomy experience as positive described in these responses to Julia’s video advance ostomy empowerment both within and beyond the context of the Julia controversy. Indeed, in their letter to the CDC, the UOAA and CCFA contend that “the misconception that one cannot lead a normal life with an ostomy pouch” is a “myth” that leads people to believe that “death is a better choice than having these life-saving surgical procedures” (Burns et al., 2015; emphasis added). With these words, this letter affronted the rhetorical leveraging of the better dead than disabled tragedy model of disability, calling that very story of ostomy life a life-threatening myth. Collectively, these activist responses refute ostomy stigma by emphasizing that ostomies are lifesaving and detailing how the lived experiences that lead up to ostomy surgery, for many, are relentless and life-threatening. The responses draw an explicit contrast between the negative before-ostomy experiences and the after-ostomy experiences and highlight that ostomies save lives and help to normalize.

Importantly, disruptive ostomy stories are not unique to protests against stigmatizing ostomy stories. In fact, as I spoke with ostomates in interviews and read additional stories online, I found that ostomy stories often focus on the empowering experiences enabled by having an ostomy. In these stories, the experiential progression is similar to what was present in the responses to Julia, the Cincinnati PD, and Grey’s Anatomy episodes. Specifically, the stories point to the experiences and events that are enabled by the ostomy, thus arguing that the after-ostomy self is improved and often preferred.

Nearly every person I interviewed said that “freedom” was the best thing about their ostomy—freedom from bathrooms; freedom to eat whatever sounded good; freedom to go to the gym, pool, or work; freedom to have sex or begin dating again; freedom from hospitals. In many ways, these stories reject compulsory nostalgia and demonstrate that after-ostomy experiences facilitate gratitude, optimism, and empowerment. An interview participant, Nora, explained to me that her own experiences with her ostomy were “very different” from Julia’s. Nora continued, “When I used to have a rectum [i.e., before ostomy surgery], I was going [to the bathroom] thirty to forty times a day. Carrying extra underwear everywhere.” In contrast, Nora told me earlier in our interview that the best thing about having an ostomy is “the freedom it’s given [her].” For Nora, her before-ostomy life was overwhelmed by urgency, trips to the bathroom, and dealing with the uncontrollability of her bowels. In contrast, she found “freedom” in her after-ostomy life specifically because
her ostomy enabled it. Similarly, Toni, who had been living with a temporary ostomy for about eight months, told me that the best thing about her ostomy was the food freedom it gave her:

Honestly, because of my ostomy, I can eat whatever I want . . . [before my ostomy surgery] I just felt like I was walking on eggshells all the time, worrying about what's going to jump out and be painful or be bad and just having food freedom is amazing and also really not being on medications feels great too. It's a huge relief.

Additionally, Morgan, who had been living with a permanent ostomy for several years, explained that life after ostomy surgery is much more “controlled” because he is “not running to the bathroom all the time. I'm not having panic moments and worrying about always having to be close to a facility . . . but not being totally controlled by a bathroom and its closeness to me . . . my life is much simpler, much more controlled.” Morgan's repeated emphasis on the control his ostomy facilitates stands in stark contrast to Julia's experiences with leaks, smells, and fear of her ostomy coming loose.

When I interviewed Stacy, who was not only severely sick for most of her childhood and teenage years but who had actively avoided ostomy surgery, I also heard about freedom and control. However, as I listened to Stacy tell stories about her life before and after her ostomy surgery, I was struck by how her experiences changed over time. She shared that her before-ostomy life was bedridden and, most of the time, spent in a hospital because her GI disease and related complications were so severe. According to Stacy, when she wasn't “stuck in the hospital,” she was “stuck in the bathroom.” Despite the restrictions her disease imposed on her life, she was afraid of pursuing an ostomy and avoided it for several years because, as she explained,

I was thinking that I was going to be miserable and also have an ostomy. I didn't think that I'd be able to travel and do more stuff outside. I wasn't thinking that I'd have a more normal life. I was just thinking “oh good, now I'm going to have additional misery.”

Eventually, Stacy decided to meet with a surgeon to discuss the ostomy surgery and was surprised when he told her “that he thought he could help [her] feel much better” and that “ostomy surgery could be a life-changer.” With the support of this surgeon, and “once people [with ostomies] explained that [she] wouldn't have to spend hours in the bathroom anymore,” Stacy decided to
pursue ostomy surgery. When I asked her to tell me how her life has been with her ostomy, Stacy said:

My view of my life now, my life post-ostomy is so positive because I have extra hours in the day because before I was spending so many extra hours just stuck in the bathroom and so now, I have this extra time every day, after surgery that I did not have before. I used to fantasize about what I would do with the extra time outside the bathroom and now I have that so it’s very special.

The change Stacy experienced between her before-ostomy and after-ostomy lives enabled her to live more fully. In addition, her own lived experiences and positive outcomes with her ostomy empowered her to become a patient advocate in the IBD and ostomy communities, with the goal of supporting others as they consider ostomy surgery and navigate after-ostomy life. For Nora, Toni, Morgan, and Stacy, life after ostomy surgery and with an ostomy was characterized not by debilitating experiences with chronic GI conditions but by many activities that were otherwise not possible before their ostomy surgeries.

As I cataloged disruptive ostomy stories, I also found many ostomy stories shared publicly in which the ostomy enabled desirable experiences and a sense of normality for ostomates. One such example is Stomalicious—an online blog by a woman named Laura who lives with Crohn’s disease and an ostomy who aims to “spread awareness of IBD and inspire others living life and traveling the world with an ostomy” (Stomalicious, 2015a). To explain the purpose of Stomalicious, Laura offered her story to readers:

As anyone with an understanding of [IBD] knows, it can be a daily battle to get out of bed, leave the house, and live a normal life. The symptoms can take over and be debilitating. After 4 years of far more downs than ups (including trying lots of different medications, nightly enemas, side effects, diets, psychologists, fistulas, abscesses, flare after flare, and several stints in hospital), I eventually decided to go down the path of surgery. On the 24th of September 2013 I had a pan proctocolectomy and end ileostomy. It wasn’t an easy decision knowing I would have a permanent stoma. Within weeks after recovering from surgery, I knew I had made the right decision. For the first time in a long time, I felt well. I felt like a new person! Not long after surgery, we made another big decision. . . . to travel the world!. I was inspired by other IBD campaigners, and I hope my story helps, encourages and inspires oth-
ers too! Traveling and living with a stoma can be daunting, and whilst there certainly may be a few hiccups along the way, having a stoma has really given me my life back, and enabled me to fulfill some lifelong dreams that a for a long time I feared may never be possible. (Stomalicious, 2015a; emphasis added)

The Stomalicious website is filled with blog posts about Laura’s travels, many of which feature her revealing her ostomy at various destinations such as the Leaning Tower of Pisa, the Eiffel Tower, and Times Square. Like the stories of my interview participants, Laura at Stomalicious focused explicitly on what her stoma and ostomy “enabled” her to do, including international travel and a life that she “feared” impossible. Further, like other disruptive ostomy stories, Laura’s story emphasized a positive shift between her before-ostomy and after-ostomy lives. Her ostomy liberated her from debilitating symptoms, ineffective treatments, and repeated hospitalizations, freeing her to pursue her dreams.

Importantly, too, like many of the disruptive ostomy stories I read online and heard during interviews, Stomalicious didn’t just paint life with an ostomy as universally positive. Laura clarified that Stomalicious is “a place to learn more about, spread awareness of and embrace our lives with IBD” and a space where people are encouraged to “share their stories, emotions, and feelings about living with IBD,” including “personal experiences of struggle” (Stomalicious, 2015b). In most cases, disruptive ostomy stories are shared in order to destigmatize ostomies by showing that life with an ostomy is not only worth living but can be desirable, while also acknowledging that it can be challenging. As Stomalicious put it, the goal is to share “the good, the bad, and the ugly,” which includes “living with Crohn’s and a stoma . . . traveling the world, food, friends, family, relationships, sex, pooping [her] pants, medication and side effects, coping and management techniques, hospitals and surgery, stoma stories, toilet trivia,” and more. The point is that those sharing disruptive ostomy stories and battling stigma aren’t working to make the ubiquitous ostomy story exclusively positive. Instead, the goal seems to be to create a rhetorical space for all ostomy stories to be valued without (the risk of) stigmatization. In each story, the ostomates trace their experiences through time, from before ostomy to after ostomy, showing that life with an ostomy has much to offer, even if there are some challenges.

Disruptive Stories, Disruptive Timelines

Disruptive ostomy stories work to destigmatize, at least in part, by defying compulsory nostalgia. Though compulsory nostalgia anticipates life after dis-
ability or after ostomy to be worse than life before, the ostomates and their stories shared in this chapter dispute just how compulsory nostalgia for before-ostomy life really is. The embodied experiences of people like Nora, Toni, Morgan, Stacy, Jessica Grossman, and Stomalicious changed through time from experiences of constraint and suffering with chronic GI disease to enabling, empowered experiences made possible through ostomies. Specifically, these ostomates are able to pursue experiences and activities like eating, traveling, and living normal (as they individually define it) lives because their ostomies became integrated into their embodied realities. In sharing their stories, these ostomates work to transform the dominating public narrative about ostomies, and rewrite what it means to live with an ostomy.

However, because disruptive ostomy stories resist compulsory nostalgia, they also frequently fly under the public radar. That is, these stories often struggle rhetorically and consequently struggle to become more mainstream because compulsory nostalgia is compulsory. The presumed desire to rid life of disability is so embedded and normalized that it is difficult, even impossible, to believe stories that value an after-disability life. Further, disruptive ostomy stories and their resistance to compulsory nostalgia are also caught up in curative logics and time expectations. As I outlined earlier in this chapter, compulsory nostalgia operates within curative time—that is, a sense of time in which we are expected to move toward cure and the eradication of disability. Kafer (2013) explained:

> In our disabled state, we are not part of the dominant narratives of progress, but once rehabilitated, normalized, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body. Within this frame of curative time, then, the only appropriate disabled body/mind is one cured or moving toward cure. Cure, in this context, most obviously signals the elimination of impairment but can also mean normalizing treatments that work to assimilate the disabled mind/body as much as possible. (p. 28)

Usually, a cure enables the sick or disabled to normalize and regain as much ability as possible. For example, prosthetic limbs enable people with limb differences to move toward normalization (Kafer, 2013, p. 107; see also Siebers, 2008). People with disability and chronic conditions are expected to long for normality through desire for before-disability life or a cure. Amputees are expected to desire prosthetics; deaf people should want to use cochlear implants; people who have been paralyzed should dream of walking again. Therefore, happiness with a disability or incurable disabilities creates a rup-
ture in curative time. When disabilities are preferred or incurable, progress toward a disability-less future is stunted and the ever-desired march toward eradicating disease and disability is stalled (Kafer, 2013; see also Titchkosky & Michalko, 2012, p. 135; Baynton, 2017). Ostomies disrupt curative time in both ways; they are considered inherently disabling and consequently cannot be curative or ever fully normalize. Therefore, stories in which ostomies are curative and enable desirable lived experiences typically have been less rhetorically viable than doom-filled ostomy stories.

Ostomies’ relationships with cures, the unequivocal desirability of cures, and curative timelines are highly complicated. For certain conditions, ostomies do hold curative potential. Familial adenomatous polyposis (FAP), a serious genetic GI condition that often results in an ostomy, causes precancerous polyps to develop in the colon and rectum. Untreated, FAP will eventually cause colon cancer in nearly 100 percent of cases (Cleveland Clinic, 2020). In many cases, those with FAP undergo surgery to remove the colon and/or rectum and live with an ostomy either temporarily or permanently to prevent the cancer polyps from developing. In other words, an ostomy offers curative-like treatment for FAP. Additionally, ostomies are often discussed as a curative option for ulcerative colitis (UC), a form of IBD that affects the colon and rectum only. Surgery to remove the colon is often discussed as “curative” (see, e.g., Cima & Pemberton, 2004) but often requires a temporary or permanent ostomy.

Despite the curative potential of ostomies for conditions like FAP and UC, ostomies are caught in the false binary between disability and cure.

15. Surgical removal of the colon is referred to as a colectomy.
16. Surgical removal of the colon and rectum is referred to as a proctocolectomy.
17. Importantly, ostomies do not definitively cure FAP. People with FAP, even if they have had their colon and/or rectum surgically removed, can still develop polyps in other areas of their GI tract.
18. While the medical establishment discusses ostomies as a curative option for UC, many people with UC who have ostomies (either from elective or emergency surgery) report that ostomies do not completely resolve all the issues caused by UC. For example, one interview participant explicitly and repeatedly told me that colectomies and ostomies do not cure UC because, even though she underwent colectomy surgery, she continued to struggle with bowel obstructions, extra-GI issues (such as dehydration and fatigue), and challenges with the ostomy itself. Also, she ultimately said that her ostomy was lifesaving and agreed that, although technically speaking, removal of the colon and rectum does cure UC, such a cure does not mean that challenges with chronic GI issues are over.
19. The distinction here between curative and cure is important. While ostomies offer curative potential for some conditions like UC or FAP, they do not fully cure in those cases. Removing the colon and receiving an ostomy in the case of UC, for example, can effectively alleviate UC in an individual since UC is specific to the colon. However, it is not uncommon for people with UC and permanent ostomies to develop systems or complications elsewhere (e.g., stomal collapse or an abscess higher in the GI tract). Therefore, I use curative as a signal...
Though ostomies are positioned as cures or at least as curative by ostomates and the medical establishment in certain cases, they are not socially granted the positive valence associated with cures because they do not normalize; specifically, they do not normalize appearance, bathroom practices, or human waste (by making it invisible). Ostomies do enable normalization, however, when it comes to leaving the hospital, establishing a healthy weight, or participating in so-called normal activities like traveling, finding a partner, eating preferred foods, or going to school. As many ostomates have told me, having an ostomy just means that you go to the bathroom differently. Implied in that statement is the idea that life with an ostomy is otherwise normal. Ostomies’ curative potential requires that cures encompass embodied difference. In an ableist culture, though, disability cannot be made synonymous with cure; therefore, ostomies cannot be fully curative and normalizing as long as they are perceived as disabling. “Disability,” as Tanya Titchkosky and Rod Michalko (2012) argue, “may participate in normalcy, but it can never be normal, let alone be valuable, enjoyable, or necessary” (p. 128). Ostomies cannot be curative because they are not positioned as a replacement for a faulty organ or body part. Instead, they are staged as an abject device that brings us closer to otherwise invisible/concealable bodily functions and accelerate the feared breakdown of our bodies through time. In other words, rather than slow progress toward disability, ostomies accelerate that timeline, and rather than tip the scales toward normality, they render bodies more abnormal.

One of my interview participants, Jo, and her ostomy story demonstrate the presumed incompatibility between “ostomy” and “cure.” Jo chose to have a permanent ostomy after being diagnosed with FAP. In telling me her story, Jo explained that she “opted to have the permanent ileostomy surgery because [she] just wanted to have one surgery and be done” because otherwise “by the age of thirty-five” she had a 100 percent chance of developing colon cancer. Later in the interview, Jo said that among the biggest challenges of living with a permanent ostomy are “the arguments that transpire” when people ask ‘why would you want that [a permanent ostomy]? Are you sure you made the right decision? Because that's gross.’” When I asked how she responds to such questions, Jo laughed and said, “I always say I’d rather be alive and here than have cancer. Even if I would have waited, I would have gotten cancer and would have ended up with an ileostomy.” Jo’s frustration with “arguments” regarding her choice to live with a permanent ostomy and avoid “multiple surgeries” and all but sure development of cancer demonstrates the conflict between ostomies and cures. Undergoing surgery to remove her colon and rectum and that ostomies can, in some cases, move an individual toward a cure, but not fully to the destination of complete cure and disease eradication.
receive a permanent ostomy is a treatment, potentially curative, for her FAP, which alleviated Jo’s worry of developing cancer. Even though her ostomy prevented the development of cancer, Jo’s ostomy is still questioned by others and is presumed undesirable. Jo’s story illustrates that the rhetorical power of ableism and its by-product, stigma, stage ostomies as inherently disabling and life with an ostomy as universally unwelcome and abject.

Additionally, while ostomies themselves serve as a visible sign of disability and difference, their curative potential is culturally negated because of the invisibility of most GI conditions. The disruptive ostomy stories in this chapter repeatedly emphasize that life before an ostomy was filled with unbearable difficulties such as long hospital stays, restricted eating, isolation, and exhaustion. Many such experiences, however, go unseen by the general public. Unless a person has a chronic GI condition or personally knows someone who does, the debilitating symptoms and experiences of such conditions are usually hidden and privatized by those suffering, at least in part because of the sometimes severe social penalties for allowing these conditions to become visible. The often invisible nature of chronic GI conditions contributes to the stigmatization of ostomies, the ubiquity of doom-filled ostomy stories, and compulsory nostalgia. In other words, before-ostomy life is falsely considered better than after-ostomy life because the severity and difficulty of before-ostomy life is invisible. This helps explain differences between the experiences of someone like Julia and those of people like Jessica Grossman or Laura at Stomalicious. Until Julia’s cancer was found, her life was seemingly free of GI issues. Julia’s ostomy therefore marked a difference in time between her “normal” life and her less-than-normal life with an ostomy. The immediate and unexpected circumstances that led to Julia’s ostomy likely contributed to her negative ostomy experiences. In contrast, for people like Jessica Grossman and Laura at Stomalicious, whose lives were chronically plagued with debilitating GI issues, ostomy surgery serves as a juncture between before-ostomy life that was disabling and after-ostomy life that returned to their versions of normal. The sequence of experiences and whether people moved toward normalization or away from it as they received their ostomies seems to play a powerful role in the kinds of experiences disabled or enabled by the ostomy, the meaning-making of the ostomy, and the kind of story these ostomates are able to tell.

### Complicating a Two-Sided Story

While the analysis I’ve presented so far is productive for tracking the significance of temporality within stigma stories and the de/stabilization of stigma,
it's essential that I pause here to complicate a picture that I am otherwise painting as two-sided and straightforward, with negative public ostomy stories on one side (doom-filled) and responses insist that ostomies are actually positive and lifesaving (bright-sided) on the other. While this suggestion very generally reflects the stories and experiences I’ve outlined in this chapter and in chapter 3, it also problematically oversimplifies the rhetorical forces involved in these stories. Thus far I have focused on the lived experiences and practices shared within both the dominant public and disruptive ostomy stories, in an effort to track the rhetorical emergence and resistance of ostomy-specific stigma. In doing so, I’ve attempted to stay with the discourse of each of these cases. That is, I’ve tried to represent the stories and the ways they were shared and received publicly, which focused most heavily on some aspects within them (e.g., ostomy-specific practices like leaking, wearing an ostomy pouch, and ostomy-specific ideological and symbolic elements like stereotypes and ableist assumptions). This has been productive for unearthing some dimensions of ostomy stigma’s rhetoricity, but it has also encouraged dichotomous thinking, pitting negative ostomy stories and the people who lived them against those with disruptive, alternative experiences. It also assumes that the two sides are monolithic, filled with people living with ostomies and chronic GI conditions who are otherwise comparable in their identities and lived experiences. Comparing apples to apples, if you will.

However, obviously not every person with an ostomy shares the same identities and experiences beyond having an ostomy. For instance, it is obviously ridiculous to compare the experiences of two ostomates’ stories based only on their shared ostomy identity: for example, to suggest that it is possible to compare the ostomy experiences of White, upper-class, cis, straight men with an ostomy, who are otherwise the epitome of normality, with the ostomy experiences of a BIPOC, lower-class, and/or queer person living with an ostomy is not only problematic but also suggests that other life experiences and identities can be parsed from ostomy-related experiences. This presumption reduces the identities of ostomates to a single identity politic—the ostomy—and neglects other co-constitutive identities and experiences that intersectionally impact lived experiences. As Nirmala Erevelles and Andrea Minear (2010) argued, citing Antonio Pastrana’s intersectional work, “part of the problem ‘of relying on a static or singular notion of being or of identity’ (Pastrana, 75) is that the single characteristic that is foregrounded (e.g., female or Black) is expected to explain all of the other life experiences of the individual or the group” (p. 129). This false truncation to a single or static being or identity is especially problematic when we know that “gender, race, ethnicity, sexuality, class, and ability systems exert tremendous social pressures to
shape, regulate, and normalize subjugated bodies” (Garland-Thomson, 2017, p. 367). It’s imperative to address the composite effects of being multiply marginalized. While I’ve so far prioritized ostomy experiences and practices, as those have been the primary focus of both dominant and disruptive stories, rereading these stories through an intersectional lens, motivated by Martínez’s (2014; 2020) counterstory, “mediat[es] multiple differences” (Erevelles & Minear, 2010, p. 130) present within these stories and provides an alternative and possibly less polarizing understanding of negative ostomy stories, particularly Julia’s.

Though most of the backlash against Julia’s Tips video was directed at the CDC specifically, it is hard to separate a critique of Julia and her real lived experiences from a critique of the CDC’s negligence in sharing her story as part of the Tips campaign. The CDC’s insistence that the videos are “real people” telling “real stories” makes the line between Julia’s truth and the CDC’s antismoking efforts particularly blurry. Consequently, it is tempting to impulsively or uncritically villainize Julia with or instead of the CDC for widely promoting a negative story of ostomies. Julia, after all, did choose to participate in the Tips campaign, and she did share experiences with her ostomy that stigmatized ostomies and those who require them to live. And it is easy to oversimplify Julia’s story and reduce her lived experiences to those explicitly shared within her Tips video. I can imagine many ostomates listening to or seeing Julia’s story for the first time while watching television on the couch after work or between streams of YouTube videos online and being stunned by the blunt depiction of ostomies. To be honest, seeing Julia’s video for the first time took my breath away as a person living with a chronic GI condition. The sharp sting of shame I felt as I identified with Julia’s fear and disgust was matched only by my frustration that the CDC, with one thirty-second commercial, could undo years of hard work to quell GI-related stigmas. However, the initial, even hasty, reactions by me and others in the ostomy and IBD communities obscure a more critical engagement with Julia’s story, which I’m attempting to foreground now. Such emotional and visceral responses to Julia’s video perhaps enabled many upset viewers, including myself, to overlook the intersecting rhetorical forces, particularly racism and sexism, that may have impacted Julia’s lived experiences with her ostomy and the ways in which her story was received in the public sphere.

As I’ve mentioned, many of the responses to and criticisms of Julia’s story were careful to not discredit Julia as a person, invalidate lived experiences with ostomies, or suggest that life with an ostomy is always easy. I haven’t seen any responses that explicitly addressed Julia’s racial or gendered identities as Black woman. However, some responses did target Julia as an individual
(Grossman’s blog, discussed earlier in this section, serves as one particularly harsh example). In general, Julia’s multiply marginalized identities as a Black woman were erased both in her Tips video and in the circulating responses, petitions, and public outcry. This is a highly problematic move that elides the compounding stigmatization that often accompanies being Black and being a woman. As Garland-Thomson (2017) has argued, “Female, disabled, and dark bodies are supposed to be dependent, incomplete, vulnerable, and incompetent bodies” (p. 365). Most individual responses to Julia and her experiences explicitly defined her solely by her ostomy identity and experiences, which signals the potential of implicit assumptions and bias toward Julia and/or suggests that responses to Julia overlooked how her racialized and gendered identities may have impacted her ostomy experience.

Even more, the letters from national organizations like CCFA and UOAA are telling of the ways in which Julia’s multiple identity politics were left unaccounted for. Neither letter addresses the unique experiences of BIPOC in the context of chronic GI conditions and ostomies. Again, Julia’s race, and gender, were ignored altogether or deemed irrelevant to her ostomy experiences; or, perhaps worse, those identities laid the groundwork for stereotypes and biases that went unchecked. The lack of intersectional awareness shown by these organizations at the time illustrates broader racial and gender inequities in the chronic GI communities, in both the expert and the public spheres. Rather than attune to the “violent interstices of multiple differences” at which disabled people of color are positioned (Erevelles & Minear, 2010, p. 383), CCFA and UOAA, and the vast majority of individual responses to Julia, focused exclusively on her ostomy identity to evaluate her story and its rhetorical role. No explicit effort was made to contextualize her experience within knowledge of the disparities that are now well known to exist across race when it comes to chronic GI conditions and ostomies (see Afzali & Cross, 2016; Montgomery et al., 2018; Sewell et al., 2010; Sharp et al., 2020). Nor did the responses from such organizations account for the broader history of mistreatment and stigmatization of BIPOC folks within medicine and the healthcare system (see, e.g., Bailey et al., 2017; Bhopal, 2001; Ford & Airhihenbuwa, 2010; see

20. The CDC does list Julia’s story under the Tips website’s “African American” category. Many Tips participants are tagged under various marginalized identities, including race, sexuality, and disability. Visitors to the website can search for participants by condition (e.g., ostomy, lung cancer, pregnancy) or by “specific groups.” In addition to all the Tips stories from Black participants, the “African American” page includes only two statistics about smoking and Black adults: “Smoking cigarettes puts you at risk for heart disease, cancer, and stroke, which are among the leading causes of death for African Americans in the United States. About 1 in 7 (14.9%) non-Hispanic Black adults in the U.S. smoke cigarettes.” No other information is provided. See CDC (2021a).
also Washington, 2006). Instead, Julia’s race and gender as well as the role of those identities (and their accompanying politics and oppression) are unacknowledged as impactful in Julia’s negative ostomy experiences. Her experiences with leaks and feeling stuck at home were tied to her personally rather than to interlocking webs of social, structural, and personal factors that likely influenced her experiences with her ostomy directly and indirectly.

In terms of the other public responses to Julia’s story, especially those from individuals in the ostomy and IBD communities, it seems that some, especially White, folks may have also engaged with Julia and her story from implicit biases rooted in privilege, Whiteness, and patriarchy, even if those biases did not explicitly manifest in their specific comments and criticism of Julia’s story. These unchecked ideologies and assumptions may have led to defensiveness toward and alienation of Julia and her right to her own lived experiences. Admittedly, this was the case for me initially, as a young White woman with IBD. I was quick to judge and criticize Julia’s willingness to participate in the Tips campaign and to stigmatize herself, ostomies, and GI conditions through her Tips story. My initial reactions to Julia, perhaps like those of others in the IBD and ostomy community, measured her story one-for-one against mine, assuming that she had equal access to healthcare, familial and social support, and the same social and political privilege that I have as a White, highly educated, fully insured, middle-class woman with the time, resources, and support to seek whatever care is necessary to navigate the complexities of living with a chronic GI condition and (the possibility of) an ostomy. My own problematic perspective offers an example of how privileged it is to see ostomy stories as only ostomy stories rather than as complex stories embedded with structures that evaluate bodies and lives differently, marginalizing some while privileging others. Re-examining Julia’s story in this more robust context helps disperse more fairly the rhetorical agency afforded to her individual story and the rhetorical blame directed at her for presenting the public with a doom-filled ostomy story.

Research has shown repeatedly that Black people, especially Black women, are less likely to receive adequate care because of racial biases that lead health-care providers to take seriously minoritized people’s experiences and reported symptoms. When it comes to cancer specifically, Black women, on average, are diagnosed later and have a worse prognosis than their White counterparts (see, for one example, Penner et al., 2012). Taking this research into account is essential in separating a critique of Julia from a critique of the CDC. What if we see Julia’s negative ostomy experiences as a reflection not of poor healthcare choices but of poor healthcare and a racist and misogynistic society? As Stella asked in her interview with me, did Julia have support
with her ostomy? Did Julia get the kind of care and support she need as she learned to live with an ostomy? I would add, was she listened to and taken seriously when she reported GI issues, or was she dismissed and stereotyped as hysterical or angry? Did she suffer with symptoms, leaks, and ostomy-related issues because she reasonably mistrusted the medical system and its ability to care for her? I don’t have the answers to these questions, but raising them is essential to justly complicating the stories we tell and accept about lived experiences with ostomy and chronic GI conditions. These questions are further necessary to resist vilifying Julia and other individual storytellers and to remind us that it was the CDC’s responsibility to resist ostomy stigma, not Julia’s.

Criticizing Julia and her experiences suggests that there is one “right” way to live with an ostomy, which, for the most part, the responses to Julia and other doom-filled ostomy stories resist doing. I don’t know the identities or experiences of every single person who responded to Julia’s story. Nor am I necessarily arguing that the criticisms directed specifically at the CDC were unwarranted. However, we must also see that the loudest and most powerful voices speaking out against Julia’s story did not acknowledge the systemic and structural oppression and stigma that undoubtedly compounded in her lived experiences. Just as the CDC or Grey’s Anatomy writers or Cincinnati PD could have done more to nuance their stories, to resist a single negative ostomy story, so, too, could the responses have been more careful, more empathetic, more aware that patients cannot isolate ostomy experiences from racial, temporal, socioeconomic, medical, or gendered power dynamics and rhetorical expectations. What I mean to say here is that identifying a right and wrong side of ostomy stories and, consequently, the stories that stigmatize and those that destigmatize, is not straightforward. It is tempting to divide the stories in chapter 3 from those in this chapter, but rather than provide a nuanced understanding of lived experiences with ostomies and the diverse ways in which ostomies are staged and made meaningful, such dichotomizing results in two single stories, polarized by the idea that ostomy experience is either bright-sided or doom-filled. Rainbows and butterflies or a complete tragedy. In sync with our assumptions regarding aging, disability, embodied and temporal experience or out of sync. Curative or crip.

Praxiographic and disruptive approaches to the rhetoricity of stigma and the lived experiences with ostomies and chronic GI conditions requires us to recognize that stigma, lived experience, and ostomies are all multiplicitous. All these entities involved in lived experiences with ostomies are intra-actively emergent (see Barad, 2007; Kessler, 2020) within specific rhetorical ecologies where many diverse forces are at work. Thus, what I’m arguing for here is
a nuanced, careful, and critical attunement to these complex forces (racism, ableism, feces, access to healthcare, leaks, temporal unfoldings, food freedom, social support, hospital stays and discharges, visceral emotions, ostomy technology, education, etc.). Such an approach not only helps us honor the disruptive stories but also allows us to see how those stories rhetorically stage the meaning of lived experiences with ostomies and chronic GI conditions to be stigmatized or not. Attending to these forces importantly shows how Julia's story was disruptive in its own right. A counterstory (Martinez, 2020) that worked to make visible an otherwise invisible story of what it is like for her as Black woman with an ostomy. Though Julia's story doesn't disrupt the hegemony of doom-filled ostomy stories, it does disrupt White ostomy stories from being the only ostomy stories.

**Conclusion**

Disruptive stories work against ableist assumptions by sharing positive experiences with ostomies, in which disability does not unequivocally decrease quality of life, sense of self-worth, or the ability to engage in desired activities. By highlighting experiences in which a future with an ostomy is positive, empowered, able, and even enticing, disruptive ostomy stories dispel fear and dismantle ostomy stigma. These stories reject the idea that a future with an ostomy is “a future of no futures” (Kafer, 2013) and, instead, show that for many, a future with an ostomy is the only future possible. These stories repudiate ableist, normalizing timelines in two key ways. First, as we saw in the activist responses to the *Grey's Anatomy* episodes and Julia’s story, disruptive stories dismiss the idea that ostomies are exclusively for the elderly or the result of unhealthy choices (e.g., smoking). Second, disruptive ostomy stories belie compulsory nostalgia and curative timeline.

The disruptive ostomy stories in this chapter present a radical (re-)envisioning for ostomy futures—that is, an after-ostomy future that is enabling. These stories both directly and indirectly protest stigma and the stigmatizing idea that all lived experiences with ostomies are defined by leaks, isolation, debilitation, and loss. Stories both disruptive and dominant not only create a social rhetoric of illness (Frank, 2013); they provide a platform for updating and revising that social rhetoric. In the case of ostomies, the stories explored in this chapter highlight that ostomies’ normalizing potential requires the idea of “normal” itself to be more diverse, complex, and inclusive, a point that disability studies scholars and disability activists have long advocated. Although many similarities emerged across the stories in this chapter, it’s clear that “nor-
“mal” and “normal with an ostomy” are different for every ostomate, and that all ostomates need space to live, share, and navigate their own experiences and stories. Certainly, many people who receive ostomies yearn for their before-ostomy lives. However, this is not always, or perhaps even often, the case. Listening to disruptive ostomy stories alongside more ubiquitous ostomy stories showcases that no ostomy single ostomy story can or should speak for all ostomy experiences.

It was my goal in this chapter to follow Segal’s call to honor and listen to as many ostomy stories as possible, especially those that are unexpected, different, resistant, or disruptive, and to enact Martinez’s call to listen to and make space for counterstories by acknowledging the always-present intersectional dynamics in storytelling. In doing so, I heard stories about lifesaving surgeries, being discharged from the hospital, eating favorite foods, traveling the world, and choosing life with an ostomy. Placing these stories in conversation with dominant public stories like Julia’s helps demonstrate the significance of listening to people as their own ethnographers and the importance of temporality within ostomy, illness, and disability experience. Julia’s and Jessica Grossman’s stories, while dramatically different, paint an incomplete picture of the embodied practices and possibilities of ostomies. Together, however, they begin to materialize a more nuanced understanding of lived experiences with ostomies and chronic GI conditions. To paint an ostomy as universally anything, doom-filled or bright-sided, is to set up a rhetorical dynamic prime for the emergence of stigma. Where the ostomy is a static object on which different perspectives are projected, social and structural forces will continue to (de)value ostomies in ways that are familiar (see Mol, 2002). In a praxiographic approach to ostomy stories, the ostomy is not a “universal object” across these stories—not something that either Julia or Jessica Grossman got right or wrong—instead, it is both emergent and made meaningful within the lives, realities (political, material, social, rhetorical), and unique timelines of individuals.

Even more, listening to this range of stories showcased the role of temporality within lived experiences and reiterated the role of ableism, racism, sexism, and normalization in stigmatization. The relationship between before-ostomy life and after-ostomy life, unsurprisingly, plays a profound role in how the ostomy is made to mean for individuals, and we can map these shifts over time by praxiographically listening to ostomy stories. When ostomy stories, like other stories of disability and illness, are shared publicly, audiences are primed to listen for a particular unfolding of experiences. Stories of embodied and temporal difference are stigmatized when ableism holds cultural power, and it is incumbent that single stories, whatever their valence or whichever
practices they tell, be placed alongside diverse alternatives, all of which need to be listened to carefully, empathetically, and intersectionally.

Paying attention to temporality within these stories also raises questions about differences across experiences when the ostomy is temporary or permanent. I do not know with certainty whether ostomies were permanent or not for many of the storytellers I’ve featured thus far, specifically when it comes to stories beyond those told by my interview participants. However, some of the language in Julia’s story suggests that her ostomy was temporary, and I do know that Jessica Grossman’s ostomy is permanent based on information on Uncover Ostomy. Therefore, comparing the experiences of Julia and Grossman, with temporary/permanent in mind, indicates some additional ways that temporality is caught up in lived experiences of those with ostomies. Specifically, people who have temporary ostomies may be potentially less inclined to reflect on and interrogate their own compulsory nostalgia. When an ostomy is temporary, longing for the preostomy self is simultaneously a longing for a potential after-ostomy self that is without an ostomy. For people with temporary ostomies, unlearning and resisting ableist assumptions might seem less pressing as the possibility of an ostomy-less live remains viable. In contrast, for people who know with certainty that they have no future without an ostomy—that is, permanent ostomates—there may be more investment (and more at stake) in rejecting compulsory nostalgia. My intention here is not to paint with broad strokes and categorize temporary ostomates and permanent ostomates as distinct and stable groups that neatly align with doom-filled and bright-sided stories. Nevertheless, as this chapter has worked to analyze the rhetorical role of temporality within stigma stories, it is important to reflect on the possible role of permanence in lived experiences with ostomies and stigma.

Finally, disruptive stories do not only reveal important insights about the relationship among temporality, lived experiences, and stigma. They also serve as one example of how stories are actively challenging stigma and succeeding. Indeed, disruptive ostomy stories are making progress in increasing awareness of ostomies, shifting what it means to live with an ostomy, and dismantling stigma. These shifts are evidenced in the CDC’s response to the backlash against Julia’s video.21 To its credit, the CDC did revise Julia’s campaign materials. Her story still depicts her difficult ostomy experience, though some of the video’s most negative ostomy depictions have since been edited out. Further, the CDC actually no longer features Julia’s solo video—it has

21. The Cincinnati PD also issued a public apology. I have not seen evidence that the writers or producers at Grey’s Anatomy responded to any ostomy-related petitions or protests.
been removed from both the Tips website and YouTube. It’s almost as if her original video never existed, and perhaps for good, but certainly complicated, reasons. Removal of her video could be interpreted as the CDC’s effort to remove the stigmatizing ostomy message from public discourse altogether. In place of the original video, Julia is featured in a collaborative one with another Tips participant, Mark, who also underwent ostomy surgery because of cancer. In their shared video, Julia no longer reports that what she hated most was her colostomy bag, and her “get over being squeamish” tip has been replaced with “keep your sense of humor. You’re going to need it” (CDC, 2015b). While Julia and Mark still stage the ostomy as a negative consequence of smoking, the harshest part of Julia’s message has been removed.

The CDC’s revisions also illustrate the significant rhetorical labor required to fight stigma; only some of the ostomy-negative message has been removed, and, still, no mention of ostomy’s lifesaving potential is included. Eleven thousand signatures, hundreds if not thousands of tweets, Facebook posts, emails, and letters all contributed to the CDC’s temporary removal of and partial revision to their message regarding ostomies. Moreover, while it’s clear that some of the protesters wanted Julia’s story removed entirely, it’s necessary to consider the implications of such a move. Many protesters made rhetorical efforts to clarify that it was not Julia’s story itself that was problematic but rather the CDC’s choice to advance a solely negative story of ostomies. Erasing Julia’s story perhaps helps minimize stigmatizing ostomy messages, but it also silences Julia’s experiences and leaves Julia and others who struggle with their ostomies to suffer in silence. Erasure privileges a different set of voices and experiences, namely of White ostomates who no doubt share common experiences with Julia but who do not share the same layers of marginalization and oppression that Julia has almost certainly endured. Eradicating stigma requires that all stories—doom-filled, bright-sided, and everything in between—be possible and heard. As many of the disruptive stories in this chapter suggest, destigmatization is not about silencing or ignoring the challenges of living with a disability, illness, or other chronic condition. Instead, it requires that no condition, disability, disease, or related lived experience render anyone “less-than-fully human” (Molloy, 2015, p. 159).

Attuning to temporality, specifically compulsory nostalgia, within ostomy stories insightfully highlights the ways in which ostomies are made to mean differently. For those, like Julia, whose before-ostomy and after-ostomy experiences transformed negatively, the ostomy is staged as a worst-case scenario and as undesirable. In contrast, for people like Jessica Grossman, Laura at Stomalicious, and many of my interview participants, whose after-ostomy experiences were desirable, even preferred over their before-ostomy experi-
ences, the ostomy itself is staged as a lifesaver. Indeed, the language of “life-saving” is used in many disruptive ostomy stories and is evidenced by positive experiences like eating favorite foods, avoiding cancer, or simply feeling better. These experiences and the positive language used to describe them enact the ostomy as a lifesaving surgery and technology, which stands in stark contrast to the ostomy enacted in Julia’s story, the Cincinnati PD’s message, and the *Grey’s Anatomy* episodes. Listening to these stories praxiographically, and with temporality in mind, demonstrates how the ostomy is done differently across experiences and can further allow us to recognize and resist the compulsivity of stigmatizing expectations or reactions.