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# Bodily Boundaries: Inflammatory Bowel Disease and Rhetorical Enactments of Self

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BODILY BOUNDARIES: INFLAMMATORY BOWEL DISEASE AND RHETORICAL  
ENACTMENTS OF SELF

by

Molly Margaret Kessler

A Dissertation Submitted in  
Partial Fulfillment of the  
Requirements for the Degree of

Doctor of Philosophy

in English

at

The University of Wisconsin-Milwaukee

May 2017

## ABSTRACT

### BODILY BOUNDARIES: INFLAMMATORY BOWEL DISEASE AND RHETORICAL ENACTMENTS OF SELF

by

Molly Margaret Kessler

The University of Wisconsin-Milwaukee, 2017  
Under the Supervision of Professor S. Scott Graham

Chronic illnesses are seven of the 10 leading causes of death in the United States and the prevalence is rising. Of the many chronic illnesses, one group of diseases present particular concern and mystery – autoimmune diseases. These conditions manifest when a patient’s body attacks itself, causing a myriad of symptoms that often leave patients debilitated. Since 2013, I have been examining the contexts in which patients with Inflammatory Bowel Disease (IBD) – one type of autoimmune disease – reconsider their bodily boundaries while managing new, challenging communication experiences. The results of this research are presented in my dissertation, *Bodily Boundaries: Inflammatory Bowel Disease and Rhetorical Enactments of self*. My work suggests that bifurcations such as mind/body, and self/other, and the boundaries of patients’ bodies and identities are context-dependent enactments, negotiated through a variety of discursive and material actors. I argue that a new theoretical approach to dualisms and material agency must be developed through scholarship that calibrates the insights of rhetoric, medicine, and humanistic approaches to technology and medicine.

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For Grandma Margaret –  
in addition to my name,  
you have given me a love for learning,  
and  
a will to persevere against all odds.

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## CHAPTER 1: INTRODUCTION

Long story short: Our bodies are fighting a Civil War with themselves. –Alisa Briguglio, contributor, *The Mighty*

My identity is very much so tied to my ostomy and how it gave me my life back –Jessica Grossman, contributor, *Uncover Ostomy*

Disease is commonly understood as an infiltrating invader, an enemy within the body that does not belong and, therefore, should be attacked and removed. Indeed, rhetorical scholars have noted the persuasive power of war metaphors in enabling patients to draw productive lines between notions of self and non-self (disease), as well as between the mind and body (see, for example Segal, 1997; Sontag, 2001). Such separations empower patients to fight these invading entities and compartmentalize the involuntary conditions of the body and/or mind as something out of patients' control. Often people "fight" disease or "win the war" against a condition, or on another level, people say "it's all in your head!" or "my body has a mind of its own."

However, one category of disease – autoimmune conditions – complicates these metaphorical and experiential divides, challenging not only rhetorical and theoretical conceptions of bodies and boundaries, but also what it is that we study as rhetoricians and technical communicators, specifically in health and medicine. Experiences like the ones described in the opening epigraphs are no doubt familiar to many patients with autoimmune disease. Bodies attacking themselves, struggles with identity, and the necessity of medical technologies characterize life with an autoimmune condition.

Typically, the immune system works defensively as an internal mechanism to identify and destroy cells that do not belong (e.g., a virus or bacteria). As the prefix auto- indicates, autoimmune disease occurs when oneself attacks oneself. In other

words, autoimmune disease behaves such that a person's immune system attacks naturally occurring cells within the body – those that are not foreign. When this happens, a chain of physiological reactions transpires, and depending on the type of cells targeted by the autoimmune activity, a range of destructive and even life-threatening symptoms manifest.

Unlike conditions in which non-native entities (viruses, bacteria, etc.) enter the body and are easily categorized as non-self, autoimmunity complicates commonplace divisions between self and non-self and/or between mind and body. For an autoimmune patient, a body with a mind of its own might not seem all that figurative. In the words of Alisa Briguglio, the bodies of autoimmune patients are “fighting civil wars with themselves” (2016). Indeed, autoimmunity raises pressing questions for rhetoricians of health and medicine working to understand patient experience. For instance, how do patients experience and talk about autoimmune diseases when they are unlike most conditions that actually are invaders in the body? How do patients, as well as scholars, talk about, conceptualize, and rationalize disease as self? Are the cells attacking the intestines, joints, or skin of these patients also self? Where and how are boundaries surrounding bodies and identities determined when the body is both self and non-self? Even more, when technologies and/or prosthetics are introduced to help treat or cope with autoimmune conditions, where do the borders between self, technology, human, body, and mind lie? Can non-self become self? Can nonhuman become human?

These very questions both ground and guide this project. In recognizing the complicated and volatile fault lines within and surrounding autoimmunity, patients, identities, and bodies, I focus on one type of autoimmune disease – Inflammatory Bowel Disease (IBD) – to explore larger theoretical concerns regarding the ways in which boundaries are drawn around the body, self, disease, and more. For patients with IBD, the innate immune system identifies health, normal cells within the digestive tract, specifically in the small and large bowels, as foreign and attacks those native cells. This causes inflammation of tissues and results in a range of symptoms from nausea and diarrhea to severe dehydration, infection, and even death.

Furthermore, for many IBD patients, autoinflammatory activity becomes so severe that parts of the digestive system need to be removed. In such instances, often a prosthetic called an ostomy bag or pouch becomes necessary. To briefly explain, when part of the small bowel, and/or part or all of the large bowel and rectum have been removed due to disease (such as IBD or cancer) or acute injury, an ostomy pouch is worn on the abdomen to collect digestive waste (see Figure 1). Although parts of these digestive organs can be removed, they typically cannot go without replacement. Therefore, an ostomy is created, which means an opening in the intestine is made and pulled to the surface of the skin (to create an opening called a stoma). Through this opening on the surface of the abdomen, digestive waste is excreted and then collected in an ostomy pouch because there is no longer muscular control over when the remaining segments of bowel evacuate.



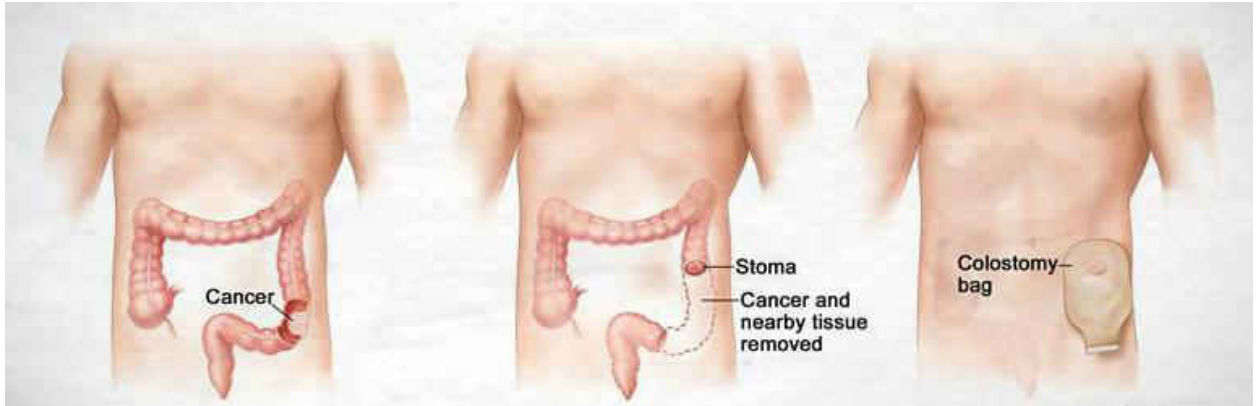


Figure 1. Stoma and ostomy pouch illustration. The first two panels show the diseased colon before and after parts have been removed; the third panel shows the ostomy pouch worn on the abdomen to replace removed colon section. Source: National Cancer Institute (Winslow, 2008).

IBD offers a particularly productive case for examining boundaries and boundary-making practices for two primary reasons: 1) IBD is an autoimmune disease, therefore the boundaries, particularly those surrounding self, non-self, mind, and body are blurred; and 2) IBD patients sometimes need an ostomy pouch, which offers a second set of identity and bodily boundaries to consider, particularly those around human, nonhuman, self, and non-self. Not only do ostomy pouches require patients to reconsider literal and figurative boundaries of their bodies, but they are also often accompanied by a societal stigma, which makes having a IBD and an ostomy even more complicated. These unclear boundaries associated with IBD present rhetorical challenges for these patients in a variety of contexts – convincing others of the existence of these conditions, establishing identities both within and outside of the IBD and ostomy communities, and maintaining a “normal” life – many of which are under examination through this project.

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<sup>1</sup> I use “normal” here and throughout this dissertation not to impose certain ideologies onto the lives and experiences of the patients discussed in this project. Instead, I use normal to reflect the language of the patients with the autoimmune, IBD, and ostomy communities.

One of my primary goals, then, is to understand how boundaries are established, maintained, and influenced in rhetorical practices of IBD patients. However, before I can elaborate on the ways in which this project studies and unpacks such rhetorical contexts and practices, I must first untangle the myriad scholarship regarding binaries to identify which framework(s) might best account for the intricacies and divisions at work in IBD and like conditions.

Indeed, dualisms have been at the forefront of academic inquiry for decades, resulting in a range of questions and alternatives regarding the ways we think, discuss, and study divisions in the world. In fact, overcoming pervasive dualistic thinking has long been recognized as one of the most challenging theoretical problems in Western philosophy. As feminist philosopher and physicist, Karen Barad notes, modernist Cartesian divisions have become a “habit of mind” (2007, p. 49). Therefore, I begin this dissertation by making the case that despite a plethora of potential theoretical solutions, the legacy of dualistic thinking still pervades much of Western thought and scholarship. Of these potential solutions, two bodies of scholarship have emerged as especially influential in humanistic inquiry: postmodernism’s deconstruction of binaries into matters of the discursive/social/cultural, and new materialist approaches that argue we pay more attention to matter and objects. Consistent across these bodies of work is a commitment to dismantling dualisms, but as Elizabeth Grosz points out, the question then becomes: “by what techniques and presumptions is a nondichotomous understanding...possible?” (1994, p. 21).

Using Grosz's questions as a starting point, this dissertation undertakes a two-fold theory-building task: first, to develop "enactments" as a balanced and rhetorically-minded approach toward dynamic boundary-making processes, and secondly, to pursue the role of these enactments in patients lived experiences with IBD and autoimmunity. The enactment framework I will develop over the cases and chapters of this dissertation will push rhetorical inquiry to reconsider our accepted notions of boundaries, ontology, and identity, as well as our positions regarding who and what is capable of acting in boundary-making practices. As I will argue, entities (like those often divided into binaries) not only come into being but become meaningful through engagement with one another. Bodies, minds, selves, non-selves, technology, humans, diseases, and much more are characterized through and within engagement with other entities. The boundaries that surround them are articulated as these entities engage with one another, and only through this mutual constitution are rhetorical practices possible. Entities ranging from language to technology, then, are equally capable of participating and influencing rhetorical practices.

Notably, the implication of this even-footing for all entities might seem at odds with centuries of rhetorical work. That is, much rhetorical scholarship examines intentionality (what rhetorical effect was x speaker aiming to accomplish?), symbolic action (what does this particular metaphor represent?) and strategy (what is the role of ethos in this speech?) – all of which are particular to human action. As such, the tension between rhetorical scholarship and the new materialist turn resides at the assumed intrinsic division between humans and all else. That entities beyond humans are

capable of rhetorical influences, for many rhetoricians, might seem disorienting, if not entirely impossible. However, if this dissertation makes only one contribution to the discipline, I hope it is this: our work must extend beyond human action.

Looking at patient narratives regarding IBD would likely foster some of the insights in this dissertation. No doubt, I will spend plenty of time looking at how patients talk. However how rhetoricians approach patient “talk” and how we understand its role in rhetorical practices can and should be expanded. Patient narratives alone will not enable me to fully conceptualize the role of the ostomy pouch, immune system behavior, or even how images act agentively. We are doing little service to ourselves, the field, and those we might hope to engage with, if we maintain tunnel vision on humans and language. “Bodies speak,” as Dolmage reminds us, as do ostomies, immune systems, images, tweets, gazes, and more (2006, p. 122). Therefore, our inquiry would benefit from expanded scholarly boundaries to account for the diverse entities that might “speak” and partake in rhetorical practices.

The diversity of what is capable of having rhetorical influence is especially significant in the realm of the rhetoric of health and medicine. As I will argue, one of the most explicit but perhaps least frequently attended to goals of rhetorical studies of health and medicine is examining lived experience. If we partition off language as the sole domain of our inquiry, then, our ability to attend to lived experience is essentially impossible. Lived experience for patients includes entities that speak before patients’ mouths even open. For example, as I hope to make clear over the next several chapters, ostomies, without the mediation of linguistic symbols, speak loud and clear for those

that wear them. Ostomies speak to wearers, the public, healthcare providers, partners, and more, and in so doing, influence boundary-making practices as well as how patients live and participate in the world. What ostomies have to say, I believe, is as equally important as what patients say for studying lived experience. The rhetorical baggage associated with an ostomy requires a profound shift in what might be considered rhetorical practice.

In order to build a foundation for this theory of enactments, I must begin by tracing postmodernist and new materialist scholarship that attends to binaries. In outlining this work and the dialogue these two areas of inquiry stage, I hope to demonstrate the need for a theory of enactments that builds on the strengths of both postmodernism and new materialisms in order to best address binaries. Consequently, the remainder of this chapter will elucidate postmodern and new materialist debates regarding binaries, focusing on implications for lived experiences and body and identity boundaries. Then, I will outline the remaining chapters of this dissertation to preview how the theory-building project of this dissertation aims to provide a productive approach to rhetorical boundary-making processes, especially regarding bodies and identities.

### **Beyond Binaries**

Scholarship categorized under the postmodern project has presumptively settled debates regarding dualisms by dismantling them into matters of the social, cultural, and discursive (for example, Haraway, 1991; Selzer & Crowley, 1999; Wells, 2010; Jordan, 2004; Butler, 1999). Much of this work, particularly in rhetorical studies, grew from an increasing recognition of the tension between materiality and discourse as “one of the

most familiar and powerful binaries” (Wilson & Lewiecki-Wilson, 2001, p. 2). For instance, Condit’s “proto-theory of linguistic materialism...seeks to bridge the gap between the ‘idea’ and the ‘material’ realm” (1999, p. 355) and Dickson’s “material rhetoric” offers a “mode of interpretation that takes as its object of study the signification of material things and corporal entities” (1999, p. 297). While these are just two examples among many, such approaches work to mediate the boundary between subject/object, language/matter, and in some cases, mind/body.

Importantly too, postmodern attention to binaries grew, in many ways, as a reaction to modernism, which maintained that truth and reality exist somewhere, waiting to be discovered – leading to the privileging of objects over subjects, nature over culture, and bodies over minds. In response, postmodernism challenged such epistemological frameworks and argued that objects/matter/nature are socially constructed through language and culture. Materiality, postmodernism suggests, is culturally constituted or socially constructed. For instance, Butler’s notion of performativity articulates bodies and materiality such that they are performances highly embedded in discourse and social understandings (1999). Similarly, Haraway’s cyborg reframes the world in terms of hybridity, not duality, enabling scholars to examine the webs of power that constrain and empower various cyborg bodies and find “a way out of the maze of dualisms in which we have explained our bodies and our tools to ourselves” (1991, p. 181).

Implied in such arguments is that bodies and internal experiences (e.g., feeling pain, experiencing autoimmunity, having an ostomy) are artifacts of cultural mediation,

and unmediated bodily experience is impossible. Bodily experiences, according to such postmodern positions, are “constructions mediated by a range of cultural practices” (Wells, 2010, p. 135). Put another way, the human body is “the most fluctuating signifier in the history of cultural expression” (Jordan, 2004, p. 327). These postmodernist discussions, taken together, compellingly contend that theories of social/cultural/discursive constitution provide a solution to binaries.

Recently though, a growing body of scholarship has re-opened the Pandora’s box of dualisms, calling for a reconsideration of postmodernist constructionism (for example, Graham, 2015; Barad, 2007; Mol, 2002; Rickert, 2013; Pickering, 2010; Bennett, 2010). As Graham puts it, “the postmodernists have been claiming to [reject the two-world hypothesis and overcome binaries] for years without actually accomplishing that aim” (2015, p. 217). Despite years of postmodernist alternatives and solutions to binaries, arguments highlighting the continued insidiousness of binaries remains.

Much of this scholarship, often operating under the broad umbrella of “new materialisms,” claims that the postmodern project actually reinscribes dualisms by privileging subjects over objects, humans over nonhumans, culture over nature, and so on (Gronnvoll, 2013; Graham, 2015; Bennett, 2010; Barad, 2007). Essentially new materialisms argue that postmodernist theories have inverted modernism. For instance, Gronnvoll writes, “the linguistic turn launched a tsunami of scholarship, of many disciplinary flavors, leading inevitably to a tipping point where discourse began to be privileged over reality. The latter was sometimes dismissed as entirely constructed by language (p. 98). Similarly, Graham argues, “where modernism privileges the real

object over the perceiving subject, postmodernism recasts the object as an extension of the subject's perception, and the object becomes an epiphenomenon of the subject" (2015, p. 19).

These critiques further contend that postmodern approaches and the upholding of binaries can be both unproductive and damaging in real-world contexts (Graham, 2015; Mol, 2002; Gronnvoll, 2013; Siebers, 2001; Wilson & Lewiecki-Wilson, 2001; Gibson, 2006). I argue – in alignment with new materialist thinkers – that postmodern approaches to materiality and bodies authorizes a version of constructivism that reifies the very binaries such approaches work to overcome, which has damaging implications for materiality and bodies. In other words, while postmodern scholars successfully recognize the intimate relationships that humans, objects, language, images, animals, cultures, etc., share, to render all such relationships as a matter of discourse, gives privilege to discourse.

Scholars including Siebers, Gronnvoll, Dolmage, and Balsamo, have argued that constructivist theories ignore the physical, material realities of bodies. On this, Dolmage claims,

The postmodern model remains influential, often to the chagrin of disabled people who feel their experiences of disability are undermined. There certainly are dangerous implications for the issues of agency when a focus on individual empowerment and bodily reclamation cedes to discussions of social construction – particular when a common assumption among 'abled-bodied' bigots is that people with disabilities are just faking it anyhow, or that they should just try harder to overcome their impairment and cure themselves (2013, p. 96)

Similarly, Gronnvoll (2013) contends that when the body is only rendered meaningful through discourse, bodily experiences are lost, she says, "erasing the body, or rewriting



it as a passive substance upon discourses are sketched, also [brings] harm. To ignore the body is to ignore the fact that bodies experience violence, injustice, and pain” (p. 103).

Summarizing the significance of these positions, Dolmage writes “social constructionism, in some ways, can be used as a method of silencing” (2013, p. 98).

In addition to these critiques regarding inadequate attention to bodies, many have pointed to the legacy of Haraway’s cyborg as problematic, even though the cyborg attempts to move out of social constructivist theories toward materiality in its own right. Scholars, particularly in disability studies, have argued that the cyborg oversimplifies the complexity of human+techno assemblages and treats cyborg status as positive or empowering, leaving little space for diverse bodies and identities (Siebers, 2001; Williams, 1997). Siebers, for example, claims that the cyborg “is always more than human...not disabled.” In fact, Siebers argues, in scholarship that advances the cyborg metaphor, “prostheses always increase the cyborg’s abilities” as a “source of new powers, never problems” (p. 745). Pointing to further concerns over who or what might be included under a cyborg or hybridized alternative to binaries, particularly “in an era where human-machine couplings are almost infinite,” Williams notes,

medical technology has at its disposal a variety of means to transform us into cyborgs, from cardiac pacemakers to genetic engineering, and from the nebulized asthmatic to the accident victim in the intensive care unit. The logic of this argument suggests that, in a technological age, such as ours, we are all ‘cyborgs’ in some shape, sense, or form. In making this claim, however, the analytic potential and discriminatory power of the concept is surely reduced” (1997, p. 1047).

If we take seriously Siebers’ and Williams’ critiques here, we might also ask: what types of bodies is Haraway (and those who have further built on the cyborg metaphor) really

referring to in theorizing cyborgs? If “we are all cyborgs” how do we account for bodily difference? If everyone is a cyborg, does every human+technology interaction make technology self? Which interactions make cyborgs, and how do we decide? Are those with prosthetics cyborgs in the same way as cell phone users with Bluetooth devices? And, are all cyborg identities positive?

Even as Haraway explores paraplegics as a cyborg example, she fails to fully account for the range of consequences (both positive and negative) that cyborg identity might produce. Erevelles too takes issue with the cyborg, arguing that “constituting the disabled subject as a cyborg actually renders as immaterial the actual struggles of disabled subjects” (2001, p. 98). Overall, critiques of Haraway demonstrate that although the notion of the cyborg provides a strong alternative to binaries, when deployed to a range of cases and bodies, the cyborg proves to have inherent problems, specifically with recapitulating a division between able and disabled bodies, the social and material, and even humans and nonhumans. These concerns, I would argue, are highly applicable to the larger concerns with postmodernism.

Furthermore, scholars including Mol and Graham have highlighted yet another problematic implication of postmodernism: the disease/illness dichotomy. In this work, however, the issue is framed not in terms of able or disable bodies or humans and nonhumans, but instead, in terms of another binary. Specifically, this binary separates disease (the domain of medical experts; the physical materialities of bodies) from illness (patient narratives; symptoms and reports on symptoms). Under this rubric, disease is frequently privileged over illness, and when the two conflict, patient’ accounts are often

ignored (see Chapter Two for a more detailed account of the implications of the disease/illness dichotomy). And, perhaps most strikingly, Graham clarifies that it isn't merely that the postmodern project is theoretically amiss; but rather, maintaining these modernist binaries is an "ethical problem" in which

The body is the authentic locus of disease, and the mind is confused, crazy, or lying. So pervasive is the lack of trust in patient report (as confusion, insanity, or malingering) that it is a mainstay of popular representations of medicine (2015, p. 118)

In other words, in establishing such divisions, "language and culture" are granted "their own agency" while "matter is figured as passive and immutable" (Barad, 2003, p. 801).

As suggested through this discussion of postmodernist approaches, overcoming binaries by privileging one element of the binary over another the other does little to solve the modernist Cartesian legacy. When everything falls to the domain of the social and discursive, as is often the result of postmodernism, the reality of bodies is lost or, at the very least, in question. Postmodern constructivist theories have perhaps moved where the boundaries are drawn or shifted which entity of a binary is considered more important, but certainly haven't fully accomplished the goal of dismantling binaries altogether.

This is not to say however, that all new materialists agree on how to move forward. In fact, the umbrella term "new materialisms" emerged precisely from the myriad theories and methodologies that have appeared in recent years. Nonetheless, new materialist scholars consistently argue, things other than autonomous humans have "the ability to make things happen, to produce effects" (Bennett, 2010, p. 5). For

example, Bennett explores a variety of rhetorical situations in which the agency of objects is compelling if not undeniable: the ingestion of food resulting in an increase of fat tissue in a human, or a power grid failing, causing catastrophic events including fires, school closures, and certainly a variety of human inconveniences; Mol (2002) traces the multiplicity of blood clot matter in various places within a hospital; and Graham (2015) investigates the various ontologies of pain, physical and otherwise, that emerge in different spaces and practices. These and other such examples of matter mattering suggest that even if materiality can be examined through the lens of symbolic construction, such approaches fall short in fully exploring the role and implications of materiality.

A new materialist approach, then, does not seek to theoretically ostracize the contextual--the social, ethical, cultural, gendered, historical, etc.--instead, new materialists advocate that we treat reality not as outright inaccessible and only constituted through language, but rather as an enactment of specific, heterogenous assemblages, within which language and culture are just a few elements. I do not wish to suggest that language and culture do not influence or engage with matter. However, to render materiality as merely a product of language, as merely symbolic, would not only dismiss a significant portion of materiality's rhetorical force, but it would continue to "separate the world into the ontologically disjoint domains of word and thing" (Barad, 2003, p. 811). Put another way, disability scholar, Tobin Siebers, explains,

I am not claiming either that the body exists apart from social forces that it represents something more real, natural, or authentic than things of culture. I am claiming that the body has its own forces and that we need to recognize them if we are to get a less one-sided picture of how bodies and their representations

affect each other for good and for bad. The body is, first and foremost, a biological agent teeming with vital and often chaotic forces. It is not inert matter subject to easy manipulation by social representations. The body is alive, which means that it is as capable of influencing and transforming social languages as they are capable of influencing and transforming it (2001, p. 749, emphasis original).

Or, as Booher argues, “there is no (‘natural’) body separable from (‘technology’) world, but only shifting continuums of interinvolvement” (Booher, 2010, p. 84). It seems, what scholars like Graham, Mol, Barad, and Bennett are advocating for is a more moderate correction to modernism and postmodernism, or what Graham calls “finding the groove” without sliding back into modernist or postmodern paradigms (213).

Indeed, finding this groove, let alone occupying it, presents challenges for scholars moving forward. As Coole and Frost argue,

society is simultaneously materially real and socially constructed: our material lives are always culturally mediated, but they are not only cultural...the challenge here is to give materiality its due while recognizing its plural dimensions and its complex, contingent modes of appearing” (2010, p. 27).

With these caveats in mind, a palpable tension remains regarding the relationship between language and materiality. This specific tension is highly relevant for autoimmune patients, whose conditions, are often characterized as “invisible,” and accordingly, whose material realities are not as easily or quickly identifiable. Too, I find the continued pervasiveness of binaries particularly problematic for work in the rhetoric of health and medicine that attempts to understand and empower patients who have lived experience that, to them, is constructed by more than language and culture, or even not by language and culture at all.

With these tensions at the forefront of this inquiry, my overarching research question for this project is: how can rhetorical studies of health and medicine account for conditions like autoimmunity, IBD, and having an ostomy pouch—conditions in which 1) both material and discursive practices are engaged, and 2) binaries and boundaries are not inherent nor static? In pursuit of answering such questions, I must also engage two secondary questions: how and why are certain boundaries afforded and constrained in different contexts, with diverse audiences, and toward varying exigencies? And, what roles do visibility and invisibility play in the rhetorical boundary-making practices of patients with these invisible conditions who are often actively concealing or revealing their bodies, identities, and conditions? Finally, in working to explore these questions, and in alignment with the interventional goals of rhetorical studies of health and medicine, I must also ask, how might a reconsideration of binaries benefit patients (autoimmune and otherwise) in their everyday experiences and interactions? These questions guide the analysis of this project and frame the thinking about each case presented.

Ultimately, I hope to shed insight on the ways in which we can understand and intervene in patients' practices by taking a closer look at IBD and ostomy pouches. My goal is to better understand patient experience regarding their own bodily boundaries and understandings of self. Each of the subsequent chapters in this dissertation, therefore, explore diverse patient experiences and trace the emergence of such experiences. In turn, I aim to use such understandings to identify which theoretical and methodological frameworks best account for lived experience while ethically and

comprehensively attending to the boundaries that are dismantled or upheld through the entanglements of materiality, discourse, selves, diseases, technologies, experiences, and more. However, identifying which theories and methodologies are useful is merely the first step in cultivating an adequate rhetorical theory to examine lived experiences and boundary-making practices. As such, Chapter Two takes up much of this work and concludes with an introduction of my enactment framework, but Chapters Three, Four, and Five employ this approach. The next section more thoroughly outlines these chapters--the content and arguments within them, as well as how each of the chapters relates.

### **Outline of Chapters**

Thus far I have argued for the need to explore how binaries and boundaries are negotiated for patients, particularly those in the context of autoimmunity and IBD. I have also contended that more engagement with the entanglements of many entities, including but not limited to, discourse, is necessary for rhetorical studies of health and medicine to comprehensively attend to patients' lived experiences. With these claims as my foundation, this project will explore a series of cases related to IBD and ostomies to suggest that binaries and boundaries are enacted through the mutual constitution of many entities. Accordingly, I work to develop enactments as a rhetorically-oriented framework to more adequately attend to a reconfigured notion of rhetorical practices that includes both discourse and materiality.

To do so, Chapter Two introduces and calibrates Barad's theory of intra-activity (2007; 2009) and Graham's rhetorical-ontological inquiry (2015) in order to begin developing this theory of enactments. Further, I explain how and why particular cases

(both public and during observations and interviews) were identified and selected for this dissertation via a brief discussion of Foucault's concepts of discourse and object formations (1973). Then, I briefly explore two patient experiences' with IBD that directly address the negotiation and enactment of particular bodily and identity boundaries. Through these cases, I demonstrate the methodological value of a theory of rhetorical enactment in enabling me to attend more effectively to all entities (material, discursive, and more) that are at work and at stake in a given autoimmune-related context.

Then, Chapters Three, Four, and Five show both how enactments are staged through specific entanglements of diverse entities as well as the range of analytic pathways this enactment framework might follow, including kairological, ontological, and visual analyses. Specifically, in Chapter Three, I analyze a public and contentious Center for Disease Control and Prevention campaign in which a former ostomy pouch wearer speaks of her negative and embarrassing experience with her ostomy and the public outcry that ensued in rejection of this portrayal of ostomies. I contend that Segal's kairology (2005) enables me to understand how and why certain identities and bodily boundaries are not only enacted but made compelling. As Chapter Three suggests, whether patients become ostomy pouch wearers or ostomates (a term used to self-identify as a person with an ostomy) has much to do with how and when shifts between affording and constraining experiences develop through space and time. Patients do not simply decide their ostomy-related identities, but instead, those identities are enacted through diverse entanglements and ontologies.



Consequently, Chapter Four reveals how various ostomy-related identities are staged through ontologically multiple ostomies. Building on Mol's theory of multiple ontologies (2002), this chapter will explore how ostomies become ontologically diverse through patient practices. Of particular relevance for rhetoricians, language emerges as a particularly influential entity within these practices and boundary-making processes. Through Chapter Four, I argue ontological inquiry within rhetorical studies need not abandon the discursive; however, an ontologically flattened position is required at the outset of such inquiry in order to identify if and when language becomes influential in the practices that enact boundaries.

Finally, as Chapter Five identifies, visual entities can also powerfully influence boundaries, resulting in enactments that fit or misfit their contexts (Garland-Thomson, 2011). Specifically, this chapter takes two well-known figures within the IBD and ostomy communities – Bethany Townsend and Sam Cleasby – as cases for examining how autoimmune, chronically ill and female bodies are engaged with in the public, particularly when these women reveal their ostomy pouches through images posted online. I interrogate why one of these women was triumphed while the other was ridiculed for looking too disabled as well as not disabled enough. Through this analysis, I argue bodies, disease, and identities become marked as disabled, attractive, chronically ill, or otherwise, as they entangle and co-articulate. Thus, an enactment framework helps to understand how particular enactments become salient via discursively, materially, and visually entangled practices.

Taken together, these chapters establish the range of analytical capability and potential insight a theory of enactments offers rhetorical studies. This dissertation moves rhetorical studies, particularly in the domains of health and medicine, toward more thorough engagement with materiality. I hope that the theoretical discussions throughout this dissertation will make clear that language and materiality cannot be untangled from one another – they come into being together and only through particular enactments and analyses they momentarily separated.<sup>2</sup>

Moreover, I contend just as language and materiality are not inherently distinct ontologically, none of the entities under examination in this project have given ontologies; instead, ontologies are done in practice. Thus, this dissertation too pushes how rhetorical studies might define and engage with ontology and how we might best engage with ontological inquiry. Finally, with each chapter, I aim to show that boundaries are particular to enactments, and consequently are fluid, shifting, and at times, unstable. Such a theory makes possible for patients to have bodies with minds of their own and for ostomies to become inseparable from the patients wearing them.

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<sup>2</sup> It is important to note that throughout this dissertation, I refer to language and materiality separately as a sort of shorthand. But as Chapter Two will explain, I consider language and materiality, and all other entities we often refer to casually as inherently distinct as only separated through entanglements with one another.

## CHAPTER 2: ON CALIBRATING & ENACTMENTS

You and I are all as much continuous with the physical universe as a wave is continuous with the ocean--  
Alan Watts

In the last chapter, I traced a variety of scholarship working to solve, overcome, or side-step the manifest issues with modernist dualisms. As I argued, recent scholarship has demonstrated, despite this expansive attention to binaries, their legacy continues. In particular, the most recent critiques have argued that humanistic scholarship has overcorrected, leading to an unbalanced focus on language and culture with insufficient attention to materiality<sup>3</sup> and bodily experience. I provided this overview to establish that the goal of this dissertation is to build a theory with which rhetoricians might more effectively address boundaries and boundary-making practices, especially in the context of patients' lived experiences. Thus, I find myself treading deep theoretical waters in an effort to attend to the myriad tenets of binary and boundary discussions within rhetoric and the humanities more broadly, regarding lived experiences, humans and nonhumans, and language and materiality.

Undoubtedly, these discussions about duality and materiality have specific consequences for rhetoricians whose domain of inquiry has historically been the discursive and symbolic. Many in the field are questioning how and to what extent rhetoricians should embrace new materialist calls and in what ways we are equipped to do so. Indeed, this has become a pressing question in the field of rhetoric of health and medicine (RHM), which often attends to the complexities of patients and their

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<sup>3</sup> This privileging of language over matter is indicative too of broader privileging across common binaries such subject over object, nature over culture, mind over body etc.

experiences, but most frequently does so through examinations of patient narrative. The question with RHM then becomes, with what rhetorical tools might we study patients' lived experiences – accounting both for language and material practices?

Therefore, in this chapter, I will begin by discussing both the importance and implications of a more materially-focused rhetorical framework, particularly for work in RHM. Then, through an exploration of two preliminary cases that highlight the plasticity of entities like self and body that have long been considered ontologically stable. In so doing, I will advocate for a new approach, calibrating the insights of Barad (2007) and Graham (2015), that I believe enables rhetoricians to at once attend to language and materiality, as well as other binaries and boundaries, in a productive and balanced way. With these theoretical frameworks as my foundation, I will end this chapter by elucidating what I'm calling a theory of enactments – a framework attuned to the ontologies staged through (sometimes rhetorical) practices in which divisions and boundaries are drawn.

### **Lived Experience and the Rhetoric of Health and Medicine**

To be clear, a move toward accounting for materiality in rhetorical practices in health and medicine is not simply an effort to be more comprehensive. Instead, many scholars have noted the problematic implications of dividing patient narratives from their embodied lived experiences. This work has specifically reasoned that focusing exclusively on text and language (patient narratives) enforces a false bifurcation of patients and their bodies. That is, when patient narrative becomes the sole avenue through which scholars come to understand patients, the material, embodied, lived

experiences of patients are severed from what is deemed relevant or useful, and in turn, often elided entirely.

As mentioned in Chapter One, this uneven focus on language over materiality/experience, especially in the domains of health and medicine, is the result of what has been called the disease/illness dichotomy (Eisenberg, 1977; Mol, 2002; Graham, 2015). As one of the many “dysfunctional consequences” of Cartesian dichotomies, the disease/illness divide drives a wedge between language and materiality by separating what patients say from what their bodies do (Eisenberg, 1977, p. 9). In part, this dichotomy emerged in an effort to give attention and authority to patient narrative, which is often subordinated to physical markers of disease (e.g. signs or symptoms made visible through examinations, MRI scans, blood work, etc.). As Mol (2002) further explains,

Social scientists have made it their trade to listen for feelings when they interview patients. And they have persistently and severely criticized doctors for neglecting psychosocial matters, for being ever so concerned with keeping wounds clean while they hardly ever ask patients what being wounded means to them. In addition to blood sugar levels, bad arteries, and other physicalities, or so social scientists have been arguing in all kinds of ways, physicians should attend to what patients experience. This is how they have come to phrase it: in addition to disease, the object of biomedicine, something else is of importance too, a patient’s illness. Illness here stands for a patient’s interpretation of his or her disease, the feelings that accompany it, the life events it turns into (p. 9, emphasis original).

According to Mol, as social scientists and humanists worked to make a way for themselves in the study of medicine, they have sequestered patient perspective/voice (illness) to their domain, leaving physicalities and bodily practices (disease) to biomedical experts. Despite this effort to bring relevance and significance to patient

narrative, this dichotomy instead has served to disempower patient narrative by granting biomedical experts “a strong alliance with the physical reality” (Mol, 2002, p. 9), and at the same time, granting humanists and social scientists reprieve from materiality.

Similar arguments have been made by rhetoricians of health and medicine as well, pointing both to the relevance and concern over distinctions between disease and illness. Segal (2005) writes, “the physician is expert in disease, and the patient in illness” (p. 147). Echoing these sentiments, Graham (2015), contends,

The disease/illness dichotomy so popular in critical/cultural studies of medicine turns out, reinforces the line of demarcation between patient and physician, further enfranchising the singular ‘reality’ of the disease over the manifold ‘perceptions’ of the illness (p. 217).

While I agree that patient narratives and language play a significant role in persuasive activity, in many contexts within health and medicine, focusing solely on language positions our analyses to overlook important rhetorical entities that have been categorized as “disease” including bodies, technologies, physical experience, etc.

To be fair, many rhetoricians have attempted to more adequately examine materiality. For example, Selzer and Crowley’s edited collection *Rhetorical Bodies* (1999) put great effort toward developing a variety of material-oriented rhetorical frameworks to explore the role of the body/disease/materiality in rhetoric. However, much of that work, like other postmodernist theories discussed in Chapter One, ultimately deconstructs materiality into language and culture. According to such work, bodies and materiality are constructed or constituted through language, only becoming meaningful when articulated symbolically. These theories then, serve to replicate the

very problem they are aiming to solve, and rhetoric continues “to ignore the body” (Dolmage, 2014, p. 2).

The disease/illness dichotomy is indicative of larger issues that arise out of postmodernist solutions to binaries. Predominately, social constructivism enables logics like “it’s all in your head.” If bodily practices, embodied experiences, and material realities become “reduced to discourse,” then patient’s embodied, lived experiences risk becoming symbolic and somehow less real or valid (Graham 2015, p. 8). Certainly, the language/matter distinction is but one divide of relevance to patient. As demonstrated throughout Chapter One, divisions between mind/body, self/non-self, human/non-human, as well as language/materiality are problematic. Indeed, Graham argues what he calls the “two-world problem” or the “series of bifurcations,” actually “gives rise to and authorizes” many of subsequent dualisms (2015, p. 21). These divisions are entangled with one another. That is, divisions between language and materiality give rise to divisions between disease and illness, mind and body, and others. Therefore, a call for increased attention to materiality in rhetorical studies, is a call for more nuanced and balanced approaches to all binaries and boundaries.

The tension that emerges from the two-world problem is of particular relevance for rhetoricians of health and medicine whose commitment to and focus on “illness” actually reinforces the very issues that RHM’s goals (attending to and intervening in lived experiences) often work to overcome. If by focusing only on patient narrative, we excise patients’ physical, bodily experiences from the linguistic representations of those experiences, it seems that rhetoricians of health and medicine ought to find new

approaches by which we can work toward dismantling assumed binaries, particularly between disease and illness. Put simply, if, as a field, we continue to only examine language, we actively uphold a binary that disempowers patients by positioning “what patients say” against “what bodies do.” In an effort to accomplish RHM’s interventional goals, I am suggesting that we take seriously calls for more balanced approaches to language and materiality, and more broadly, all binaries.

Taking up these calls then, the following section will explore two preliminary cases of women with autoimmune disease, who engage with the boundaries of their in very divergent ways. As I will show with these cases, self is not a stable entity but instead is articulated by dynamic boundaries. Furthermore, I will highlight the increasing need for understanding patients embodied, lived experiences as enacted through such entanglements. As we will see in the first case, the self is becomes non-self through entanglements with autoimmune disease. The second case then, will demonstrate a case in which the non-self, an ostomy, is transformed through acceptance of the self.

### **Case One: When Self becomes Non-self**

Sharilynn Battaglia is one of many contributors to The Mighty – a website that publishes “real stories by real people facing real challenges” in order to “face disability, disease, and mental illness together” (“Who We Are,” 2016). Using one of Battaglia’s articles as an exemplar case, I will analyze her account of what it’s like to live with an autoimmune condition in order to demonstrate the common autoimmune patient’s experience of living with self as non-self.



To begin, Battaglia, who has been living with an autoimmune disease for over twenty years, describes having an autoimmune disease is “a lot like playing Jenga. Only we [autoimmune patients] are the tower” (2016). To help illustrate this comparison, she writes,

When you first start playing, does the tower look like it’s under attack? Does it look like it’s in imminent danger of collapse? Of course not. But it is. It’s exactly the same with us [people with autoimmune disease]. Why do you think they are called invisible illnesses? The attack is all happening on the inside, through the blood to whatever the target of the day is. But just because our diseases work quietly on the inside, and just because the effects of our diseases aren’t as noticeable, that doesn’t mean we aren’t sick.

Even though autoimmune diseases do not necessarily manifest visibly as Battaglia notes, they “work quietly on the inside,” and despite this containment within the self, these diseases, at least according to Battaglia, are not self. It is perhaps a little odd to think about the internal activity of our body as non-self; after all, the external boundary of the body is commonly considered to be the skin. However, for Battaglia, what is happening inside of her – her autoimmune disease – is not self. Her immune system and its autoimmune “attacks” are separate entities that operate within her in ways that she does not control.

To explain further, she suggests autoimmune patients’ immune systems are “always on attack.” She writes,

[Autoimmune patients’ immune systems] go after blocks of muscles or joints and push them out of balance, or they pull at blocks of nerves, creating raggedy areas that send tremors through our whole structure... You see, a healthy immune system knows what is foreign and what is not. You catch a cold, it sees a virus, it attacks. End of story. With us, it’s not so easy.

Here, Battaglia’s autoimmune disease shifts from self to non-self, or at the very least, her experiences with her autoimmunity are enacted such that those specific “confused”

responses within her body are not her. Instead, she argues, such immune systems do not just “attack body parts,” instead they attack “our bodies. The bodies of people you know and love.”

Importantly too, it’s not just that immune systems are constantly confused; instead, “just like in any war, troops take rest periods. So do our diseases. They hide on us.” And, when autoimmune diseases decide to come out of hiding,

they may pick and choose what to attack first in each person, just like you choose which block to pull out when it’s your turn in Jenga. But eventually, the attack spreads and the tower falls...And it will happen over and over.

This sort of agentic, intentional behavior attributed to the autoimmune disease further deepens the divide between conscious, controlled self, and non-controllable, invading non-self.

In her embodied experience of autoimmunity, Battaglia’s notion of self is under attack by what is quarantined off as non-self. To be sure, autoimmunity is the immune system behaving in an atypical way, but this atypical behavior does not transform the immune system to physiological non-self. The misbehaving immune cells are still native to the body, however, when those misbehaving cells lead to painful or unwanted experiences (e.g., symptoms) new bodily boundaries emerge. In other words, it’s not just that Battaglia conceptualizes the confused immune system activity of her disease as non-self, it’s that her experiences (physically, psychologically, perhaps even socially) enable her autoimmune system to be divided from her self. Battaglia highlights the fluidity of the boundaries surrounding self, non-self, body, and mind, specifically when the self becomes non-self. However, the boundaries enacted in her case are not

representative of inherent or stable ontological difference. Autoimmune patients do not always experience self as non-self. Recognizing these shifting boundaries as contingent upon particular entanglements, the next section will track an enactment in which non-self becomes self.

### **Case Two: When Non-Self Becomes Self**

If instances in which the self becomes non-self for autoimmune patients exist, then it seems reasonable that there are cases in which the reverse occurs – in which the non-self becomes self. As briefly described in the first chapter, for some patients with autoimmune disease, the use or integration of technologies as treatments becomes necessary, and these cases provide a way in which to explore the potential of non-self becoming self. In particular, for patients with IBD, the ostomy pouch is often required, and for the many patients with ostomies, notions of self become increasingly complex. Is the ostomy pouch self? Is the self a cyborg? Can nonhuman become human? If so, how, when, and toward what end? To explore these questions, I turn to Jessica Grossman, a contributor to *Uncover Ostomy*, an online “awareness campaign working to break the stigma surrounding ostomy surgery” (“About Us,” 2016).

As a contributor to the site, Grossman blogs regularly discussing her personal experiences with IBD and ostomies, offering advice and support for others on topics ranging from clothing and exercise to dating and wedding planning. Of Grossman’s many posts, I will examine just one, entitled, “13 Years of Different: Bag-Mitzvah Edition” (2013). In this post, Grossman celebrates her 13-year ostomy anniversary. Reflecting on her past 13 years, she writes, “on January 30th, 2003, I was told that I needed to choose between life with an ostomy or death. 13 years later, I am here. Alive.

Healthy. And celebrating...my "Bag-Mitzvah." In addition to celebrating the life she was able to continue due to her ostomy, Grossman uses this post to offer 13 bits of "wisdom" to her readers.

Over the course of the 13 points, Grossman specifically highlights the importance of acceptance, openness, and empowerment for people with ostomies. As I will show, through Grossman's points of advice, she not only highlights the importance of acceptance, but she describes her experiences through which her technology became self. Specifically, Grossman begins her list with the following sentiment: "There is no better choice that you can make in your life than to accept yourself for who you are."

On this point, she elaborates,

Having accepted my ostomy as part of who I am has given me the confidence to not only live my life, but to live it the way I want to live it. If there's one thing you can take away from this whole post – do whatever it takes to get yourself to accept who you are (emphasis mine).

Here Grossman does not suggest that readers learn to accept having to wear an ostomy. Instead, she advocates for acceptance of the previously non-self, nonhuman ostomy into her notion of self. Accepting the ostomy means accepting herself for who she is, the self enacted through her lived experiences, and she recommends others with ostomy pouches do the same.

Building on this acceptance of self, Grossman then recommends that people with ostomies must educate others about their "difference" because people "won't understand what your difference really is." To support this point, she offers her own experience,

I was able to explain that the ostomy is a lifesaving surgery and that, without it, I would be dead. I can explain that it's not gross, it is weird, but it's me and I am damn proud to be alive (emphasis original).

Grossman explicitly identifies the ostomy as self in this passage, which suggests no boundary between self and technology for her. Her ostomy becomes part of her self. Note, Grossman explains the ostomy "is me," not "I decided the ostomy is part of me" or "I talk about my ostomy as if it's part of me." It's not that Grossman simply decided her ostomy was self, but rather that through engagement with the technology, through her practices and experiences, non-self becomes self.

In addition to reminding readers to "not let [your] difference stop you from doing what you want to do," Grossman specifically tells readers that being different and having an ostomy, makes them "special" and such specialness is not only valuable but tied to identity and self. Reflecting on her personal experience, Grossman writes, "My fiancé treats me like gold because he loves everything about me – including my stubbornness and my ostomy. It makes me who I am and that's all he cares about" (emphasis original). It is because her ostomy is part of her self that she is special, unique, and loved. Ultimately, the borders of Grossman's body and self are not limited to the boundaries of her physical body (e.g., the skin), enabling the ostomy to become self.

### **On Calibrating Intra-Activity & Rhetorical-Ontological Inquiry**

The cases of Grossman and Battaglia demonstrate a few critical points. First, these cases enact two incompatible versions of self. For Battaglia, boundaries around self arranged internally, allowing her autoimmune disease to be partitioned from her self.

Conversely, Grossman's self extends beyond the commonplace boundary of the skin to

surround her ostomy as self. Looking at these contradictory cases brings to bear the pressing need for a theoretical and rhetorical approach for understanding such inconsistencies. Secondly, these cases point out that autoimmunity requires a nuanced approach to divisions, particularly, to understand how boundaries between and around language, materiality, self, non-self, mind, body, human, and nonhuman are dismantled as well as established and maintained. Battaglia's and Grossman's cases reveal, at least in certain instances, establishing and maintaining binaries can be quite productive for patients or certain bodies and identities.

Many scholars too have noted this point, suggesting that an additional concern regarding postmodernist solutions to binaries is the desire to dismantle all binaries in every context (Manderson, 2005; Bennett, 2009; Wells, 2010, Krummell, 2001). For instance, while examining how patients react after life-altering surgery, Manderson identifies the "need" for patients to separate themselves from their bodies, highlighting the "important and ongoing tension" that exists for "people who, on an everyday basis, have to deal with their bodies as objects" (p. 406).

Additionally, in an autoethnographic piece regarding her own experiences with MS, Krummell explains that dealing with her condition has led to an "inevitable distrust of her own body, requiring her to rely more and more on her mind" (2001, p. 68). Bennett, too, suggests divisions between subject and object have even ameliorated human suffering and promoted happiness and well-being in certain instances (2009). In such examples, a tension arises between the theoretical or philosophical desires to overcome binaries and the lived divisions that scholars experience or observe.

Consequently, a theory that attends to both the concerns over upheld binaries while maintaining a space for productive binaries seems necessary on both theoretical and practical levels.

In looking at cases like Battaglia and Grossman, in which boundaries are enacted in diverse ways, it becomes clear that it's not simply that we need a better theory to do away with binaries. Instead, we need a robust framework in which we can more adequately understand how boundaries and divisions become rhetorically possible and powerful. Such a framework not only has the potential to better account for what's happening in these cases on a theoretical level, but also to help patients (as well as other stakeholders, no doubt) make meaning out of their experiences to in an effort to cope, understand, and move forward given the circumstances of their patienthood. In searching for such a framework, I turn to Barad's intra-activity (2007) and Graham's rhetorical-ontological inquiry (2015) as the first step in developing theory of enactments to capture and examine autoimmunity, embodiment, and selfhood. In drawing on Barad and Graham, I am working to make a space in which binaries can be dissolved (e.g., my ostomy is part of me) as well as space for binaries to be established (e.g., my immune system is not me).

*Boundaries that Do Not Sit Still*

In developing her theories of agential realism and intra-activity, Barad begins by recognizing,

what is needed is an analysis that enables us to theorize the social and natural together, to read our best understandings of the social and natural phenomena through one another in a way that clarifies the relationship between them (2007, p. 25).

In other words, what is needed is a theory that accounts for the messy relationships between various entities while not reinscribing inherent dualisms. In developing such a theory, Barad asks many of the same questions I am posing throughout this dissertation,

What is entailed in the investigation of entanglements? How can one study them? Is there a way to study them without getting caught up in them? What can one say about them? Are there any limits to what can be said...how to responsibly explore entanglements and the differences they make? (2007, p. 74)

Working to answer these very questions, Barad fosters her theory of intra-activity founded on the premises that “boundaries [between human/nonhuman, culture/nature, language/matter] do not sit still” (p. 171) and “the line between subject and object are not fixed” (p. 155).

Indeed, according to Barad, there are no preexisting entities in the world, no a priori subjects, objects, bodies, or minds, but rather such phenomena emerge in “intra-actions.” Barad clarifies,

the notion of intra-action (in contrast to the usual ‘interaction,’ which presumes the prior existence of independent entities or relata) represents a profound conceptual shift. It is through specific agential intra-actions that boundaries and properties of components of phenomena become determinate and that particular concepts (that is, particular material articulations of the world) become meaningful (p. 139).

Put another way, entities (things, words, objects, subjects, etc.) are constituted through their mutual entanglement with other entities (note the difference here from the common postmodern idea that language and culture constitute objects). There are, therefore, no preexisting entities that can be categorized into inherent binaries. The world “is a dynamic process of intra-activity” (Barad, 2007, p. 140).



Barad's intra-activity requires that "matter" is not a "mere effect or product of discursive practices" but instead an "agentive factor" within entanglements (2007, p. 32). Accordingly, meaning is not confined to "individual words or groups of words" but is enacted through intra-actions (2003, p. 820). Entities become meaningful through articulations with other entities, through intra-actions. If no preexisting entities exist, but are distinguished through enactments, then boundaries and binaries too are enacted through intra-active entanglements (often including both materiality and language). And, through these intra-active entanglements both entities and distinctions emerge and dissolve. This approach has the potential to help rhetoricians more adequately attend to materiality by offering a productive alternative to binaries, but an alternative in which language is still often an integral part. For Barad, language and materiality (and all other entities) are not naturally separate in the world, but their separability is staged through what through specific "cuts."

Drawing contrast with inherent, stable "Cartesian cuts," Barad offers the notion of "agential cuts" – distinctions that emerge through practices (2003, p. 815). Critical to the idea of agential cuts is that we reconsider the role of nonhuman entities without taking the distinctions between human and nonhuman as "foundational" or given (2007, p. 32). Through intra-actions, specific agential cuts are enacted; in one intra-action a cut between subject and object might be enacted, while in another, a different cut that unifies subject and object might be enacted. Consequently, intra-activity requires a shift in conceptions of agency:

agency is a matter of intra-acting; it is an enactment, not something that someone or something has...Agency is 'doing' or 'being' in its intra-activity. It is the

enactment of iterative changes to particular practice – iterative reconfigurings of topological manifolds of spacetime-matter relations – through the dynamics of intra-activity (2007, p. 178)

In other words, agency is enacted as entities come together in specific intra-active practices, and agency is certainly not confined to human entities. Who and what are capable of participating in agentic practices is shifted to include human, nonhuman, language, matter; although, as Barad sees it, even those categories are not fixed or inherent in the world. Instead, the entities that make up the world come together in space and time, and any entity is capable of participating and influences these agential enactments.

The significance of this reconfiguration of agency and attunement to intra-activity is that the world is no longer made up of preexisting objects, subjects, cyborgs, minds, and bodies, and the need to overcome or uphold binaries is no longer necessary. Instead, under Barad's rubric, the entities previously understood as binaries or hybrids only emerge through their activities within enacted phenomena. As such, different practices stage different agential cuts, and we can begin to see enactments of binaries – upheld or dismantled – as agential cuts that are enacted in time and space. The benefit of this shift from “questions of correspondence between descriptions and reality” to “practices/doings/actions” Barad explains, “bring[s] to the forefront important questions of ontology, materiality, and agency” (p. 802).

Instead of assuming or reinscribing “hardwired” divisions in the world, intra-activity provides a way for scholars to make sense of how phenomena come into being through practices. Under an intra-active framework, different patients are engaged in

different practices in which different agential cuts are enacted. Entities including self, non-self, disease, immune system, language, ostomy, and others are fluid and enacted intra-actively through specific practices. Accordingly, I adopt a lexicon of “doing,” “enacting,” and “becoming” to suggest the lively, agentic processes that stage different enactments of boundaries and divisions surrounding patients’ lived experiences, bodies, and identities (processes that I will more fully elucidate in Chapters Three, Four, and Five). In so doing, I attune my focus to the enactments in which the intra-actions in which agential cuts are enacted.

It’s important to note, however, Barad’s theory of intra-actions and agential cuts considers language in particular ways, such that discourse does not directly equate to language. Barad quite explicitly recognizes the important role language plays in intra-actions; however, she attunes our understanding of language such that discourse does not have inherent boundaries. Instead, she argues, “discursive practice are ongoing agential intra-actions of the world through which local determinacy is enacted...meaning is not a property of individual words or groups of words but an ongoing performance in the world” (pp. 820-1). Barad begins theorizing the role of language in intra-actions, but as philosopher, not rhetorician, she does not fully engage the implications such a paradigm shift might have on rhetorical studies.

Therefore, in the following section, I calibrate Barad’s intra-activity with Graham’s rhetorical ontological inquiry, which, according to Graham, “seeks to balance the opposing forces of human- and object-centered accounts” (2015, p. 209). Indeed, Graham’s rhetorical-ontological inquiry of pain compellingly demonstrates the

simultaneous importance of attending to materiality and language, as both act in important rhetorical ways (p. 84). Combining Barad and Graham for this project on IBD and autoimmunity results in a useful heuristic for attending to all agentic entities including materiality, objects, bodies, non-selves, language, subjects, minds, selves, etc.

*Embodied Doings in the World*

Of the many new materialist frameworks, few take specific care to maintain a productive space for language in combination with materiality. Graham's rhetorical-ontological inquiry (2015), however, emerges as one of the most promising and productive tools with which rhetoricians might address materiality, particularly of the body, without abandoning the commitments of rhetorical work. A rhetorical-ontological inquiry, according to Graham, balances the language/matter divide, and subsequently other modernist dualisms, through a "study of practices" (p. 88) in which "the material and the ontological are at the center of inquiry" (p. 7). One goal of rhetorical-ontological inquiry, Graham explains, is to "transcend" the problematic legacy of dualistic thinking that I have been outlining over the course of this dissertation so far.

Clarifying the way in which language should be accounted for, Graham builds on Mol's study of ontologies in medical practice, in which she too examines language but in a very strategic way. In contrast to analyses of patient narrative, Mol advocates that we "listen to" each person (and their reports) under analysis as if she is her "own ethnographer. Not just an ethnographer of feelings, meanings, or perspectives. But someone who tells how living with an impaired body is done in practice" (Mol, 2002, p.

15). Thinking of the cases presented in this chapter as entangled phenomena of bodies, diseases, and experiences “done in practice” has specific implications:

It is possible to listen to people’s stories as if they tell about events. Through such listening an illness takes shape both as material and active...This illness is something being done to you, the patient. And that, as a patient you do” (Mol, 2002, p. 20).

As such, Graham argues, “language is doing” (p. 84), therefore, his rhetorical-ontological inquiry studies different “doings” in the world including “the practices of speaking, writing, visualizing, representing” (p. 36). By shifting our analyses to practices and sites of practices (following Mol, 2002), we can best understand the ways in which such practices stage particular realities and object formations (p. 31).

Through his analysis of pain management and the formation of “pain” as an object across sites and practices, Graham develops rhetorical-ontological inquiry as a “form of inquiry that can go all the way from the microscale, local practices...to networks” of many, diverse entities. Importantly too, rhetorical-ontological inquiry is grounded in multiple ontologies theory (see Chapter Four for a more thorough discussion), which, put briefly, “is a theory of doing and being” in which “the kinds of actions you habitually perform” stage the reality in which you engage” (p. 31).

This aspect of rhetorical-ontological inquiry is integral to what I am attempting throughout this dissertation: to find ways to simultaneously account for all entities involved in a rhetorical situation as a means of understanding how specific boundaries are done and how the entities involved in those boundary-making practices enact specific notions of self. For instance, Graham uses rhetorical-ontological inquiry to demonstrate the entanglement of medical expertise, imaging technology, patient report,

diagnostic testing, and pharmaceuticals to enact and bring into being fibromyalgia as a disease. Similarly, in my calibration of intra-activity and rhetorical-ontological inquiry, I am interested in investigating the entities involved in the intra-activity that enacts specific practices and stages divergent ontologies of ostomies, selves, and bodies.

Bringing Graham and Barad together on this point is especially insightful. Rhetorical-ontological inquiry helps attune my work to the kinds of intra-actions “habitually performed” in various IBD contexts that result in specific doings or enactments of boundaries and divisions. The point here is that intra-actions are enacted in specific entangled, embodied practices. These practices, habitually done, stage specific ontologies of self, ostomy, non-self, etc. Through intra-active practices, ontological borders are drawn. To unpack the complexity here further, the following section details the ways in which the integrating intra-activity and rhetorical-ontological inquiry sheds light on the cases of Grossman and Battaglia. However, first, I must explain how calibrating Barad and Graham demands a particular strategy of curating artifacts for this dissertation (including the cases presented in this chapter). In what follows, I will summarize discourse and object formations part of Foucault’s enunciative analysis as the artifact curation approach necessary to leverage the insights of Barad and Graham for rhetorical studies.

### **Enunciative Analysis: Discourse Formation and Formation of Objects**

A key aspect of calibrated intra-activity and rhetorical-ontological inquiry for a theory of enactments is that all entities are examined as they emerge in intra-actions. An enactment analysis cannot assume any divisions even in the artifacts curated. However, rhetorical analyses often make an a priori agential cut and only collect and analyze

language and linguistic artifacts. In order to avoid this cut at the outset of my work and to fully and appropriately employ Barad and Graham, however, I turned to Foucault's formations of discourse and objects as data curation heuristics that enabled me to identify intra-active phenomena without assuming an agential cut between language and other objects for analysis. That is, Foucault's discourse and object formations (1972) serves as a platform for gathering intra-active phenomena, rather than only linguistic phenomena. This approach enables me to explore the role of language within intra-actions and agential cuts, without enforcing agential cuts on phenomena myself. To elucidate this data curation method further, this section will introduce Foucault's discourse and object formations with particular focus on its relevancy for rhetorical studies.

Over the course of three years, I have worked to curate public cases and associated artifacts relating to patient experience with IBD and ostomy pouches. Artifacts assembled in this process include campaign materials for a health advocacy campaign by the Center for Disease Control and Prevention (Chapter Three), news articles and blog posts written by and for patients with IBD and ostomies (Chapters Two, Three and Four), interviews and observational data of with women with IBD and ostomies<sup>4</sup> (Chapters Three and Four), and social media content including artifacts with

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<sup>4</sup> Over the course of three years, I conducted a qualitative study including ethnographic observations, interviews, and surveys in order to capture and analyze the lived experiences of patients with IBD and/or ostomies. In total, I conducted approximately 200 hours of ethnographic observations at an annual retreat for women with IBD and/or ostomies. During these observations, I had permission from organizers and attendees to observe at any time (including focus groups, guided activities, and social time). Additionally, I conducted follow-up interviews with 9 women, all of which attended this retreat (a list of interview questions is included in Appendix A). Lastly, as part of this study, I conducted an online, national survey to gain further insight into this patient population (see Appendix B for a list of questions). I do not directly include findings from that survey in this dissertation, however,

several social media awareness and fundraising efforts including Get Your Belly Out, OstomyOutdoor, and #IBDSelfie (Chapter Three, Four, and Five).

In managing these artifacts, I employ Foucault's enunciative analysis, which has been explored extensively by rhetoricians (Graham & Herndl, 2011; Phillips, 2002; Biesecker, 1992; Blair & Cooper, 1987; Longo, 1998). Such an analysis guides rhetoricians to examine what Foucault calls discourse formations and the formation of objects, by asking two primary questions:

- "How is it that this statement appears rather than some other?" (Foucault, 1972, p. 22)
- "How do rules and constitutive regularities of a discursive formation produce a statement about a specific type of object and not some other statement?" (Graham & Herndl, 2011, p. 151)

Put another way, these questions require attention to how and why certain statements were made possible and what types of objects are made possible with those statements.

In his discussion of enunciative analysis, Phillips (2002) highlights the value of Foucault's discourse formation, particularly in relationship to the rhetorical study of invention. Phillips defines discourse formation as "the emergence of statements in a broad field of discourse" (p. 333), and through these formations, objects are formed. For example, in Graham & Herndl's deployment of enunciative analysis, they examine discourse formations that establish and influence the object of "pain" (2011).

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I've no doubt that conducting and analyzing that survey influences the overall findings of this dissertation, therefore I make mention of it here. This qualitative study was approved by UWM's Institutional Review Board.



Importantly though, such discourse formations, as well as the objects that emerge with them, are highly governed by knowledge, power, and subjectivity, and through this regulation, particular discourse formations are made possible while others are constrained.

Who speaks, the sites from which the speaker speaks, and the positions of that speaker highly influences the formation of discourse and its associated objects (e.g. in my work, these objects might include the self, ostomy, IBD, body, etc.). And, as I argued in Chapter One, rhetoricians must remember, who is capable of “speaking” is not limited to humans; ostomies, immune cells, images, also “speak” and influence these formations. Therefore, as I will clarify later in this chapter, a theory that accounts for how such entities come into being and how they influence rhetorical practice is necessary.

Essential to enunciative analysis, too, is the notion that these formations are not “wholly coherent entities” but instead are “riddled with incoherence and contingency” (Phillips, 2002, p. 333) Through these incoherences and contingencies, “points of possibility” for alternative discourse formations and objects are staged. Phillips notes, “contradictions are important not only as new statements and different discourses, but also as points of possibility...spaces within which certainty and regularity are disabled and possibilities become possible” (pp. 333-4). Explaining further, Phillips suggests,

These are spaces of dissension because they are places where the incoherence and contingency of the discourse is experienced directly and, therefore, the production of dissenting discourse becomes possible for those who have momentarily recognized the instability. Spaces of dissension, thus, can be conceived as inventional spaces (p. 334).

These points of possibility, the incoherence and contradictions, are precisely where I focused during my artifact curation--where, when, and why contradictions and inconsistencies emerge in the discourse formations related to IBD, ostomies, and the related binaries and boundaries.

That is, I narrow in on instances in the discourse in which incoherence or contradictions developed in the formation of self, identity, ostomy, IBD, etc., in order to map the emergence, boundaries, and differences across those formations. Much like Graham and Herndl's study in which they argue "enunciative analysis suggests that 'pain' is a discourse object constituted differently in different professional disciplines" (2011, p. 151), my project illuminates instances in which self, ostomy, body, identity, and disease are enacted differently to uncover why and how these objects emerge as contradictory or incoherent. However, Graham and Herndl (2011) emphasize that fully understanding the object formation of "pain" required they "supersede" assumed boundaries and ontologies of pain (p. 151). Therefore, I use enunciative analysis as a way to "supersede" a priori agential cuts regarding the artifacts that stage objects like self and ostomy.

That is, discourse and object formations enable rhetoricians to identify the agential cuts and boundaries enacted in phenomena. Rather than select only linguistic representations for this dissertation then, I worked to identify object formations in which I could trace the incoherencies and contradictions with the IBD and ostomy communities. As such, the chapters in this dissertation feature a series of dueling cases, so-to-speak, much like the cases of Battaglia and Grossman presented in this chapter. To

illustrate both the value of curating object formations rather than language cut from its phenomena, as well as the analytic potential for calibrated intra-active and rhetorical-ontological approach, the next section deploys enactments as my way of doing analysis.

### **Lived Experience & Enactments**

As mentioned previously, calibrating intra-activity and rhetorical-ontological inquiry results in the development of a new analytic frame that examines enactments. As the composite of Barad's and Graham's insight, a theory of enactments navigates various boundaries and binaries, examining how they come to be and how they come to have agentic influence in the contexts of IBD and autoimmunity more broadly. Essentially, a theory of enactments reframes rhetorical activity as both diffuse through entanglements of many entities (intra-active) and persuasive toward a particular exigency, whether intentional or not, in which a specific ontologies and boundaries are staged through patient practice (rhetorical-ontological). This reframing makes space for fluid boundaries and works then to understand how and why certain agential cuts are enacted and how and when they become meaningful.

Moreover, thinking of practices in health and medicine as enactments pushes the purview of our inquiry beyond patient narrative to richer accounts of the intra-activity that stage specific experience and practices. In focusing this analysis on enactments, I can treat the reports of women not as descriptions of their feelings or perspectives, but as reports on events – on things that happened through their own practices as they entangled with the practices around them. Subsequently, my analysis does not attend to the ways in which Grossman or Battaglia said or described certain experiences or

ideas, instead, my analysis focuses on what types of boundaries and binaries were done and enacted in the events upon which Grossman and Battaglia report.

Indeed, a theory of enactments in rhetorical studies of health and medicine is a methodological posture – a way of being that attunes us to particular insights – through which we might help stakeholders identify how meaning-making happens in given contexts, what entities are intra-actively involved and toward what end, and how those stakeholders might use that insight to navigate those contexts. For example, ignoring the material agency of autoimmune activity makes it difficult to understand patient lived experience, and equal important, to find ways to intervene in those experiences. Therefore, a study of enactments aims to effectively engage with the range of entities at work in a given context to explore the rhetorical practices involved in autoimmunity.

Together Barad's and Graham's theories are apt to examine how patients with IBD and ostomies experience and engage boundaries of their selves, bodies, and conditions. Accordingly, a theory of enactments accounts for which entities are at work in a given space, practice, and moment within a rhetorical situation, whether discursive, material, or else. Calibrating Graham and Barad enables me to orient my analysis to the entities that co-constitutively intra-act in specific practices to enact particular bodies, objects, binaries, identities, boundaries, etc. For instance, in Grossman's case, the intra-activity of her self, ostomy, disease, society, husband, body, and perhaps more, are staged through her everyday practices, that, in turn, enact the specific boundary of her ostomy as self. This enactment has specific rhetorical consequences as made manifest in her post celebrating her Bag-Mitzvah. The specific enactment of her ostomy as self

works rhetorically to bring positivity and empowerment to the IBD and ostomy community. In sharing this specific enactment of self through her blog post, Grossman calls others to both engage in specific practices as well as share those specific practices with others in a celebratory, accepting way.

In contrast, the intra-activity entangled with Battaglia – her body, self, autoimmune cells, intestinal walls, immune system – are staged through her practices and enact a boundary around her autoimmune disease, in which it becomes non-self. The enactment of autoimmune disease as non-self too has specific rhetorical implications. For one, this division draws attention to the seriousness of autoimmune disease and the little control she has over it. Too, with her autoimmune disease as non-self, she can further explore her everyday lived experiences that shape and are shaped by this division. Sharing such experiences sheds light on the difficulties of living with an autoimmune disease, drawing attention to the “invisible” disease as well as its consequences for the person in which the non-self acts.

To review, in either of the cases explored in this chapter, boundaries and divisions are enacted through intra-actions of disease, self, non-self, bodies, technology, minds, language, culture, and more, in specific rhetorical contexts. Postmodernism might suggest we make sense of autoimmunity by seeing it as socially constructed by the current medical culture and constituted through language within that culture, while new materialisms risks losing sight of the powerful role language and culture play in the meaning-making of autoimmunity. Therefore, examining autoimmunity and its associated experiences as enacted provides a way to more adequately account for and

balance the roles of the diverse entities involved. A theory of enactments is concerned with the specific practices that divide various entities, as well as the practices in which no such divisions are enacted. Barad and Graham productively investigate the vibrant intra-actions of entities across and through time. Calibrating their insights, I propose enactments as a methodology for 1) examining who and what are involved in the boundary-making practices within IBD, ostomies, and autoimmunity and 2) evaluating the ways in which certain enactments become influential and salient. Tracing these enactments allows me to understand the powerful role boundaries play in these contexts.

Furthermore, in calibrating Barad and Graham, I hope to respond to Graham's calls for "increased attention to the reciprocal relationship among words and things" (p. 206) and for future rhetorical-ontological work that is "interventional" (p. 218), by expanding rhetorical studies of health and medicine into the domain of enactments. Graham suggests, "rhetorical-ontological inquiry can use its investigational resources to catalyze and assist interventional and emancipatory projects in a wide variety of domains" (p. 215). Calibrating intra-activity with rhetorical-ontological inquiry has set me on the path to take up both of these calls. A theory of enactments builds on new materialist and ontological inquiry by examining entities and the practices that stage them, and in so doing, has the potential for identifying ways in which we can intervene in those practices. For my work in particular, I am advocating that combining rhetorical-ontological inquiry and intra-activity provides a way to do theory that examines when, why, and how certain boundaries and divisions are enacted toward

particular rhetorical exigencies, and helps to map the spaces in which I might be able to improve the multifaceted complexities of living with IBD, ostomies, and autoimmunity.

Continuing to build this calibrated theory, in Chapters Three, Four, and Five, my goal is to trace how and what enactments are staged through particular patient practices. To do so, I will examine a series of contradictory or incoherent objects (e.g., self, ostomy, disease, body) as they are staged through specific enactments. In Chapter Three, we will meet Julia, a CDC representative who grew famous in the IBD community for making public her particular ostomy experience. As we will see, the enactments in Julia's case, in comparison to many others in the IBD community, stage particular identities through particular trajectories of intra-active experiences. As I examine Julia and conflicting cases through an enactment lens, I am to expose why divergent identities are staged across seemingly similar entanglements of humans and ostomies.

### CHAPTER 3: WEARING & BECOMING: ENACTING DIVERGENT IDENTITIES

You go wherever it goes. You have no control. If it comes loose, it smells. I had no control. I had to wear it for a whole year. I was at home the majority of the time because I was scared that it would come loose and it would smell and I didn't want to be around anyone. I was really kind of like stuck at home -Julia, CDC Spokesperson and cancer survivor

I know what it's like to see your reflection in the mirror and feel unattractive. I used to be disgusted at the very thing that restored my health. But then I realized, that anything that has the power to save a life can be nothing but beautiful -Gaylyn Henderson, Founder of the advocacy organization Gutless and Glamorous

To begin this chapter, I'd like to introduce one of the most famous figures within the IBD and ostomy communities in the last several years: Julia.



Figure 2. Julia in one of her Tips from Former Smokers video.

Julia and her fellow “former smokers” have been featured on TV for the last three years as part of the Centers for Disease Control and Prevention’s (CDC) Tips from Former Smokers campaign, a nationwide effort to decrease smoking. At first, anti-smoking efforts might seem unrelated to my work on IBD, ostomies, and autoimmunity, however, Julia and her participation in the CDC’s campaign, grew famous because of the experiences Julia presents regarding her temporary ostomy pouch after she was



diagnosed with colorectal cancer. Otherwise outside of the IBD and ostomy communities, Julia, and the experiences she highlighted, steeped her in a nationwide controversy regarding the CDC and Julia's decision to broadcast explicitly negative experiences with an ostomy pouch as an effort to persuade viewers to quit smoking.

That is, Julia and the CDC were highly criticized for their willingness to use the ostomy pouch as a scare tactic, much in alignment with the other videos and ads in this campaign, to confront viewers with the "reality" of smoking. Although assuredly well-intentioned, Julia's video subordinates the life-saving potential of ostomy technology to the seemingly more important mission of decreasing smoking across the US. That the CDC elided alternative, more positive, experiences with the ostomy, provoked outrage on the national stage by organizations like the Crohn's and Colitis Foundation of America and the United Ostomy Association of America, as well as thousands of individual patients who flooded the CDC's social media accounts and even developed a massively popular petition, calling for an apology as well as a recall of Julia's video.

I introduce you to Julia and the controversy she incited as they provide a particularly rich site for deploying the enactment framework developed over the course of Chapter Two. As I contended in that chapter, bodily and identity boundaries, particularly around self, are enacted through specific intra-actions staged in everyday practices. In looking at cases like Battaglia and Grossman (see Chapter Two), it becomes clear that diverse, often contradictory, enactments are made possible through the intra-activity of many entities (words, technology, society, disease, bodies, identities, etc.). A theory of enactments, then, is deliberately calibrated to examine the specific practices in

which boundaries – in terms of bodies, identities, objects – are enacted or done. To do this theory, to put it into practice, my goal for this chapter is to move out of the dense theoretical conversation of Chapter Two, and into a more applied discussion of what a theory of enactments brings rhetoricians and technical communicators. Accordingly, this chapter will examine a range of cases including Julia, in which diverse object formations are staged in order to understand why and how those divergences came to be and what consequence those objects have on identity. As I will detail later in this chapter, I identify two primary ostomy-related identities within this community of patients – ostomy pouch wearer and ostomate.

Importantly, as part of this application of an enactment approach, Segal's kairology (2005) is highly useful to understand how these divergent identities come to be through intra-actions and enactments. Attending to the role of kairos in enactments is especially helpful to explain when and how particular enactments become possible and persuasive. After all, a key concern of this dissertation is understand how enactments surface as powerful and influential. Much has already been said on the notion of enacting, performing, or doing (Butler, 1999; Mol, 2002; Graham, 2015; Pickering, 2010), however, to build on Graham, this chapter is interested in what makes enactments relevant to and capable of rhetorical activity, and, what that might mean for patients with IBD and ostomies. Throughout the rest of this chapter then, I will briefly describe Segal's kairology and its relevancy as a heuristic for 1) understanding the experiences and identities enacted across the cases presented and 2) bringing these cases into conversation with rhetoric of technology scholarship.

## **A Kairology of Enactments**

In an effort to examine the relationships among and consequences of enactments, throughout this chapter, I will deploy what Segal (2005) coined a “kairology.” A kairology, Segal explains, is “a study of historical moments as rhetorical opportunities” (p. 23). Such an approach enables a rhetorician to understand how, when, and why certain moments and arguments are persuasive by investigating the “conditions of time, place, and audience” (p. 22). Importantly, as Segal carefully notes, a kairology is more than a chronology; it is a study of “contingency and fitness-to-a-situation” (p. 22). That is, Segal advances this approach to kairos in order to examine when and how “arguments have a quality of truth” in specific situations. By examining those arguments (enactments) in relationship to the rhetorical situation from which they emerge, we can begin tracing (hi)stories rhetorically. It is worth reminding here that an enactment analysis is focused on listening to people’s stories as if they are “events” — that which is done in practice. Therefore, as I deploy a kairological analysis in this chapter, the “rhetorical opportunities” under examination are events or doings staged through specific intra-actions and agential cuts.

Further, Segal’s kairology focuses on “vectors,” the opportune alignment of rhetorical threads that make possible a given moment. Segal explains,

An illness is an illness by fitting into a taxonomy of illness (the medical vector), by being situated in a certain way between cultural elements (the cultural polarity vector), by being visible as a disorder (the observability vector) and providing some otherwise unavailable release (p. 23).

In other words, an illness comes into being when and where these vectors intersect. In the lexicon of an intra-active framework, Segal’s insights can be reframed as follows:

when the medical vector, cultural polarity vector, and observability vector intra-act, illness is enacted. The alignment of these vectors are intra-actions. When vectors align, when entities intra-act, enactments come into being and potentially become rhetorically powerful.

This kairological approach is particularly useful in understanding the enactments of patients because it shifts my focus toward practices and agential cuts enacted through space and time. Put another way, kairology builds a foundation to examine the emergence, transformation, and relationship between different IBD and ostomy pouch experiences, specifically helping me to understand 1) how these experiences and events gained traction persuasively, publically, and personally, 2) how these various experiences are connected across time and space and 3) how the unfolding of experiences over space and time enact particular identities through agential cuts.

In this chapter then, I am guided by the following question: how do some patients become ostomy pouch wearers while others ostomates? I build on the notion that only certain conditions make possible given enactments and objects to explore how kairologies of intra-actions in which the ostomy is involved enact diverse identities through particular patient experiences. That is, this chapter is focused on the alignment of vectors that make particular identities possible. This kairological approach is especially useful in studying how various discourse formations come into being through time because it works to understand how and why such formations emerge. However, before jumping into a kairological discussion of how identities unfold within

the ostomy community, it is important to recognize that rhetoric of technology scholarship has already identified a recurring kairology of technology (Clark, 2007; Koerber, 2000). While this scholarship is not typically connected to kairos, revisiting this scholarship through a kairology provides a valuable foundation to examine enactments of ostomy pouch identities.

*Kairology of Technology: Moving from Affordance to Constraint*

Many rhetoricians and allied scholars have demonstrated that entanglements of humans and technology are often framed as positive, empowering, and beneficial (Jordan, 2004; Clark, 2007; Koerber, 2000). One need not look far to find an example in which life with technology is pitched as better than life without it: A vacuum that cleans the house for you!; Need to lose weight? Wear this watch and see the pounds melt away; For when there's just too much snow to shovel – the Snow blower 3000! Of course these are fictitious gimmicks, but they are no doubt of a familiar flavor. Technologies + human = empowered human.

Recognizing this mainstream discourse regarding technology, rhetoricians of technology have challenged the fundamental affordance of technology, revealing that often constraints materialize once technology is circulated (Clark, 2007; Koerber, 2000; Balsamo, 1996; Toffoletti, 2007). That is, human+technology entanglements are often pitched as liberating and positive, yet when introduced and incorporated into society, often technology actually serves to constrain or control users in particular ways. Koerber compellingly argues, “after technologies are designed, produced, and marketed,” they are “always touted as liberating, but then lose this liberating potential once they become established parts of our lives” (2000, p. 68).

Moreover, Clark recounts Tapscott's 1996 example of the so-called liberation of Wal-Mart workers who receive a handheld device that scans barcodes and are suddenly empowered by faster and more direct access to product information (e.g., history, price, stock, etc.). Perhaps equipping disenfranchised workers with technology is empowering in some regard; however, as Clark notes, it does little to solve the more complex social, economic, and ethical inequalities surrounding often disenfranchised and low-wage workers. As Clark argues, "there is a long history of empowerment narratives associated with the birth of new technologies" but this is a "utopian story" – one that falsely purports the empowerment of human and technology assemblages (2007, p. 157).

In other words, the intra-action of humans, technology, society, space, and time enacts positive experiences; however, over time, these intra-actions shift and negative experiences are made possible. Accordingly if intra-actions of patients and ostomy<sup>5</sup> follow this kairology of technology, ostomy patient enactments should also move from affordance to constraint. The ostomy might first emerge empowering and affording, but once fully integrated into the everyday practices of the wearer, should become constraining.

To explore this further, I navigate my way through a range of divergent experiences, intra-actions, and identities that emerge kairologically for patients with

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<sup>5</sup> I am collapsing a much more complicated intra-action here. All the entities involved in these intra-actions cannot possibly be detailed here. I'd like to also clarify that I refer to the entities "human" and "ostomy" so as to not continually distract my argument by unpacking that such entities are constituted through the intra-actions, not prior to it. As Barad would have it, ostomy and human do not exist prior to intra-acting. Since I'm taking this position at the outset of my analysis, I will often refer to entities by commonplace names as a sort of short hand.

ostomies to pursue the following questions: Do the intra-actions emergent for patients with ostomies follow the already identified kairology of moving from affording to constraining experiences? Does shifting from affordance to constraint enact particular ostomy pouch identities? How might the identity enacted differ in cases where the kairology unfolds differently? In so doing I will 1) look for ways in which the intra-actions of ostomies relate to this already identified kairology of technology and 2) attempt to correlate these kairologies with diverse identity enactments.

In what follows, I begin with a more detailed consideration of Julia. As we will see with Julia and other cases like hers, constraining experiences play a particularly influential role in the identity enacted, but Julia's experiences and identity are not necessarily representative of the experiences and identities of all patients with ostomies. Therefore, I situate Julia's case within the context of other patients with ostomies that both align and conflict with Julia in an effort to identify if there are consistent kairologies correlated with the ostomy pouch identities. I will make the case that constraining and affording experiences are enacted through specific intra-actions with ostomies, and in so doing, I will complicate the current kairology of technology. Finally, I will end by describing the value of kairological tracings of enactments, drawing connections between the findings of this chapter and larger implications for the rhetorical studies.

### **Enacting Constraint**

While Julia and her experiences might have received the most attention and criticism, other such cases have gained traction in the IBD and ostomy communities as well as the mainstream media. What ties these cases together is a common experience in which

wearing an ostomy pouch shifts patient experiences from affordance to constraint, challenging the wearer in negative, unwanted ways. How such experiences emerge in relationship to intra-acting with an ostomy over time is the focus of this section.

First, I explore Julia's case in conjunction with an instance regarding a Cincinnati police lieutenant who used the potential of receiving an ostomy pouch as a scare tactic with high school teens, as well as experiences I noted during my ethnography. The ostomy intra-acts with these patients transforming the embodied, lived experiences of patients' from affordance to constraint. What's more, when the ostomy entangles intra-actively with these patients a particular identity – ostomy pouch wearer – is enacted. And, when this identity is enacted, a particular agential cut is staged between ostomy and self.

### *Julia*

In early 2014, the CDC's on-going Tips from Former Smokers campaign released its latest TV and online commercials, one of which featured Julia, a middle-aged former smoker diagnosed with colorectal cancer due to long-term smoking. Despite developing colorectal cancer and undergoing chemotherapy and several surgeries, Julia devotes the majority of her video to the ostomy pouch she had to "wear for a whole year" as a result of her cancer (Centers for Disease Control, 2015). Taking advantage of a visual opportunity, Julia holds her ostomy pouch up for the camera as she explains, "I had chemo and two surgeries, but what I hated the most was the colostomy bag" (Centers for Disease Control, 2015). In this moment, Julia situates receiving an ostomy pouch as the worst of her experiences with cancer – worse than chemotherapy and two



surgeries.<sup>6</sup> To explain her experience with the ostomy pouch even further, she goes on to say,

You go wherever it goes. You have no control. If it comes loose, it smells. I had no control. I had to wear it for a whole year. I was at home the majority of the time because I was scared that it would come loose and it would smell and I didn't want to be around anyone. I was really kind of like stuck at home (Centers for Disease Control, 2015).

Julia builds on her negative experiences with the ostomy pouch by explaining that she felt like she had “no control” and that she could not leave her house because her pouch might “come loose” and “smell” (Centers for Disease Control, 2015.). Further establishing that the requirement of wearing this technology was the most negative, life-changing result of having cancer, Julia holds her ostomy pouch as far away from her body as possible, extending her arm fully toward the camera (see Figure 3).



Figure 3. Julia in one of her Tips from Former Smokers video.

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<sup>6</sup> Importantly, Julia's ostomy pouch was temporary, as evidenced by her use of the past tense when describing her experiences. That is, after about a year, Julia was able to have what's called a "takedown" surgery, in which her ostomy pouch is replaced by an internal re-routing of her intestines, such that the ostomy pouch is no longer needed.

Even more compelling, Julia's "tip" for smokers is not to quit smoking because it can cause cancer; instead, she warns, "my tip is to get over being squeamish. You're going to be emptying your bag six times a day" (Centers for Disease Control, 2015). When Julia suggests to "get over being squeamish" and explains, "you have no control" and that she was "stuck at home," she focuses on the ways in which her everyday experience of wearing her ostomy pouch limited her. Implied here is that in Julia's life prior to receiving her ostomy, she had control and she was not stuck at home. Intra-actions with Julia's ostomy shifted her life from positive to negative, from affording experiences to constraining ones. These intra-active experiences then result in a distinct division between Julia and the ostomy. Her ostomy is agentially cut from her self through the kairological transformation from affordance to constraint.

*Cincinnati Police Lieutenant*

Not long before the release of Julia's video, in 2013, a Cincinnati, Ohio, police lieutenant spoke with at-risk teens as part of a larger effort to decrease the city's gun violence and youth gang participation. As a means to persuade and likely shock these high school students, the lieutenant described the following scene during his presentation: "You're not killed, but you're walking around with a colostomy bag<sup>7</sup> and that's just not the way to get a girl's attention, by limping down Warsaw Avenue with a colostomy bag" (Warren, 2013). Though it's unclear what ostomy pouches have to do with limping, the lieutenant urges his audience to perceive the risk of needing an ostomy pouch as more

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<sup>7</sup> A colostomy bag is a specific type of ostomy pouch, used when all or part of the colon is removed.

persuasive and frightening than participating in gun violence by presenting particular constraining ostomy-wearing experiences.

Moreover, these comments exclusively position the ostomy pouch as a consequence of such gun violence, ignoring the far more common medically necessary reasons for needing an ostomy pouch. To be fair, a gunshot wound to the abdomen could necessitate an ostomy, but of the many consequences of participating in gun violence, needing an ostomy pouch is far less likely than other results (e.g., injury, jail, homicide). It remains unclear if the lieutenant had first-hand experience wearing an ostomy pouch; however, based on public comments made regarding his presentation to the students, he was only speculating how having to wear an ostomy pouch could affect these teens.

Regardless of the lieutenant's personal intra-actions with an ostomy, this case both exemplifies and is contingent upon a broader public stigma surrounding ostomy pouches.<sup>8</sup> Because the generalized public perception regarding ostomy pouches is negative, it likely seemed appropriate and compelling for the lieutenant to use wearing this technology as a means of persuasion vis-à-vis fear. Overall, the police lieutenant suggests the lived experiences entangled with an ostomy will transform the lives of his audience negatively enough that his audience should avoid practices that might risk needing an ostomy.<sup>9</sup>

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<sup>8</sup> Scholarship on ostomy stigma and the psychosocial implications of undergoing ostomy surgery is expansive. See, for example, Smith, et al., 2007; Danielsen, et al., 2013; and McLeod, et al., 1986.

<sup>9</sup> Of course, I do not mean to downplay the seriousness or the admirable intentions of either Julia or the police lieutenant. I do not wish to argue that a correlation between long-term health consequences and gun violence is not a serious concern nor that Julia did not suffer or struggle with colorectal cancer; the details of her personal health journey are unknown.

### *Wearing an Ostomy Pouch*

The everyday practices and embodied experiences of both Julia and the police lieutenant suggest constraint and decreased ability as a result of intra-acting with an ostomy. In order for Julia's and the lieutenant's comments to resonate specific intra-actions had to occur in a specific unfolding. The constraints experienced by Julia and threatened by the police lieutenant rely on previous affordances. Life without or prior to an ostomy is experienced (or hypothetically experienced) as more affording than life with the technology. Importantly too, the sites in which these intra-actions are staged are consequential. That is, both Julia/CDC and the police lieutenant speak from positions of authority and credibility, therefore, an audience unfamiliar with ostomy pouches would likely be more inclined to accept the experiences enacted by Julia and the lieutenant as accurate and demonstrative of the norm.

Despite the unlikelihood of gun wound-related ostomy pouches, the ostomy pouch experience presented by the lieutenant was contingent upon his audience – high school students – and their knowledge and understanding (or lack thereof) of an ostomy. That is, the lieutenant's comments make sense in a specific medico-cultural milieu, one that readily accepts wearing an ostomy pouch as negative and undesirable. The lieutenant's matter-of-fact way in describing experiences with these technologies suggests a correlation between gun violence and ostomy pouches is obvious, and according to the lieutenant more horrible than death or paralysis, even though, receiving an ostomy pouch post-gunshot wound could very well save the life of that victim. I make note of this here because I would argue in both cases that neither the lieutenant nor the CDC were working from ill intent. In each case, the implications of

presenting these negative experiences of wearing an ostomy pouch becomes subservient to a larger goal, be it anti-smoking or anti-gun violence. In so doing, the ostomy pouch is staged as a persuasive tool that represents the negative, disabling consequences of other risky behavior, and wearing an ostomy pouch is far worse than any potential non-ostomy experiences.

Even more, in my ethnographic work, several interview participants reported similar experiences with their ostomies. One interviewee admitted, "I can't wear the clothes I want to...I can't be a normal 22 year old. I can't go to the bar or club or take dance classes. My friends want to hang out, but I can't go to parties with them." Here, my interview participant focused on a series of experiences she could not participate in due to her ostomy pouch for a variety of reasons. She suggested that the anxiety of having an ostomy pouch in addition to the difficulty of concealing it under her clothes and finding the energy to leave her apartment all lead to this series of activities she longed to engage in but felt she couldn't. Additionally, during my ethnographic observations, I noticed several instances in which women who would soon have surgery that would result in no longer needing the ostomy pouch celebrated the "death" of their ostomy pouches by writing sort of jovial obituary-like statement like "RIP" or "You will not be forgotten or missed" directly onto the ostomy pouch. These sort of symbolic goodbyes to ostomy pouches suggest that the ostomy was not considered part of the wearer and therefore could "die" a separate "death." Even more, celebrating that death or separation for the ostomy suggests that the experiences associated with a non-ostomy life are preferred.

*Becoming an Ostomy Pouch Wearer*

Following the same kairological trajectory as that described by Clark and others, these intra-actions with the ostomy pouch shift the everyday experiences for these wearers from affordance to constraint, resulting in specific identity enactments. Taken together, these wearers' embodied experiences stage an identity of ostomy pouch wearers. By that I mean that for people like Julia, the intra-active entanglement of the ostomy pouch, the wearer's knowledge and experiences, and even societal perception, enacts an identity in which the focus lies in the act of having to wear this technology – being limited or constrained by what wearing the technology entails. Ostomy pouch wearers subsequently enact specific boundary-making practices in which an agential cut between ostomy and wearer is maintained.

For Julia, because her everyday experiences seem to move from those that are more positive (life without an ostomy) to her negative experience of wearing an ostomy pouch, a boundary is enacted between herself and the technology, resulting in an identity in which a separation between herself and the ostomy pouch is maintained. Distancing herself from the technology, Julia calls her ostomy pouch “it” several times, and even holds the ostomy pouch away from her body with full arm extension, signifying the separation of her able body from the constraining technology. Such a separation is intra-actively staged and makes possible an identity in which the ostomy pouch is not only different, even foreign, to the wearer, but also restricts (often negatively) the wearer's physical and mental state. Julia, her experiences, the CDC, anti-smoking efforts, and her audiences intra-act to agentially separate the ostomy from her self.

These experiences were undoubtedly persuasive for certain audiences and perhaps Julia's video and the lieutenant's comments were successful in decreasing smoking and gun violence. However, that is not to say that audiences of these enactments were exclusively smokers and at-risk teens. The experience of constraint highlighted by Julia and the lieutenant becomes problematic precisely because their audiences included a more general public. The embodied experiences, intra-actions, and identities enacted with Julia and others like her "have a quality of truth" in certain contexts, but when circulated with broader audiences including the larger IBD and ostomy communities tension emerges regarding what enactments are most representative of common ostomy intra-actions and identities (Segal, p. 23).

Despite the compelling experiences presented in the cases of Julia and the police lieutenant, reactions to their cases suggests that alternative intra-actions and enacted identities are both possible and rhetorically influential. In the next section, I aim to explore these reactions as well as conflicting experiences and identities staged in the contexts of *OstomyLife* and *Gutless and Glamorous*. As the analysis will demonstrate, it is not that perspectives of people like Julia are different from the cases I'm about to describe. Rather, the kairological unfolding of the everyday lived experiences follow a different trajectory, which, in turn results the enactment of in different identity and bodily boundaries.

### **Enacting Affordances**

In the previous section I discussed the kairology of affordance to constraint; that is, how for some patients intra-acting with the ostomy transforms their embodied experiences from positive, acceptable, or desirable to negative or constraining experiences. Such a

transformation results then, in an enactment of an ostomy pouch wearer identity in which an agential cut is staged between ostomy and self. However, as alluded to through this chapter, this kairology is not consistent with the experiences of all patients with ostomies. In fact, the backlash that both Julia and the police lieutenant received indicate drastically different experiences with ostomies that many in the community share. The kairology of affordance to constraint is clearly a common one for ostomy pouch wearers, however, it is certainly not representative of a universal ostomy experience.

Consequently, in this section I will explore an inverted kairology, one that shifts from constraint to affordance, enacting entirely different identity and bodily boundaries. For many with ostomies, life prior to ostomy surgery is burdened by constraining experiences like long hospitalizations, debilitating symptoms, and frequent surgeries, medical tests, and appointments. Receiving an ostomy often enables patients to move beyond these constraining experiences, affording opportunities that without the ostomy were not possible. To explore these alternative experiences further, I will first outline responses to Julia and the police lieutenant and then explore several additional cases align with this alternative kairology. In doing so, I aim to illustrate not only that an alternative kairology is possible through different intra-actions, but also that this kairology of constraint to affordance enacts an entirely different identity – the ostomate – in which patients come to self-identify through their ostomy.

*Response to the CDC and Cincinnati Police Lieutenant*

In response to the CDC's campaign, thousands of IBD patients, ostomy wearers, and allies rallied in an effort that resulted in the CDC's temporary removal and ultimate



revision of Julia's video. While the updated video maintains Julia's negative experience, comments describing the ostomy pouch as "gross" and technologies that "smell" have since been removed. A petition to take down the video, which garnered over 10,000 signatures, explains, 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 those lifesaving surgeries" (Rund, 2015). Further, the petition argued, 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). These comments provide valuable insight regarding the strong pushback against Julia's video. Those who spoke out against the video did not reject Julia's experience outright or argue that the constraints of wearing an ostomy pouch do not exist. Instead, the focus of much of the resistance to Julia was that wearing an ostomy pouch was being positioned solely as negative – gross and constraining – ignoring that for many, wearing an ostomy pouch enables a life that would otherwise be impossible due to the disease or condition that preceded the ostomy.

Responses to the Cincinnati police lieutenant note similar concerns. A local news station quoted one Cincinnati citizen with IBD:

When this went out publicly it presented an image of a colostomy bag as unattractive, disgusting, and related to gangs. It 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).

This commenter notes that the lieutenant's comments are particularly persuasive and concerning because they reached an audience of "those who have never heard about a colostomy" (Warren, 2013). Those with previous experience or knowledge of ostomy

pouches may have been more critical of the lieutenant's comments, or at the very least, may have had broader medico-cultural context within which to situate the comments. However, for those who have no previous knowledge of these technologies, the sole experience associated with these technologies would be that of negativity and constraint. These responses highlight the variability across the intra-actions of patients like Julia and others within the ostomy community. While Julia felt her ostomy constrained her, those who publically responded to this enactment of life with an ostomy revealed that their experiences moved in the opposite direction. Intra-acting with an ostomy afforded experiences that were otherwise constrained without an ostomy.

Relatedly, many advocacy organizations, outreach and support groups, social media campaigns, and blogs exist that are doing the very work of trying to overcome the stigma associated with IBD and ostomies that is frequently cited in the responses to Julia and the police lieutenant. I'd like to explore two such efforts here: Gutless and Glamorous and OstomyLife. These two are both campaigns actively opposing the mainstream negativity and stigma tied to IBD and ostomies through blog posts, social media efforts, and visual displays of their ostomies. Common across Gutless and Glamorous and OstomyLife is the message that ostomies save lives and afford their wearers with the ability to engage in otherwise impossible experiences. A brief description of these efforts follows.

#### *Gutless and Glamorous*

Founded by IBD patient and ostomy pouch wearer Gaylyn Henderson, Gutless and Glamorous is both an online advocacy organization and social media campaign that

circulates with the hashtag #GutlessandGlamorous. After struggling for years with a “never ending cycle” living with IBD and undergoing “multiple hospitalizations, multiple surgeries, multiple procedures, and millions of doctor visits,” Henderson founded Gutless and Glamorous to “provide support, education, and awareness” and “to erase the stigmas and misconceptions” regarding both IBD and ostomy pouches (Henderson, n.d.). Unlike Julia and the Cincinnati police lieutenant, Gutless and Glamorous celebrates wearing an ostomy pouch and the organization’s website features several pictures of Henderson in which she reveals her ostomy pouch.



Figure 2. Gutless and Glamorous founder, Gaylyn Henderson displaying her ostomy pouch. This image is featured on the landing page for Gutless and Glamorous.

The landing page for Gutless and Glamorous includes the following quote in large, bold letters:

**My body tried to kill me. Yet I survived. But it left behind a constant reminder that I must look at daily. I know what it’s like to see your reflection in the mirror**

and feel unattractive. I used to be disgusted. But then I realized that anything that has the power to save a life can be nothing but beautiful (Henderson, n.d.).

Here, Henderson not only recounts how, before her receiving her ostomy, her body “tried to kill [her]” but she also draws attention to the fact that she initially felt “unattractive” and “disgusted,” much like Julia did. The difference between Julia and Henderson, though, is that over time and her everyday practices with her ostomy, Henderson has grown to “realize” that her ostomy’s “power to save [her] life can be nothing but beautiful.” It is not that Henderson never experienced wearing her ostomy pouch as negative or inhibiting; instead, as she explains, through her everyday experiences with technology, its critical affordance became clear: the ostomy saved her life. Overall, intra-acting with the ostomy affords many experiences that would otherwise have been impossible for Henderson. As she recounts, multiple hospitalizations, surgeries, procedures, and doctor visits constrained her prior to her ostomy surgery, but as her ostomy was integrated into her life, her experiences shift from constrained to empowered.

#### *OstomyLife*

Much like Gutless and Glamorous, Laura Cox, an “Ostomy Lifestyle Specialist” who contributes to an online community called “Ostomy Life” uses her online platform to explore how her life has improved since receiving her ostomy. I’d like to focus on a specific post from Cox, entitled “10 Things I’ve Done Since Having Ostomy Surgery.” In this piece, Cox shares her “short-list” of the things she has “accomplished and experienced” so that readers realize they “can do anything with an ostomy!” (Cox,

2016). Among the things on the list, Cox includes traveling abroad, graduating college, running competitively, and backpacking the Canadian Rockies.

She explains that prior to her ostomy surgery, she “gave up” running, an “activity [she] loved” due to her Ulcerative Colitis diagnosis.<sup>10</sup> But after receiving her ostomy she “realized she was in the best shape of [her] life, even with an ostomy” which enabled her to finish a half-marathon and three different obstacle course races. In addition to being able to return to running post-ostomy surgery, Cox also graduated college, an accomplishment she did not think was possible prior to receiving her ostomy. She recounts,

There were many hospitalizations during my semesters, a few medical withdrawals from classes and countless tears. I remember my college boyfriend pulling me on his longboard to class for two months because it hurt so much to walk.

However, due to the health that she regained after her ostomy surgery, she was able to finish the necessary requirements and graduate cum laude.

Adding to the list of things her ostomy “has allowed [her] to accomplish,” Cox includes “carry[ing] out normal life/work/exercise/social schedule” and “go[ing] to professional sports games and concerts” even though she admits these might seem like “small” accomplishments. For her, though, “compared to [her] life before getting ostomy surgery” these are “huge” even in comparison to being able to go on extended backpacking trips. Regarding such trips, she adds that her ostomy is actually beneficial for going to the bathroom in the woods, so she considers her ostomy an “advantage.”

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<sup>10</sup> Ulcerative Colitis is one of the most common diseases categorized under the umbrella of Inflammatory Bowel Diseases.

All of these accomplishments considered, Cox summarizes that her “ostomy has allowed [her] to live the life [she’s] always wanted to live.” Throughout this post, Cox draws contrast between her previous life without an ostomy and the life she feels she is now able to live. Without her ostomy, she explains that her Ulcerative Colitis inhibited her from participating in many of the activities she so enthusiastically accomplishes and writes about now. Like Henderson and the other members of the IBD and ostomy communities who responded to Julia and the police Lieutenant, Cox’s experiences shift from negative, undesirable ones prior to her ostomy surgery to empowered, positive experiences with her ostomy. As, Cox emphasized, her disease prior to ostomy surgery was so severe that she had to “give up” many of her favorite activities. But receiving her ostomy pouch alleviated her of those devastating symptoms and enabled her to return to many of the activities she thought had become a part of her past. Transitioning from negative life experiences to positive life experiences through the addition of her ostomy enables the ostomy to become fully integrated into Cox.

#### *Integrating the Ostomy*

The positive, life-saving experience of wearing an ostomy pouch has publically emerged largely in an effort to draw contrast and provide an alternative to the constraining experiences presented through figures like Julia or the Cincinnati lieutenant. Many IBD patients, including Gutless and Glamorous’s Henderson and OstomyLife’s Cox, battle chronic disease and suffer for extensive lengths of time before receiving their ostomy, therefore, when they receive their ostomies, which enable them to experience life beyond hospital stays, doctor visits, painful symptoms, and surgeries,

their embodied experiences are transformed from constraining to empowered. Indeed, ostomy surgery and receiving an ostomy pouch often saves the lives of patients.

This is not to say that wearing an ostomy pouch is free of challenges for these patients, but instead, that often ostomy pouches relieve them of crippling symptoms and other unwanted everyday experiences, allowing those patients to return to activities that were not possible prior to ostomy surgery. Intra-acting with an ostomy pouch for people like Henderson and Cox becomes life-saving and enables a quality of life that was impossible prior to receiving the ostomy pouch. The negative experiences leading up to ostomy surgery are worse for these patients than the challenges presented by wearing an ostomy pouch; therefore, their ostomy pouch wearing experience shifts from constraint to affordance through the intra-activity staged through wearing an ostomy.

Moreover, the responses to Julia and to the lieutenant's comments highlighted here are reflective of a larger, community-wide sentiment that experiences with ostomy pouches are life-saving and empowering. The UOAA argues ostomy surgery "enables a person to enjoy a full range of activities, including traveling, sports, family life and work, even though they have a stoma, and may wear a pouching system" (United Ostomy Association, 2011). The president of the UOAA explains, "People consider it [ostomy surgery] disfiguring and gross. Ostomies, like mastectomies, save lives, period. Unfortunately, all people can focus on is crapping in a pouch" (Yakich, 2013). It seems reconfiguring the portrayal of and perceptions regarding ostomy pouches and overcoming the experience put forth by more powerful institutions and people is a

difficult and complicated task. The material realities of “crapping in a pouch” are undoubtedly challenging for wearers and are accompanied by unfortunate and deeply embedded cultural stigmas. Despite these challenges, however, campaigns and organizations like Gutless and Glamorous and OstomyLife continue to gain popularity.

Much like Julia and the lieutenant’s experiences, the successes of Cox and Henderson are contingent upon their audiences. Unlike the experiences enacted by Julia and others that focus on constraint, the primary intended audiences for OstomyLife and Gutless and Glamorous are those who have IBD, already wear ostomy pouches, and/or are allies to those communities. Therefore, these audiences are likely already aware of the constraints of wearing this technology and are perhaps seeking a space or organization in which wearing an ostomy is accepted and even embraced. The ostomy-positive focus of Gutless and Glamorous and OstomyLife fits the given medico-cultural moment precisely because it provides an alternative experience of ostomy pouch wearing. Instead of further participating in a culture of stigma, Gutless and Glamorous and OstomyLife “aptly meet” the “conditions of time, place, and audience” by offering ostomy pouch wearers, and society more generally, a new sense of what it is and can be like to wear an ostomy pouch (Segal, 2005, p. 22). Further, the experience of wearing enacted in these cases is most persuasive in contrast to constraint experiences for an audience of ostomy pouch wearers who 1) are open to or already consider wearing their ostomy pouch as a positive experience and 2) have long-term or permanent ostomy pouches.



Perhaps most importantly, this group of ostomy pouch wearers often self-identifies differently than ostomy pouch wearers like Julia. When these experiences and perspectives intra-act with a positive and/or permanent experiences with the ostomy, often the resulting identity enactment is not an ostomy pouch wearer, but instead the ostomate, a way of self-identifying through the technology that suggests its full integration into notions of self. In order for the ostomate identity to be enacted, agential cuts surrounding self must include the ostomy. The ostomy becomes self through the kairology of constraint to affordance and enables this ostomate identity.

#### *Becoming an Ostomate*

The particular embodied intra-activity of moving from constraining to affording experiences stages agential cuts in which boundaries between self and ostomy are dissolved, enacting the an ostomate identity. Consequently, patients become ostomates. As one blogger described, "I am an ostomate...removing my colon has saved me much pain and misery...it is a legitimate lifesaver" ("An Open Letter," 2015). In my ethnography as well, I identified several instances in which those wearing ostomy pouches explicitly shift from "ostomy pouch wearers" to self-identified "ostomates." For these wearers, the ostomy pouch saves lives and empowers wearers to live, as they describe it, "normally."

Indeed, many of the IBD patients whom I spoke with throughout this project suggested that embodied practices with their ostomy enabled them to integrate their ostomy as part of themselves. One interviewee told me, "Getting my ostomy was the best decision I ever made for me. I'm not trapped in the bathroom anymore. I can live my life." Even more, another interviewee said, "I definitely consider myself an ostomate

and I let my [ostomy] bag hang out.” She further shared her pride in her ostomy when she explained, “I’m not ashamed if people see it under my clothes. It keeps me alive – why would I want to hide that?” This participant’s desire to share her identity as an ostomate, or at the very least not hide it, uncovers important insight: as the ostomy pouch is integrated into her identity, she finds confidence and pride in her ostomy.

The ostomate identity enacted here aligns in informative ways with Dolmage’s insight regarding disability and identity. Dolmage argues “almost all disability labels work through synecdoche, urging us to see the disabled person as their broken ‘part’” (p. 102). Here, Dolmage refers to the labels through which mainstream society tends to categorize differently abled bodies. For ostomates, this undoubtedly rings true. However, ostomates themselves urge mainstream society to focus on their “broken part” by identifying with their technological augmentation. Enacting an ostomate identity “urges” others to see these patients as inseparable from their ostomy.

This identity is characterized by intra-activity with the ostomy pouch in which it is not separated from the wearer, with an emphasis on the life-saving function of the ostomy, and a desire to make visible their “ostomateness.” Their ostomy pouches are an integrated, important, and positive part of themselves. This self-describing practice also builds community and expresses pride that would be less explicit otherwise. Such acceptance of wearing the technology is conducive to ostomy-positive experiences and is made possible through the embodied intra-action in which the ostomy pouch saves, relieves, or enables the wearer. As such, the agential separation between self and

ostomy enacted with ostomy pouch wearers is not enacted here. Instead, the boundary-making enacted with ostomates encompasses the ostomy into self.

### **Ostomy Kairologies: Affordance and Constraint**

The analysis presented here examines kairological shifts on the intra-active level. By that I mean, this analysis works to understand how various lived experiences stage intra-actions in which particular boundaries and subsequent identities are established. On one hand, the experiences enacted with Julia and the Cincinnati lieutenant suggest that when lived experience prior to an ostomy is more positive than that of after receiving an ostomy, the resulting intra-action and boundary making practices separate self from ostomy. When a patient is engaged in an affordance to constraint kairology, an enactment of the ostomy pouch wearer identity becomes possible. On the other hand, the experiences enacted with women like Henderson and Cox indicate that when the lived experiences prior to receiving an ostomy are negative, challenging, or constraining, often results in experiences with the ostomy in which intra-actions stage an ostomate identity, dissolving the separation between self and technology. When a patient is engaged in a constraint to affordances kairology, the enactment of an ostomate identity becomes possible. Investigating the kairological conditions within which these various enactments emerged and how they relate to one another highlights the importance of taking into account both space and time in an enactment analysis, as well as the importance of audience – who hears or see these enactments and how they participate in the enactments and intra-actions in rhetorically powerful ways.

What this kairology also shows is that the ostomy pouch itself becomes neither empowering nor constraining, but rather affordance and constraint emerge from intra-

actions among the technology, its wearer, previous experiences and perceptions, society, stigma, symptoms, medical history, engagement with advocacy campaigns, and more, that occur in specific moments and spaces. Paying particular attention to when, how, and why these enactments emerge. This point is especially relevant because it sheds insight on current rhetoric of technology scholarship that suggests a particularly kairology or trajectory for engagement with technology. In fact, the analysis provided in this chapter actually challenges what has been considered the general kairology for technology: shifts from affordance to constraint as technology is introduced and entangled with humans, society, discourse, etc. While affordance to constraint is certainly common within the ostomy community, it is not the only kairology that is possible and it is certainly not the only kairology that can be rhetorically influential.

A comprehensive kairology of ostomy pouch wearing complicates enactments even further. As my analysis demonstrates, broader public conversations regarding ostomy pouches often positions them as negative and constraining, yet many ostomy pouch wearers are working against that enactment to show that wearing an ostomy pouch actually enables and empowers those who wear them – as evidenced by Gutless and Glamorous and other “ostomy-positive” campaigns and advocacy organizations including Get Your Belly Out, “World Ostomy Day,” OstomyLife, and Uncover Ostomy, to name a few. This enactment analysis suggests that simply equipping a patient with an ostomy pouch does not grant that patient with the agency or ability to decide whether or not the experience is positive or negative, nor whether or not that patient will be a wearer or ostomate. Instead, through patients’ everyday practices and

the intra-actions that are staged through such practices, a range of boundaries regarding identity, body, and self become enacted.

In other words, it is neither accurate to suggest that intra-actions between humans and technology<sup>11</sup> result in increased agency or control, as Clark demonstrates with the case of the Walmart price-check gun or as often theorized through the notion of the supercrip; nor, is it accurate to suggest that human and technological intra-actions automatically constrain agency or leave it unchanged, as might be the case with Julia. Instead the potential for both of these to occur is made possible through the diverse intra-actions staged within the everyday lived experiences enacted with Julia, the police lieutenant, or Gutless and Glamorous and OstomyLife. And, in none of these cases is the experience or identity enacted a matter of personal perspective, attitude, or ability.

As I continually emphasize, the rhetorical work in each of these cases is that of enactments of self, non-self, ostomy wearer, ostomate, or otherwise. Focusing that the practices or experiences that are enacted or done “suggests that activities take place but leaves the actors vague” (Mol, 2002, p. 33). No individual entity is the actor in these cases, despite my focus on particular figures like Julia or Henderson. I simply focus on the human as part of my methodological effort to treat these humans as ethnographers of their own lives, reporting on the events and practices in which they participate and in which intra-actions are staged and boundaries are done (Mol, 2002, p. 15). I should also

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11 Importantly, Barad would strictly resist describing intra-actions in such a way as she argues that “humans” and “technology” or any such entities do not exist outside of their intra-actions. However, for the sake of expediency and simplicity here, I am making discursive choices so as to not muddy this particular line of thinking.

note, although examining such cases enables me to categorize them into larger identity groups like ostomy pouch wearer and ostomate, it is not that these identities are static. Intra-actions shift, no doubt, in space and time, based on the everyday practices involved.

Finally, a kairology of ostomy pouches is more than a chronological tracing of the technology; it is a tracing of experiences and intra-actions as they emerge in opportune moments. Investigating the relationship between wearer and worn reveals the entanglements of bodies, identities, discourse, technology, society, medicine, and culture that make a given narrative of ostomy pouch wearing possible and persuasive within a given medico-cultural moment.<sup>12</sup> Analyzing these cases as they emerged kairologically helps to account for the differences in that are enacted through divergent intra-actions in experiences vis-à-vis discourse and object formations.

What's more, a kairological approach reveals the intricate ways in which particular identities develop through these multifaceted relationships between wearers and worn. With ostomy pouches, divergent embodied experiences stage at least two identities: ostomy pouch wearer and ostomate. This kairology highlights not only that divergent identities exist within the ostomy community but also helps to expose how these identities develop and maintain over time. To focus exclusively on certain technologies or to rely solely on synchronic analyses of technology limits the depth of

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<sup>12</sup> To be clear, it is neither my intention nor within the scope of this essay to trace the entire rhetorical history of ostomy pouches. Instead, I am focused on exploring the embodied experience of wearing an ostomy pouch via several individual accounts of wearing to more fully understand how and why such divergent narratives exist.

what a rhetoric of wearability need include. Instead, examining the conditions that made Julia's case compelling to some but deplorable to others, or those conditions that make Gutless and Glamorous a successful organization, provides rich insight into how ostomy pouches are worn over time, resulting in experiences in which one wearer's life is debilitated while another's is saved. Undoubtedly, a kairological approach has much to offer rhetoricians and allied scholars interested in exploring the larger contexts in which technologies play a role.

What remains uncertain, however, is the status of an ostomy when these divergent experiences and identities are enacted. I made the case that for ostomates, the ostomy becomes part of self, while for ostomy-pouch wearers, it does not. However, the findings of this chapter about ostomy-related identities prompt several additional questions regarding the role and status of the ostomy: Does the ostomy remain an ontological cohesive entity in these intra-actions and enactments? Is it possible for the ostomy to ontologically diverse? If so, what would that mean for a theory of (rhetorical) enactments, and more importantly, for patients as they engage with these technologies in their everyday lives? Taking up these questions, the next chapter draws Mol's theory of multiple ontologies to more thoroughly explore the intra-actions behind diverse identities highlighted in this chapter. Foregrounding my analysis in notion that ontologies are not static, but instead enacted in practice, Chapter Four contends that the ostomy, across these diverse identities, becomes ontologically multiple.

## CHAPTER 4: THE OSTOMY MULTIPLE

In practice a disease, atherosclerosis, is no longer one. Followed while being enacted atherosclerosis multiples—for practices are many. But the ontology that comes with equating what is with what is done is not of a pluralist kind. The manyfoldedness of objects enacted does not imply their fragmentation. Although atherosclerosis in the hospital comes in different versions, these somehow hang together. A single patient tends to be supplied, if not with a single disease, then at least with a single treatment decision. Clinical findings, pressure measurement, social inquiries, duplex outcomes, and angiographic images are all brought together in the patient's file. Together they support the conclusion to treat invasively—or not to do so. This, then, is what I would like to term multiple to convey: that there is manyfoldedness, but not pluralism. In the hospital the body (singular) is multiple (many)—Annermarie Mol, *The Body Multiple*

Questions about the material nature of discursive practices seem to hang in the air like the persistent smile of the Cheshire cat—Karen Barad, *Meeting the Universe Halfway*

Examining cases ranging from Julia to Gutless and Glamorous in the last chapter demonstrated that enactments of particular bodily divisions are, at least in the case of IBD and ostomies, highly entangled with identity. For patients, like Julia, the addition of the ostomy shifts life experiences and everyday practices in negative, constraining ways, which results in the continued separation between self and ostomy. In contrast, for patients with similar experiences to those of Gutless and Glamorous, the life prior to receiving an ostomy was hospital-ridden, painful, and even verging upon death, therefore, receiving the ostomy is transformative such that patients entangle with their ostomy and learn to see themselves with and through their new “colon” so-to-speak. Such cases show the range of patient identities enacted through everyday practices and experiences and the important role *kairos* plays in enactments.

Chapter Three's analysis is telling of the types of identity and bodily boundaries that are possible and common within this community, but falls short in fully exploring just how those enactments come to be. That is, how are specific intra-actions and agential cuts, particularly around the self, enacted in those identities? It's clear that



divisions relating to self actively influence which identity is enacted, but not exactly how different notions of self are possible. Based on the cases presented in both Chapters Two and Three, the ontological stability of self remains unclear – is it possible for multiple “selves” to be enacted? Taking up these questions, this chapter will address the self in its diverse becomings for patients. To do so, I will first return to the work of Barad, Graham, and Mol to clarify the methodological position necessary for this work. Then, using a series of divergent object formations of self and ostomy, I will outline four emergent ontologies of the self, making particular note of the way in which these ontologies are enacted toward rhetorical ends and what that might mean for future rhetorical inquiry.

### **Ontological Flattening**

Driving this chapter is one important stipulation: I will not make a priori distinctions between the entities at work in a given enactment, that is, no assumed divisions between words and things, humans and nonhumans, selves and non-selves. Instead, the goal of this chapter is to examine a series of conflicting object formations in order to understand how different separations or agential cuts are made. To explain this point more thoroughly, I must return to my calibration of Barad, Graham, and Mol.

Barad’s theory of intra-activity and agential cuts is contingent upon a chaotic, messy, and highly active sense of the world. As she explains:

The world is a dynamic process of intra-activity and materialization in the enactment of determinate casual structures with determinate boundaries, properties, meanings, and patterns of marks on bodies...through which part of the world makes itself differentially intelligible to another part of the world and through which causal structures are stabilized and destabilized” (2007, p. 140)

In other words, the “stuff” of which the world is made comes into being through relationships with one another. Often, at the outset of an inquiry, categories are taken for granted. The stuff of the world is neatly, often unconsciously, boxed into self, non-self, human, nonhuman, mind, body, etc., While such boxes undoubtedly bring efficiency to an analysis by relying on categories that have been calcified through centuries of inquiry, they do little in cases where those entities shift and transform, taking on new borders in different enactments. When the self of Julia is done differently than the self of Gutless and Glamorous, how do we understand self? Can these different selves share an ontology? Can these selves be the same?

Taking Barad seriously here, my analysis takes as its foundation that there is no ontological difference until this stuff of the world – “phenomena” – intra-act to enact “agential separability” (p. 140). Entities co-articulate with one another through space and time and in so doing enact agential cuts – divisions that separate and differentiate entities within and from each other. As Barad puts it,

The world is not populated with things that are more or less the same from one another. Relations do not follow *relata*, but the other way around...Mattering is differentiating, and which differences come to matter, matter in the iterative production of different differences” (pp. 136-7).

In this difficult web of words, Barad offers two points. First, matter, in its noun form, comes into being through relationships with other matter (including linguistic/discursive matter). Secondly, what comes to matter – have meaning and significance – is also done through these entangled relationships. These two points together suggest that boundaries are enacted through entanglement of entities (intra-actions) and these entanglements bring meaning to the divisions enacted (agential cuts).

Importantly, Barad is not alone in suggesting that ontological boundaries are done through practice and distinctions among the entities involved can only be layered on after the fact. Both Mol's theory of multiple ontologies and Graham's rhetorical-ontological too rely on this ontological flattening. According to Mol "ontology is not given in the order of things, but instead, ontologies are brought into being, sustained, and allowed to wither away in common, day-to-day sociomaterial practices (2002, p. 6). Building on this conception of ontologies, Graham further argues "differently situated material activities...produce different objects" (2015, p. 31). To summarize, when entities intra-act, ontologies are "brought into being" and through this being "different objects" are produced.

Undoubtedly, this raises challenging questions for rhetorical work. If ontologies are done in sociomaterial practices, what, then, is the role of language? If not through language, how do certain enactments become rhetorical? In much scholarship, language is often treated as that which represents underlying ontologies, and practices often are "reduced to talk" (Graham, p. 8). As rhetoricians well know focusing on "talk" is not simple feat, but in terms of ontological inquiry, the effect of reducing practice to talk is representationalism. Illuminating this relationship between ontological difference and representationalism, Barad contends,

Representationalism is the belief in the ontological distinction between representations and that which they purport to represent; in particular, that which is represented is held to be independent of all practices of representing. That is, there are assumed to be two distinct and independent kinds of entities—representations and entities to be represented. (2007, p. 46)

Under the postmodern rubric, words do the representing. Words are the spear by which the world is cut up and access to ontologies is accessed. As a consequence, inquiry and theorizing becomes “a spectator sport of matching linguistic representations to preexisting things” (Barad, 2007, p. 54). The focus falls on linguistic practices, eliding other entities that might participate in creating divisions and boundaries in the world. In fact, the need to examine intra-actions and agential cuts is lost because language becomes the only practice through which we can know objects. The very idea of representation purports the idea that “words” are separate from the “things” that they represent. In this sense words serve a mediating role, not an intra-active one.

Therefore, under the ontologically flattened framework I’m taking in this chapter, how I attend to words within enactments becomes a tricky task. As a rhetorician, I, of course, recognize the power and influence of language. However, attending to language without slipping into representationalism is key in operating under an ontologically flattened methodology. As Graham notes “rhetorical analysis traditionally comes with an attendant focus on language and representation” (2015, p. 81). I am attempting to account for the role of language in intra-actions by treating language as part of intra-actions through which agential cuts are made. Further, in bridging this gap between a representationalist understanding of ontologies and a more new materialist approach in which ontological differences are not given in the world, Graham’s rhetorical-ontological inquiry is particularly insightful.

As mentioned in Chapter Two, Graham makes the argument that “language is doing. It has impacts and consequences – social, political, material” (2015, p. 84).

Making this shift to treat language as one of the practices through which ontologies are staged helps Graham to sidestep manifest issues with representationalism. In this sense, words do not represent, words enact, words participate in intra-actions. Indeed, if language is doing, then, a study of these practices

focuses not so much on what people say or what texts mean but rather on how representational activity circulates and contributes to a deeper ecology of practices in which those acts of representation are embedded (p. 69).

This means that language can and often does play a vital role in the intra-actions and agential cuts that stage ontologies. If, at the outset, language is not “presumed to serve a mediating function between independent existing realities” but instead, we focus on “the practices and performances of representing” like both Graham and Barad suggest, we can both account for the role language plays in intra-actions without assuming inherent ontological and representational distinctions (Barad, 2007, pp. 47 & 49). With an attunement to the role of language in intra-actions, I can investigate the intra-actions in which language plays a powerful role, particularly in the agential cuts that are enacted. Indeed, words come into being through intra-actions, as much as they participate in the agential cuts made through those intra-actions.

As I will demonstrate through my analysis in this chapter, in some cases words play a particularly powerful role in intra-actions. But the distinction between words and other intra-acting entities can only be made through analysis, not in advance of it. Like Barad, I am interested in “mattering,” therefore, I must begin from the position of ontological flattening in which there are no given ontological differences, but rather, ontological differences become enacted in specific contexts. Especially relevant to my

dissertation is the ontology of “self.” Under this ontologically flattened rubric, the “self” is not is not inherently ontologically different from “non-self,” just as words and humans have no *a priori* distinction from objects and nonhumans, and so on. Instead, through specific intra-actions, agential cuts are enacted in which self and non-self come to be.

Taken together, this scholarship has critical implications for my work studying the ways in which boundaries are enacted and the cases in which those enactments have rhetorical influence. As such, this chapter operates under the idea that “the ontology of a thing lies at the intersections of its doing, gathering, and presence,” at the intersections of its intra-activity (Graham, 2015, p. 212). I deliberately begin by flattening assumptive ontological distinctions, and instead, work to “be attentive to the iterative production of boundaries” by examining the chaotic intra-activity that emerges (Barad, 2007, p. 93). Thus, I can make *a posteriori* ontological categorizations based on the agential cuts (boundaries) enacted in each case. To illustrate this point, the next section details a series of enactments, much like those presented in the previous chapter. However, here I’m interested in explicitly addressing how agential cuts are enacted and what ontological repercussions those cuts might have.

### **From Parasites to Self: Agential Cuts & Ostomy Patients**

Across the data collected for this project, the object formations suggest four primary or common agential cuts, which I am calling: parasite, pet, cyborg, and self. Each of these agential cuts is staged through particular practices and intra-actions that various ostomy pouch wearers and ostomates engage. In this section, I will describe each of

these agential cuts moving from ostomy as discretely non-self to fully self, working to unpack the intra-actions present.

### *Parasite*

The first of the agential cuts I'd like to explore is the ostomy as a parasite. With strong negative connotations, parasitic agential cuts are enacted in cases where the intra-activity between patients is such that a division between self and ostomy becomes distinct, often due to the ostomy's undesirability and the challenges it presents for a patient. Recall Julia and her commercial with the CDC as explored in Chapter Three, intra-acting with her ostomy resulted in series of negative experiences for Julia. Consequently, throughout her video, Julia continually refers to her ostomy as "it," enacting a very distinct separation between herself and the ostomy. In so doing, Julia's ostomy becomes a parasitic attachment to her, separate but deeply entangled.

Using the depersonalizing pronoun "it" like Julia does is a common discursive practice to refer to an ostomy, though naming the ostomy is also a common practice for many in this community. I noticed this naming practice throughout my ethnography, having had the opportunity to meet various ostomies – Stella, Gandalf, Stewie, Sophia, and others. What's particularly interesting about naming is the reason patients often provide doing so. Naming is done for a variety of reasons, but commonly, is done as a means for patients to distance themselves from their ostomies. As one interview participant explained to me, "I was told to name my ostomy so I had someone to blame, someone to yell at." Moreover, explaining why naming is powerful for patients, another interview participant said, "I know [naming] helps others to detach – to separate their identity."

The agential cut between self and ostomy enacted in each of these cases has interesting resemblances to a parasitic relationship. Traditionally parasites rely upon their hosts for survival, while the inverse seems true for patients with ostomies.<sup>13</sup> That is, these patients depend upon their ostomies for survival, yet a separation between ostomy and the wearer becomes a discrete characteristic of this intra-action. Indeed, the ostomy pouch wearer identity described in Chapter Three seems to be enacted most commonly when the ostomy becomes a parasite. Literal parasites are defined by the fact that their dependency is at the expense of their host, which is much the same in the aforementioned ostomy cases. Even though many of these patients realize that their ostomies are medically necessary for survival, the ostomy's entanglement with the wearer is too at the expense of the quality of life and desired everyday experiences of the wearer.

#### *Pet*

Similar to the parasitic agential cut just described, pet<sup>14</sup> cut enacts a separation between patient and ostomy, but one that whose valence is not necessarily negative. I termed this agential cut pet precisely because the separation enacted frequently appears accepting, and in some cases even friendly or jovial. For instance, while naming an ostomy often is associated negatively, for some ostomy wearers, naming is less so.

Through her laughter, an interviewee told me that because she has given her ostomy a

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13 Notably, I used ostomy metonymically to refer to both stoma (the opening on the abdomen through which the end of the intestine is pulled to the surface of the skin) and the actual ostomy pouch. The practice of referring to them simultaneously through a single term "the ostomy" or "the stoma" is a common practice within the IBD and ostomy communities.

14 The notion of the pet or companion is highly theorized in the emerging field of animal studies (see, for example, Haraway, 2008; Rudy, 2013). That said, in naming the agential cuts present in ostomy intra-actions, I am theorizing this idea in a different way.



name, “when [her] ostomy makes noise in public, [she] can just say, ‘Oh, Sophia feels like talking to you!’” Additionally, in a blog post in which the “funniest remarks” from patients with ostomies were compiled on The Ostomy Connection, an education and advocacy websites for IBD and ostomy patients, one patient said, “I call my stoma ‘Politician’ because it’s either full of crap or making a lot of noise but not producing<sup>15</sup> a damn thing.” Through the intra-actions enacted in such remarks, the ostomy becomes a pet-like, a distinctly separate object, yet one that is closely linked to the wearer.

Similarly, in a blog on the Ostomy Outdoors page, the founder of the site explains how her ostomy came to be known as Wilbur:

As strong as the logical part of my brain is, I also have an even bigger side of my brain that is pure whimsy. This part sees my stoma as this crazy little critter on my belly that likes to dance, sing, and spit...Wilbur...seemed like a perfect name for my stoma. After all, in the book [Charlotte’s Web], Charlotte had described Wilber as “some pig” and “terrific” (Skiba, 2012).

As you can see in this passage, naming the ostomy, while enacting a separation, does not always come with or result from negative experiences with the ostomy. Instead, it seems, at least in these cases, that naming stages a friendship or kinship with the ostomy in which the wearer can deal with being entangled with the technology without the ostomy becoming a fully integrated part of the self.

This agential cut is also enacted in cases where the ostomy goes unnamed. For example, in my ethnographic work, I observed a long discussion among ostomy pouch wearers in which they described having an ostomy as similar to “having a baby.” They explained that an ostomy requires you to carry a changing bag and to adjust to life with

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<sup>15</sup> “Producing output” is a phrase used to describe the waste yielded through the stoma into the ostomy.

a new companion. The intra-activity enacted in such descriptions suggests an individual self apart from the ostomy, but too stages a more accepting relationship. Common across these cases is an ostomy that becomes pet – closely linked, under the responsibility of the wearer, but a distinct object with distinct behaviors and needs.

### *Cyborg*

The agential cuts enacted when the ostomy becomes cyborg<sup>16</sup> moves away from relationships in which the boundary around self is exclusive of the ostomy. Instead, the agential cut enacted here specifically includes the ostomy as self, but suggests a “more than self” status. To illustrate, consider the following tweet by ostomate (Figure 5), Vicky Mulholland, who commonly tweets about life with her ostomy.

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<sup>16</sup> The notion of the more-than-human cyborg has been theorized extensively in disability studies under the concept of the “supercrip.” See for example, Lewiecki-Wilson, 2003; Hardin & Hardin, 2004; Booher, 2010. However, little of this work explores the supercrip in terms of intra-actions, ontologies, and enactments.



Figure 3. Tweet from Vicky Mulholland in which the intra-action with her ostomy enacts an agential cut in which the self is cyborg.

To give brief context, Mulholland's tweet, as part of the #myillnessisnotyourinsult social media initiative, is in response to instances in the media in which ostomies, IBD, and other similar conditions are used to insult or stigmatize (much in the vein of the Julia video). Even through Mulholland's brief tweet, a particular agential cut is enacted: intra-acting with the ostomy transformed Mulholland into "superwoman" giving her more-than-human cyborg status. Through

intra-actions with her ostomy, both Mulholland and her ostomy become cyborg, superhuman.

The superhero theme is a common one throughout the IBD and ostomy and autoimmunity communities. Sometimes used as a metaphor for expressing the immense challenges patients with these conditions must overcome to live “normal” lives, the superhuman cyborg ostomate is enacted differently in the cases I’m discussing. For instance, Gut Girl is a self-proclaimed IBD superhero, who, through wearing her ostomy pouch, “fights IBD” and gives others the “tools” to do so too (see Figure 6) (Ringer, 2012). The intra-action of the ostomy, Gut Girl, descriptions of herself and her superhero status, her personal experiences with IBD, her role with the IBD community, social media, and likely more, entangle such that an agential cut is enacted around her self and the ostomy, resulting in ostomy as cyborg self.



Figure 4. Gut Girl, the IBD superhero is pictured here displaying her superhero armor fully equipped with an ostomy pouch.

Taken together, these cases demonstrate certain intra-actions, particularly involving positive experiences with the ostomy, in which the ostomy and self become cyborg self.

*Self*

The last of the four agential cuts that emerged as common in this project enacts the ostomy as self. Unlike the other three ostomy enactments, this one has no unique or clever name ascribed to it; it is simply self. The ostomy becomes self when the agential cut made surrounds the ostomy such that the ostomy is fully integrated into the self of its wearer. Thus, this ontology aligns most directly with the ostomate identity described

in Chapter Three. Ostomates like, Gaylyn Henderson of Gutless and Glamorous and Heidi from Ostomy Outdoors, as well as many who participated in my project, are intra-actively engaged with their ostomies such that their ostomies become themselves.

For example, during interviews, one participant told me “[the ostomy] is all who I am” and another said her ostomy was “absolutely” part of her. Much the same is Jessica Grossman, of Uncover Ostomy, who I described in Chapter Two. In several of the blog posts on her site, Grossman explains that her ostomy “is part of [her]” or “part of who [she] is” (Grossman, 2016). Even more, writing of her experiences with her ostomy before she had a takedown surgery to replace her ostomy with an internal pouch, Shawntel Bethea, a contributor to The Mighty, wrote, “My body wasn’t weird. I was unique...Sure, I was different. I still am. But I have grown to love myself for that” (Bethea, 2016). What’s interesting about Grossman and Bethea in particular, whose experiences are presented across several blogs is the way in which their descriptions shift when they discuss their ostomies. In both cases, the writers begin by saying “my ostomy” but seem to seamlessly, perhaps subconsciously, shift to “my body,” “me,” and “who I am” without enacting an agential cut between themselves and the ostomy. Consider, Grossman’s comments in fuller context:

I decided right away that I was going to be ok with myself as soon as I woke up from surgery. That’s not the case for everyone. I have met many people who have suddenly woken up with an ostomy, having no clue what it was until a doctor explained the “thing on their abdomen” and who were more scared and upset more than they’ve ever been in their lives. I’ve also met people who knew they were having surgery, but still needed time to adjust. It is ok to take the time you need to love yourself. It doesn’t always happen over night and it’s not a race for who can get there first. Don’t get down on yourself because you’re not loving your difference the moment it appears (Grossman, 2016, emphasis mine).

Throughout this passage Grossman switches between “ostomy” and “I,” which suggests her ostomy becomes no different than her hair, her mind, or her personality, all of which people regularly talk about distinctly while maintaining those elements as part of self. For ostomates like those described in this section, the intra-active integration of ostomy into self becomes so seamless that the ostomy’s boundaries become indistinct from self.

### **Multiple Ostomy Ontologies**

In following Barad, Graham, and Mol, who have compellingly argued that ontologies come to be through practices, it becomes clear that the enactments of ostomies the in practices described above are not simply different perspectives of ostomies. Instead, four ostomy ontologies are being enacted through specific agential cuts. Enacted through two agential cuts, the ostomy becomes non-self, in one case an unwanted non-self and in the other, an acceptable non-self. In contrast, in the two other agential cuts, the ostomy becomes self, either more than self or completely integrated (see Table 1).

**Table 1. The Multiple Ontologies of the Ostomy**

Ontology	Explanation
Parasite	Ostomy becomes explicitly distinct from self in correlation with negative experiences.
Pet	Ostomy becomes separate from self in correlation with experiences that are accepted or even positive.
Cyborg	Ostomy becomes self+. More than human status is enacted through entangling with the ostomy technology in correlation with positive experiences.
Self	Ostomy becomes self, indistinct from other bodily parts or identity, often in correlation with positive experiences enabled through the ostomy.

Accordingly, the question becomes how can the ostomy have four ontologies? How can the agential cuts presented in each of these cases enact the same, yet different, object?

I began this chapter with the methodological position of ontological flattening purposefully in order to investigate the possibility of diverse agential cuts. Looking more closely at each of these cases suggests that the ontology of the ostomy cannot possibly be a priori to intra-actions, but instead, the ontology of the ostomy is enacted through specific agential intra-actions. While this point is critical to my argument, it can be productively extended by Mol's theory of multiple ontologies (2002), which provides a way to account for the multiplicity of agential cuts enacted with the ostomy.

Mol's work hinges on the idea that ontologies are done in practices and that examining these practices reveals how objects are enacted in practice. As she explains,

If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come into being – and disappear – with the practices in which they are manipulated. And since the object of manipulation tends to differ from one practice to another, reality multiplies. The body, the patient, the disease, the doctor, the technician, the technology: all of these are more than one. More than singular (p. 5).

In focusing on what is done or enacted as both Barad and Mol suggest, theoretical space for ontological multiplicity opens up. When we examine how practices stage agential cuts in which objects are enacted, the ostomy multiples, just as disease does in Mol's analysis. For example, in describing surgery to treat atherosclerosis, the disease (in which blood arteries harden) under examination in Mol's work, she writes, "Reality follows: atherosclerosis is enacted as something that can be pushed aside by a balloon" (p. 102). We might say similar things about the cases presented in this chapter: 1) the



ostomy is enacted as a parasite, 2) the ostomy is enacted as a companion, 3) the ostomy is enacted as more than self, 4) the ostomy is enacted as self.

Furthermore, I must emphasize that it is not simply that different versions of the ostomy exist or that different people have different perspectives about the ostomy. Rather, by assuming no ontological differences at the outset of this chapter, it becomes “possible to understand” the ostomy as manipulated in practices,” which as Mol explains, has the “far-reaching effect” of multiplying reality (p. 5). The ostomy is not a “universal object” but is manipulated in its intra-action with other entities (medical histories, personal experience, minds, bodies, selves, surgeries, images, blog posts, tweets, etc.). The ostomy becomes a parasite or cyborg through specific practices in which intra-actions stage agential cuts. But these agential cuts are neither fixed nor permanent, leaving space for the ostomy’s multiplicity.

Critically though, the ostomy multiple is tied to sites of practice (Mol) or regimes of practice (Graham). In Mol’s version, an ontology is “bound to a specific site and situation” (p. 55). Take for example, Mol’s discussion of the role of location in enacting specific bodily ontology,

Because doing a woman is not the same thing in the supermarket as it is in the classroom, because staging a man in bed is quite different from staging a man at a professional meeting, it is possible to investigate what it is to perform this, that, or the other...A lot of things are involved. Black ties and yellow dresses. Bags and glasses. Shoes and desks and chairs and razors...Out in the streets one does not need a penis to perform masculinity. But in communal showers at the swimming pool, it helps a lot (p. 38-9).

The body becomes female indeed due to the practices in which the body is enacted, but also due to where those practices are done. That the body becomes female relies upon the intra-actions of specific entities including both time and space.

Extending this point, Graham proposes “regimes of practice” as a way of incorporating less geographically specific notions of space (2013; 2015). Clarifying this broadened sense of location, Graham and Herndl write,

Mol (2002) is quite physical in her sense of “site of practice” as a “where” – as a physical location of a set of practices – an understandable move considering her focus on atheroscleroses distributed through different spaces in a hospital. But the idea of specific physical sites of practice is less useful in our inquiry into pain medicine. We could easily say that the diagnosis occurs in the examination room, but that would be a somewhat myopic view. Diagnosis occurs equally in a variety of locations, for example, the examination room, the laboratory, the library, the Internet. Pain management is a spatially distributed practice...we will refer to “pragmatic regimes of engagement” or “pragmatic regimes,” an all-encompassing term, for example, action, practice, habit. In short, a pragmatic regime of engagement is a way of interacting with the world from which emerges orders of value and agency attributed to people and objects (Graham & Herndl, 2013, p. 114, emphasis mine).

These pragmatic regimes are especially important for accounting for language in the more diffuse understanding of practices and enactments presented in this chapter. As Graham explains, regimes or practices “are sites of doing, and doing includes the practices of speaking, writing, visualizing, and representing” (2015, p. 35).

Consequently, language can and often does play an integral role in ontological enactments, a particularly important point for rhetorical work. Unlike Mol’s praxiographic work in which she identified the multiplicity of disease through ethnography of practices in specific locations, my work combines such observations

with a variety of other discourse and object formations. Because of this difference, I must attend to the role of language in intra-actions presented throughout this chapter.

Let's return for a moment to the introduction of this dissertation. There, I made the case for a calibrated analysis in which Barad's intra-activity and Graham's rhetorical-ontological inquiry were combined to establish a study of enactments, some of which prove to be rhetorical. In that calibration, I pointed to Graham's argument that language is a type of doing as a critical part of my analysis, and as such, used this premise to explore a range of language practices as a means of studying patient's lived experiences through their stories, blog posts, tweets, and conversations with me as well as others. In this chapter as I argued for examining the agential cuts that are done or enacted in practice, my analysis, like that of the other chapters, focused on the way in which words, phrases, descriptions, and the like, brought to the surface various agential cuts in which ontological differences were enacted.

Too in the opening of this chapter, I briefly touched on the implications of representational approaches to ontologies. If on one hand is language – that which represents – and on the other hand are objects – that which needs representing – an “ontological gap” is created, from which questions regarding our ability to access and know objects fall (Barad, 2007, p. 47). In an effort to avoid such theoretical quick sand, I'd like to offer a final metaphor for understanding the role of language in the practices that stage ontologies.

There is no doubt, especially for rhetoricians, that language plays an important role in practices that stage ontologies. “Events are made to happen by several people

and lots of things,” Mol argues. “Words participate, too. Paperwork. Rooms, buildings. The insurance system. An endless list of heterogeneous elements that can either be highlighted or left in the background, depending on the character and the purpose of the description” (2002, p. 26). For the purposes of this project, particularly the work of this chapter, language stages the doing. That is, words<sup>17</sup> have a special role in enacting the agential cuts in which the ostomy becomes pet, parasite, self, or cyborg. As evidenced by the cases presented here, the descriptions, reports, confessions, powerfully participate in the agential cuts that are made. Language is a necessary entity in the enactment of separations from or inclusions into the self.

Importantly though, language is only the tip of the spear through which these cuts are made, not the spear itself. Words may do the cutting, but such cuts are only possible through all elements of the spear. The handle, leather, thrower, the space and time in which the cut is made, the exigency for the cut – all these elements too must co-articulate intra-actively to perform a cut. The tip of the spear is but one part of the intra-action necessary to stage an ontology, and we might focus on the entity that cuts in as a means of understanding how certain enactments are made to be rhetorically influential. Indeed, words clearly do the cutting from which the ostomy ontologies in this chapter are done, however, this is not always the case (as we will see in Chapter Five). Nonetheless, recognizing the agential separability made possible through intra-acting language requires the expertise of rhetoricians. Who better to understand the role of

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17 To be clear, when I refer to “words” I am referring to a nuanced conception of words as embodied movements, metonymic for a suite of discursive practices.

language in the enactment of ontologies? Who more adequately attuned to the ways in which enactments become rhetorical?

Ultimately, ontological multiplicity is an important aspect of a theory of enactments. This chapter argues that the ostomy is ontologically multiple, transformed through sites and practices. Further, this chapter sheds light on the diverse entities and ontologies that give way to the multiple identities, especially in this dissertation ostomy pouch wearer and ostomate. These arguments are critical to the theory-building work of this project, but the insights of this chapter are also relevant in contributing to the ongoing conversation regarding how rhetoricians can best conduct ontological inquiry without abandoning the important role of language.

Yet, as Barad, (as well as Mol, Graham, and other new materialist scholars) has argued, language is only one important entity in the intra-activity of the world. Therefore, identifying who and what else is rhetorically powerful in intra-actions and enactments is key to a thoroughly developed theory of enactments. Chapter will take up this important work by examining visual elements including images and ways of looking in order to investigate how agential cuts might be staged through entities other than language.

## CHAPTER 5: MISFITTING: THE ROLE OF VISUALITY IN ENACTMENTS

Disability fluctuates, growing visible, then invisible, then visible again, becoming both ever-present and haunting— José Alaniz, *Death, Disability, and the Superhero: The Silver Age and Beyond*

Feminism is about giving women choice. Feminism is not a stick with which to beat other women with. It's about freedom, it's about liberation, it's about equality. I really don't know what my tits have to do with it. It's very confusing— Emma Watson

Over the course of the last several chapters, my goal has been to demonstrate the analytical value of attuning rhetorical analyses to the intra-actions and agential cuts in which particular enactments become powerful. In Chapter Three, such an approach revealed the diverse identities that become possible through kairologies of specific intra-actions. Further, Chapter Four unveiled how within intra-actions the ostomy becomes ontologically multiple through specific intra-active agential cuts via language. To assume that language is the only intra-acting entity with the capability of influencing agential cuts, however, risks sliding into postmodern preoccupation with language. Therefore, at the core of this chapter is an effort to identify who or what else might become the tip of the spear – that is, what entities other than language might become most influential in agential cutting.

As the previous chapters briefly alluded to, a powerful element within the IBD and ostomy communities is the visual. Julia holds her ostomy away from her body was a visual act that participated in the cut between self and non-self (Chapter Three). Gut Girl's identity becomes both solidified and empowered through images of herself in her superhero armor (Chapter Four). Moreover, several advocacy campaigns encourage IBD and ostomy patients to post pictures of themselves including the Get Your Belly Out campaign in which participants post pictures revealing their bellies (ostomy-clad,

scarred, swollen, etc.) to make visible these conditions and the IBD Selfie campaign that asks participants to post selfies to show everyday life with IBD.

My point here is that visibility seems to play an integral role in enactments and agential cuts, especially in regards to IBD, ostomies, and chronic autoimmune conditions. However, the role of these visuals in intra-actions and enactments has not been fully theorized, particularly in cases where superficially similar images take on very different rhetorical lives. Consequently, this chapter sets out to investigate how we might adequately account for visuals under the rubric of enactments to make sense of how and why particular images become powerful. Drawing on the notion of “misfitting” from disability theory, I will explore two final cases to investigate how agential cuts are staged in visual enactments and what is at stake in such agential cuts. As part of this analysis, I will also turn to Gries’ insights regarding visual rhetorical transformations and the role of particular ways of seeing to understand how certain enactments fit in certain rhetorical contexts while others do not. First though, I’d like to introduce to the main characters of this chapter: Bethany Townsend (Figure 7) and Sam Cleasby (Figure 8).



Figure 5. Bethany Townsend (Walker, 2014).



Figure 6. Sam Cleasby (Cleasby, 2015b).

### *Bethany Townsend*

In 2014, a young woman by the name of Bethany Townsend posted online a picture of herself sun-bathing in a bikini. Seemingly, there is nothing exciting or newsworthy about such a post, especially in the age of the selfie (Jurriëns, 2016). However, within days of posting, Bethany's picture had gone viral, with over 12.4 million views (Walker, 2014). Bethany's image stood out from the millions of other online selfies because she wears to ostomy pouches. Since posting, Bethany's image has been viewed worldwide, being championed as a heroic act that not only gives, but elicits, confidence in herself and others with IBD, however, as she explains it, the image was initially simply intended for her husband's viewing.

### *Sam Cleasby*

Also in 2014, UK blogger Sam Cleasby, uploaded a blog entry about going to the bathroom. However inappropriate this entry might initially sound, Sam's story wasn't about what happened behind the bathroom stall door. Instead, this entry was an



emotionally-charged and intimate letter entitled “Dear lady who tutted at me for using the disabled loo.” In this post, Sam details an embarrassing and hurtful incidence in which she was scoffed for using a disabled bathroom without looking disabled, even though Sam is. Her visual marker for disability – her ostomy – is just hidden beneath her clothes. About a year after this entry, another of Cleasby’s blog posts attracted substantial attention. This time, instead of being criticized for lacking visual evidence of her disability, Cleasby was criticized for looking disabled. That is, in a series of images posted to her blog, wearing lingerie and skirts, Cleasby reveals her ostomy, and was subsequently chastised for “sexualizing disability.”

At the core of both Townsend and Cleasby’s cases are images of female, ill bodies. More than three years later, these women, their images, and the receptions their images received, remain influential within the IBD and ostomy communities, which begs the question, what about these images made them so rhetorically powerful? Despite both gaining rhetorical traction, Townsend’s and Cleasby’s cases incited quite conflicting responses, which requires me to further ask, how might an enactment framework enable me to account for these divergences? What might an examination of these images as enacted through specific agential cuts reveal about their agentic capabilities? On one hand, Townsend was celebrated for bravery and beauty in displaying her ostomy. On the other, Cleasby was condemned for not looking disabled in one context, yet looking too disabled and too sexy in another. Put another way, Townsend fits her rhetorical context, while Cleasby does not – she misfits.

## **Misfitting**

The idea of fitting and misfitting is an apt metaphor for making sense of Townsend and Cleasby's conflicting receptions. Developed by disability studies scholar, Rosemarie Garland-Thomson, misfitting responds to what she saw as a pressing concern to better understand "lived identity and experience of disability as situated in place and time" (2011, p. 591). Like this dissertation, Garland-Thomson relies heavily upon the work of Barad to establish this disability theory framework in which entities (what she refers to as becomings) emerge in the world, instead of simply existing with inherent ontological properties. Misfitting, Garland-Thomson explains, is

an encounter in which two things come together in either harmony or disjunction. When the shape and substance of these two things correspond in their union, they fit. A misfit, conversely, describes an incongruent relationship between two things: a square peg in a round hole (p. 593, emphasis original).

Moreover, misfitting, is an "explanatory concept" to think through "a particular aspect of world-making in material-discursive becoming" (pp. 591-2). In terms of enactments of particular bodies and identities, then, misfitting occurs when "world fails flesh...whether it is a flight of stairs, a boardroom full of misogynists, an illness or injury, a whites-only country club, subzero temperatures, or a natural disaster" (p. 600). Certain bodies, in their intra-active becomings, misfit their environments or situations. People in wheelchairs misfit stairs. Bodies with penises misfit bathrooms labeled "Women." Left-handed students misfit right-handed desks.

When material-discursive becomings are enacted in spaces and times that are designed and equipped for different enactments, a misfit occurs. In other words, misfits are a type of agential cut. For example, when a paraplegic misfits stairs, the

entanglement of person, wheelchair, injury, stairs, etc., is consequently marked as disabled. In an effort to fit then, the paraplegic might navigate to a wheelchair ramp. Physical misfittings, like the wheelchair and stair example, for disabled and non-normalized bodies, more broadly, are abundant; however, to assume all misfits are environmental or architectural shrinks the analytic potential of this concept.

That is, enactments can misfit in ways that extend beyond physical space, as I will demonstrate with Townsend and Cleasby. For patients with autoimmune diseases, including those with IBD and ostomies, the square pegs and round holes are more than physical. As an “invisible disease” IBD’s symptoms do not manifest visibly which results in disease severity and even existence coming into question (Joachim & Acron, 2000; Donoghue & Siegel, 2000). IBD patients often find themselves invisible to society whether by concealing their own disease or by having their disease doubted from lack of visible evidence (Defenbaugh, 2013; Moore, 2013; Valeras, 2010).

Certainly, patients with IBD and ostomies can physically misfit, however, more commonly, these patients misfit visually. Because IBD is seemingly invisible to the public, patients deploy a range of visual strategies to not only make their disease visible but to consequently bring disease into being. In other words, patients commonly attempt to visually enact their disease. As is oft cited in visual theories and scholarship, ways of seeing become ways of knowing (Foucault, 1973; Daston & Galison, 2007; Fountain, 2014). An important intra-active entity in making IBD or ostomies known, then, is the visual – images, displays, gazes, and the like. When the visual intra-acts, particular agential cuts are made possible which stage fits and misfits. Using misfitting

as a metaphor, the goal of this chapter is to understand how and when Townsend fits while displaying her ostomy while Cleasby misfits and is shamed both for failing to display her ostomy as well as for doing so.

Before jumping to a more thorough discussion of the Cleasby and Townsend's cases though, I must first address the way I am approaching visual elements as intra-active entities, especially images and the ways images are viewed. Under an enactment framework, images become entities that circulate, intra-act, and engage in agential cutting. This position departs from much visual rhetoric work that treats images as synchronic representations, therefore, I turn now to Gries' "rhetorical transformation" as a productive heuristic for examining these images as intra-actively co-articulated within particular enactments. Her work suggests that these images are neither static representations, nor disengaged from intra-active engagements, which helps to account for how these images take on divergent rhetorical roles as they are circulated. Images are lively, chaotic, entities that come into being through their entanglement with other entities.

Situating Gries' notion of rhetorical transformation within my own work, in the next section, I consider how agential cuts are enacted in highly visual enactments and which entities are most powerful in agential cutting regarding visuals. I specifically contend two ways of seeing – the clinical and male gazes – agentively influence enactments. Therefore, I introduce scholarship on these gazes and synthesize this work with Gries and my enactment theory to situate the subsequent analysis of Townsend and Cleasby.

### **Transformative Gazing**

The mainstays of visual rhetoric scholarship, according to Gries, are “representational and synchronic approaches” that fail to “fully account for an image’s rhetorical complexity” (2015, p. 58). She insists,

we need theories and empirical methods that better account for an image’s intense, unfolding, and distributed materializations in order to make visible how they become consequential in divergent ways” (p. 58).

Taking up this call, Gries theorizes rhetorical transformations as an alternative way to study images that attends to the “process in which [images] become rhetorical in divergent, unpredictable ways as they circulate, transform, and catalyze change” (p. 28). In order to examine these rhetorical transformations, Gries suggests we trace “singular images” through their “distinct, albeit divergent, rhetorical lives (p. 28). Thus, as an approach, rhetorical transformation lends itself productively to my project’s interest in unpacking conflicting enactments, especially as this chapter aims to illustrate how the enactments in Townsend’s and Cleasby’s images become so rhetorically divergent.

However, it’s important to note that a rhetorical transformation does not simply suggest we examine images as they circulate and transform as inert objects. Indeed, this approach requires a reconfiguration of how we understand images (Gries, p. 7). When treated as freeze frames, visual artifacts either come to stand in for objects or are treated as floating signifiers that scholars give meaning. Rhetorical transformation requires that we move beyond treating images and other “visual things,” as Gries calls them, as “already materialized” objects for analysis, and instead, situate visuals as “mediators, able to transform, modify, and rearrange collective space as they co-influence assemblages in which they are and become a part” (p. 62). Just as Barad argues all

entities in the world come into being and become meaningful through intra-actions with other entities, Gries argues, visuals “are not determinate things that embody specific fixed characteristics and properties” (p. 70).

Under the rubric of rhetorical transformations, Gries proposes that we study an image as an event – “a dynamic network of distributed, unfolding, and unforeseeable becoming” (p. 27). In this sense, images become entities that intra-act, entities that participate in agential cuts, and entities that participate in enactments that may or may not fit. Gries uses rhetorical transformations as a way of questioning how things become powerful – what entities intra-act, in what space and through what time. Much the same, this dissertation questions how specific enactments become powerful and what consequences that has for bodily and identity boundaries, making a rhetorical transformation approach apt for examining the images of Townsend and Cleasby as they circulate and become meaningful. Put another way, both Gries’ work and this dissertation are interested in how agential cuts are made and what rhetorical implications such cuts engage.

Therefore, critical to examining visuals as dynamic becomings in rhetorical transformations, visuals need be traced “as they undergo divergent change and flow – as pure event” (Gries, 2015, p. 29). This, in turn, helps to illuminate the “rhetorical roles” and “rhetorical life” that develop from the rhetorical transformation of these images (p. 36). For example, Gries traces the divergent changes and flows of the Mona Lisa to uncover the “complex and unpredictable” rhetorical life that “Mona Lisa has come to lead” (p. 36). As Gries describes,

[the Mona Lisa] took on a variety of rhetorical roles, many with transnational consequences. As early as 1919, for instance, Mona Lisa worked to protest against the museumification of art when surrealist artist Marcel Duchamp provided a version of her with a moustache and a goatee. Later, in the 1960s and 1970s, it became a diplomat, as the Mona Lisa was loaned to the United States in an attempt to improve Franco-American relations, and the image made a stunning appearance in John F. Kennedy's speech at the unveiling of the National Gallery of Art (p. 34).

Here we can briefly see how the Mona Lisa circulated, transformed, and catalyzed change through various spaces and times (p. 27). In one intra-active entanglement, the Mona Lisa became activist, in another, diplomat. Treating the Mona Lisa as an unfolding, dynamic event, shapes the way in which Gries accounts for what the image comes to mean in intra-active relationships with various entities (audiences, space, time, policy, culture, etc. – none of which pre-exist these intra-actions).

The result of such work is a reframing of how images become rhetorical and how and when agential cuts are made. As we will see through a more thorough discussion of Townsend and Cleasby, visual elements, like language in Chapter Three, can come to play a powerful and influential role in the agential cuts that are staged in particular enactments. Grounding rhetorical transformations in intra-actions stages specific agential cuts itself. According to Gries:

in our intra-actions with them, visual things under study only become temporarily determinate when we take a snapshot of their mobility and make an 'agential cut,' marking them (objects), as well as other things we engage with to perform research, off from us (subjects) (p. 70).

The cut that is made between viewer and viewed through images undoubtedly effects the rhetorical role and life in which images are transformed. However, the cut between viewer and viewed is not the only cut made possible when examining images as events in rhetorical transformations, nor is the viewer/viewed the only cut worth exploring.

Indeed, this chapter is interested in the diverse agential cuts that stage fits and misfits – how images take on particular intra-active roles that fit or not. Identifying who or what is most influential agential cuts with visuals is a primary concern of this chapter. As Gries makes clear, it is not that “in any given phenomena, all entities equally contribute in degrees and types of influence, nor that human beings must always be involved” (p. 69). Specifically, Gries cites a variety of entities that might alter intra-actions and participate in visual phenomena, one of which is particularly relevant for the types of enactments staged with Townsend and Cleasby: the gaze (p. 28). Gries explains,

as images materialize in different versions and enter into divergent associations, they become rhetorically diverse as they work alongside other entities, human and nonhuman, abstract and concrete, to alter collective life. Such alteration includes, as many rhetorical scholars have noted, establishing a particular way of seeing or gaze (pp. 27-8).

This is a seemingly passing point in Gries argument, however, I think the idea that gazes or ways of seeing have the potential to intra-actively engage in powerful ways is worthy of further development.

What becomes clear in looking at Cleasby and Townsend is that the ways in which their bodies were seen, or gazed upon, plays a powerful role regarding if and when their enactments fit or misfit. Different gazes intra-act with the images of Townsend and Cleasby and influence the fitting and misfitting that occurs. Particularly, as these images intra-act with two ways of seeing – the clinical and male gazes – diverse agential cuts are staged. So as to more fully explore these gazes before tracing their intra-active role in both Townsend and Cleasby’s images, the next sections will very



briefly describe each gaze, highlighting the relevance of these gazes in the enactments of Townsend and Cleasby.

*The Clinical Gaze*

First theorized by Foucault (1973), the clinical gaze is an “observing gaze” (p. 107) deployed through the eye of a trained physician, in which a disease is brought to “declare its truth” (p. 112). That is, through this particular way of seeing disease, a doctor gazes upon symptoms and signs of a disease, which in turn, brings that disease into being. In terms of intra-actions, visual things (e.g., x-rays, blood tests, visually evident symptoms like swelling or bruising) entangle with the trained clinical gaze of a medical expert, and through this co-articulation, a disease or condition is staged.

For those in the IBD and autoimmune disease community, more broadly, bringing these diseases into being with the clinical gaze is not a simple feat. That is, IBD does not often manifest in visible ways. Autoimmune activity occurs within the body, under layers of opaque tissue, making the visibility of these conditions often impossible without intra-action with apparatuses, such as microscopes, pathologies, MRI machines, etc. Making IBD visible as it intra-acts with the clinical gaze of a medical expert is made possible because medical professionals have access to such apparatuses to help gaze upon the disease. However, the clinical gaze has not taken permanent residence strictly within the sight of medical professionals.

Indeed, recognizing the migration of this particular way of seeing into the public sphere, Johnson redefines the clinical gaze as a “diagnostic hermeneutic,” an “interpretive frame” in which those beyond trained experts “take on the diagnostic gaze of the physician, searching body and speech for symptoms (2010, p. 470). The diagnostic

hermeneutic, in other words, provides a way for the public, media, and others to appropriate the particular way of looking that medical professionals train for years in order to deploy. Because society has become inculcated in the culture of medicine and science—specifically in the ethic of embracing visual evidence above much else—the clinical gaze has been absorbed into public culture such that certain bodies, particularly those who enact certain identities (e.g., disabled, ill, ostomate) must provide visual evidence in order to support those identities. The clinical gaze has trickled beyond of the domain of experts and society has adopted it as a way visually assessing the conditions of others, which in turn, stages particular agential cuts regarding bodies in the public. The diagnostic hermeneutic is capable of enacting cuts between what self becomes self and non-self, who or what becomes able disable, and who becomes ill and or not.<sup>18</sup>

For instance, Graham’s work on fibromyalgia explores the difficulty patients have in validating their disease without the entanglement of medical technologies that bring pathological evidence into view (2009). Graham explains that visual data from Positron Emission Tomography (PET) scans lead to the “legitimization of fibromyalgia” (p. 385). Put another way, the intra-activity of the body, fibromyalgia, symptoms, patient reports, PET scans, and the clinical gaze come together to visually and rhetorically to enact and legitimize the ill body and identity. However, the public does

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18 The types of agential cuts I’m interested in this chapter are slightly different than those discussed in the previous chapters. Until now, I’ve mostly been interested in cuts regarding self, non-self, human, and non-human. In this chapter, though, I’m more interested in cuts among able-bodiedness and sexuality. Following Barad, I recognize such cuts as “specific form[s] of embodiment that [are] co-constituted through boundary-making practices” (2007, p. 158).

not often, if ever, have access to a patient's PET scans. Fibromyalgia, IBD, and other such conditions, then, are not easily revealed to the public's clinical gaze. Enactments of these conditions must find ways to fit without intra-acting with medical apparatuses like PET scans. For those with IBD and ostomies, like Townsend and Cleasby, posting pictures online is one way of doing so.

However, as a rhetorical transformation approach reminds us, Townsend, Cleasby, and others cannot control the entities in which their images might intra-act once their images are circulated and transformed. While the clinical gaze might be one such entity that intra-acts with these images, it is often not the only one. Under other gazes, the "becoming" of these images "intensifies with each new actualization and with each new encounter" (Gries, 2015, p. 28). Therefore, I'd like to briefly explore the other predominant intra-acting gaze entangled with these images: the male gaze.

#### *The Male Gaze*

Many scholars within feminist and disability studies have raised questions and concerns regarding ways of looking at particular bodies (Mulvey, 1975; Haraway, 1987; Bordo, 1993; Price Herndl, 2001; Doane, 2003). Through this work, the male gaze, like the clinical gaze, has been theorized as an especially problematic way of looking. This male gaze is an objectifying, controlling gaze of the dominant regime – sometimes referring literally to men, but in other cases to hegemonic and oppressive forces such as science, medicine, or the government (Mulvey, 1975; Balsamo, 1996; Caeton, 2011; Brunner, 2013; White-Farnham, 2013; Lowry, 2013). Much has been written on the male gaze and its relationship to and effects on the female body, and scholars including

Garland-Thomson (2009), Mulvey (1975), and Doane (2003f), have focused primarily on the male gaze as one that directly sexualizes the female body by men.

For example, Doane argues the male gaze “is in control” (2003, p. 80) and Garland-Thomson writes, the male gaze “is a position of privilege...which entitles men to look at women,” as an act of “dominance” (2009, p. 41). Similarly, the male gaze, according to Price Herndl, is “concerned with commodity, with sexuality” (2001, p. 264). Overall, this work identifies a particular way of seeing in which the viewed female body becomes commodified, controlled, and sexualized, often for lust and reproduction. As a gaze that dominates and objectifies, the male gaze is often compared to the normalizing gaze described in Foucault’s panopticon, a type of viewing that surveils and “makes possible to classify and to punish...[to] establish over individuals a visibility through which one differentiates [those under surveillance] and judges them (1977, p. 187). Such ways of looking enact particular agential cuts regarding what is normal and abnormal, desirable and undesirable, and that which should be displayed and that which should be hidden.

Further, Bordo argues that it’s not merely being surveilled by the male gaze that deems particular enactments desirable, normal, or acceptable. Seeing other bodies entangled with the male gaze – witnessing the male gaze as an outsider – also creates pressure to stage particular bodies. Bordo explains, images in which bodies have normalized, “function as models against which the self continually measures, judges, disciplines, and corrects itself” (1993, p. 25). In terms of enactments, this surveilling male gaze normalizes through intra-active entanglements with bodies, sexuality,

anatomy, society, viewers, images, and more. The consequence of intra-activity in which the male gaze co-articulates is the need for certain bodies to normalize and stage particular enactments. That is, in order to fit, bodies must visually normalize to the expectations of the male gaze. When the male gaze is engaged, enactments of images and the bodies within those images, take on particular rhetorical roles, often divergent from that which is staged with the clinical gaze. Put another way, the clinical and male gazes require visual enactments to fit in different ways.

In the following analysis, I examine Townsend and Cleasby to understand how the various intra-actions with the male and clinical gazes stage fits and misfits. As images of Cleasby and Townsend circulate and intra-act with the male gaze in some moments and clinical gaze in others, how do the intra-actions entangled with these images change? What agential cuts are enacted through these gazes and consequently, what role do these gazes play in the fitting and misfitting of Townsend's and Cleasby's enactments? To investigate how and toward what end agential cuts are enacted with these gazes, the next section will more fully explicate Townsend's and Cleasby's images, tracing their rhetorical lives as they transform and catalyze fits and misfits.

## Bethany Townsend



Figure 9. Bethany Townsend (Walker, 2014).

Clearly, in her picture, Townsend is wearing her colostomy bags as she presumably sunbathes. When asked about the image, Townsend reported “it was just a picture that I got my husband to take on holiday and it was just for me and him really (“Dare to Bare,” 2014). After receiving positive feedback from her husband and others, Townsend shared the image with Crohn’s and Colitis UK – an organization that raises awareness, money, and support, for those with IBD in the UK – transforming the image far beyond a personal picture for her husband. Not long after, Townsend was featured on a variety of news and pop culture broadcasts in the UK, explaining her picture and her ostomies.

In response, thousands of other ostomy and IBD patients tweeted in support of Townsend, calling her an inspiration for the IBD and ostomy communities. In fact, one Twitter responder wrote that Townsend is “such an inspiration, especially in a world that’s so judgmental about how a woman should look in a bikini” (Walker, 2014). In response to this positive feedback, Townsend explained she shared this picture to demonstrate women with ostomies “have nothing to be ashamed of” (Blumm, 2014).

However, before this image was circulated to the more public audience, Townsend admitted it was her husband who encouraged her to take and post the photo. She explained her husband told her, “If we go on holiday, I want you to wear a bikini” because as her husband puts it, Townsend has a “great body” despite having her ostomies. In fact, in various iterations of her story, Townsend remained steadfast that she did not wear a bikini or reveal her ostomies in public for over three years because she had a lack of confidence (Blumm, 2014). Yet, with the encouragement of her husband, what I understand as intra-action with the male gaze, Townsend revealed her ostomies and body to her husband and the public.<sup>19</sup>

Even more, the accepting male gaze involved in Townsend’s case becomes a powerful entity in the intra-actions and agential cuts staged. Through the intra-action of Townsend, her ostomies, her husband, the male gaze, this image, the bikini, and social

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<sup>19</sup> Importantly, I consider the male gaze involved in these enactments specifically because Townsend states that this image was intended for the gaze of her husband (Blumm, 2014). As feminist scholars point out, it is difficult and often unproductive to assume that any images of women are victim to the male gaze because the images appear sexual or provocative. In many cases, women advance their sexuality and empowerment through displaying their bodies in ways that disregard the male gaze (Stuart, Kurz, Ashby, 2012; Greco, 2015 ). Therefore, I am to make no judgment about the way Townsend dresses or displays her body sexually (or not). Instead, I am accounting for the explicit relationship, noted by Townsend herself, between Townsend’s image and the male gaze of her husband (and possibly others, as the image circulated publically).

media, Townsend's image visually enacts a normalized body. This intra-action agentially cuts the body as acceptable and sexual. Put another way, the image as a "pure event" transforms through intra-action with "particular way of seeing" (the male gaze) (Gries, 2011, p. 28). The recurring emphasis on how Townsend's husband found the image attractive and acceptable became an influential entity in the enactment of Townsend's image, helping the image to fit within the male gaze. However, this image's rhetorical life was not only entangled with the male gaze.

As Townsend's image materialized within the Crohn's and Colitis UK, the organization remarked, this image helped to "shine a bright light on...Inflammatory Bowel Disease" ("Bethany Townsend's photo," 2014). Crohn's and Colitis UK's explanation points to this image's intra-action with the clinical gaze in the public. That is, Bethany explains the popularity and wide-reaching effects of this image weren't "just a big deal for [her], but for other Crohn's sufferers" because it "shone a much-needed spotlight on bowel disease" as current treatment options are limited (Kenyon, Edwards, Meddings, & Harvey-Jenner, 2014). As Townsend's image intra-acted with the public's clinical gaze of the public, IBD itself could come into being. An agential cut regarding disease is enacted. IBD was made visible as Townsend's image circulated with society, entangled with Crohn's and Colitis UK. Thus, the image not only became validation for IBD and ostomies, for chronic illness that otherwise goes unseen and unknown, but the image also fit with the clinical gaze. Displaying her ostomy provided the visual evidence required by the clinical gaze, allowing Townsend to fit.



In review, Townsend's image manifested in rhetorically powerful ways through the normalized agential cuts of both the clinical and male gazes. Her image could enact the rhetorical role of disabled or chronically ill as well as desirable female. The agential cuts made across the gazes align, hence, in both enactments the image actualized as positive, celebratory, and empowering. However, what happens when the male and clinical gaze enact conflicting rhetorical lives for a single image? How is the rhetorical becoming of that image transformed? What if visual enactments misfit? If a visual enactment fits under one gaze but not another, what happens? Can simultaneously, divergent visual enactments be reconciled? Turning to Cleasby image that was criticized for looking (or not) disabled helps answers these very questions. The next section will detail visual enactments with Cleasby in which she was criticized due to misfitting.

### **Sam Cleasby**

Blogger, Sam Cleasby writes regularly about her experiences with IBD, making her a well-known IBD and ostomy community member. Her website and blog have become a place to explore IBD and ostomy issues regarding "self-esteem, body image, and loving yourself" (Cleasby, 2015). While her entire platform works to empower, educate, and promote IBD patients with IBD awareness, two of her blog entries – "To the woman who tutted at me for using the disabled loo" and "Sexualizing disability or normalizing life with an illness?" – are especially relevant in investigating visual enactments and agential cuts. Together, Cleasby's entries reveal entanglements among IBD, the clinical gaze, the male gaze, and the female body, in which misfits are enacted. Unlike Townsend, intra-actions regarding Cleasby's disease, identities, and body misfit both

the clinical and male gazes, resulting in backlash and rejection of Cleasby's enactments. In what follows, I will unpack each entry, emphasizing the role of each gaze in the agential misfitting staged.

*To the Woman Who Tutted at Me for Using the Disabled Loo*

Before exploring this first blog entry, I must offer a spoiler of sorts. This entry contains no images. The majority of this chapter so far has focused on pictures as the "visual thing" transformed; however, in this entry, the "visual thing" transformed is her physical, fleshy bodyself.<sup>20</sup> Contrasting the visual event described in this first entry with the literal images of Cleasby included in the second entry provides an illustrative tracing of how the clinical and male gazes were at work in the intra-activity and enactments of Cleasby as female and chronically ill. Like images, Cleasby in photograph or in flesh is a "visual thing" existing in a "dynamic state of flux" of "location, form, medium, genre, and activity" (2016, p. 158, emphasis mine).<sup>21</sup> Although visual rhetoric scholarship tends to focus on images as the "visual things" we study, visibility extends far beyond that which a camera can capture (Gries, 2013). The medium of the visual thing under examination in this first blog entry is Cleasby's bodyself in its physical manifestation, and much like examining an image as it transforms, I am working to track how the visibility of Cleasby intra-acts in particular contexts.

With that clarification, the opening lines of this blog read:

Dear lady who loudly tutted at me using the disabled loos,

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<sup>20</sup> I use "bodyself" here as a way to not invoke an agential cut between Cleasby's body and self, as is often done in causal discourse.

<sup>21</sup> I must also make note of the role of language in the enactments staged in Cleasby's case, especially. Using a blog to explore visibility in enactments requires me to walk a difficult line. In each enactment described throughout this analysis I recognize language as an influencing entity, but am working to remain focused on the rhetorical transformation of the visual elements.

I know you saw me running in, with my able bodied legs and all. You saw me opening the door with my two working arms. You saw me without a wheelchair. Without any visible sign of disability. You tutted loudly as I rattled the handle with my hands that work perfectly and my able voice call to my kids that I'd be out in just a minute (Cleasby, 2015a).

Here, Cleasby explains what her recent experience of using the public disabled bathroom must have looked like to the woman watching her. With her "able bodied legs," "two working arms," and "without a wheelchair," or "any visible sign of disability," the on-looking woman had no reason to believe that Cleasby was justified in using the disabled bathroom. The gaze of this woman did not intra-act with entities that would enable an agential cut in which Cleasby could become disabled. Without a wheelchair, missing ligaments, or any other "visible sign" of disability, the clinical gaze could not enact an agential cut such that Cleasby was fit for the disabled bathroom.

Cleasby continues,

My lack of wheelchair may have suggested to you that I was some lazy cow who didn't care. Some inconsiderable bitch who was using something I wasn't entitled to. (I actually carry a card to explain that I'm entitled to and have a disability key if you'd have cared to ask). You may have seen my face blushing as I caught your eye and assumed I was showing guilt at blagging the disabled loos. The fact is that I have no bowl. I have a pouch form from my small intestine which can't handle volume and so I have to go to the toilet and poo several times a day. My lack of large intestine means that my stool is totally liquid as I have no means of absorbing the fluids in food and so it's really hard to hold it when I need to go. I sometimes have accidents which means a large toilet that has a sick right by me means I can clean myself up when things go awry.

The stark and honest language in this passage demonstrates the challenges of both living with an invisible disease and engaging with the clinical gaze. For Cleasby, her invisible disability enables the clinical gaze to transform her into a "lazy cow" and "inconsiderate bitch" who was using something she "wasn't entitled to" (Cleasby, 2015a). The clinical gaze intra-acting with Cleasby, the visibility of her body and disease

(or lack thereof), and the location of this enactment, agentially separates Cleasby from that which should occupy the disabled bathroom. Cleasby misfits the disabled bathroom. If Cleasby's visibility included disabled arms or legs, a wheelchair, or some other visual sign of disability, the intra-activity staged in this case might enable her to become disabled (Barad, 2007, p. 148).

Cleasby ends this blog by calling readers, and society more generally, to action, which in many ways might be understood as a call for the dismantling of the public's clinical gaze:

The next time you see someone who doesn't "look disabled" using a toilet. Or someone busting through and crashing into the toilets noisily. Take a moment. Remember that not all people who have the right to use disabled toilets are in a wheelchair. Some of us have a jpouch, a lot of us have an ostomy bag that needs emptying and changing with the use of space, a skin, and a bin. And even more of us just don't want to shit our pants in public. Think about the nearly 300,000 people in the country who have inflammatory bowel disease...who need to use the toilet urgently, noisily, smellily...It's an embarrassing enough thing to deal with before having to see disapproving looks.

In this passage, Cleasby directly addresses how looking disabled and being disabled are not interchangeable. Despite this, as the visibility of Cleasby co-constitutes in the intra-activity with the clinical gaze, the agential cuts staged are powerfully influenced by the gaze itself. As Gries suggests, "things" beside humans, in this case the clinical gaze<sup>22</sup>, have the "potential to alter reality" as it materializes in "multiple and distributed encounters" (2015, p. 32). When the clinical gaze co-articulates in this intra-action, Cleasby's bodyself misfits, because the entity (or types of entities) that would enable her

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<sup>22</sup> I treat the clinical gaze, and gazes more generally, as not contained within a particular human, but as articulated within intra-actions. Gazes occupy space between entities that become viewer and viewed.

to fit are invisible. Because her ostomy is concealed, she misfits when intra-acting with the clinical gaze.

*Sexualizing Disability or Normalizing Life with an Illness?*

The second of Cleasby's blogs under review here was posted approximately a month after the disabled bathroom entry. In this post, Cleasby reacts to the critique that images she posted of herself were "sexualizing disability." (Cleasby, 2015b). Below are two of the images that were directly criticized (Figures 10 and 11).



Figure 10. Cleasby revealing her ostomy (Cleasby, 2015b).



Figure 71. Cleasby revealing her stoma (Cleasby, 2015b).

In the first of these images, Cleasby's ostomy is revealed, though is perhaps not the central focus of the photo. The second image, however, highlights Cleasby's stoma – the healthy end of intestine pulled to the surface of the skin, over which an ostomy pouch is worn to collect digestive waste.

Describing the reason she decided to have her husband take these images and her own motive for posting them, Cleasby writes,

I wanted to show that my stoma didn't remove me from my femininity, sexuality, or who I was before. I wanted to show the world that it was nothing to be ashamed of, that I was proud of my ostomy (Cleasby, 2015c).

However, when these images were circulated online, they were not received positively by all audiences. In fact, Cleasby says, “I have been subject to a few comments about sexualizing disability...and I wonder am I guilty of that?” (Cleasby, 2015c). In working toward an answer, she explains how such a critique is even possible,

It’s so easy to use a woman’s body against them, to suggest that showing flesh is in some way a dart in the heart of feminists everywhere...It is odd isn’t it that when we see semi-naked photographs of men that there is no backlash, no one suggesting they are belittling the campaign by showing their bodies (Cleasby, 2015c).

Here, Cleasby recognizes the role and implications of the male gaze in the “showing” of a woman’s body and flesh. As these passages point to, the male gaze intra-acts in particularly influential ways, making “particular articulations” of this image meaningful and staging specific agential cuts in which the image becomes sexualized (Barad, 2007, p. 148). This enactment of a sexualized image, however, was not received positively like Townsend’s image; instead, sexualization of this image was condemned by a series of comments claiming the image is gross, disgusting, and attention-seeking (Cleasby, 2015c). Cleasby’s images become powerful as the diseased or disabled body is enacted, but are confronted with resistance in their becoming as sexual. These enactments conflict in their rhetorical becomings. The disabled body enacted in these images cannot simultaneously be a sexualized body. The disabled body misfits the male gaze.

Tracing across these posts suggests that Cleasby finds herself and the IBD community at odds under the scrutiny of the clinical and male gazes. In one enactment (using the disabled bathroom), intra-action with the clinical gaze incited pressure to

visually enact disability in order to legitimize Cleasby and her disease. Yet, when images of Cleasby circulate and transform with the male gaze, she is criticized for sexualizing and objectifying the disabled body. This tension arises, at least in part, because images as circulating events that unfold, mediate, transform, shift, and materialize in particular intra-actions cannot have a singular, intended audience. Rather, “both intended and unintended audiences play an interactive role in remixing, appropriating, and spreading images” and circulation of these images is not controllable (Gries, 2016, p. 158). Cleasby’s images perhaps were intended for intra-action with a clinical audience, enactments are not under the direct influence of any one entity. Thus, despite Cleasby’s intentions for these images, when circulated, they perhaps unpredictably intra-act with the male gaze, staging a second misfit for Cleasby.

### **Misfits & The Fantasy of Stable Bodies**

When a particular intra-action misfits an element within its becoming, an opening for rhetorical incongruence occurs. For example, the image and the gaze are incongruent when the image of Cleasby does not necessarily conform or normalize in the way that the clinical gaze nor the male gaze requires. As the image of Cleasby comes into being with either the clinical or male gaze, it misfits. In one instance, the clinical gaze fails to intra-act with what would be expected as a sign of disability (e.g. wheelchair), therefore, the gaze and the image misfit, leading to an agential cut in which Cleasby becomes able, and therefore, misfit for the disabled bathroom. Similarly, because the disabled body typically cannot become sexy under the male gaze, the images of Cleasby’s stoma and ostomy misfit with the male gaze and enact an agential cut in which the images become both sexualized and disable, two agential cuts that are not simultaneously acceptable.



Misfitting occurs when particular entities co-articulate visually enacting a non-normalized body, be it disabled, able, sexy, or otherwise.

Furthermore, when images are transformed such that they become misfits, they come to stand out. Misfits do not normalize. Referring to a way of being in the world called “doing being ordinary” (Sacks, 1984), Garland-Thomson suggests that misfitting manifests when certain enactments do not do the ordinary. She elaborates,

A reasonable fit in a reasonably sustaining environment allows a person to navigate the world in relative anonymity, in the sense of being suited to the circumstances and conditions of the environment, of satisfying its requirements in a way so as to not stand out, make a scene, or disrupt through countering expectations (2011, p. 596).

Accordingly, Cleasby’s image gains attention as it does not satisfy the requirements of the gaze with which it intra-acts. Both the clinical and male gazes require a normalized body, and when such an image is not enacted with Cleasby, rhetorical dissonance transpires. She is criticized and shamed. She misfits.

Conversely, the notion of fitting helps to uncover how and why Townsend’s image becomes popular and influential. Her image, when intra-active with the clinical gaze, enacts a disabled body, and when intra-active with the male gaze of her husband, enacts a sexually acceptable body. In many ways she “satisfies the requirements of her environment” just enough by participating in a normalized activity (sunbathing) in the appropriate environment (on vacation, near a pool), that when her image intra-acts with the clinical gaze, it never fully becomes disabled. Instead, the image enacts an able, female, and sexualized body and identity for Townsend. Her ostomy only enacts IBD, but does not necessarily transform the image into that of a disabled person. As a former

model, the image of Townsend features her slim, tanned body – a body that current society accepts as sexual – and when the ostomy entangles with this sexualized body, the image transforms into a heroic and brave enactment. Notably, “the ideology of ability exerts enormous pressure on...whether a body is viewed as having sexual properties” and those who are agentially separated as disabled are rarely allowed to enact sexuality (Siebers, 2008, p. 163, 175). Unlike Cleasby, Townsend’s image becomes rewarded for staging a body that is at once fitting under the clinical gaze and the male gaze. Townsend fits.

When it comes to intra-actions in which visuals are involved, the gaze can become the tip of the spear that enacts cuts. Within enactments, the gaze becomes the powerful influence through which certain bodies become acceptable as disabled, able, sexual, etc., If and when different gazes conflict in their agential cutting, tension arises, transforming those images in ways that were not necessarily intended or anticipated.

As Garland-Thomson summarizes,

attending to the dynamics of misfitting and fitting urges us to cultivate the rich particularity that makes up embodied human diversity...Our experience of living eventually contradicts our collective fantasy that the body is stable, predictable, or controllable, creating misfits for all of us...The concept of misfitting shifts this model. The body is dynamic...sometimes it fits and at other points or moments, it does not (2011, p. 603).

No doubt, the body and images of bodies as stable is a “fantasy” that dissipates within an enactment framework. Images dynamically and often unpredictably fit in certain enactments and misfit in others. When analyses trace the agential cuts made possible through the vibrant actualization of visuals, the consequences of particular intra-actions emerge. Simply put, “the material particularity of encounter determines both meaning

and outcome” (Garland-Thomson, 2011, p. 598). Understanding the intra-actions of Townsend’s and Cleasby’s images in relationship with the male and clinical gazes helps to uncover how the images enact disability and sexuality as well as how the images become rhetorically divergent.

### **Visual Enactments & Rhetorical Inquiry**

Ultimately, the insights of this chapter not only contribute to a theory of enactments, but also suggest important implications for rhetorical inquiry. In this final section, I will connect the findings of this chapter to the theory-building goal of this dissertation and broader applications for studies within rhetoric, especially regarding visuals. In so doing, I hope to challenge future work to attune analyses to an intra-active model so as to better address the lives of visuals, as well as other entities, as they fit and misfit environments, contexts, and intra-active entanglements.

Taking images as events that are staged intra-actively and that become meaningful through agential cuts explores another dimension of enactments. As I argued in Chapter Three, focusing on the entity that especially encourages an agential cut, enables us to understand how certain enactments become rhetorically salient. Building on this notion, this chapter suggests that, like language, particular ways of seeing, stage specific cuts that come to fit or misfit. Bringing the insights of Barad, Garland-Thomson, and Gries together demonstrates another avenue that rhetorical scholars can pursue in an effort to attend more fully to lived experiences as well as diverse bodily and identity boundaries.

Much in the way rhetoricians are highly equipped to understand that role of language in entanglements and enactments, we too are well-suited to interrogate the

role of visual entities “become capable of coproducing all kinds of actions” (Gries, 2013, p. 69). Visuals, like language, and potentially a range of other entities, have the potential to contribute within intra-actions in important ways. Attuning our work to such agential capacity sheds light on the tensions that emerge when visual entities travel across gazes, through spaces, within time, and among diverse entities to enact identities, bodies, and rhetorical roles.

## CHAPTER 6: CONCLUSION

We may not choose our emotions or our attachments, but once we recognize them, we can cultivate them in certain ways – Jenell Johnson, *American Lobotomy: A Rhetorical History*

Each of chapters in this dissertation tells a different story, and each story uncovers a new reality regarding what it is like to be chronically ill, what it is like to have and be a body that attacks itself, and what it is like to wear an ostomy. Telling these stories brings to light the difficulty of living with diseases and conditions that might otherwise go unseen. I have been profoundly moved several times throughout this project by the gratitude and sense of relief expressed toward me and this project by the women I've worked with. Telling the stories of how these women live and how IBD and ostomies transform their lives has been inexplicably humbling, and caring enough to tell these women's stories is precisely the reason they have allowed me to do so.

This has been rewarding work, yet I know I have told only a few of the many stories and experiences worth telling about IBD, ostomies, autoimmunity, and patients' lived experiences more broadly. As Johnson poignantly writes,

There is something missing...tens of thousands of stories that will never be told. Those stories, and the faces, voices, and lives behind them, haunt this story, as they haunt all histories. Histories are intrinsically rhetorical. They select and interpret a certain reality for their audiences and each time something is made present, something is made absent by default (2015, p. 178).

While Johnson's sentiment here speaks to a type of historical story that this dissertation does not tell, the insight is relevant here. As must be the case in an enunciative analysis, I've selected particular stories to tell in this dissertation – stories of ostomies, stories of internal civil wars, stories of bathroom stalls – which at once makes certain insights

present and others absent. In collaboration with the women I observed and interviewed throughout this project, the stories I've aimed to tell seek to make visible the rich possibilities for both disciplinary insight and intervention in the domains of chronic illness, patienthood, embodiment, identity, and materiality.

However, as I conclude this dissertation, one important story remains to be told. That is, I must recognize my own entanglements and investments within this project. To do so, I begin by offering a series of reflections regarding my role as researcher in this project. Then, I reflect on the notion "entangled ethnography" – a methodology developed by anthropologists Ginsburg and Rapp (2013) – as it effectively describes the type of work I performed through this project. I hope to not only share important aspects of my approach but also spark a conversation within the rhetorical studies of health and medicine regarding the type of work we do and how we go about conducting that work.

### **Entangled Ethnographer**

Nearly ten years ago I was diagnosed with Crohn's disease, a type of IBD. And, like many of the women present in this dissertation, I have spent weeks in the hospital. I have longed for the ability to participate in activities like running, traveling, and going to parties with friends. With a swollen, bruised, and stitched belly, I have looked in the mirror and questioned my ability to look attractive. And, later the same day, I have been questioned by college professors, bosses, and even strangers for not looking sick. I have lost sleep over the potential of needing an ostomy, a technology that has often seemed an unfair reward for having a terrible disease. Each and every day I live and

experience many of the incredibly personal and intimate experiences described by the women I have worked with throughout this project.

The experiences shared, the boundaries agentially cut, and the enactments staged throughout this dissertation are not distant to me through some analytic screen. I am more than participant-observer, and my work requires more than recognition of my position and self-reflexivity. I did not simply attend and participate in activities during my ethnographic work, nor did I “objectively” write down the words of my interview participants. And, no doubt, my position, experiences, and identities play a significant role in the way I conduct my work and theorize about IBD, autoimmunity, and patient experience. I do not believe, however, that being an IBD patient should disqualify me or the findings of my work. In fact, having IBD has lead me down scholarly paths that would not otherwise have been possible. Simply put, my entanglements make me all the more equipped to conduct this research.

In offering these reflections, I hope my work draws attention to what I consider to be one of the key questions in rhetorical studies of health and medicine: how do we attend to our personal identities and entanglements? It is not uncommon for rhetoricians of health and medicine to study and theorize about conditions that scholars are personally connected to (for example, Segal, 2005; Johnson, 2015; Koerber, 2013). Often rhetoricians simultaneously occupy many roles in their work ranging from researcher to patient, caretaker, and in some cases, healthcare provider. Thus, our field must have more thorough and sustained methodological and theoretical conversations regarding how these positions specifically shape our work and our discipline. As many

other rhetoricians of health and medicine find themselves in similar entangled positions, I hope this project might start a more engaged conversation about how we attend to our identities and how we manage the insights they foster. To begin this conversation, I'd like to explore "entangled ethnography" as I consider it to be a particularly helpful and sustainable approach that rhetoricians of health and medicine might adopt to better attend to our own entanglements. In what follows, I will describe this methodology and argue for its value in simultaneously positioning researchers and examining others' lived experiences.

In their study of learning disability transition programs in New York City, Ginsburg and Rapp deploy what they call "entangled ethnography" as a way to transform "longstanding ethnographic methods: participant observation fieldwork, long-form qualitative interviews, life histories, and analysis of media and secondary documents" (2013, p. 187). Specifically, these authors use the term to describe being "simultaneously inside and outside the world [they] were studying through ties of kinship or caring" (p. 88). As parents of children with learning disabilities, Ginsburg and Rapp found themselves "productively caught up in the projects" they were conducting, "at times taking an active role in enabling the very activities [they] were examining" (p. 187). Ginsburg and Rapp's positions as both inside and outside the communities of their research poses interesting challenges to the knowledge claims possible through their ethnographic work. They readily admit that they "actively" participated in their own study at times, though they just as readily see this participation as a critically important part of their work.



Being researchers as well as co-participants challenged these ethnographers to continually examine how their roles influences those they were studying. Even more, Ginsburg and Rapp see entangled ethnographic work as part of an ethical commitment to their research participants. They explain,

Had we not been able to reflect on our own experiences, the research pathway might have never become apparent to us nor would we have been in a position to contribute new knowledge on this crucial but emergent area of concern. Our own entanglements helped us to understand the significance of this life transition [in a learning disability program] as an encompassing challenge to the ongoing project of disability rights, and not just for the particular circumstances for our own children (p. 193).

Here, we see Ginsburg and Rapp accomplishing many of the goals I also set out to achieve in terms of my own entangled positionality. That is, the authors “reflect” on their own experience and then use those reflections as a “position to contribute new knowledge” and to “understand the significance” of their work. Much the same, I aimed to reflect upon and draw on my own identities and experiences throughout this project in order to better understand the experiences of Julia, Gut Girl, Jessica Henderson, and every other patient observed.

What’s more, it is because Ginsburg and Rapp see the goal of their ethnography not only to learn about those they study, but also to actively intervene if and when possible, that their entangled ethnographic approach is particularly productive.

Entangled ethnography aptly describes how I see the work of this project as well. As an entangled ethnographer in the autoimmune disease community, I can leverage my expertise as an autoimmune patient, while recognizing the deep, complex challenges and circumstances of those who participate in my qualitative research, and ultimately

attempt to serve as an “ally in making public the realities of...human difference” (Ginsburg & Rapp, 2013, p. 196).

In advocating for an entangled ethnographic approach, I am also taking a position on autoethnography. Through I agree with Crawford and others, that “autoethnography provides another way in which researchers might productively account for their own experiences and identities” (1996, p. 161), I do not wish to fully (re)position myself as a part of my data. I consider an entangled ethnographic approach to most appropriately authorize me to conduct my ethnographic work by positioning myself as both insider and outsider, without completely submitting myself as an object of inquiry.

For example, in contrast to the entangled ethnography conducted by Ginsburg and Rapp, in which they accounted for and included their own participation in the research, their knowledge claims extend beyond their own experiences. They used their positions as a triangulating mechanism through which they understood and made claims about those they were studying. In contrast, an autoethnographic piece by Poulos (2010) is written exclusively as a creative narrative (except for a few final reflective paragraphs that serve as an afterword) about Poulos’s own experience with the subject matter under inquiry. Poulos does little to triangulate this experience with others’ experiences nor does he work to generalize the insight from this experience for a broader community.

Autoethnographic work undoubtedly has its place among viable methodologies, however, because I do not have an ostomy pouch, my status as an insider is only

partial. Even more, as is made manifestly clear in my personal life as well as in my data curation, autoimmune disease can and often is variable for each patient. Taking my own life as data without triangulating it in the way that entangled ethnography requires would be a risky step toward speaking for others – a move I earnestly work to avoid. Therefore, I advocate for entangled ethnography as a productive way to accomplish RHM's exigencies, without integrating my personal experiences into my work.

Throughout my exploration of autoimmune disease, I used entangled ethnography as a productive and ethical methodological framing for my research, to account my insider/outsider status, while attending to the diverse enactments and lived experiences of many others within the IBD community. Three years of entangled ethnographic observations and interviews nested within larger public cases enabled me to trace boundaries and binaries across a diverse range of patient experiences and contexts in an effort to theorize the best ways in which I might understand and theorize such rhetorical practices. Nevertheless, much work remains, especially in regards to technology, agency, materiality, and intervention. In the final section, I will describe what I believe are both limitations to this study and areas for future research. In so doing, I hope to foster additional work on lived experience, enactments, and boundary-making processes for patients as well as other stakeholders.

### **Future Directions**

One of the primary future directions for work that extends this dissertation is engagement with rhetoric of technology scholarship. At times, I have mentioned and briefly discussed insights that rhetoric of technology offers this study (see Chapter Three), yet these discussions have merely skimmed the surface of what more through

engagement with rhetoric of technology might produce. In particular, the notion of “technology” itself and the extensive work that has been done regarding embodiment and technology, particularly along the lines of posthumanism and digital spaces<sup>23</sup>, likely could build upon this enactment framework in a variety of domains including virtual reality (e.g., medical students can virtually practice surgical technologies, long-term hospitalization patients can virtually visit places beyond hospital walls, and patients with cognitive injuries can virtually practice moving injured or paralyzed limbs to stimulate brain activity) and medical technologies (e.g., 3D printed organs, smart tattoos, pacemakers, implantable RFID, and cochlear implants). Future work that synthesizes enactments more robustly with rhetoric of technology would surely enrich the work I’ve begun here.

Further, future scholarship that directly engages the role agency plays in enactments as well as the insights enactments bring to our definitions of agency seems particularly important as the field moves toward interventional goals. I have operated under Barad’s particular notion of agency (see Chapter Two), however, the insights of this dissertation have the potential to build upon and extend how our field theorizes agency, especially moving toward diffuse agency across intra-actions including nonhuman entities like ostomies. Ontological flattening, in particular, requires a distributed approach to agency that need be more fully theorized (see Chapter Three). In so doing, we have the opportunity to more fully engage with non-discursive entities that participate agentively within rhetorical contexts.

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<sup>23</sup> For example, Jack, 2016; Meloncon, 2013; Grabill & Pigg, 2012; Sun, 2009.

Finally, the questions I've asked and the issues I've raised over the course of this project have lead me into complicated theoretical terrain. Nevertheless, I'm confident that the enactment approach advocated for here lays the groundwork for more directly interventional work. In fact, this theoretical conversation affords a rich understanding of the lived experiences of IBD, ostomies, and autoimmunity, which in turn, highlights a variety of sites of intervention that could be pursued in future scholarship. For instance, the Julia controversy in Chapter Two exposes a place where the insight of rhetorical studies and technical communication could be incredibly helpful. The CDC clearly had a particular audience in mind with their Tips from Former Smokers campaign, which obscured the complex rhetorical territory of more diverse audiences within the IBD and ostomy communities. This dissertation illustrates the continued need for health organizations and other authoritative voices to more effectively and comprehensively engage with diverse patients and experiences. Indeed, one of the most pressing outreach avenues for this research is with organizations like the CDC and others I collaborated with during my ethnography.

Moreover, during observations and interviews, I noticed a variety of communicative practices in which the insights of my work could be useful. Patients often expressed concerns over the ways healthcare providers assumed boundaries of the body, especially in misplacing control and agency with sentiments like: "your body failed you, therefore you need an ostomy" or "changing your diet might help cure your IBD." Too, society's normalized sense of what certain bodies and identities should look like and which practices are acceptable for particular people identifies another space

where I feel the findings of my work could improve patient experiences and outcomes. I hope through continued inquiry into the domains of IBD and autoimmunity, as well as sustained collaboration with organizations and patient groups, I might be able to develop a website or at the very least, a series of artifacts (e.g., infographics, fact sheets, role play activities) to help patients understand and navigate these problematic situations. It's clear that patients are gathering in digital spaces in order to help each other succeed in a variety of practices and situations, therefore, I hope these insights would enrich those conversations.

In the end, I hope this project sparks a variety of conversations in rhetorical studies and technical communication regarding the type of work we do and how we go about conducting such work, as well as, what assumptions we hold regarding divisions and boundaries and how we might attune our analyses to more comprehensively engage with lived experiences within health and medicine and beyond. With this dissertation, I have attempted to tell stories that at once re-articulate duality and boundary-making practices and transform the approaches we take in rhetorical studies. As Mol reminds us, "there are a lot of ways to live...and daily life is what, when it comes to it, matters most to people" (2002, pp. 181 & 184). My goal was and continues to be strengthening our capacity to conduct entangled work, attend to lived experience, and find ways to intervene. Expanding our theories and methodologies to make way for the diversity of everyday life seems like an excellent place to start.

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## APPENDIX A: INTERVIEW QUESTIONS

The following includes a list of preliminary interview questions used throughout this study. Additional follow-up questions were asked per individual interviews.

1. Please describe your history with IBD and diagnosis.
2. What types of treatments have you considered or used since your diagnosis?
3. Please describe your experiences with selecting these treatments?
4. What kind of conversations did you and your healthcare provider have about your treatments, specifically your ostomy or j-pouch?
5. What other resources did you consult in selecting a treatment or understanding how a treatment may impact you and your life?
6. What changes, if any, have your ostomy or j-pouch require in your:
  - a. Social life
  - b. Everyday routine
7. How do you feel about your body and appearance in general?
8. What would you consider your most positive feature of your appearance/body?
9. What would you consider your most negative feature of your appearance/body?
10. What factors, if any, do you think affect how you think and feel about yourself?
11. In what ways, if any, do you think your ostomy or j-pouch has changed how you view yourself and your body?

## APPENDIX B: SURVEY QUESTIONS

The following is a complete list of survey questions. This survey was sent out via various social media (e.g., Reddit, Facebook) and health advocacy groups within IBD and ostomy communities. In total 103 responses were obtained with this survey. Importantly, the results of this survey were not directly presented in this dissertation, however, I've no doubt the findings influenced other portions of this study.

1. Please indicate your age
  - a. < 20 years old
  - b. 20-29 years old
  - c. 30-39 years old
  - d. 40-49 years old
  - e. 50-59 years old
  - f. 60-69 years old
1. Please select your gender.
  - a. Female
  - b. Genderqueer/ Androgynous
  - c. Intersex
  - d. Male
  - e. Transgender
  - f. Transsexual
  - g. Cross-dresser
  - h. Female-to-male
  - i. Male-to-female
  - j. My identity was not listed (please specify) x
2. What is your highest level of education?
  - a. Did not complete high school
  - b. High school/GED
  - c. Some college
  - d. Associate's degree
  - e. Bachelor's degree
  - f. Master's degree
  - g. Advanced graduate work or Ph.D.
  - h. Other (please specify)
3. What is your current marital status?
  - a. Single, never married
  - b. Married or domestic partnership
  - c. Separated
  - d. Divorced
  - e. Widowed

4. Please select all of the following that apply to you and your chronic illness.
  - a. Crohn's disease
  - b. Ulcerative colitis
  - c. J-pouch, S-Pouch, K-Pouch
  - d. Ostomy
5. Please select the answer that most accurately describes when you were initially diagnosed with IBD.
  - a. Less than a month ago
  - b. Within the last 6 months
  - c. 6-12 months ago
  - d. More than 1 year ago
  - e. More than 5 years ago
  - f. More than 10 years ago
  - g. I have not been diagnosed yet
6. Please select the answer that most accurately describes how long you have had a medical technology for IBD (i.e., j-pouch, ostomy).
  - a. Less than a month ago
  - b. Within the last 6 months
  - c. 6-12 months ago
  - d. More than 1 year ago
  - e. More than 5 years ago
  - f. More than 10 years ago
  - g. I do not have any medical technologies for my IBD
  - h. I do not currently have a medical technology for my IBD but I have a surgery scheduled within the next year
  - i. I do not currently have a medical technology for my IBD but it is likely that I will have one within the next 5 years
  - j. I used to have a medical technology for my IBD but I no longer do
7. Is your medical technology permanent?
  - a. Yes
  - b. Maybe
  - c. I don't know



8. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
My life has changed significantly since I received my medical technology.				
I am happy that I have a medical technology.				
Having a medical technology has improved my quality of life.				
Having a medical technology has improved my overall health.				

9. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
My life has changed significantly since I was diagnosed with IBD.					
I am happy now that I have been diagnosed with IBD.					
Being diagnosed with IBD has improved my quality of life.					

10. From 1 (most information) to 7 (least information) please rank the sources in order of how much information you receive from them regarding your IBD.

- \_\_\_\_\_ Gastroenterologist
- \_\_\_\_\_ Family member
- \_\_\_\_\_ Support group
- \_\_\_\_\_ Another healthcare provider (please specify)
- \_\_\_\_\_ Website (please specify)
- \_\_\_\_\_ Social media site
- \_\_\_\_\_ Other (please specify)

11. From 1 (most information) to 7 (least information) please rank the sources in order of how much information you receive from them regarding your ostomy or j-pouch.

- \_\_\_\_\_ Gastroenterologist
- \_\_\_\_\_ Family member
- \_\_\_\_\_ Support group
- \_\_\_\_\_ Another healthcare provider (please specify)
- \_\_\_\_\_ Website (please specify)
- \_\_\_\_\_ Social media (please specify)
- \_\_\_\_\_ Other (please specify)

12. From 1 (most information) to 7 (least information) please rank the sources in order of how much support you receive regarding your IBD.

- \_\_\_\_\_ Gastroenterologist
- \_\_\_\_\_ Family member
- \_\_\_\_\_ Support group
- \_\_\_\_\_ Another healthcare provider (please specify)
- \_\_\_\_\_ Website (please specify)
- \_\_\_\_\_ Social media (please specify)
- \_\_\_\_\_ Other (please specify)

13. Which complications have you experienced with your ostomy or j-pouch?

- a. I have not experienced any complications
- b. Discomfort or pain
- c. Difficulty in engaging in social activities
- d. Medical complications (pouchitis, failure, allergic reactions, etc.)
- e. Social stigma
- f. Changes in body image
- g. Emotional or psychological distress
- h. Other (please specify)

14. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)	This statement does not apply to me. (6)
I consider my j-pouch part of my identity.						
I consider my ostomy part of my identity.						
When I describe myself, I include my j-pouch.						
When I describe myself, I include my ostomy.						
Receiving a j-pouch has changed how I see myself.						
Receiving an ostomy has changed how I see myself.						
Receiving a j-pouch has negatively affected my self-perception.						
Receiving an ostomy has negatively affected my self-perception						

15. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)	This statement does not apply to me. (6)
I consider my j-pouch part of my body.						
I consider my ostomy part of my body.						
Receiving a j-pouch has changed my body image.						
Receiving an ostomy has changed my body image.						
When I look at my body, my j-pouch is the first thing I notice.						
When I look at my body, my ostomy is the first thing I notice.						
Receiving a j-pouch has changed how I dress.						
Receiving an ostomy has changed how I dress.						



16. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	This statement does not apply to me. (5)
I consider my IBD part of my identity.					
When I describe myself, I include my IBD.					
Being diagnosed with IBD has changed how I see myself.					
Being diagnosed with IBD has changed how I think about myself.					
When I look in the mirror, the first thing I think about is my IBD.					
IBD has changed my body image.					
IBD has affected my self-perception.					
IBD has affected my self-esteem.					

17. How has your IBD changed your body image?

- a. IBD has not changed my body image.
- b. IBD has negatively affected my body image.
- c. IBD has positively affected my body image.
- d. I prefer not to answer.

18. How has your ostomy changed your body image?

- a. I do not have an ostomy.

- b. My ostomy has not changed my body image.
- c. My ostomy has negatively affected my body image.
- d. My ostomy has positively affected my body image.
- e. I prefer not to answer.

19. How has your j-pouch changed your body image?

- a. I do not have a j-pouch.
- b. My j-pouch has not changed my body image.
- c. My j-pouch has negatively affected my body image.
- d. My j-pouch has positively affected my body image.
- e. I prefer not to answer.

20. How (if at all) has being diagnosed changed your life? (short answer)

21. How (if at all) has receiving a j-pouch changed your life? (short answer)

22. How (if at all) has receiving an ostomy changed your life? (short answer)

23. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Agree (4)	Strongly Agree (5)	Does not apply to me. (6)
Being diagnosed with IBD has changed how my doctor and I communicate.						
Being diagnosed with IBD has changed how my family and I communicate.						
Being diagnosed with IBD has changed how my coworkers and I communicate.						



Being diagnosed with IBD has changed how my friends and I communicate.						
Being diagnosed with IBD has changed how my partner and I communicate.						

24. To what extent do you disagree or agree with the following statements:

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Agree (4)	Strongly Agree (5)	Does not apply to me. (6)
Receiving a j-pouch has changed how I communicate with my doctor.						
Receiving an ostomy has changed how I communicate with my doctor.						
Receiving a j-pouch has changed how I communicate with my family.						
Receiving an ostomy has changed how I communicate with my family.						
Receiving my j-pouch has changed how I communicate with my coworkers.						
Receiving my j-pouch has changed how I communicate with my friends.						
Receiving my ostomy has changed how I communicate with my friends.						

Receiving my j-pouch has changed how I communicate with my partner.						
Receiving my ostomy has changed how I communicate with my partner.						

25. Have you ever named your ostomy?

- a. Yes
- b. No
- c. Prefer not to answer

26. Have you ever named your j-pouch?

- a. Yes
- b. No
- c. Prefer not to answer

27. After receiving your j-pouch or ostomy, how likely are you to do the following activities?

	Very Unlikely (1)	Unlikely (2)	Somewhat Unlikely (3)	Likely (4)	Very Likely (5)	This statement does not apply to me. (6)
Ask for a promotion at work.						
Try something new.						
Take a vacation or travel.						
Go shopping.						
Introduce yourself to someone new.						
Tell others about your chronic illness.						
Apply for a new job.						
Go to the gym.						
Socialize with my friends and/or family.						
Go on a date.						

28. Which of the following do you use as coping strategies for your IBD?
- I don't feel like I need to use coping strategies.
  - Call a friend or family member.
  - Sleep.
  - Work out.

- e. Eat.
  - f. Avoid social activities.
  - g. Engage in social activities.
  - h. Attend a support group.
  - i. Engage in social media sites related to IBD.
  - j. Engage in other social media sites.
  - k. Craft.
  - l. Tell others about IBD.
  - m. Other (please specify)
29. Which of the following do you use as coping strategies with your j-pouch or ostomy?
- a. I don't feel like I need to use coping strategies.
  - b. Call a friend or family member.
  - c. Sleep.
  - d. Work out.
  - e. Eat.
  - f. Avoid social activities.
  - g. Engage in social activities.
  - h. Attend a support group.
  - i. Engage in social media sites related to IBD.
  - j. Engage in social media sites.
  - k. Craft.
  - l. Tell others about IBD.
  - m. Other (please specify).

## CURRICULUM VITAE

### Education

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- Ph.D. English, Professional and Technical Writing** 2017  
Department of English  
University of Wisconsin-Milwaukee
- M.A. English, Professional and Technical Writing** 2014  
Department of English  
University of Wisconsin-Milwaukee
- B.A. English, Honors, *summa cum laude*** 2013  
Department of English  
Honors College  
University of Wisconsin-Milwaukee

### Publications

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- Card, D.J., Kessler, M.M., Graham, S.S. (forthcoming). Representing without representation: A feminist new material exploration of patient experience in federal pharmaceuticals policy. In A. Booher & J. Jung (Eds.), *Feminist Rhetorical Science Studies: Human Bodies, Posthuman Worlds*. Carbondale, IL: Southern Illinois University Press.
- Kessler, M.M. (advanced contract). Autoimmunity and Negotiations of Self: An Enactment Approach to Health and Medicine. In L. Meloncon, S.S. Graham, J. Johnson, J. Lynch, and C. Ryan (Eds.) *The Rhetoric of Medicine As/Is: Theories and Concepts for an Emerging Field*.
- Kim, S., Graham, S. S., Ahn, S., Olson, M. K., Card, D. J., Kessler, M. M., DeVasto, D. D., Roberts, L. R., Bubacy, F. A. (2016). Correcting biased Cohen's Kappa in NVivo. *Communication Methods and Measures*. 10(4), 217-232.
- Graham, S.S., Kessler, M.M., Card, D.J., Olson, M., Ahn, S., Sang-Yeon, K. (2016). Conflicts of interest among patient and consumer representatives to FDA Drug Advisory Committees. *Annals of Internal Medicine*. 165(8), 606-607.
- Kessler, M. M. (2016). Wearing an Ostomy pouch and becoming an ostomate: A kairological approach to wearability. *Rhetoric Society Quarterly*, 46(3), 236-250.
- Graham, S. S., Harley, A., Kessler, M. M., Roberts, L., DeVasto, D., Card, D. J., ... & Kim, S. Y. (2016). Catalyzing Transdisciplinarity A Systems Ethnography of Cancer-Obesity Comorbidity and Risk Coincidence. *Qualitative Health Research*, 1049732316656162.

- Kessler, M. (2015). Review of Rhetoric in the Flesh: Trained Vision, Technical Expertise, and the Gross Anatomy Lab. by T. Kenny Fountain New York, NY: Routledge, 2014. *Communication Design Quarterly Review*, 3(4), 91-96.
- Klos, L. A., Greenleaf, C., Paly, N., Kessler, M. M., Shoemaker, C. G., & Suchla, E. A. (2015). Losing weight on reality tv: A content analysis of the weight loss behaviors and practices portrayed on The Biggest Loser. *Journal of Health Communication*, 20(6), 639-646.
- Kelly, A. R., Miller, C. R., Fanning, S. N., Kessler, M. M., Graham, S. S., & Card, D. J. (2015). Expertise and data in the articulation of risk. *Poroi*, 11(1), 1-9.
- Klos, L., Greenleaf, C., Cass, T., Paly, N., & Kessler, M. (2014). Pre-health professionals' attitudes about obesity before and after an obesity and weight management course. *Journal of Nutrition Education and Behavior*, 46(4), S129-S130.
- Klos, L., Risse, V., & Kessler, M. (2012). To weigh or not to weigh: An examination of the relationship between self-weighing behavior and body image among adults. *Body Image*, 9(4), 551-554.

### **Conference Presentations**

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- Kessler, M.M. (2017) Toward advocacy and intervention in health and medicine. Association for Teachers of Technical Writing. Portland, OR.
- Kessler, M.M. (2016). Beyond a rhetoric of patient deficit: Using actor-network theory to diagnose the problem of prescription drug labels. Association for the Rhetoric of Science, Technology, and Medicine. Philadelphia, PA.
- Kim, S., Graham, S. S., Ahn, S., Olson, M. K., Card, D. J., Kessler, M. M., DeVasto, D. D., Roberts, L. R., Bubacy, F. A. (2016). Bias correction for overestimated Kappa in NVivo. Paper presented at the 66th annual convention of the Inter-national Communication Association. Fukuoka, Japan.
- Kessler, M.M. (2016). Wearing an ostomy pouch and becoming an ostomate: A kairological approach to wearability. Modern Language Association Convention. Austin, TX.
- Kessler, M.M. (2015). Wearing an ostomy pouch and becoming an ostomate: . Toward a rhetoric of wearability. National Communication Association Convention. Las Vegas, NV.
- Graham, S.S., Kim, S.-Y., Kessler, M.M., Card, D.J., DeVasto, D.M., Ahn, S., Olson, M., Bubacy, F., Roberts, L. (2015). The Effects of Differential Inclusion on FDA Pharmaceuticals Policy Deliberation. Seventh International Conference on Science in Society. Chicago, IL.



- Kessler, M.M. (2015). Terminal node problems: An actor-network analysis of prescription drug labels. Association for Teachers of Technical Writing. Tampa, FL.
- Kessler, M.M., Graham, S.S., Card, D.J., Keith, W.M., Anderson, C. (2014). Packaging risk of innovation adoption: A rhetorical ethnography of continuing medical education. Association for the Rhetoric of Science and Technology. Chicago, IL.
- Graham, S.S., Card, D., Kessler, M.M., Keith, W.M., Kim, S-Y., & Hartke D.M. (2014). The effects of differential inclusion on FDA pharmaceuticals policy deliberation. National Communication Association. Chicago, IL.
- Graham, S.S., Keith, W.M., Kessler, M.M., Card, D., Kim, S-Y. (2014). A Data-Driven Approach to Genre Analysis: Statistical Typification and Argumentative Outcomes Modeling Association for Teacher's of Technical Writing. Indianapolis, IN.
- Klos, L.A., Greenleaf, C., Paly, N.A., Kessler, M.M., Faraiq, A., Bork, E., Kobert, M., & Packard, D. (2014). Weight loss trajectories on popular reality television shows: a content analysis of The Biggest Loser. Poster presentation at the annual meeting of the Society for Behavioral Medicine, Philadelphia, PA.
- Klos, L., Greenleaf, C., Paly, N., Kessler, M., Shoemaker, C., & Suchla, E. (2013). Losing weight on reality TV: a content analysis of weight loss behaviors and practices portrayed on The Biggest Loser. Paper presented at the annual meeting of the International Society for Behavioral Nutrition and Physical Activity, Ghent, Belgium.
- Klos, L., Kessler, M., & Wheeler, L. (2013). Weight and weddings: a content analysis of diet and physical activity-related messages within bridal magazines. Poster presented at the annual meeting of the International Society for Behavioral Nutrition and Physical Activity, Ghent, Belgium.
- Kessler, M.M., Klos, L., Wheeler, L. (2013). Weight and weddings: A content analysis of diet and physical activity-related messages within bridal magazines. University of Wisconsin-Milwaukee Undergraduate Research Symposium.

## Teaching Experience

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### Instructor of Record | University of Wisconsin-Milwaukee

- Writing, Speaking, and Technoscience in the 21<sup>st</sup> Century | English 310
- Health Science Writing } English 207
- Business Writing | English 2015

## **Research and Industry Experience**

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<b>Research Affiliate</b> Public Engagement and Science Communication University of Wisconsin-Milwaukee	<b>2013 - Present</b>
<b>Technical Writing Intern</b> Facilities Operations Services Training The Walt Disney Company	<b>2016</b>
<b>Research Analyst</b> Responsive Writing Solutions	<b>2016</b>
<b>Undergraduate Research Fellow</b> Body Weight and Shape Laboratory University of Wisconsin-Milwaukee	<b>2010 - 2013</b>

## **Professional Service**

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<b>Graduate Student Representative</b> Medical Rhetoric Standing Group Conference on College Composition and Communication	<b>2015 - 2017</b>
<b>Graduate Student Representative</b> English Department University of Wisconsin-Milwaukee	<b>2015 - 2017</b>

## **Honors and Awards**

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<b>Advanced Opportunity Fellowship</b> Graduate School University of Wisconsin-Milwaukee	<b>2014, 2015, 2016</b>
<b>ATTW Methods Workshop Scholarship</b> Association for Teachers of Technical Writing	<b>2016</b>
<b>Chancellor's Graduate Student Award</b> University of Wisconsin-Milwaukee	<b>2013 - 2014</b>
<b>Chancellor's Academic Leadership Award</b> University of Wisconsin-Milwaukee	<b>2010 - 2013</b>