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Obstacles, Transitions, & Perspectives: An In-Depth Look at the Spectacle of Deviant Bodies

A thesis

presented to

the faculty of the Department of Communication

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Master of Arts in Professional Communication

by

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May 2015

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spectacle; stigma

ABSTRACT

Obstacles, Transitions, & Perspectives: An In-Depth Look at the Spectacle of Deviant Bodies

by

Taylor C. Manning

This autoethnographic study is an attempt to humanize the deviant behaviors and bodies of eating disordered and physically disabled persons in Western culture. The narratives included within are from the author's own personal experiences as a heterosexual, eating disordered, disabled man. The narratives unfold chronologically in ways that explicate the transitions between identities and the onset and acceptance of each. The goal of this study is to unveil aspects of both eating disorders and disabilities as they relate to the locus of attention surrounding individuals that experience them. The researcher argues that the attention a deviant body draws from others may form the deviant body as a *spectacle* that can be either *eagerly sought* after, or *reluctantly ascribed* to, the individual that holds it.

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CHAPTER 1

ACHIEVING SPECTACLE THROUGH BODILY DEVIANCE

Many events in my life have led me to place great value on the study of human communication. The wealth of experiential knowledge we each possess as individuals would be meaningless if we were unable to share it with one another. This work, in its entirety, is a bucket pulled from the well of my personal experiences as an eating disordered, permanently disabled, heterosexual male. My goal is to share with readers very intimate and vivid recollections of my past that are most germane to discussions in the field of communication.

My argument is that eating disorders serve a communicative function beyond the simple pursuit of the ideal body, and that disability is far more than just a physical state of being. Both eating disorders and my disability have served as identities that I have used to my advantage at different stages in my life; each has served to elevate me as a spectacle in different ways. The concept of spectacle will be referred to throughout this text as the principle connecting factor between my identities.

Body as Spectacle

The term Spectacle is most commonly used to refer to visual artwork such as film, sculptures, paintings and tattoos (Horine, 2008). Though the term “spectacle” itself is very common, its application to the body as a form of art requires some sculpting. The most useful explanation of spectacle as it will be discussed in my thesis comes from Horine’s (2008) analysis of tattoos as a body modification that signifies culture. Horine’s (2008) explanation of spectacle is the most definitive:

“Spectacle involves a visual appearance that is the *locus of all attention*, a site that draws all eyes. Not only can spectacle *be* a person or an object, it blurs the boundary between them. As spectacle a person can become an object” (p. 19).

Like tattoos, more natural and less voluntary bodily deviances such as extreme thinness or physical disabilities can elevate an individual as a spectacle to be judged as artwork. This thesis will discuss the positive and negative aspects of “spectacle” as it can be both voluntary (e.g., tattoos, extreme thinness) and involuntary (e.g., bodily deviance, amputations). In my early adolescence and teen years I was overweight, and I was ascribed unwanted spectacle as the fat boy in class. As an eating disordered male, I was eager for spectacle; I worked voluntarily at creating my newly-thin body as a spectacle to be the focal point of everyone’s attention. In present day, as an amputee, I face involuntary, ascribed spectacle every time I enter the public sphere, and although I make efforts to reduce it, the intrusive gaze of others is unavoidable.

Eating Disorders as Eager Spectacle

My eating disorders began as an obsessive fixation on my weight and restrictive eating behaviors, but they evolved into an identity that I believe granted me the spotlight or spectacle that I was truly starving for. What I thought to be a good diet/exercise regimen as a boy transformed into what I now know was Anorexia Nervosa, which I lovingly refer to as Ana. Anorexia Nervosa is rarely diagnosed in men, because in western culture concern with one’s own weight is considered a feminine notion. It is for that reason I was unable to gain the recognition I wanted from Ana alone.

I removed myself from the ascribed spectacle of being largely overweight and positioned myself closer to the socially accepted thin-ideal. The recognition one receives from weight loss

is ephemeral, and I hungered for my peers' attention more than anything. Attempting to make my newly acquired thinness discussion fodder amongst my peers, I began to ritualistically binge-eat high calorie foods in public to shock them and then recluse to the closest private place to vomit. I knew even then that I was forging a new identity through the disorder Bulimia Nervosa, which I lovingly refer to as Mia.

Ana and Mia were my closest loves for years. I used them to communicate to my peers that I too was disgusted by my former obesity, and I was given a wealth of attention for my hard work. Even mere acquaintances in my small Southern Appalachian high school were led to believe that I was struggling *from* eating disorders, but I argue that I was giving a voice to my struggle *through* my eating disorders. Without Ana and Mia I would have been simply a skinny guy, but with them I became a poetically tortured soul with the ability to captivate audiences.

Disability as Ascribed Spectacle

Captivation of attention is the prime characteristic of spectacle, but the valence that I place on spectacle, like my identities themselves, has evolved with age. I lost the need to maintain my eating disordered identities whenever I received the ascribed spectacle of physically disabled. Unlike the spectacle I became through my eating disorders, the attention that I receive from my amputated leg is unwelcomed because I have no control over its solicitation, and it is viewed by others as a limitation of my ability regardless of context. In a sense, the onset of my identity as a disabled man greatly reduced the symptoms of, and value that I placed on, my eating disorders.

My disabled identity also communicates messages to my peers, but it does so without requiring any effort on my part. In fact, all of my efforts are steadfastly focused on concealing it

from my peers and the public at large. I carefully controlled how and to whom I revealed the fact that I lived with Ana and Mia, and I believed myself to also be in control of the way my peers would receive it. Conversely, my disability constantly begs the pardon of those who encounter me, and my awareness of that continually brings me discomfort.

The spectacle that my identities create, through reifying my marginalized status are deeply seated in my privileged status as a heterosexual, white, male. Before writing through my past experiences for autoethnographic analysis, I had never truly considered how my masculinity could affect the way that people interpret my eating disorders or disability. It was through reading the works of others that I came to understand how my masculinity likely prevented my doctors from diagnosing me with eating disorders, and why my leg amputation is often mistakenly assumed by others to have come from valiant, God-loving, military service. The former maintained my privileged status as a male, even while working against me in the long run, and the latter elevated my specific subcultural status among males as a perceived military man.

Disability Stigma's Mediation of Spectacle

Disability stigma encompasses a great deal of limiting stereotypes and negative attitudes that are directed at persons with disabilities. "Passing," which I will discuss in more detail later, is a term associated with a disabled individual's ability to mitigate stigma by appearing to be able-bodied. The ability to "pass" can be extremely valuable because by appearing as able-bodied, a disabled person can avoid becoming a stigmatized spectacle in public. Whereas an individual's eating disorders may be used as a means to gain eagerly sought after position of spectacle, the stigma of disability and lack of control one has over revealing their bodily difference to others places them reluctantly in a position of ascribed spectacle. There are no

rituals necessary for one to solicit spectacle as a disabled person; there are, however, many rituals that disabled individuals use to avoid having it ascribed to them.

Writing Through Experiences as Research

This essay is written from the critically-reflexive first person perspective. The autoethnographic method has the ability to give voice to minority groups that otherwise would have no real voice in the marketplace of ideas (Goodall, 2004). The method in this particular case serves as a deep dive into my own experiences while living as an eating disordered, disabled, heterosexual male. The personal narratives are woven with and compared to information drawn from relevant scholarship that is intended to help readers conceptualize the significance of events.

This essay revolves around discussions of masculine embodiment, identity formation, and spectacle. My overall intention is to share intimate and revelatory experiences in order to humanize eating disordered males and persons with physical disabilities while deconstructing long-held societal misconceptions about each; in hope, doing so will facilitate readers' critical examination of their own perceptions of these marginalized groups.

Critics of the autoethnographic method may argue that this essay's grounding in a single individual's experiences reduces credibility or authenticity and that it offers less utility as a form of research for that reason; but as Bochner (2001) states:

“The question is not whether authenticity is possible but whether the ideal of authenticity is good and useful and whether it is an ideal to which we should aspire. It's not an empirical question; it's a moral and ethical one”(p.147).

Morals and ethics are both constructs drawn from human emotion; such things could never be examined in depth through sample-sizes or mathematical equations. Autoethnographic research creates a narrative journey for readers to embark on via the lived experiences of informed scholars from marginalized populations. The style of writing I use is atypical to the jargonized language of the social sciences, and is intended it to create an emotional connection between reader and author that fosters more critical examinations and thoughtful processing of the topic being discussed (Boyle & Parry, 2007). In present day, social media and internet platforms have allowed for a great deal of individuals to share their own personal lives with the masses, and for that reason the autoethnographic approach may be more easily accepted by younger readers and more easily employed by younger researchers (Boyle & Parry, 2007, p.186).

Autoethnographic research reveals a great deal of personal information about the author, and in turn can have consequences for them professionally and socially (Ellis, Adams & Bochner, 2011). I have given due process in safeguarding the identities of individuals that are implicated in my narratives by referencing them through pseudonyms, and as a consequence of discussing my personal life and cultural environment some of my closest relatives and friends are at times portrayed in a negative light. Regardless of the value I place on relationships with those included in this research, relational ethics are essential to consider.

Beyond considering the effects on others whom are implicated in one's research—the researcher must give due care to safeguarding one's own self in the process of conducting autoethnography (Carpenter, 2010). My personal narratives are used throughout this thesis to reveal dark, troubling, stigmatizing and often painful happenings in my past. Writing these narratives required me to reveal my insecurities, doubts, fears, and shortcomings, not only to those who read them, but to myself as well. I chose to write without subscribing to the fear of

social judgment, ironically such fears are what catalyzed the formations of the identities that I discuss.

Too often, academics take for granted their level of insight into their own cultural experiences; it was easy at times to misconstrue the fact that I am intimately aware of the struggles involved with living with eating disorders and disability to mean that it is common knowledge. I believe my experiences may serve to help friends and family improve the quality of interactions that they have with others like myself, but it is not my intention to suggest that my experiences and outlook will be wholly representative of theirs. Rather, my intention is to illuminate how very different human experiences can be, and how they are all valuable in humanizing our diversities.

When it comes to the issue of using autoethnographic inquiry to investigate my own disability, Scott (2013) rightly warns against claiming insider status to the culture because the disabled community is extremely diverse and classifies a myriad of conditions both mental and physical. Claiming the ultimate and all-encompassing role of disability is foolish because no such role exists, and I could never conceptualize even my own eating disorders and disability in their entirety. It will take a multitude of bold researchers that are willing to put themselves under the magnifying glass in order to examine and assemble even the smallest aspects of their experiences into a useful whole.

Autoethnography is especially useful when investigating eating disordered males. The plethora of academic literature surrounding body dysmorphic and eating disordered behavior is vastly limited in terms of describing the lived experiences of males who suffer from them (Strother, Lemberg, Stanford & Turberville, 2012). The overwhelming majority of research has focused on the effects, treatment, and recovery from eating disorders in female sample

populations; often men are only included in such studies as a comparison or control group to better facilitate understanding of female sufferers (Bjork, Wallin, Petersen, 2012, p. 460-461). The common characterization of the disorders as feminine often leads to heterosexual, eating disordered males being misconstrued as homosexuals who, similar to women, are believed to have developed eating disorders “as a consequence of their aesthetic-driven culture” (Drummond, 2005, p.287). Through my research, I have found no first-person scholarship concerning heterosexual males with eating disorders, and qualitative research that incorporates multiple persons’ narratives falls short of investigating eating disorders or disabilities in such depth.

This work is based on my own subjective experiences and will not be wholly representative of the experiences of others who identify as eating disordered or physically disabled. The transitions between my eating disordered and disabled identities are laid out in chronological order, and each narrative is preceded by a literature review of relevant scholarship as it relates to each individual experience. The eating disordered and disabled identities are narrated in slightly different voices, as I experience being a disabled man through a much more informed and educated lens than I did my eating disorders. The narratives of my eating disordered identities explain a time when I was markedly more insecure, lonely, embarrassed, and lacked the language to fully express or understand what I was going through at the time. The narratives of my disabled identity are of more recent experiences that I have had throughout many years of studying sociology and communication.

The narratives used throughout this autoethnography were all written from my current recollections of experiences that I have had in the past. Although I did refresh my memory by reading through some of my old personal journals, none of the passages in this thesis are quoted

verbatim from them. Each narrative is representative of a different aspect of my bodily history that I felt germane to the topics of spectacle and identity. Throughout the process of creating these narratives, I worked to also keep a small journal of my research reflections on the method as I experienced it, and each of those reflections can be found at the end of chapter four.

Not everyone who lives with eating disorders or disabilities follows the same academic path that I have, and I have been lucky enough to use my experiences to expand my field of study. Luckily, I have worked with the strong support and encouragement of my professors, and the wealth of resources from academics with similar interests available through my university's library. I am not the first person to begin an academic discussion on the topic of eating disordered identities, and in order to better understand the claims that I make it is important to know what has been said by those who have come before me. In order to enhance comprehension of the following section it is important to reiterate that research is scant in regards to heterosexual males with eating disorders, and my narratives are entering a long-standing discussion that has almost entirely focused on the effects of eating disorders for teenage and adult women (Strother et al., 2012).

CHAPTER 2

The Large Body: Research of Eating Disorders

Western culture is largely believed to be home to and responsible for the birth of eating and body dysmorphic disorders. Anorexia nervosa (Ana) and bulimia nervosa (Mia) are the two most prevalent and widely recognized eating disorders (EDs) in the United States; they are classified in the DSM-IV as psychological disorders. Sigmund Freud was the first to diagnose the disorders as what he believed to be an extension of hypochondria (Lager & McGhee, 2003). Now, nearly a century after Freud's initial diagnosis, the disorders have been reconstructed and given their respective names, yet they are still considered and treated as forms of mental illness.

Ana and Mia are assumed in present day to be predominantly affecting white, middle-class, and upper-class females in the United States, but that assumption is giving way to research findings that BN and AN are affecting women world-wide through online social media forums as well (Wolf, Theis, & Kordy, 2013). These disorders are indicative of an identity conflict for their sufferers, and though they are mainly discussed in the languages of medicine and psychology, there is a more cultural and personal side to the disorders. Rich (2006) argues that they are socially constructed and maintained. The idea that the eating disordered behavior is socially constructed and maintained lends to claims that exposure to dramatized accounts of EDs and peers who suffer from them could increase one's likelihood of developing an ED (Pascual, 2001).

Some argue that sufferers of EDs are motivated internally by: "rebellion, selfishness, perfectionist tendencies, feelings of inadequacy and pressure from society"(Lager & McGhee, 2003, p.266), but research provides support for the view that EDs are spread in a socially communicable way (Rich, 2006). Not only are EDs often suggested to be negative effects of

globalization and the pervasive expansion of western media culture, but Ana and Mia also have evolved into their own subcultures, and sufferers are now using the internet as a means to maintain their disordered identities (Wolf et al., 2013). The most outstanding difference between offline recovery groups and online communities is related to the invention of online negative enabling support groups or ONESG (Haas, Irr, Jennings & Wagner, 2010). Proliferation of such websites has caused a public outcry for censorship, and questions concerning freedom of expression have been raised in response. Many sufferers believe EDs to be not only a lifestyle but a physically expressed and communicated act of protest.

Communicating Through Eating Disorders

Much has been written about the power of EDs as communication tool. As the disorder mainly affects women, they are often thought to be a communicative vessel for women to protest female objectification and control in western society (Cooks, 2009, p.102; Holte, Nordbo, Espeset, Gulliksen, Skarderud, 2006, p. 561; Lager & Mcghee, p.291; Scott, 2008, p.117). Food performances have long been used in civil protests. Throughout history “Resistance to and through food as the exercise of power” (Cooks, 2009, p.94) has been a method of peaceful civil disobedience for centuries such as Mahatma Gandhi’s protest of the Hindu caste system in India. Cooks (2009) takes a different view of self-starvation by viewing it as a gaining of power both for and over one’s self rather than a destructive view of one’s body image, and that Ana was a direct response made by women to resist the metaphor of “food-as-body.” Consequently, resisting the metaphor reproduces the thin-ideal for women as their food resistance causes the forced embodiment of their prescribed normative behavior of diet restriction (Arnold & Doran, 2007). In a sense, positive reinforcement of Anorexia nervosa is supportive of problematic yet societally normative female behaviors (Cooks, 2009). Though the communicative powers of

protest through starvation are historically related to larger societal issues, EDs have been suggested on a smaller scale to be protests against familial control.

Family members serve an important role in mediating the behavior of eating disordered relatives, and they are important to consider for many reasons. Arnold and Doran (2007) discussed family as not only a catalyst for perpetuating EDs but also as a complication of family relationships for mothers, yet, in childhood, each of the researchers viewed EDs as acts of defiance against feminine objectification and as an act to gain power both over themselves and within their families. Family members' and friends' demands that the authors "fix themselves" for the safety of their children were futile. For Arnold and Doran (2007), attacks on their disordered identities only further strengthened their disorder as a response to outsiders' attempts to control their behavior. The same response is common for eating disordered teens who are committed to in-patient rehab facilities against their own will; the young teens form connections with one another based solely off of their desire to maintain the disorders through resisting the control of authorities (Rich, 2006, p.297).

Control is a very important aspect of eating disorders. Control of weight, control over when to conceal or reveal the disorder and ultimate control of the self to determine when to cease disordered eating behavior are what creates a guise of power through self-restriction (Holte et al., 2006, p.559). Arnold and Doran (2007) further explained the conflicting purposes of their own eating disorders in adulthood stating: "By engaging in restricted eating, we both exhibit self-control . . . and loss of control. . ." (p.330). Self-control is in the defiance of their own natural urges to eat, social urges to eat in particular ways, and development of methodological strategies to do so. Being "told to stop" had negative effects on their recovery; they found such a message is "ineffective and ultimately may serve to encourage the very behavior it appears to reject"

(p.333). Again, the resistance to control and attacks on their identities are significant in the ways that they mirror identities formed through religion, a faith that despite all opposing forces and evidence they maintain devoutly.

Family members and friends often do more harm than good by trying to police the behavior of their loved ones who develop eating disorders. Once an ED becomes noticeable to those around the sufferer, family, friends, and doctors typically attempt to control and monitor him; research has suggested that attempts to control or be critical of a sufferer's behavior may only cause them to more steadfastly resist change (Rich, 2006). For that very reason, many young individuals with ED identities use the internet as an outlet to express themselves free of persecution, censorship or control (Ferreday, 2003; Haas et al., 2010; Stommel, 2008; Wolf et al., 2013).

Although the sufferer's best interests are in mind, their loved ones attempts to help them are not perceived as supportive (Haas et al., 2010). This at times leads persons living with eating disorders to "online negative enabling support groups" or ONESGs (Haas et al., 2010). The humanizing terms "Mia"(bulimia) and "Ana"(anorexia) are used frequently on ONESGs, and the sufferers write devotionals in which they rededicated themselves to Ana or Mia in ways much similar to religious prayers (Haas et al., 2010). The ONESGs serve as a perfect example for the cultural development of EDs, as it is very rare for anyone living with Ana or Mia to identify as a *sufferer*. When further examined, Haas et al. (2010) found that "expression of commitment to ana [sic] was a key characteristic of establishing a pro-ana identity" (p.47). Anorexia Nervosa and Bulimia Nervosa have become subcultures of their own, and those labelled as sufferers often consider the disorder to be a part of their authentic identity (Hope, Steward, & Fitzpatrick, 2011).

ONESGs are important to consider because of what they represent: a shared will of sufferers to maintain the disorder as an identity which grants both a locus of control and community membership. The digital age has made it much easier for those living with Ana and Mia to provide open disclosure and positively reinforce one another's behavior, but the positive reinforcement of the disorders existed long before the internet. Television and print media have long been suggested as the progenitors of eating disordered behavior in teens (Pascual, 2001). Although blogs and different forms of one-to-many communication media have provided a much larger sense of community and commitment for ED sufferers in the digital age, in the past Pro-Anorexia material existed only in the minds of individual sufferers as they compiled tips and tricks through dramatized accounts of others stories in print media.

Mediated Proliferation of Eating Disorders

Print media was the most common vehicle for raising preventative ED awareness, and women's health, fashion, and entertainment magazines often included discussions of eating disordered behavior (Lager & McGee, 2003). Unfortunately, this practice may not have functioned in preventative ways. Using entertainment magazines to spread ED awareness poses several problems. Such magazines feed gender-role stereotypes which perpetuate the thin-ideal for women—Ana and Mia stories (whether triumphs or failures) provide readers with “road-maps” to aid in the drive for perfection. Mooney, DeTore and Malloy (1994) conducted a study of women's perceptions of other women related to food choice, and found that “in a sample of magazines widely read by college students, every publication aimed toward women featured at least one nutrition or low fat recipe article, while men's magazines generally lacked even basic food advertisements”(p.434).

The pervasive objectification of women in popular culture encourages women to be not only more critical of other women's eating habits, but far more critical in overestimating their own body size/shape (Mooney et al., 1994). To conceptualize this relationship, Mooney et al. (1994) explain that when asked to evaluate others based solely on diet information women would estimate lower levels of "attractiveness, intelligence, conscientiousness, calmness, daringness, and spontaneity"(p.437) in women who had diets composed of higher fat content.

Perhaps led by a need for dramatic substance and novelty, such magazines inaccurately depict ED in only its most extreme forms. The print-media obsession with AN and BN became a catalyst for their spread among teenage girls and young women. Lager and McGee (2003) found that for women who already have a negative evaluation of their weight, "anorexia articles give readers goals to strive for" (p.279).

Narrative depictions in women's magazines that focused on a single woman's struggle, regardless of their intent, serve to negatively impact the recovery of individuals who are already ED sufferers and to lure those with negative self-evaluation into the ED lifestyle (Pascual, 2001). Narratives "heroicize" the illness itself and "seduce readers into taking up the route of starvation by making them believe anorexia is the solution to gaining control"(Pascual, 2001, p.349). Because EDs are viewed as primarily a "female issue," the EDs become signifiers of a feminine identity, facilitating the formation of EDs and close ties with other sufferers as a "community of women who survive in suffering, 'an elite fraternity'"(Pascual, 2001 p.348).

A Deeper Look at Identity Formation

Whereas individual sufferers may evaluate their eating disorders as positive identities that offer power and control, eating disorders are more commonly recognized as psychological

disorders. Disorders being held as a positive identity could explain why a great deal of persons with eating disorders across multiple studies describe ostensibly supportive conversations with non-sufferers as leaving them with an overall feeling of being misunderstood. The psychological discourse surrounding the disorders medicalizes sufferer's rituals; this is problematic in that it constrains the sufferer's identities and makes them appear unstable. Critical theorists view this as a marginalization of the ED sufferers; medical discourse serves "at least to understate . . . the other human and social dimensions of individual experiences of these disorders"(Rich, 2006, p.294).

ED sufferers often discussed self-actualization and identity formation within the ED community; some narratives provided by sufferers were indicative of more than one view of self (Scott, 2008). Maintaining multiple identities often causes sufferers to question "which identity is the most authentic?" Authenticity was an often-discussed issue in face-to-face interviews (Hope et al., 2011; Rich, 2006). ED sufferers often found it hard to differentiate emotions, decisions and desires caused by their disorder and those that they felt were representative of their "authentic self" (Hope et al., 2011). Regardless of perceptions of authenticity however, there was a clear sign of identity formed in the choice of language in the interviews—"people don't say, 'I have anorexia,' they say, 'I am anorexic'" (Hope et al., 2011, p.25). Once a person begins to identify as "anorexic" the disorder becomes more than simply a signifier of identity; it becomes that person's perceived membership in social groups of sorts.

Eating Disordered Males

Lager and McGee (2003) introduced the term "hidden anorectic" to describe a sufferer who is more than 15 lbs underweight for her height, yet still does not identify with the extreme cases depicted in the media she consumes. I extend this term to include men with eating

disordered behaviors, because the characterization of the disorders as feminine both makes physician diagnoses less likely, and as Strother et al. (2012) found, the view of the disorder as “feminine” causes many men to feel emasculating shame which prevents them from seeking help and keeps their disorder hidden. In refutation of the misconception that eating disorders are female problems, the National Institute of Health claimed in 2008 that men accounted for one million cases of eating disorders, and researchers believe that number to be underestimated (as cited in Strother et al., 2012, p.347).

Males often go undiagnosed because they give more medically reasonable justifications for pursuing weight loss than women do, and they are “less likely than females to seek psychological help” (Greenberg & Schoen, 2008, p.466). Even after seeking help and classifying themselves as ‘recovered’ men still discuss feelings of shame (Bjork et al., 2012, p.463). More often than pursuing weight loss specifically through starvation and purging of food, men’s focus tends toward attaining muscle definition through compulsive over exercise (Bjork et al., 2012; Strother et al., 2012; Greenberg & Schoen, 2008).

To the extent that eating disordered males restrict their diets, it typically is in pursuit of defined muscularity in the form of six-pack abs (Greenberg & Schoen, 2008). Furthermore, men are also more willing to pursue illicit means such as steroid and stimulant use in order to achieve muscularity and thinness (Greenberg & Schoen, 2008; Strother et al., 2012). Men more frequently develop a disorder known as body dysmorphia in which “an individual is over-concerned, or obsessed, with certain parts of their bodies,[sic] in which they misperceive as being irregular or extremely unattractive” (Strother et al, p.350).

One significant difference between men and women in regards to weight history is that men more often than women develop EDs after having been overweight, especially whenever

they have been obese during childhood (Strother et al, 2012). The researchers go on to state that “childhood bullying is common in males who may react to this trauma by conscious or unconscious manipulation of body shape” (p.348).

Beyond symptomology, very little attention has been paid to the lived experiences of males with eating disorders; after a lengthy search for similar studies I can comfortably claim that this thesis is the first to do so. The symptoms of eating disorders are often mentioned, but rarely detailed in such depth as the autoethnographic method allows for. A single first-person account allows for an illumination of the disorders in the areas that a sufferer finds most important rather than areas which unaffected researchers find the most interest. Such narratives may have the ability to humanize the disorders, and explicate in detail, some the ways in which they are developed and maintained.

Eager Spectacle: The Onset of Eating Disordered Identity

The following is an examination of my embodied experiences as a heterosexual male living with both anorexia and bulimia nervosa. Though my narrative is a reflection of my own personal experiences, I expect the content may resonate with others who have developed identities under the terms anorexic and bulimic. I argue that an overwhelming focus on gender has served to restrict research from expanding the field of knowledge regarding males.

One of my hopes is that this research has the ability to reach beyond the realm of academe and actually influence the general public as Goodall (2004) suggested it may. As the field of qualitative inquiry is revolutionized to include more artistic forms of expression, so too should it be revolutionized for public consumption (Herrmann, 2012). The aesthetic and artistic freedom of expression available through autoethnographic research stands to create something

that could directly inform a broader audience (Goodall, 2004). When writing an academic article, one enters an ongoing conversation with other academics of similar interests; I attempt in this thesis to enter this conversation candidly with my own experiences and an understanding of how they apply to those of others. Goodall (2004) suggested that communication researchers view narrative as “a field of study, as a collection of life stories we give to the world, [that] needs to address a broader public audience,” and to do so we must “communicate our research to new audiences in a language they understand” (p. 190). In hopes, the narratives included within this autoethnographic thesis will cause the information to be more resonant with readers both inside and outside of academe.

The next section will begin with the onset of my eating disordered identities as a 15-year-old, and end at the onset of my disabled identity at the age of 19. I chose to form the initial narrative by detailing my self-perceptions as they were directly influenced by my peers, and subsequently reinforce my own experiences with those of other eating disordered individuals from research as they apply.

From *Fat Boy* to *That Boy*

Until the age of 15, I never saw myself as a *fat boy* when I looked in the mirror; my loving mother and father always positively reinforced that I looked muscular rather than obese. At 15-years-old I weighed 234 pounds and was only 5’3” tall. I suffered a great deal of ridicule for my weight in elementary school, and it grew exponentially from the years of sixth to ninth grade. The average day involved at least one mention of deplorable nicknames ascribed to me by my peers: Tanker tits, Butt stomach, Tig ol’ bitties. Writing the words now feels so trivial, benign and emotionless, but at the age of 15 those embarrassing monikers haunted me.

The first semester of ninth grade was the longest four months of my life. I was too ashamed of myself to tell my family of the torment I was suffering. Though it sounds cliché, I remember several nights I cried myself to sleep over what had been said to me that day and in fear of what would be said next. The height of my torment usually peaked in the lunchroom—any efforts I made to change my weight became a further source of humiliation. I suffered ridicule from multiple angles: I was insulted for my weight in regards to developing enlarged breasts, a double-chin and a sagging stomach, yet my eating choices were a source of further embarrassment as consuming salads and diet drinks led to epithetical assaults on my otherwise privileged masculinity and heterosexuality when my oppressors called me a “pussy” or “faggot.”

I remember one specific lunch when I was laughed at and called faggot for getting a salad, and though I refused to participate in the conversation, it seemed to last for the entire period. The boy who called me a faggot continued to explain to me that I was a *fat boy* and that eating one salad was never going to change that. I remember every one of the mocking faces surrounding me, showing their teeth in laughter and the horror I felt when Tonya, a girl with whom I was enamored, halted at the table to defend me. The blood surged through my rounded cheeks for every word that she used to scold them; my first crush, motivated by pity, spoke on my behalf as I nervously shoveled more tasteless lettuce into my face. I had learned to deal with hateful judgment and ridicule, but her heartfelt pity drained my soul. I stood up quickly, dumped my tray in the garbage and walked swiftly to the closest bathroom as the boy said “Aww we hurt his feelings.” I made sure there was no one in the bathroom and walked to the last toilet stall in the aisle closing the door behind me; I could feel the heat of the blood in my face like a fever. I pulled my shorts over the tops of my shoes so that no one passing through could identify me if they heard; then I sat on the toilet in overwhelming anger, trying to resist the urge to cry. I

clenched my fists so tightly that my fingernails cut deep into my calloused palms. I hated them all; I wanted them to die painfully and slowly for the ways that they had made a mockery of me. It was not long before the hatred I held for my oppressors turned inward.

“For anorexia, the repertoire of originating factors delineated by experts is complex and lengthy. It includes psychic or attitudinal conditions, familial and cultural factors, and somatic variables” (Pascual, 2001, p. 341). The most appropriate in regards to my particular case would be age-related cultural factors as reflected in high school bullying. Young males often experience bullying in high school, as their masculinity is used to negotiate acceptance and dominance into such heteronormative environments; the bullying rituals of young males have created an environment that fosters a “culture of cruelty” (Kindlon, 2000). Bullying is extremely important in regards to the development of eating disordered behaviors in males like myself. Weight history is an important differential factor between men and women with eating disorders as “men frequently have been mildly to moderately obese at one point in their lives before developing an eating disorder, and were particularly susceptible if obesity was present in childhood” (Strother, et al, 2012, p. 347). The common response to weight-related bullying for young males is a “conscious or unconscious manipulation of body shape.” (Strother et al, 2012, p. 348). My oppressors continually reinforced the idea that my body was too far gone and too overweight to ever fix by dieting; my goal became to prove them all wrong.

Meeting Ana

The salads I was ridiculed for eating at lunch hadn't really helped affect any kind of weight loss; my lethargy and comfort-eating at home counteracted any benefits just as my oppressors had told me they would. Each night I promised myself I would start dieting the next day, and each night I had a celebratory binge, eating everything in sight. The broken promises

only exacerbated my weight gain, until the day I discovered a cultural zeitgeist known as the Atkins diet that allowed me to eat great amounts of certain foods. Gradually, I became more obsessive and restrictive of what I allowed myself to eat and developed what I would later come to know as Anorexia Nervosa (Ana). Ana was a diet coach to help me in my struggles; she convinced me that fat couldn't stay in my system if it had no carbohydrates to stick to. The best part was that I could eat as much meat & cheese as I desired because each had 0 carbohydrates—the diet was perfect for a binge eater. I realized that if I kept exercising more each day while never introducing more carbohydrates into my diet I would lose weight twice as fast! Ana and I created a strict diet and exercise regimen that I swore to abide by and never cheat:

Breakfast: 1 Low-carb wheat wrap with 1 tablespoon of extra-crunchy peanut butter.

Lunch: Hamburger patties with cheese prepared on a Foreman grill (Any amount)

Dinner: Hamburger or unseasoned chicken on foreman grill (Any amount)

Total # of Carbohydrates: 7 grams

Exercise: 1.8 mile Jog

My parent's bathroom had two mirrors, and I remember spending at least a few minutes after every shower scrutinizing my evolution. Once I began seeing a visible change in the size and shape of my face, I started drying my entire body completely and standing on the scale naked in order to know my exact weight. I became so obsessive that I would weigh my appendages individually to know the exact weight of each leg and arm. Every shower and every bowel-movement was followed by a measure of my weight; I made certain that the number was lower each day. My energy dwindled as quickly as my physical size; there were nights that I would awake, paralyzed, lying in bed next to my half-eaten plate of dry hamburger meat.

The bullying continued for some time; I didn't even notice when it stopped because I had internalized a majority of it. My fatigue and depression kept me in an emotionless lull throughout most days, and the empowerment and pride one might expect to experience from weight loss were absent. I never succeeded at losing weight; I was constantly failing at losing it fast enough. My diet coach Ana became my love; she would always help me stay motivated and striving for visible, calculable, change. I had no idea that we were developing a relationship initially, but her words kept me inspired:

Remember how much your family loves you—especially your mom and dad.

They love you so much—so much that they can't see what you've become.

If they knew how you were being treated at school it would break their hearts—you must never tell them!

Please don't let them feel pity for you—Don't make them feel this way.

I love you—I feel your pain—I have suffered with you—I don't want to suffer anymore either.

Let's show the assholes out there how strong we are together

I will help you.

We decided that if I wanted success I would have to make drastic changes—lunch was changed to one hamburger patty and became my only meal of the day. When my parents became concerned about my fatigue and diet I would tell them that I had eaten a big lunch at school or that I was sleeping off a headache. Somehow, I never managed to see my eating behaviors as

disordered, yet I felt an urge to lie about them to my family because I viewed it as my secret weapon of mass reduction.

In early May 2004, my mother took me to the family practice physician to get a prescription for allergy medication. When the nurse asked me to step onto the weight-scale she seemed baffled and said, “That can’t be right....whoever filled your chart out in December had your weight as 234!” I remember rejoicing at the shocked look on her face when I told her that “I did weigh 234 in December.” Looking down at the scale with immeasurable pride—I now weighed exactly 130 pounds.

Did you see the look on her face? It’s because you’ve done the impossible!

This whole time, you did this on your own! Do you have any idea how strong you are?

Look at the miracle diet ads on TV—lose 10 pounds in 30 days—HAH!

I love you

With a loss of weight that easily paralleled symptoms of a terminal illness, I was still not diagnosed with any form of eating disorder. My weight loss was met with congratulations, admiration, and reinforcement from a nurse who was also practicing a form of the low-carbohydrate diet. Greenberg and Schoen (2008) discussed the impact of gender on diagnosis: “. . . males may give more medically reasonable motives for dieting than women and therefore may not be diagnosed” (p.465); because I had unhealthily overweight in the past, my dieting was defensible. Drawing from the research of Currin, Schmidt, and Waller (2007), “even though the same diagnostic criteria for eating disorders are applied to men and women, physicians are more likely to recommend treatment when the patient is female” (as cited in Greenberg & Schoen, 2008, p. 465).

If weight history was more recognized as an important contributing factor for male development of eating disorders, then my weight history of obesity would have been a factor that led to my diagnosis. Unfortunately, my masculinity and healthy weight at the time gave me the status of “hidden anorectic,” someone who may have very severe anorexia but does not fit the stereotyped severity that is so commonly displayed in media (Lager & McGhee, 2003, p.268). Rather than see that my weight loss was clearly extreme, I was judged by my outward appearance, and I looked much healthier than I had since childhood.

Becoming—Unbecoming Spectacle

Finally! I was experiencing what I had been waiting for. Every person that I knew had something positive to say about my accomplishment; I had lost more than 100 pounds in a single semester of school. Teachers, students, family members of friends and others all complimented me on how great I looked. The amount of attention I received was intoxicating, and above all else addictive.

My preoccupation with my diet subsided over the summer before sophomore year. I was still obsessively conscious of my weight, but I could no longer control my desire for tasteful foods. Restricting my diet for so long had made me crave foods that I hated before; okra, green beans, baked potatoes, corn bread and other home-cooked meals came first. Eventually, I relapsed into my old binge eating habits. Even though I did not gain weight quickly, I would perceive the fluctuations in my size as drastic when I looked in the mirror. Every bite of food had the power to make me feel visibly fatter. Regardless, I was finally confident that I would never be bullied about my weight again; I returned to school for my sophomore year with a newfound confidence.

To my surprise, I returned to school to find that the attention I received for my weight loss had subsided. I was an average-sized person for the first time, but I was left without a special accomplishment to boast. I began to strive for muscle definition once my fat was gone, and I became obsessively fixated on the mirrored reflection of my stomach and chest. I swore to never again be labelled as Tanker Tits or Butt Stomach. Ana was never happy with my decision—I had to gain size in order to build muscle. I can still remember her voice in the back of my mind every time I took a bite of food. Ana had become much more than a diet coach to me, and her influence over my behavior and emotions drastically increased with time.

What the hell are you doing Taylor?

Do you not feel your skin rolling on your stomach when you sit? I see it and so does everyone else...

That isn't muscle—it's fat—you're getting tanker tits again. Look in the mirror and point your chin down!

Do you see the fat hanging? I'm so disappointed in you I don't know what to say.

When you realize that you are fucking up—it will be far too late...

Thanksgiving 2004, I drove to meet some friends at the Mexican restaurant in town. Tonya, the girl who defended me at the lunch table the previous year, had become a close friend of mine, and she brought her boyfriend along. When our food finally came out, I had more food than anyone else at the table. Tonya's boyfriend commented "Wow, how did you ever lose weight eating that much shit?" I explained that I was eating a lot more now in order to build muscle and that my goal was to get six-pack abs. He laughed while proceeding to explain to me that normally, fat people who lose weight can't ever get abs because of loose skin, and that I

would never get them eating “that fatty shit.” I can’t remember what she said, but for the second time Tonya defended me, only exacerbating my shame. Ana had accompanied me to dinner, as always, and she was clearly embarrassed by my lack of insight.

Did you hear what Tonya said? It was amazing to her how much weight you lost!

You thought you would look better muscular? You look fat—did you see her boyfriend?

He’s smaller than you and I guarantee you he has abs—that’s why she likes him—I mean Jesus look at his acne.

He laughed at you Taylor—you have embarrassed yourself—How many fucking carbs were in that meal?!?!

When I left the restaurant I remember seeing the buttons stretching on my shirt, even though the shame I felt seemed to be constricting my torso as it shortened my breath. Turning down a bumpy back road, I felt my chest shaking no matter how hard I tried to flex my pectoral muscles—I had become fat again. I pulled to the side of the road in the throes of a panic attack. A mania overcame my entire being; I wondered how I could let this happen. Just as when I was 234 pounds thinking I was muscular, I was guilty of the same offense now. I could feel the fat attaching itself behind my nipples and below my navel.

See... I was right...I told you that you were making a mistake

You don’t see what everyone else does, and your friends don’t want to hurt your feelings, but her boyfriend doesn’t care to tell you what’s real.

He knows you’re not a threat to him—you’ve read about the Low-carb diet and how everyone gains their weight back.

I told you to stay with our diet—but you wouldn't listen—now it will weeks before you can work that meal off.

I still love you—but I can't forgive you for turning us into a joke again.

Returning to Spectacle

My perceptions of my own body at this time were exaggerated by the fear of reliving my past experiences as a victim to bullying. I had internalized the remarks made about my chest and abdomen, and the terror of wearing the monikers of Tanker Tits or Butt Stomach again overrode my ability to pursue my goals in achieving muscularity. As with many men, (Griffiths, Murray, & Touyz, 2014), subscribing to masculine gender norms made me more susceptible to being critical of their bodies in terms of muscularity. In my case, pursuit of muscle definition was impossible if I couldn't lose the fat that I perceived to be heavily deposited my lower stomach and chest. As someone who was “over-concerned, or obsessed, with certain parts of [my body]” which I misperceived as being “irregular or extremely unattractive” (Strother et al., 2012, p. 350) I clearly was suffering from body dysmorphic disorder. My invisible, inward facing hatred and wrath manifested itself in the form of an outward performance. Scott (2008) describes, “One cannot see the effects of self-hatred without a physical, usually deemed abnormal, performance of it, such as cutting or purging” (p.131). These performative moments were greatly influenced by my status as a hidden anorectic at the time; my starvation had not yet become visibly extreme enough to communicate my self-hatred and protest of my past identity to others. Hidden anorectics are unable “to find a voice through their eating disorder in the way ‘severe’ anorectics do” (Lager & McGee, 2003, p.268). On my way home from the Mexican restaurant that Thanksgiving, I heard the voice of my struggle for the first time.

Falling for Mia

I leaped from the car and forced my fingers into my throat to expel the meal that was coming between myself and my goals, but it wasn't working. Remembering that food begins to be digested as soon as it comes in contact with saliva, I realized that I was running out of time! I pictured that spit, vomit, feces, dead rats, and boogers had been in my food—it didn't help. I unsheathed the straw from my diet soda and shoved it deep into my mouth, slicing the back of my throat and refusing to withdraw it until I vomited. The metallic taste of saliva built underneath my tongue with each empty heave until finally, my entire body tightened in success. By the time my stomach was empty my face was swollen and red, but I felt more satisfaction than I felt from eating the meal itself. I realize now that my biggest trigger was criticism, and to some degree, it still is today. I had lost my willpower, and had returned at my worst point to 150 pounds. Ana suddenly wasn't enough for me, I became infatuated with her sister Mia (Bulimia Nervosa). Ana and Mia together gave me such security, the two would neither become jealous nor abandon me.

Ana: I am still with you Taylor—I won't EVER go away, but I'm afraid that now your loss of weight is too hard to maintain

It wasn't me—it was you that stopped—so you're the one to blame...

You've felt my presence all along, but have never known my name.

My name is Ana, look me up—study me and learn my ways

My sister Mia loves you too and she can help you change.

If I couldn't eat healthy then I wasn't going to eat at all. I scoured the internet for resources on extreme weight loss; I read everything I could find about Ana and Mia. Borrowing from the stories of women that looked emaciated and skeletal, I knew that I had to get rid of all the fat in my stomach before I could ever see my abs. My will-power was revived by the narratives of the women online—the ominous danger and near-death experiences appealed to my boredom. I wanted to be thin. I wanted the spotlight. I wanted a struggle to call my own again. I wanted to push myself beyond what I thought was possible, and I wanted it all immediately.

I knew that no one would be impressed by my weight loss anymore; it was old news and no one gives compliments for not gaining weight back. I had become fat again, and the limelight was fading. The achievements and recognition of my struggle had dissipated, and I was just like everyone else. I needed a new struggle to overcome. I needed it to be obvious, but most importantly I needed it to make and keep me thin. My second obsession with weight was deliberate, I needed to become bulimic. I never wanted people to know that I was bulimic, and I never wanted them to know I was anorexic. I wanted it to be obvious enough that they would accuse me of being both; my addiction to positive attention had overshadowed my thin-ideal. Mia became much more than a friend; an infatuation was born from the freedoms she granted me. Her guidance changed my outlook entirely:

Mia: Wear your pain openly, but never admit we're here.

You've learned to love, you managed to change, but the end is far from near.

Ana is not strong enough to help you now—that's clear.

She worries now that you've lost your will, but I will quell her fear.

I demand you show your suffering—they will all revere.

It's you and I and Ana now— but we'll take the wheel from here.

My willpower to diet was completely broken; I incessantly craved bread, potatoes and other healthy but high-carb foods. In the beginning, if I ate so much as a single French-fry I would engorge myself by eating loaves of bread, drinking gallons of milk, scarfing down chocolate bars and ice cream. I performed so poorly with Mia initially that I knew I would hurt myself trying to impress her. My solution came from an online sufferer's story of her own recovery: simply eat until I was so full that my body had no choice but to vomit.

Mia was very different from Ana—it became impossible to hide our relationship from others the more infatuated I became. Eventually Ana's diet plan became complete starvation, and when I ate in order to placate my friends or family I would sneak into the woods behind my house to meet Mia. She taught me to chew my food intensely because the extra jaw motion would burn calories, while making the food small enough for her to dispose of easily. I became a student of my own disorders. Others' stories of recovery became blueprints, and I built from them my own innovative ways to preserve my health and secrecy while maintaining my disorder. I became the master architect, building fortified barriers to my temple that others would come to see as the walls of my inescapable prison. Ana and Mia were both so proud of me, and they supported me more each day:

Look at how much you've changed—they're all so shocked and stunned

You are now a spectacle—Your pariah days are done.

Remember where you came from—Remember how you were shunned

Don't ever forgive them or yourself—just show them what you've become!

We joined the track team as long distance runners, but my diet held me back from achieving any awards. Winning didn't matter to me like it did my teammates; I ran so people would see how active I was. In my mind, the ultimate achievement would have been to faint from exhaustion. If I got blurred vision and started seeing black spots I ran harder; I never felt like I had tried hard enough because I could never make myself faint. I wanted them to see my collapse as a manifestation of my will to succeed; the glory of self-sacrifice combined with the illusion that it was for the team. Being thin was now secondary to what had become a passive form of public suicide; I would imagine those whom I hated most as they latched onto the spectacle my death, crying and hugging each other, pretending to have compassion for me in the end. My journal contained the truth, filled with stories and names of people who tormented me when I was fat, and I would picture it damning their names forever. My body was a fully erect middle-finger directed sternly at the face of any person who doubted my ability to be thin, which I assumed was everyone.

Unlike anorexia, my addiction to bulimia developed from an informed decision; I actively studied the rituals of the culture before subscribing myself to its lifestyle. The internet was instrumental in my pursuit of weight-loss. I perused social networking sites dedicated to the stories of recovery which almost always included the diet and exercise regimen of the woman when her weight-loss was at its peak. Like the anorectics who use magazine testimonials as "how-to manuals" (Lager & McGhee, 2003, p. 280), I used the sites as how-to manuals to craft and perfect my own methods of starvation. Many narrative accounts of ED dramatize the illness in such a way that it positions those who have suffered as heroes and role models to younger readers that have poor self-esteem (Pascual, 2001,p.349). Although I never viewed women in the narratives as heroes, I was aware of the spectacle that they achieved through their suffering, and I

wanted to be revered in the same light. I studied their methods and used them to polish my own. I was interested in recovery, but all I wanted to recover was my position as spectacle in the eyes of my peers.

My eating disorders became common knowledge. No one was comfortable enough to question me directly, other than my closest friends. I reveled in the attention, the whispers and the shock value of my disorder. I remember standing beside the lunch table and exhaling all the air in my lungs, sucking my stomach up into my ribcage and clasping my hands around my torso to show that I could touch my fingertips. Some days I would buy the entire loaf of buttered bread from the lunch counter and absorb the gaze of everyone around me as I devoured it, only to purge immediately after. I had quickly become more addicted to being the spectacle of attention; I wanted to be grossly underweight to shock them even if it wasn't considered attractive. I still never admitted the disorder to anyone but my girlfriend at the time.

Mia & Ana: They envy you in your struggle Taylor—they never had to try

Show them how you're in control—see the envy in their eyes

Mock them with your binging, then purge until you die.

It was Ana who brought you to me—She and I are on your side..

If anyone tries to stop you—you must be strong enough to fight.

Never forget your darkest days—or how we led you to the light.

In my Honors Anatomy and Physiology course I made the boldest move thus far. The topic of the day's readings were eating disorders and their effects on the human body, and I couldn't help it. I outed myself in the most spectacular fashion as an expert in the field; I had

compiled so many tricks and so much knowledge about anorexia and bulimia that I had never had opportunity to share. I felt stronger than the petulant fools surrounding me who thought that a simple book could teach them my art, and I felt offended by the descriptions of Mia and Ana's followers as lost, insecure addicts. I depicted myself as an Anorectic-bulimic proper, and in one self-aggrandizing swoop I explained and justified my methods to counter nearly every negative effect that the disorders could have. Anorexic-bulimia was *my choice*, not some crippling fucking addiction.

Ana & Mia: They're calling you a girl—Delusional and erratic.

A closeted, door-closed homosexual—a salad eating faggot!

Interrupt the transmission—Lets introduce some static

Tell them how we saved your life—when you were at your fattest!

Clear your name and have them know you've never been an addict

If you don't explain yourself today—Your reputation's had it

We are your lovers, and your religion—Don't let your teacher be dogmatic.

I took control of the classroom as the teacher stood astonished at the blackboard. I began asking students to pick side-effects and I would explain how to prevent them: 1) Tooth Decay: Swish cold water immediately after purging, water is a base that dilutes acid 2) Esophageal erosion: Take twice the suggested dose of tums antacids 10 minutes before each meal 3) Swollen face/Blood vessel rupture: Never kneel when purging, stand upright to avoid blood rush. I went on countering negative side-effects for a few minutes until the teacher asked, "What about

cardiac arrhythmia, strokes, and heart attacks?” I had no good answer, and when class ended my teacher pulled me aside.

The sympathy of others only further pushed me to exacerbate my symptoms; I had become an actor, a liar, and a fraud. I feigned the will to recover in order to prevent my parents from being told and to increase others’ sympathy; I was forced into a special group therapy session one day per week with peers from a variety of other stigmatized addictions: suicidals, cutters, bulimics and anorexics. My participation in the group proved to have a negative effect on the more senior members, as I would willingly share my techniques and methods with them outside of therapy. I remember feeling so distinguished when my name came over the intercom and I was pulled from class for counselling once a week. *Let them whisper, I thought, my name will spread like a wildfire through this school and when the smoke clears I will be the focus.* It wasn’t until many years later that my identity as an anorectic-bulimic began to fade, and periods of lethargy and absence of exercise still even now continue to cause a spontaneous recovery of symptoms.

An Identity Forged: The Illusion of Struggle

The medical discourse used to discuss eating disorders consistently prescribes the label of “sufferer” to the individual; the ideology that often accompanies such labels is that the individual is suffering *from* bulimia or anorexia (Holte et al., 2006; Hope et al., 2011; Rich, 2006; Scott, 2008). In my case however, the disorder manifested as an embodiment of suffering that was invisible to or overlooked by others; it became an art-form, a silent protest and an identity for me that resisted efforts to define (Scott, 2010, p. 136). Rather than suffering *from* the disorders, anorexics and bulimics tend to positively evaluate disordered behavior to be empowering and beneficial as it positions them as spectacle, distinguished from their peers (Rich, 2006). Pascual

(2001) states that “although researchers are divided as to the primary cause of the disease . . . they agree on its target: to seize selfhood [or] gain a sense of self” (p. 342). Research suggests that the Ana and Mia are responses to macro-societal expectations on women to conform to a specific body-type (Arnold & Doran 2007, p. 312; Lager & McGee, 2003, p.267); I believe that the disorders in my case manifested from internalized objectification and criticism, and evolved to a sense of distinguished identity that I eagerly sought after.

I didn't realize at the time that I was searching for an identity that separated me from any other males who competed with me for the spotlight. I became the antithesis of my former identity of the fat boy who was easy to talk to. I used the disorder as a manipulative way to get attention without openly begging for it, and a way to get unwarranted compliments. But most of all I wanted to shock and disgust people with the spectacle of my disorder; I wanted those who told me I couldn't ever be thin to see that they were wrong. My body was a message to those who doubted my ability: *I will die before I ever become your joke again*, I thought. And I meant it.

I desired to be the ultimate example of willpower, perseverance, self-control, and strength; anybody who has ever felt the pain of hunger knows the strength it takes to resist food when it is available. I was eager, even desperate, to be the spectacle, the reference point, which everyone used when they talked about transformation. The widely held view that the disorder was for women did not bring me shame; it only increased the level of spectacle I was able to achieve through my deviant behavior. After leaving the fishbowl-like environment of high school, the spectacle that I was so eager, lost its impact once again. I became aware of my addiction to the disorders whenever I continued the rituals even though they didn't serve to grant me the attention they had in the past. But one day my disordered behaviors dissipated

spontaneously, when a new identity thrust me back into the locus of attention: the day I began a transitional journey to an identity of disabled amputee. I achieved a new kind of spectacle that required no rituals or performance to attain, a spectacle that I can never remove or control.

Rybarczyk et al. (1997) discusses a possible explanation for how losing my right leg eased my recovery from my eating disordered identity:

“The limited research on *positive adjustment to disability* has focused on the changes that take place in an individual’s value system. Specific value changes that are thought to be necessary for positive adjustment include *moving away from basing one’s worth on either physical qualities or comparative value*[emphasis added]”(p.249).

After such a strong focus on my eating disorders, it may be jarring for readers to transition so quickly to a focus on my disability, but the quick transition is one way in which this autoethnography parallels the experiences that it details. I too was jarred, when I was forced to quickly turn from eating disorders and to face the identity that had been thrust upon me. At the age of 19, I was not prepared to discuss life as an amputee; my relationships with Ana and Mia never received the closure that is so common in dramatic love stories; I never said goodbye, nor did they. The day I became disabled, my focus shifted instantly to my permanent physical difference as an amputee. As they do in this autoethnography, the spectacle and focus I maintained through my eating disorders came to a jarring, unwelcomed and unexpected stop.

CHAPTER 3

The Deviant Body: Researching Disabilities

Amputees may form social identities based on how they believe themselves to be perceived by able-bodied others (Scott, 2013), and disabilities of all kinds are socially limiting due to the stereotypes and stigmas that are borne out of their existence (Goffman, 1963). Beyond physical limitation, there are social norms that constrain the extent to which disabled individuals are able to elucidate their frustrations with others. Especially for individuals who experience traumatic amputation in adulthood, the pain, fatigue, and frustrations associated with a loss of independence can greatly affect the psyche of a new amputee (Ajala, 2011; Kratz et al., 2010). The experience of chronic pain can serve to alienate the family and friends of a person with disability, because the emotional and physical pain experienced through the newly acquired disability can cause compassion fatigue in caregivers (Esposito, 2014). There are social norms and etiquette that dictate how much of one's own suffering should be shared with others. Although family and friends' acceptance of negativity, complaints, misdirected anger and emotional breakdowns may be high initially, it decreases over time if the disabled individual shows no sign of improvement (Esposito, 2014).

Close friends and family are likely most prepared to provide consolation, care and sympathy immediately after a loved one experiences an amputation, but the ebb and flow of emotional suffering after limb loss does not peak until several months later (Kratz et al., 2010). One might expect that the trauma immediately after experiencing a limb amputation would be the most emotionally stressful, but the amputee's social interactions are initially limited to caregivers and medical professionals that are sensitive to their loss. Months after recovery from the injury itself, amputees begin to experience new difficulties in re-mastering their environment,

and after exiting controlled familial and medical environments, amputees are eventually exposed to the drastic changes in the way they are interacted with socially (Rybarczyk, Nicholas & Nyenhuis, 1997). The negative social impacts of a visible disability are unavoidable, and amputees with prominent limb loss fall victim to a societal construct known as *disability stigma* (Goffman, 1963).

Disability Stigma: A Negative Form of Spectacle

Goffman (1963) was the first to investigate to the concept social stigma and its negative effects on a stigmatized person's identity. In his groundbreaking work, Goffman (1963) loosely defines disability stigma as “abominations of the body” (p. 4). As the first researcher to examine the concept, his description is worth quoting at length. Goffman describes a stigmatized person as:

“an individual who might have been received easily in ordinary social intercourse[, yet] possesses a trait that can obtrude itself upon attention and turn off those of us whom he meets away from him, breaking the claim that his other attributes have on us”(Goffman, 1963).

Disability status' ability to override other qualities individuals have speaks a great deal to ways in which a person's physical disability becomes an ascribed negative social identity that is imposed upon them.

Much research has been done since the work of Erving Goffman, and his concept of stigma is often used in social research on people with disabilities in the workplace (McLaughlin, Bell, & Stringer, 2004; Schur, Kruse, Blasi & Blanck, 2009; Scott, 2013), in academe (Broyer, 2011; Scott, 2013;), and in the general public (Couser, 2005; Ellis, 1998). Although interactions

within the workplace are beyond the scope of this autoethnography, the assertions made in such studies can easily be extended outside of organizations. An organizations' offensive tendency to value the perceptions and experiences of non-disabled people as they are affected by encountering persons with a disabilities, mirrors a larger cultural emphasis on how non-disabled people can be helped in adapting to needs of disabled people.

The research of disability in professional settings almost entirely focuses on able-bodied peer perceptions of the disabled individual (McLaughlin et al., 2004). Harter, Scott, Novak, Leeman and Morris (2006) attempted to illuminate the ways that popular discourse negatively impacted perceptions of the disabled, yet nearly the entire work focused solely on the able-bodied staff members. Specifically, it examined the benefits that able-bodied staff members receive from working with disabled; the disabled in effect became offensively infantilized and viewed as tools to help evolve staff members' abilities to empathize or sympathize with diverse others. From this perspective, persons with disabilities are valued primarily in terms of their ability to change the viewpoints of their 'previously' ignorant, able-bodied caretakers (Couser, 2005, p.139). Further, media portrayals of persons with disabilities lead the non-disabled to view them in a subordinate light as "many journalists. . . still hold narrow views about people with disabilities, make subconscious assumptions about who they are, and are not trained to report on people with disabilities in a non-stigmatizing way"(Zhang & Haller, 2013, p.330); the shortcomings of Harter's et al. (2006) research suggests that perhaps academics may hold similarly narrow and limited views.

Stigma is the most commonly interrogated social phenomenon in regard to disability, yet even this concept involves ascribed stereotypes rather than the lived experiences of people who face that stigma (Goffman, 1963). Too often, able-bodied researchers investigate the intricacies

of disability management with little regard for the individual's interpretation of his/her own disability. The effects of stigma on the disabled individual can never be fully captured by statistical or didactic approaches to knowing, and there is an ever-growing need to examine the ways in which our society is limited by our lack of strides to reduce stereotyping and misconceptions borne out of that stigma.

How does disability stigma affect the individual in social and organizational contexts? The answer depends not only on the way disability manifests in the individual, but also on that individual's ability to conceal or pass as able-bodied (Goffman, 1963). The aesthetics, required accommodations and estimated permanence of a person's disability can affect their opportunities a great deal (McLaughlin et al., 2004; Schur et al., 2009). In the competitive environments of western society, "accommodations [for the disabled] are likely to be viewed as unfair— unjustified and expensive 'perk[s]'—especially when seen as making the accommodated person's work easier. . ." (Schur et al., 2009, p. 385). If a person's disability cannot be easily observed, peers may begin to resent that individual because of the accommodations afforded to them, however it is very common for disabled individuals to downplay the effects of their disability in front of peers while seeking their acceptance (McLaughlin et al., 2004; Murray, 2005). This is problematic because disabled individuals often put forth concerted effort to make communication partners comfortable with their disability, and to do so often requires them to negate the extent of their actual suffering in exchange for acceptance (Murray, 2005, p.432).

When a person's disability can be temporarily concealed in order to appear able-bodied and avoid stigma it is considered "passing" (Goffman, 1963). An amputee's ability to pass as able-bodied with prosthetic devices, though beneficial in many circumstances, can be very damning to the flow of conversation if the individual is discovered to be disabled. Being

discovered can make the disabled individual appear disingenuous for not being more forthcoming about their body's deviance (Murray, 2005). Similar to a non-disabled person's distaste for accommodating disabilities that are concealable in the workplace, a disabled person passing in public may cause other disabled individuals to mistakenly confront them about their undeserving use of accommodations such as handicapped parking and bathroom stalls. The broad application of the singular term disability causes for within-group "othering" that perpetuates stigma perceptions amongst the disabled as well.

Dividing Lines in the Disability Community

The social landscape gets even more difficult to navigate for those negotiating the stringent politics within the disabled "community." The disabled may be more divided and hierarchical than any other minority group; "people with disabilities build communities through a more transparently political process than other groups" (Siebers, 2001, p.748). Again, disability is a term that encompasses more than physical disadvantages, and the within-group hierarchy and othering tactics meant to distinguish levels of suffering among the disabled are often so rigid that it is unlikely that any individual would refer to themselves as a member of the illusory disabled community (Couser, 2005, p.124). Individuals with disabilities reserve the right to claim or refute their status of "disabled" contextually, as there are certain arenas in which each person may be more proficient and unaffected by their conditions.

There are also divisions in social treatment, as "people react more negatively to some disabilities than to others" (Colella & Varma, 2001, p.313). Majorly, in regard to physical disabilities, the ability to conceal one's difference from others is relative to one's placement within the hierarchy of the disabled community. Passing "is seen by many people with physical disability as pivotal in avoiding stigma, and the social identities of disabled people so often hinge

upon the public availability of this information” (Murray, 2005, p.436). The ability to pass does limit stigma in social situations, therefore disabled persons who experience more stigma are less likely to view passers as equal within the disabled community. Furthermore, persons with congenital limb loss in early life often have higher chances of graduating college, being employed, and identifying with the disabled community than do individuals who become disabled later in life (Ajala, 2011, p.193). It seems all too obvious that differences in treatment and ability could cause for within-group strife amongst individuals with a myriad of diverse disabilities that have their own stigmas attached to them.

Ascribed Spectacle: The Onset of Disabled Identity

Disability begets stigma, as stigma begets a negative view of the stigmatized individual’s worth in society. A disabled man becomes a more pronounced spectacle in western society, as the attention his body draws from onlookers is focused on his lack of ability. Stigma becomes ascribed spectacle with an inherently negative valence. Although every day now I am granted spectacle, it is not something I eagerly seek as when I was an eating disordered boy. I get attention even when I don’t want it, compliments that are unwarranted, and I shock and perhaps even disgust people with the spectacle of my disability. I no longer have to starve myself to stand out in public. As a disabled man, I am incessantly asked to retell the events that led to the loss of my right leg, often to strangers who otherwise would likely have no desire to speak to me. Persons with bodies that deviate from the norm in the way that mine does, are often asked to justify themselves and explain their bodies (Goffman, 1963). I have told an abbreviated version of my leg amputation to strangers and acquaintances more than a thousand times over the last six years. In what follows, I tell an elaborated and much more vivid version of how I recovered from

my sought-after eating disordered identities and came to embrace my ascribed identity as an amputee.

Transitioning to a New Spectacle

Throughout my adult life, my most beloved possession was the Yamaha R6 sport-bike that I purchased when I was 19 years old. I dreamed of having that machine for as long as I can remember, and when I finally purchased it, the feeling was beyond any level of satisfaction that words could describe. The freedom and power between my legs and at my finger-tips became another form of addiction, and I could not go more than a day without riding my motorcycle.

One particular day, I was on my way to visit my grandmother whom had just graciously offered to help pay for my tuition at the community college. The road was covered with beautiful shadows as the sun shined through the roadside trees, and although at times I would accelerate very quickly, I wasn't really in a hurry to get anywhere. As I rounded a corner, some children in the back of a red convertible Jeep turned around in their seats to watch me, just as I watched motorcyclists when I was younger. I decelerated in order to put some distance between myself and the Jeep; when there was a sufficient amount of room between us, I decided to show off.

Downshifting into second gear, I twisted the throttle, released the clutch, and the front tire of the motorcycle leapt from the ground to its maximum height as the exhaust pipe emitted a deafening roar. I stood on the rear foot-peg with my head raised to a height higher than the motorcycle's front tire as the children began jumping and pointing with excitement. When I started getting closer to the Jeep I loosened my grip on the throttle as the front tire came back in contact with the ground just close enough for me to see the astonishment on their faces. After a short time, I waved goodbye to the boys and passed the Jeep to continue on my route to my grandmother's house.

Several miles later, I knew I was approaching the two most crowded gas stations on the back road I was travelling. I downshifted into second gear in order to raise the sound of my engine on approach and hopefully get some looks from the high-school girls pumping gas. Travelling at 60 miles per hour, I quickly noticed a white car drifting into my lane, and I moved close to the shoulder to make sure the driver could see me. Before I could blink an eye, the white car cut across my lane without signaling. I stomped my bike's transmission into first gear, and I pulled the front brake into the tightest fist I have ever made as the rear wheel lifted into the air. Impact was inevitable. My motorcycle struck the back door of the car with such a force that the car was spun into the parking lot of the gas station.

Immediately upon impact, my hands were ripped from the motorcycle and my body took flight into the air as I looked down at the cars below me. In my mind was an anxious need to give my full attention to the moment, because I knew that whenever I struck the ground there was no way I could live through it. Luckily, I was wrong; my hands were the first thing to touch the ground 60 feet later as I rolled onto my back and skidded 93 feet from the point of impact.

When I came to a stop, I raised up to a seated position quickly to make sure that I wasn't paralyzed. I looked at my arms; they were barely scraped. My legs looked perfectly fine—there wasn't a scratch on either of them. I looked at my feet and realized that I could only move my left ankle. *I must have broken my leg, but thank god!!! I'm not paralyzed.* When I realized that I had only broken my leg, I looked to see if my motorcycle was totally demolished. It was.

The smoking wreckage of my motorcycle was a terrible sight; *I'll never be able to talk mom and dad into letting me get another one.* I suddenly felt a strange sensation and realized that the backside of my shorts was warm and wet. I looked around to see if I had landed in some sort of puddle. Lifting the blue-tinted visor from my helmet as I raised my leg to see what I was

sitting in, I saw it. The splintered and frayed femur bone protruded out of the bottom of my shorts. I pulled my shorts back to see that my leg had been cut almost completely off. I reached down and tried to scoop some of the gravel-covered meat back into a pile before my mind fully registered what was happening to me. I can remember the clicking sound my bone made when an involuntary twitch caused me to scrape it across the rough pavement as the rest of my leg lie motionless.

The yellow fat cells, red muscle fibers, and gray elastic tendons all looked so foreign; it was as if I was watching a movie of someone else's life. I jerked in fear and watched the bone flail in the air as veins snapped and a huge burst of hot blood squirted several feet from my femoral artery. I unstrapped my glove on my left hand and grabbed on to the calf of my now amputated leg. I dug my fingernails into the calf muscle to see if I could even feel it; I pinched so hard that I tore through the thick skin of my leg and felt my fingernails touch underneath it. Blood continued to cascade from my leg, and I looked to see its stream rolling down the hill away from me. It was at this point that the pain started; it was unlike any feeling I had ever experienced.

"HELP!!! SOMEONE PLEASE COME HELP ME!!!" I saw two women running towards me in the distance as I laid my back onto the hot pavement to pull my phone from the blood-soaked pocket of my shorts. *I don't wanna die...I don't wanna die* I whimpered to myself as I dialed my mother's telephone number and shoved the phone into the helmet. I tried to gather myself before she could answer the phone, because I knew it was going to be the last time I ever got to talk to my mother. I couldn't leave without telling her how much I love her.

Hello?

Momma!?

What's wrong baby?

Momma, I don't have a lot of time right now. So, you've gotta listen real careful and remember what I say Okay?

Oh god, what's wrong?

I wrecked my motorcycle really bad and I...I'm dying Momma. I love you so much. I'm so sorry I put you and dad through this. Please tell dad not to blame himself for letting me get this bike, okay? I want you to know that you are the best momma in the whole wide world Ok? Please take care of Chancey for me! Tell my brother I love him so very much, and momma tell him he is my hero.

Oh god! NO! Honey, you're okay! Tell him yourself.

No mommy. . . I've lost too much blood, and they, they can't save me. I didn't wanna leave you without saying goodbye. I love you more than you'll ever know. I'm not scared momma, and the only thing I want right now is for you to know how much I'm sure gonna to miss you. They're taking my phone away momma, please just say goodbye to me so I know you're okay. . .

Taylor I love you so much son

I love you too momma.

There was a woman kneeling in front of me, unwrapping some kind of equipment as the second woman to arrive at my side pulled the phone from me and handed it away. "It's really

bad, we're gonna have to cut your clothes off honey." In less than a minute I was lying naked on the hot pavement as a swarm of people surrounded to watch me die. "If I had known I was gonna die like this today, I would have at least trimmed up some of the hair down there. . . I swear ladies, it doesn't always look that bad." My joke fell on deaf ears as a numbing cold grew from my fingertips up my arms and deep into my chest; it took my breath away. *This is it*, I thought. "Ma'am, Will you please. . . hold my hand for a minute? I can't get it to quit shaking."

The woman's face flushed with tears as she squinted her eyes and sat down beside me. She laced her fingers between mine and lifted my hand into her lap as we waited for the ambulance. The pavement was burning the back of my head, so I raised up just long enough to see the astonished faces of two young boys in the back seat of a Jeep and wave goodbye to them for a second time. I laughed aloud at the things in life that I once thought mattered, as I smiled and thought, *what a beautiful day to die*.

The woman kneeling in front of me was a nurse, and she saved my life on her way home from work that day. She was only three cars behind me when I wrecked, and somehow managed to wrap my leg with a tourniquet. The doctors would later tell me that I was less than 10 heartbeats away from death when she had managed to stop the bleeding. I still, to this day, have never gotten the courage to thank her.

When the paramedics arrived and lifted me onto a gurney, they began running with me through the tall grass of a nearby cow field to where the Life Star helicopter had landed. My lower leg rolled off of the stretcher and dangled for a brief moment before they stopped to restrain me; I screamed in pain as I watched pieces of my kneecap dangling against the blades of grass. When they finally loaded me into the helicopter I was flown to the University of Tennessee medical center. As I exited my first helicopter ride ever, it was once again just like a

movie scene. Bursting through doors, there was a herd of people in white coats surrounding me speaking in medical jargon. I asked the doctor “Am I going to live?”

We’re going to do everything we can to make sure you do. We’re going to give you something for the pain to help you sleep so we can work on your leg. Count backwards from 10, and don’t worry. You won’t remember any of this.

Owing an Explanation to Others

Research surrounding the lived experience of traumatic amputations is scant in general, and it seems, to be non-existent in communication literature. The reason I detail the events that led to the loss of my right leg is to not only tell the story but also to exemplify what people have expected me to tell nearly every week after the day I left the hospital. I have been asked to tell this story by strangers I cross paths with in public, but I tell a less affective and traumatic version that still satisfies their curiosities. The more a person deviates from the norm of what is expected, the more that person is expected to volunteer personal information about himself (Goffman, 1963, p.64). Over time it became necessary for me to develop a version of my story specifically to share with those curious enough to ask for it. A man who becomes disabled must have “. . . a ‘memory,’ that is, in this case an accurate and ready accounting in his own mind regarding the facts of his present and past which he might owe others” (Goffman, 1963, p.64-65). I subconsciously developed an objective, medicalized storytelling voice that allows me to speak scientifically about the happenings of that day; I was unaware of this process until I investigated it for the purposes of this autoethnography. The objective, medicalized language I use to re-tell my story to general others allows me to avoid welling up with the emotions at the devastating events as told in the previous narrative.

Why must I answer to the curiosity of complete strangers? Disabilities come in many different forms, but I would argue that none stirs the curiosity of onlookers more than a limb amputation.

“What’d you do to your leg? Why are you limping like that? What have you done to yourself? If you don’t mind me asking, what happened? Can I ask you a personal question? Military? You a veteran? An old buddy of mine lost his leg in a car accident a couple of years ago, how’d you lose yours if you don’t mind me asking [note the attempt at reciprocity]? How long ago did that happen? That’s awful, did you feel anything? Did it hurt? I bet you went into shock when it happened. Did they take it off when you got to the hospital or...? Can I see it? Thank you for your service. Do you remember anything from when it happened? How much do those legs cost? How fast were you going? Were you still conscious? I bet that hurt like hell, didn’t it? Was it your fault?”

Research on stigma suggests overtures like these imply that “the stigmatized individual is a person who can be approached by strangers at will, providing only that they are sympathetic to the plight of persons of his kind” (Goffman, 1963, p. 16). It has been and remains troubling for me that the worst day of my life is the only thing that anybody wants to hear about when they talk to me. I have found no research that discuss the effects of such interrogations on the psyche of amputees, but I know that I cannot be the only one who lives this way. The dearth of social scientific work in this area “may stem from the interactionist emphasis on the ‘beholder’ rather than the ‘holder’ of an experience such as stigma” (Ellis, 1998, p. 527). The social sciences are concerned with the way my presence affects others, and only rarely does the focus shift to the ways that their communication affects me. I am expected to “minimize the presence of difference as much as possible, to give it as minimal visibility as possible” (Broyer, 2011, p.53), and when I

fail to meet those expectations I unfailingly am confronted and interrogated about the etiology and extent of my disability.

Amputees use language to sculpt their identities as they relate to the term disability, and amputees may only contextually define themselves as disabled, meaning that an amputation is not always indicative of disability. From my eating disordered identity to becoming an amputee, my interpretation of other's perceptions of my body has been the *de facto* measure I have used to evaluate my worth in life. When I initially became disabled I was horrified of my amputation's possible effect on my future in terms of sexual relationships, and even the simplest conversational flirting. Although there are individuals who fetishistically fixate on amputees as sexual objects (Alaniz, 2012), those individuals are by and large heterosexual males, fixating on females. Western culture is so highly fixated on the most minute and nearly unnoticeable negative valences of bodily blemishes and asymmetries (Ellis, 1998) that I wonder how, with an asymmetry as profound as a missing limb, could I ever be perceived as attractive again?

Over hundreds of conversations, I have developed stock phrases that I use to deal with individuals of any age, and at any level of distinct curiosity. I use attention buffering and misdirection to my advantage to avoid crossing the fine line between "that's interesting" and "that is horrifically sad." At times when I am feeling depressed, sullen and downtrodden, I have overshared information that has made others uncomfortable; there is a delicate *pas de deux* that I feel compelled to perform in order to safeguard individuals from their own curiosity. It becomes my job to make sure that others are comfortable throughout the entire conversation; it becomes my job because, as Goffman (1963) states ". . .since the stigmatized person is likely to be more often faced with these situations than are [non-stigmatized persons], [s/he] is likely to become more adept at managing them"(p.19). When I am able to hide from my reluctant spectacle as an

amputee by passing as able-bodied, those who are unwise to my stigmatized identity often unintentionally throw dirt on my identity as they dig a conversational hole so deep that they require my help to pull themselves out of it. Amputees often find “passing” as able-bodied to have a preventative effect on the spectacle of their disability as it causes for stigmatizing interactions, but it can become very uncomfortable for all parties when the amputee’s bodily difference becomes apparent.

Passing as a Normal: Hiding in Plain Sight

As single college-aged men sometimes do, I have had nights where I wake up at an apartment full of strangers. One weekend I rose to be greeted by 4 acquaintances—2 of which I hadn’t seen in years—and two complete strangers. I woke up in someone else’s house, lying in bed next to a young woman that didn’t live there, without my prosthetic on—and without crutches. The heat of the night had faded into the chilling reality that I had disassembled myself the night before. I had every reason in the world to take my leg off then, but suddenly I was frantically scurrying to put myself back together before she could wake up.

Given Goffman’s (1963) claim that “when a stigma is immediately perceivable, the issue still remains as to how much it interferes with the flow of interaction” (p. 49), and I was horrified by the thought of being watched and interrogated as I put myself back together. Young woman lying beside me was a “pre-stigma friend,” (p. 40) or a friend who hadn’t spent much time with me after I became an amputee. The last thing I wanted to do was put on a prosthetic assembly seminar. It is impossible to put my leg on in front of “normal” like herself without being scrutinized and questioned about the process. An amputee’s body becomes spectacle, as “they quickly become sources of fear and fascination for able-bodied people, who cannot bear to look at the unruly sight before them, but also cannot bear not to look away” (Siebers, 2001, p. 746).

Unlike the eager spectacle of my eating disorders, I do not enjoy being recognized as deviant in the ascribed spectacle of disabled. The last thing I wanted in this moment was to be stared at.

DAMN IT! I thought, *I don't have any alcohol to make my liner hold suction—I can't put my fucking leg back on!* In a hungover panic I hopped to the bathroom in my underwear and fill my mouth with sulfur-laden water, I swallowed a couple of gulps before filling my mouth and holding it. Hopping back to my leg that was still wearing the shoe and pants from the night before, I spat the water into it and rubbed it around the inside of the socket for lubrication. I slid into the socket with the liner on my leg, and closed the air-tight valve that holds it in place... *Success!* I buttoned my pants and limped into the hallway, to realize that I must have fallen at some point in the night because my prosthetic foot was turned slightly inward.

Even when it causes me pain or discomfort, I still find it important to wear my leg in front of people who don't know me well, and the research of Murray (2005) has shown me that I am not the only amputee that feels this way. Most often, I wear my prosthetic for the benefit of the people around me; my difference has the ability to make others uncomfortable, especially if they haven't spent much time around amputees. Murray's (2005) study suggested that being aware of other's discomfort with my own limb loss could cause me to perpetually cater to them by wearing a prosthesis (p. 433). On this morning, I had only briefly been acquainted with everyone else in the house—and I didn't feel like talking about my life with them.

Two large bull dogs roamed the small living corridor between the bedroom and the kitchen. I thought about something I learned years ago—even the nicest of dogs are put off by my crutches. I briefly remembered that one of the dogs growled and snapped at me the night before, even though I was *passing* as a normal! The young woman I didn't know—Tracy, it turned out—said “Don't look at that one, and don't touch him! He's mean!” as the dog thrust

his massive snout into my crotch. I walked backwards a few steps, and the hinge in my prosthetic bent under my weight because of my inward twisted foot and I stumbled. The dog instantly raised its lips, exposing all of its teeth to me and began snarling ferociously—“Buuuuuck, leave him alone! That’s not fair-he can’t run from you hahaha!”

Although I resented her comment, I have to admit I was thinking the exact same thing. “Fuck you,” I muttered under my breath, unsure whether I was talking to the dog, her, or myself. My head was throbbing with every brain-swelling beat of my heart, as it feebly attempted to piece together the night before. I saw that my crutches were still leaned against the wall behind the couch where I had left them 7 hours before, and I knew better than to use them in front of *those* animals.

“Can I get a cup of water from your sink guys?” “NO!” they answered, obviously teasing me. I dragged my feet into the living room to grab a dirty cup from the coffee table in front of them and stumbled over a cell phone charger—pulling the cellphone to the ground in a crash. “Shit, I’m so sorry, I didn’t see it” “Jeeze Gimpy, why don’t you break some more stuff!!” Millard said, still obviously teasing me. I chuckled it off apologetically and walked to the sink. As I waited for the water to turn warm, I remembered vividly explaining my motorcycle accident to the girl I had woken up beside.

“I heard you called your mom to say goodbye to her before the EMT’s made it there” she said. The words flashed through my mind along with a visualization of her saddest face, all but begging me to reveal the dramatic details. The water spilled over from the cup, burning my hand, returning me to the present with more anxiety than before.

I looked at Holly and asked her if she would take me back to where my car was parked in the city. Sighing loudly, she looked at the other two roommates sitting on the other couch and said, “Tracy, you’ve got to go to work—will you and Millard take him?”—“Naw let’s make him walk! Hahahaha” Millard cackled as I sipped the rancid, egg-smelling, tap water. “Do you mind if I make us some coffee for the road Gimpy?” At that point I had gotten tired of all the gimp humor, but I realized that I was too hungover to start an argument in someone else’s house about how I didn’t feel as though I was being treated fairly. “Not at all, douchebag” I said as we all chuckled for a moment.

Nearly an hour later all five of us piled into the back of a large truck and began winding down the beautiful, nauseating, back roads to Food City before returning to my car. Walking through the grocery store, we stopped to play the claw-drop game for a stuffed animal that couldn’t have been worth more than a dollar. The hallway was full of electric wheelchairs, plugged into the wall waiting for customers with disabilities. “Cripple....Hey Cripple---There ya go!” Millard said, pointing to the wheelchair closest to me. I dug my fingernails into the palm of my hand, trying to keep my temper; *I mean they really are such nice people. I can’t understand why this fucker won’t lay off of me. Why is he so damned incessantly fixated on my leg?*

I raised my voice to express my frustration, “Dude...I’m going to the counter, getting a Gatorade and a pack of smokes, then I’m getting the hell out of here. I’m not trying to ride in that noisy fucking chair for the five minutes I’m here.” Immediately after finishing my sentence, an elderly man sat in the chair and pulled out to do his shopping. *God, how could I be so rude in front of that man? I identify more with him than I do any of these losers.* I was sick, angry, and red-faced with rage and embarrassment. “Haha, I’m just messing with you gimpy—you look like you’re having a lot of trouble walking without those crutches.”

“HAH!!!” I exclaimed sarcastically and walked the other direction in the fluorescent light-mare for anyone with the slightest headache. After getting a drink and some cigarettes, I walked outside with Karyn—the girl I had spent the night with. “I don’t like how you let people make fun of you like that; it’s wrong.” “What should I do then Karyn? Start a scene and explain something that 20-something years of living around other people couldn’t teach him? I wanted to hit him in his nose but that won’t solve anything.” “I just think you let peop—.” “I’m too hung-over for your pity, spare me, it’s not your life to worry about. I think they are good people that don’t realize how offensive they are being. They heard me joking with you and Holly joking with me, and they think they can too. Let it go. I just want to get back to my car.”

Minutes went by as we stood in silence and watched people come and go from the storefront of the grocery mecca. “I’m an ass Karyn, I’m sorry. I just, I’m used to this shit and it just ...ah...I don’t know, I get defensive when other people want to help defend me, ya know?” I suppose I had developed a distaste for being defended by others back when I was bullied for my weight, my disability status however, could never be fixed by any amount of self-control or restrictive behaviors like my weight could.

Millard walked out pushing a grocery cart to the back of the truck, and I started helping unload cases of water into the truck-bed. “Hey, Taylor?” It was the first time Millard had used my name, and his solemn tone completely took me off guard. I already knew before he spoke that he was feeling remorse or at least trying to behave as if he was. “What’s up brotha?” I ask, trying to preemptively lighten up the moment. “I’m really sorry man, I had no idea you only had one leg, and neither did Tracy. Holly told us inside; I’m really sorry bro I feel like an asshole.”

As happens so often, the script flipped as I felt I needed to console Millard about his actions and explain to him how I wasn’t upset, I knew he was joking, and that it happens all the

time. “I knew you didn’t mean anything by it bro, you didn’t know... It happens all the time—people see the crutches and”— *Interrupting me quickly* “I saw the crutches and thought you just twisted your ankle or something bro, I had no idea you were actually hurt or anything.” “Exactly, but I’m not actually hurt, it was like 6 years ago Millard, seriously don’t worry about it—I’m definitely not upset at you bro and I really appreciate your apology.”

Tracy walked up as we finished loading the truck and began apologizing as well, “I’m sorry for joking about your leg—I didn’t know—that was an awful joke.” I couldn’t stand the awkwardness of their apologies, my best efforts were directed at downplaying their folly and the level of offense I took from it. When they finally dropped me off back at my car, I drove home without the radio on as I thought of how much the morning events applied to the thesis I was writing.

The offensive things that Tracy and Millard had been saying all day were not intended to offend me. “For example,” as Goffman (1963) says, “while a lame boy may seem always to present himself as such, strangers can momentarily assume that he has been in a temporarily incapacitating accident”(p. 74). They had deduced from my crutches that I was only temporarily disabled; if my disability were only temporary I would have been laughing along with them given Murray’s (2005) suggestion that “. . . temporarily disabled persons promote self-definitions that state ‘this deviance will not always be me’” (p.436).

My ability to “pass” as a non-disabled individual was compromised when my new acquaintances became aware of my crutches. Assuming that my limp was impermanent, they began to interact with me as if I were a “normal” by chastising me based on a straw-man caricature of the extreme disability that they did not know I actually embodied (Goffman, 1963). My ability to “pass” led me to witness the ways in which my disability is mocked, and

consequently led me to the uncomfortable need to diffuse the situation by negating how offended I was. I felt forced to console my oppressors in order to rid myself of the discomfort that they caused me. The ability to conceal one's limb absence by using prosthetics can make it extremely difficult to "broach the subject with others" (Murray, 2005, p.436).

Broyer (2011) experienced disability stigma at a young age in the ways that I experienced it in transition to my disabled identity: over time my amputation was relatively meaningless to me until the attention of others positioned me as a spectacle (p. 38). I rarely consider myself different from others, until after they have called attention to my difference. I do not believe that Millard and Tracy would have ever been so openly discriminatory if they had known of my disability beforehand, but their lack of tact in joking around with me made it hard to forgive them.

As I contemplated on the morning for the rest of my long trip home, I started to think of whether or not I should include this story in my thesis. I remember that Couser (2005) advocated the autoethnographic method for its ability to take an experience like this one and write it; thus rendering it visible to a public beyond those with whom I interact daily (p. 140). Perhaps my experiences could help others avoid or deal with social missteps like those which I endured that morning. I spent the rest of the drive deciding whether I was comfortable with the idea, and I suppose now that I must have been.

The curiosity of adults undoubtedly affects the way they communicate with me, but I must use a great deal more caution when explaining myself to children who are equally, if not far more curious about my leg. My own sense is that children need not be burdened with the existential crises one undergoes following a limb amputation, and after hundreds of trials I have finally crafted ways to strategically answer their questions without shattering their fantastically

innocent paradigms. The following story explains a specific time in my transition to embodiment in which I was unable to deal with the curiosity of children in an effective way. The experience itself served as a catalyst to my social awareness of children-at-large. The following narrative takes place at the end of my first vacation to the state of Texas.

Keeping Austin Weird: Curiosity Intrigues me, Language Minimizes

It's 106 degrees, mid-day in Austin, Texas. I'm crutching around the outside of an Apple store while my friends Lisa and Jesse search for phone cases inside. My hands are cracked, calloused, and dehydrated from a week's worth of vacation without my prosthetic. I raise my left hand to look at the time on my watch—my hand is bruised from the repetitive motions required to walk on crutches. It is two hours until our flight leaves for Dallas. I feel the eyes of every person as they fixate, examine, and avert from my leg; I want to go home.

There are no empty benches nearby. I rarely accept offers to sit down; I don't know why. It's been seven days since I have worn my prosthetic, and the phantom pain has returned. I resist the urge to move my residual limb back and forth—I know it will shock people too much. It feels like someone is pulling my toenails off while my foot is asleep—but my toes have no toe-nails, and they are connected to a prosthetic foot on the other side of the country that is propped up against my bedroom wall. *Jesus Christ—how long does it take to find a cover for your phone?* The heat combined with my unusually extreme phantom sensation is causing me to sweat profusely—I look down and see sweat drops hitting the ground underneath the open leg of my shorts. It's the first time I've seen that happen before.

I become self-conscious watching people frolic about this outlet mall with friends, family, spouses, and children; often when they see me they stop smiling—even when I've smiled

back. A sharp pain shoots through my pinky finger on my left hand; I'm holding too much of my weight on my crutches. I move the arm-pit pads of the crutches to my elbows and bow my head to rest on my forearms. I realize this stance is probably awkward to those passing by, but I no longer care because I am exhausted. Briefly I console myself, *Your prosthetic would have driven you mad on the plane; and it's so hot here that you would have sweated until it fell off. Your leg muscle has atrophied so much that the prosthetic leg won't fit correctly when you get home... Your crutches wouldn't have fit in a bag....*

I feel a hot breeze blowing through cooling the sweat on my arms and neck. Naturally, I turn my body to an angle to prevent my shorts from fluttering and exposing my residual limb. "What happened to his leg daddy?" I hear a young boy say—I look up, smile, and wave at the boy so he won't be scared. I feel like the watch on my wrist is the only thing keeping people from thinking I'm homeless, so I stand in ways that expose it most obviously to passers-by. As I place my forehead back into a resting position on my arms, I feel a hand tug on my shorts—nearly pulling my pants off on my right side. It's not a phantom sensation.

Being in the social sphere without my prosthetic on draws a great deal of attention; I often avoid being seen in public without a prosthesis on, even when it causes me pain.

Three children—missing various baby teeth from each of their smiles are standing less than 3 feet in front of me staring at my leg. I rarely miss the opportunity to chat with curious children; I never want them to grow up being afraid of people like me. Parents often scold their kids for looking, "Don't stare, it's not nice." Normally when a family with children enters my immediate area—I can see the strain on the faces of the parents as they anticipate the darndest things kids could say. These children had exited the Apple store without guardians.

Two little boys and one little girl—each appeared to be less than 6 years old—were staring at me with curious smiles and vacant eyes. I could tell they weren't scared of me, but I was torn from a self-loathing daydream by a violation of my private space. I stepped back with my heel, leaving my crutches in place to buffer some distance between myself and the boy tugging on my pants. "Whoa little man, where are your parents?" "They're inside" said all three of the children in unison. "Maybe you should go find them, they're probably worried about you" I coaxed. "They're right there!" said the little girl pointing at two women through the window. Two women were standing behind the window inside of the Apple store; one of them waved at the little girl as she pointed, but she didn't acknowledge me. Suddenly I was surrounded by the three children, circling me with their gaze fixated where my leg was *supposed to be*. "Where's your leg at mister?"... *Incinerated and pulverized into dust at some hospital crematory* I thought to myself. "I don't have one," I said, as they began squatting and trying to look up my shorts. Every move I made they countered immediately—*I can't shake them*.

People were walking by without looking, and I assumed they didn't want to get involved. The little girl ran up to a man about my age who was walking with his girlfriend, "Hey mister! *Look* he doesn't have a leg!" Part of me was embarrassed, but I actually laughed because I saw how uncomfortable it made them. As they continued walking I yelled, "And now, for my next trick!!!!" sarcastically pretending to be a street magician like one I had seen nearby. The charade was quickly drawing attention as the children started putting their hands on the crotch of my pants and trying to feel for my leg; I was mortified when I looked around at the number of people staring—it was no longer my narcissistic paranoia—I was the reluctant center of attention. I hopped around and tried to block them away from me with my crutches as the boy

who initially tugged my shorts grabbed the bottom of my pant leg and tried to look up my shorts. I smacked his hands away, and he giggled as he ran out of my reach.

I saw two people watching from tables on the patio of some restaurant that probably wouldn't serve me, considering the way I was dressed. I believed they were filming me with the cameras on their phone. *Damn, I don't want to go viral like this—I can't hit this kid...* “STOP IT!” I yelled, and held my arms up at the women whom I assumed to be the guardians of the children, as if to say “Are you not seeing this? Help me!” Each of them returned the same gesture to me, and I realized that I was not going to get any help from them. The kids were so happy and laughing as they continually cornered me in awkward positions. *I am being molested in some kind of ridiculous game of tag that I can't stop.* I saw more people with phones pointed at me, and I believed I was being filmed by everyone.

“Show us your leg!”—“I can't show you my leg; stop it right now!” Bursting into laughter they were literally jumping up and down with excitement. “Why not?!?!?” For the first time I wished that children were scared of me. “Show us your leeeeeeg, Show us your leeeeeeg” they started singing loudly as they skipped around me... *This...is not...fucking...happening to me right now.*

The little boy grabbed at my pant leg for a third time and I put my hand on his forehead and shoved him backwards. He lost his balance and fell on his butt, laughing, and jumped back up like it was a game. They each started doing it as if they wanted to be shoved back too; he did make it look kind of fun. Finally my friends walked out laughing—completely unaware of how traumatic the scene unfolding was for me. The children started following us down the walkway away from the store; I turned around to stomp my foot and shoo them like stray animals. They loved the interaction and kept running back, until finally one of the women walked out and

yelled each of their names followed by an angry “Get back here right now!!! Leave that poor man alone!”

That poor man? I thought.

The kids ran to the woman, and streams of profanity flew through my mind... I felt like a poor man after all, who couldn't solve the situation himself. We left the mall and drove straight to the airport. It was when I was taking my shoe off at the security check that I noticed the small chocolate handprints smeared all over the waist and leg of my camo shorts.

“The full range of reactions that are enacted toward me in the public sphere make it clear to me that there is something that is different, something that is other, that my body is something that needs investigation and justification”(Broyer, 2011, p.39). The children were entranced by the novelty of my disability; I can assume very comfortably that I was the first amputee they had ever been exposed to before. The same may be true of the woman who so kindly asked the children to “leave that poor man alone.” Exposure to persons with amputations like mine can help prevent nondisabled individuals from developing negative stereotypes or help them to overcome them (Schur et al., 2009). In this particularly extreme case, I was accosted by the children and avoided by their guardians likely due to my obvious position as a disabled other. Murray (2005) argues that such uncomfortable interactions may result from failure to wear a prosthetic leg in public (p. 428), and I would have to agree

I was in a process of failing: 1) failing to cope, 2) failing to pass as normal and 3) failing to handle the situation myself. As a stigmatized individual, I am likely to feel that “to be present among normals nakedly exposes [me] to invasions of privacy, experienced most pointedly perhaps when children simply stare”(Goffman, 1963, p. 16). The more recent autoethnographic

research of Broyer (2011) explains the distinct interactional differences between adults and children by saying her disability was "...nonexistent before children stared and commented on it or before adults stared, and then quickly averted their eyes in order to make it appear as if they were not looking"(p.38-39). I find the only people at fault in my harassment to be the mother or guardian of the three children for not being responsible for them, and for communicating aloud that she thought I was a "poor man."

I echo the sentiments of a 33-year-old amputee's narrative from the research of Rybarczyk et al. (1997) as she states "Children are very open about asking about it [my disability], and I'm open with them. Mothers, however, can sometimes be rude. I've had them pull their children away from me. They seem embarrassed by my physical appearance" (p.246). I, however, was more concerned with the language use employed by the mother in my own narrative than I was by her restraining of the children. Her language ripped me from their view as an interesting individual worth interrogating, and positioned me as a *poor man* that need be left alone. Her words were so powerfully offensive to me because of my self-stigma that I had created by internalizing what I believed others to be thinking of me in the moment. I believed that I appeared poverty stricken because of my lack of a prosthetic limb, through visions of what Cooley (1902) would call my *looking-glass self* (as cited in, Ellis, 1998).

I had discerned through my own observations and social awareness that I was the only visible amputee crutching around that mall in Texas, and I was hyper-aware of the way others were likely perceiving my clothing and lack of a prosthetic. I was horrified of being thought of as unworthy of occupying space in the mall as a *poor man* or a *crippled man*, and I knew that my outfit achieved the former whereas my crutches made obvious the latter. Such insecurities were spawned from my own self-stigma. I sometimes "consciously hold negative attitudes about

[myself] as a result of [my] altered body and consequent disability” (Rybarczyk et al., 1997, p.247). Drawing from Williamson (1995), Ryzbarczyk et al.. (1997) goes on to state that “. . . being predisposed to self-consciousness in public situations [can be] significantly correlated with activity restriction” (p.248). Although crutches may grant me relief in many ways, they are very restricting in my ability to move about in public without drawing the attention of others, and this often forces me to be self-consciously aware of the troubling spectacle I embody when I use them. When people see my crutches they often examine me, perhaps to see why I am using them. When I use crutches rather than a prosthetic leg, my body deviates significantly from what others expect to see, and I have become keenly aware of the discomfort my body appears to inflict on able-bodied others.

My obvious differences from able-bodied persons without amputations would likely mislead readers to assume that I find community within social spheres occupied by other disabled individuals. This is a misconception borne out of the use of the blanket-term “disabled” under which there are a countless number of referents that do not relate or identify with one another. The following describes my misconstrued membership in the disabled community, a community that is divided and has “its own prejudices and internal pecking order” (Couser, 2005, p.124). My goal is to explicate the linguistically constructed conception that there is a solidarity-infused community that exists for what one would likely think of as *my kind of people*.

Passing over Community: The Hierarchy of Authentic Suffering

The term *disabled* has many applications but is primarily used as an adjective to categorize individuals who have physical or psychological characteristics that deviate from the norm in a way that impedes their ability to navigate or interact in an able-bodied world. The myriad of different physical and mental characteristics are all encompassed by the singular term

disability. This conflation has created the illusion that there is a distinct disabled community of which individuals naturally become a part upon developing a disability; this is not the case.

Excluding situations in which one is seeking accommodation or monetary support, individuals with disabilities often work to distance themselves from their ascribed status of *disabled* (Broyer, 2011). As a participant in disability culture, I have borne witness to the strictly enforced and unwritten rules in what I call *the hierarchy of authentic suffering*. This hierarchy is the result of the defensive and offensive othering tactics that happen within the population of disabled individuals. I am only able to account for those within my own realm of disability—lower-extremity amputations that affect physical mobility. From what I can ascertain, the hierarchy is as follows:

Bilateral Hip Disartics—(Wheelchair users)

Bilateral AKAs—Both legs amputated above knee

Hip Disartics—Leg removed at the hip

AKA/BKAs—1 amputation on each leg of differing lengths

Bilateral AKAs—both legs amputated above the knee

AKAs[me]—Above knee amputations

Bilateral Knee Disartics—both legs amputated at the knee joint

Knee Disartics—amputated at the knee joint

Bilateral BKAs—Both legs amputated below the knee

BKAs—Below knee amputation

Single/Double Foot Amputation

This hierarchy, is less a form of claiming status than it is a claim to authentic suffering. It is socially unacceptable within amputee culture to complain about one's own suffering in the presence of, or try to console, others who are positioned higher on the hierarchy. This is a strange phenomenon—and one's position on the hierarchy is relatively static, depending on each individual's level of mobility and access to resources such as prosthetics and physical therapy.

If a foot amputee (FA) begins talking about how much she has suffered while in the presence of an above-knee amputee (AKA), then the AKA is likely to “console” the FA in terms that position the latter as suffering less in comparison to the AKA: “At least you can still...,” or “At least you don't have to...,” or “Just be glad that...”. I have been on both sides of this discussion before at different times in the past, and it fosters a competitive environment of one-upmanship when amputees begin comparing the qualities of their lives.

I came to realize that a hierarchy existed as I began spending more time around other amputees. Outside of the prosthesis clinics that I have been to, I have only rarely met other leg amputees in public that were not “passing” (Goffman, 1963). I used to only see other amputees briefly in the lobby of my old prosthetic clinic, before being ushered to a closed room like a doctor's office. For the past year however, I have been receiving prosthetic care from a fellow amputee and relative of mine in New Orleans, where I am allowed much more freedom to interact with other amputees and hear their stories. The time that I have spent there has helped construct and solidify my view that a *hierarchy of authentic suffering* exists.

One of my relatives is a prosthetist as well as a LBKA or left below-knee amputee, and I am an RAKA or right above-knee amputee. Even though he is a veteran prosthetist who has

helped fit amputees with prosthetic limbs for decades, in moments of frustration I rehearse my resentment of him as being ignorant of how much more suffering my amputation causes me than his does him:

He could still run if he really wanted to; he still has his knee. His suspension system is way superior to mine and it always will be because of how short my femur is. He expects me to NEVER use crutches? He's on a high horse because his leg is so much easier and faster to put on. He may know what's going on but he has no idea what it feels like, so who the hell is he to try to console me?

I only feel this way when I'm particularly frustrated with my own situation, but were he not a prosthetist and if his age was closer to mine I would feel this way all the time. I told his son, who is also a prosthetist, about my frustration and he laughed saying: "T, you're not the only one. Guys come in here all the time that are (Insert higher level amputations) and they all tell him he doesn't know what it's like for them . . . some of 'em actually get mad at him." I remember hearing him say that as I watched Mr. Ron (Prosthetic technician) filing away at a wooden prosthetic leg that was being made to fit an AKA that was uninsured. The joints were primitive, the aesthetics were minimal, and I was thinking how much better off I was than whoever would receive that leg. Mr. Ron was whistling while he slowly sanded at the wooden calf of the prosthetic; he is one of the few true artisans left in the business. He placed the leg on the table and began to walk across the room to get another tool, and as he walked I watched him limp and drag his leg. Mr. Ron was and still is a right hip disarticulation amputee, and since that day I have felt unworthy of claiming any suffering in his presence. I don't feel sorry for Mr. Ron; I respect and acknowledge his position above me on the hierarchy. In honesty, although I would

expect his struggle to be greater than my own, he often appears to fare much better than I do in regards to living and enjoying life to its fullest.

These happenings depict the politics of a sub-group of leg amputees, which is a sub-group of amputees, which is a sub-group of mobility disabilities, which is a subgroup of physical disabilities, which doesn't include mental disabilities. So, even the most exhaustively focused micro-level of the disability population, the othering methods that we induce serve to completely thwart the formation of any community. On the macro-scale it is almost laughable to imagine a community being formed under the blanket term *DISABLED*, which includes everyone from the blind, quadriplegics, the depressed, obese people, and even folks with carpal tunnel syndrome. When there are no grounds on which to commiserate, it seems unlikely that any disabled individual will find an immersive community outside of their sub-sub-sub-sub-sub-groups.

It is much easier to empathize with a man who has no shoes, so long as he isn't standing next to a man with no feet. "Physical disability is at once a personal experience and a shared cultural creation—the experience *of a body through a body in relationship with other bodies*" (Scott, 2013). The term *other bodies* encompasses other deviant bodies of fellow amputees and physically disabled individuals. The simplest, most primitive form of community is one that is based on propinquity, yet "when not institutionalized, [the disabled] are often geographically dispersed. . ." (Couser, 2005, p. 124).

Aside from the insider's perspective I have gained from prosthetic care offices that I have had access to, I'm very limited in the amount of interactions I have had with other amputees. Couser (2005) specifically addressed the issue at hand by saying "In any case, since disabled people do not share a single condition, they cannot be—nor should they be—represented as a monolithic community" (p. 124). Although Couser (2005) attributes the pecking order and

prejudices in relation to the disconnection between mental and physical disabilities, I extend this assertion to encompass the entire range of lower-limb amputations. Using Couser's (2005) own words to describe that "all of these differences create potential fault lines within the group as a whole; far from monolithic, then, the category of disabled people is inflected with differences that profoundly affect identity politics (p. 125).

To date, I have never heard another amputee even allude to the existence of a hierarchy within the disabled community, but all of the amputees I have spoken with appear to be tacitly aware of our differences. The fact that we are all forcibly grouped together by the term "disabled" based on our lacking something in comparison to able-bodied "normals," perhaps causes us to distance from each other in attempt to maintain our own individual identities. The closer one is to being able-bodied based on appearances, mobility, treatment and behavior, the more distanced he or she is from being accepted as an equal within the disabled community.

The level of spectacle one is ascribed to for their disability has a positive relationship with their level in the hierarchy of authentic suffering, as those who are more capable of "passing" as able bodied are less able to claim membership to the disabled community. "Passing as a normal" allows a disabled individual to intermittently prevent himself from being ascribed as a reluctant spectacle in public, which arguably causes them to suffer less social consequences for their bodies differences. I often catch myself feeling superior to people that are positioned lower in the hierarchy when they fail to "pass" as well as I do, yet when they exceed me in ability, I tend to discount their achievement as being less than my own. As I watch them walk step-over-step up a staircase I think, *they have it easy compared to what I've been through*, but deep down I know that statement can't always be true.

CHAPTER 4

Spectacle: Take It or Live It

Though there are obvious overtones throughout this entire work that refer to the effects of ideal masculinity on my identities, it is important to note that it serves a slightly different function in the case of my eating disordered identities than in my disabled identity in regards to spectacle. Control and agency were seized and exemplified through my eagerly sought spectacle of eating disordered male, whereas they were negated by the reluctantly ascribed spectacle of disabled amputee. Curbing my desires to eat, and controlling my body's ability to digest food, I viewed as the ultimate seizure of agency and control over the ways which others would perceive me. My loss of that control happened upon the onset of my disability, and furthermore I found myself with a new need to project a mastery of my own environment. I believe that my perceptions of ideal masculinity have a notable effect on the valence that I place on ascribed spectacle, a socially constructed view of myself which I have no ability to manipulate and must, reluctantly, accept.

As a young boy, I suffered a great deal of bullying and negative attention under the ascribed spectacle of *fat boy*, and although I loathed the negative attention I received, I formed an identity based on what my oppressors thought of me. I hated what I represented to those who cast their gazes upon me in judgment of my physical body. I was told by others that I could never change, and I began to believe that I was destined to be labelled as Tanker Tits or Butt Stomach for the rest of my life. Initially, the only time I received recognition from other students in my high school was for the negative character traits that they were able to deduce from my apparent fatness.

The majority of my teenage years were spent learning that my physical size was something that separated me from and disgusted my peers, so I decided that the only way to be accepted by them was to reduce it. I believed that by losing weight I would achieve acceptance, and I was right. I was showered with praise for my incredible feat; losing 100 pounds in a single semester of high school gave me a taste of a different kind of spectacle, one that was eagerly achieved rather than ascribed. The shower eventually turned cold, as I then became an embodiment of the norm, and just as soon as I came to love the praise and spectacle I had achieved for my efforts, I faded into obscurity as an average male. I was no longer being bullied, yet I had acquired a taste for compliments and acknowledgment that could not be satiated.

In an eager attempt to regain my spectacle among my peers, I developed what I believed to be a method for regaining the spotlight. I began making efforts to become the thinnest boy in my high school. I started by embracing Anorexia Nervosa and starving myself for weeks on end, my hope was that my peers would grow worried and provide me once again with the positive reinforcement of saying “You don’t look fat!” When my emaciated figure stopped drawing attention, I adopted a new strategy that I studied diligently on the internet: becoming bulimic.

Bulimia became my way of showing that I too was disgusted with my previous spectacle as a *fat boy*, and my purging rituals were symbolic of that disgust. It was never good enough to simply remove food from my system; I wanted the warning signs to be flashing in front of the faces of all my peers and superiors. I wanted them to know I was lost and focus their attention onto worrying about my health; I knew that if I could do that, it would be because they were finally noticing how thin I was. I achieved what I was so eager for: my peers were no longer focusing on my weight itself, they were focusing on how absurdly thin my body had become. I neglected to mention earlier in the thesis that I used their attention to gain status within my

school. I knew people were talking, so I branched out socially and made an effort to talk to and become liked by every person that I could. It led me to be elected by my peers as junior-class president and Mr. Junior in 11th grade, and in my final year of high school I received a landslide victory in my campaign for Student Council President, a position that was voted on by the entire student body.

Tanker Tits got elected to be your President ya 'll! To me, the election felt like a vote for the most attractive and likeable person in the school. Knowing that my thinness and rituals were giving me the attention that I had been starving for, I believed them to be the only things valuable about me as a person. Through Ana and Mia I was able to captivate the attention of my peers through word-of-mouth, and I made sure that every time I was around others I was politicking for them to like me on a personal level. If they didn't like me why would they care that I was starving to death? Without Ana and Mia, my only other options were to be ridiculed or completely unnoticed, and I feared both of those alternatives more than death.

My death was something that I romanticized during the embracement of my eating disordered identities; death to me was the ultimate achieved spectacle. I yearned for it, not out of a hatred for life, but out of a lust for recognition as the antithesis of Tanker Tits. No one told me that high school relevance wouldn't transfer into life after graduation; I learned that lesson through experience. People in line at the gas station, in the aisles of the grocery store, in cars that I passed in traffic, none of them gave a damn that I was starving myself. I realized the folly of my own actions, but I had become addicted to the rituals themselves. I could not rid myself of the perceived need to starve and purge when I did eat, until the day that I lost my leg.

Staring at my insides as they lay scattered across the pavement, I saw the yellow fat cells that I hated, and I wanted nothing more than to put them back into my body. It was a spectacular

feeling, clinging to the life that I had been convincing myself for years that I wanted no part of. Just before accepting death, I accepted myself for the first time in my life since childhood. *How foolish*, I thought, as I realized myself to be the biggest bully that I had ever known. My near-death experience created a solace for me, and removed my need for others' approval. I wanted another chance to live for me, without caring about how others perceived my body. I was never fully granted that.

I awoke in the hospital with the newly ascribed spectacle of a disabled amputee, and didn't become fully aware of my body's new ability to draw attention until months later. Initially, I thought that people poured into the hospital in droves to show they were happy that I was still alive, and as I sat at the end of a cafeteria in the hospital I lost control of myself and began to laugh in their faces. I remember their shocked expressions as they were likely contemplating my sanity; my awareness of their contemplation only exacerbated my uncontrollable laughter. *Half of these fuckers don't even know my middle name*, I thought to myself as they sat stunned by my inappropriate behavior. Laughing was not a decision I made, but I had no language to explain how I was feeling. I would assume that the gathering of people surrounding me at the cafeteria table were equally uncertain of how to communicate their concerns to me. Humor had always been one of my strongest coping mechanisms, and is still to this day. I never cried over the loss of my leg at the time, but I have since wept over the ways it seems to make people to feel uncomfortable to be in my presence.

Since that day, I have put forth tireless efforts to hide my difference from those around me, but I am not ashamed of my amputation. I attempt to hide my disability for the same reason I attempted to lose my weight, because each of them solicit negative reactions from people who don't know me well enough to understand that they don't define me. I could not hide my obesity,

just as I cannot hide my disability, yet the onset of the latter caused me to place more value on my mind than on my physical body.

After seeing the way my disability changed the interactions I had with other people, I became fascinated by all levels of study within the social sphere. I began to excel in college in my studies of sociology, and graduated to a masters' program in communication studies. My experience of eating disorders and disability provided me with a wealth of knowledge that helped me to empathically understand others much better than I could have without them, and became the impetus for this autoethnographic thesis.

Discussion

This thesis makes several contributions to literature across multiple fields of study. In regards to the method itself, this autoethnography is the first to discuss both eating disordered and disabled identities. Furthermore, it is a rare autoethnographic account of the lived experiences of a heterosexual, eating disordered male. The paper is less about the experience of disability or eating disorders *per se*, than it is about how the two are each forms of identity that maybe, and were for me, intimately connected to spectacle. To date, the human body as spectacle has not been examined in the extant literature through critically reflexive narrative. This thesis uses the concept of spectacle in a very unique way, and is also the first to argue that there are both eager and ascribed forms of it.

The narratives and research included in this thesis can inform in the fields of psychology, medicine, communication, disability studies, masculinity studies, and critical feminist scholarship. The experiences detailed throughout this thesis will hopefully serve to help academics, relationship partners, friends and family of eating disordered or disabled individuals

better understand what they face in a society that is pervaded by objectification and criticism of bodies that deviate from the norm. With a better understanding of how one might experience eating disorders or disabilities, it becomes much easier to relate to and provide support to someone that suffers through either. I must reiterate that my experiences are unique to me, and other eating disordered or disabled men and women may not place the same value on their identities as I have. In hopes, it will show others that they are not alone in their struggles.

Implications for Future Research

Future researchers would benefit from a recognition of how the autoethnographic process is a very tedious and revealing method of research, and I would warn against using this method in pursuit of one's graduate thesis. A thesis is unlike other academic scholarship; it has a deadline and can prevent graduation from one's academic institution if the paper is not finished in time. When I initially decided to pursue an autoethnographic thesis, I was unaware of how strenuous the process would become. Any reservations that arose concerning the personal nature of my paper was met with the uncomfortable reality: I had no time to change my mind.

Before crafting the narratives included in this thesis, I required a much better understanding of the autoethnographic method itself. At first thought, it seemed like the easiest process imaginable, but I quickly found that was not the case. Some stories are better left untold, and some need told more than others. It becomes the job of the researcher evaluate the worth of the experiences they share, based on the goals of their research. There were many narratives that I worked for countless hours on that never met the criteria to be included in this thesis, but writing them helped direct my focus in other passages that did.

I believe it is extremely important to maintain a journal of researcher reflections that discuss the process of conducting autoethnography itself. I believe that researchers' critical reflections they find while conducting the process may further add to our understanding of the method as a whole. I was privileged to be enrolled in a communication studies program in which I received one-on-one suggestions, criticisms and insight from each of the professors in my department. Had I not been granted such privilege, I would likely have given up on the pursuit of my degree. I believe there is much more work to be done than what I have accomplished with this thesis, and I hope that others will use and critique it as they add to their own knowledge.

Researcher Reflections

There are many aspects of both my disabled identity and eating disordered identities that were cognitively inaccessible to me prior to my writing and researching of them. Before interrogating my eating disordered identity, I lived in denial of my previous struggles with Ana (anorexic identity) and wholly accepted Mia (bulimic identity) as I had purposefully acquired the latter. Prior to crafting my own narrative accounts of living with a disability, I was unaware of the ways that it had served as a catalyst for my interests in sociology and communication studies. I have read the detailed narratives and significant statistics of other researchers that blazed the trail for me to follow, and I stray from the path they created in hopes that it will illuminate aspects of each that are consistently overlooked in more traditional forms of research.

I was surprised by the myriad vivid memories that surfaced as a result of this autoethnography. Although this work is written in a way that speaks very matter-of-factly about various identities and my transitions between them, the process of these transitions went unnoticed as I lived them. Through the use of the autoethnographic method as means to study both my own experiences and the experiences of others through existing research, I was able to

fully conceptualize Ana, Mia, and my disabled identity. Each of these identities now intersect in my subconscious and throughout these narratives in a way that has furthered my understanding of myself. I have by no means recovered from my eating disorders, but facing them in this way, while not my intent, has been therapeutic in some ways.

My eating disordered identity is very much a part of my past, but I am still subject to a spontaneous recovery of symptoms. I would be lying if I said that writing these narratives didn't invite old habits to resurface; writing myself back into a disordered identity was not something that I thought was possible until I focused my lens on what it used to mean to me. Nearly every time I move from this laptop and crutch to the bathroom, I stop and raise my shirt in front of the mirror over my sink. As I look at my reflection, I see the face of a man with different problems. When I release my shirt and grip the hard-plastic handles of my crutches, I hear the clanking of the weathered and weakened metal that has carried me for years. I turn to my bedroom and see the different prosthetic pieces that put me together in a way that masks my deviant body for the public. As I put my leg on in front of a full length mirror, I strap a tight elastic band around my waist as a fail-safe to ensure my leg won't come off, and I can't help but notice the way my skin rests above it like the top of a muffin.

I am never satisfied. My perfectionist tendencies often hurt my progression, as even the work that is this thesis is not good enough for me. I want to tell more of my story: my extreme phantom pains, the way friends interacted with me in the hospital, the amputee fetishists/fakers/devotees that stalked my social media, the times that I have been mocked as a drunk for limping as I walked, and the way I pushed guilt onto my friends for continuing to live their lives. Learning to accept my own difference allowed me to reframe my world in a way that decreased the impact of my ascribed spectacle, and furthermore made it possible for me to

reconnect with friends that I alienated by projecting the problems I had with myself onto them. My understanding of the process could never have been so thorough had I not read through the experiences of others after writing my own.

I have dragged a highlighter across the most enthralling narratives I could find, and though many parallels can be drawn between my own experiences and those I was reading about, none discussed eating disorders or disabilities in the same manner that I have. I have discussed these negative aspects of my identity in the ways that they have shaped my life positively, and I have gotten what I was searching for. The works of others have opened my eyes to the fact that even though I rarely recognize them in passing, there are others who have lived or will live the same experiences that I have, and if I were a religious man, I would pray for them. Ana and Mia still visit from time to time, and my views of my body in relation to both disability and weight will likely regress and evolve accordingly. I may never conquer the demons that I have created for myself, but at least now, I know them by name.

The Anxiety of Self-Revelations

Through writing my own detailed personal narratives, I have unveiled aspects of my own psyche and life that I would have otherwise left un-interrogated. Some aspects of my life have been under a veil, hidden, even from me until now. I'm afraid that my own experiences truly are insignificant when held in comparison to the myriad of struggles throughout the human condition; we are the only species that ponders its own worth in regards to its own kind. When I read my own narratives, I am afraid of how other academics will perceive them. As a 26-year-old man, I have spent as many years in adulthood that I have spent as an amputee—my evolution from teen to adult happened in the midst of my disability's onset.

I have been isolated from others my own age in many ways; I have many acquaintances and few very close friends. None of my close friends live within two hours distance; so much of the relationships that I have are maintained through cell-phone conversations and random visits from each of them. This affects my narratives in an unforeseen way—most of my experiences in the social world have been at one of five places: gas stations, restaurants, bars, the gym, and school. The graduate program for communication studies, in which I am enrolled, is sparsely populated, and a restructuring of the department I entered has left me removed from several members of my original cohort of students.

Most of the previous paragraph was to set the scene of my unique social existence; I spend the vast majority of my time in isolation at my apartment or in moderate isolation as a student in the classroom. Now whenever I am home alone—I'm drafting narratives to investigate my subordinated position in society. Imagine waking up every day in order to paint a picture of your struggle for others to learn from, and then imagine having to draft it in a dramatic and engaging manner in order for them to give any attention to it. I find myself wondering why I even started this journey in the first place.

I'm afraid for people to hear detailed narratives from when I have been in bar environments, physical altercations, intimate or erotic endeavors, because I am afraid that it will have an effect on their perceptions of me as an academic. There is no other method of research that delves so deeply into the personal life of the researcher than autoethnography; I have become both *the researcher* and *the researched*. I am the interview participant that I must attempt to understand, cannot use a pseudonym for, and that no institutional review board will protect.

I continually do a great deal of contemplating on the social repercussions of releasing my own narratives for public consumption. I have become a retroactive narcissist in the ways which I shed light on my past, and I fear people will read my narratives and think that my life is always a depressive struggle to overcome. Cataloging my experiences into narratives has created a sort of “lowlight reel” of all my troubles. It is impossible to totally capture my life experiences in writing—so I wind up picking apart my own past with a fine-toothed comb in order to tease out the dramatic details that were often mundane when I initially lived them. Consequently, I wind up dwelling on past experiences now—even when I’m not writing them.

I used to regularly communicate on social media platforms like Facebook, but I deleted my accounts because I didn’t want my historical present to embarrass me in the future. Now I find myself wondering whether I should do the same in regards to my graduate thesis.

Should I delete my writings, forget the assignment and take comprehensive exams? If I choose that route, will someone come around years from now that shares my standpoint and do what I did not have the gall to? Regardless of which decision I make—I have equal opportunity of regretting either decision for the rest of my life. Interrogating my own psyche has left me with a strong awareness of myself as a cynic.

As a man, I have become a critical scholar with a strong respect for feminist ideals. When unveiling my internal dialogue for the consumption of readers, there are times when my thoughts do not match the values that I claim. I fear that, at times, I may be perceived as sexist based on a readers interpretations of my personal thoughts or perversions. At what point do I censor myself? Is it ethical for me to censor? Is it ethical for me not to? Researchers have an obligation to protect the anonymity of confidentiality of their research subjects. When I tell my story openly, am I accurately and ethically representing myself or am I abdicating my obligation to protect

myself? I can only know the message I intend to send to my readers, but I can never truly know how they will receive it.

My father bears the burden of providing me with perspective and consolation—he helps to jar me back into a world that doesn't simply revolve around me. I call him every time that I write, and he listens intently to every word, providing me with feedback along the way. In fact, throughout the stages of writing this reflection—I have been calling home to express my conflicting thoughts and read to him what I have written. He used the words of two different authors which he believed synopsized my conflict:

“When you look into an abyss, the abyss also looks into you.” –Friedrich Nietzsche

“It is by going down into the abyss that we recover the treasures of life. Where you stumble, there lies your treasure.” –Joseph Campbell

I have knowingly embarked on a journey into my own abyss; where I have stumbled in the past are the times that I selectively represent to the reader. I often outsmart myself through tacit denial of my circumstance, and then as I write somehow reality begins to weather away any plausible deniability. In hopes, I'll find some treasure around here somewhere.

The Process: Is it Changing Me?

I noticed over a conversation with my friend in which I am explaining my thesis work to, that I barely mentioned anything other than my own narratives. I am admittedly overly self-absorbed after days of being cooped up in my apartment reading and writing about amputees and eating disorders. I found it odd that I was explaining the fact that I used to have an eating

disorder to someone that I hadn't seen for any length of time in over a year. I wonder now if this paper is making me more comfortable with sharing my past, or if I am in some sort of scholastic psychosis that has me believing it's not embarrassing to completely expose my intrapersonal privacy to my peers, professors, and professionals. Is it my self-focus in writing becoming obnoxious and transmuting itself into my daily life?

I calm myself by realizing that, before I entered graduate school I never had the language to have such conversations. I've exposed myself to the very parts of this discipline that interest me the most, and I have done so resolutely. I decide again every day that I am not going to forgo the opportunity to share my paradigm by taking comprehensive examinations instead; in 3 days my choice will be irreversible. I have daydreamed at times about keeping these writings to myself and simply reveling in the fact that I finally know myself. Better, anyway. I imagine it would be therapeutic in the way that writing a hateful or apologetic letter and never mailing it is, but I know that I would regret not trying to follow my advisor's advice to "be brilliant!"

I never feel change as it happens, but I know that each semester I have grown as a person because of what I have read and studied. I wonder what kind of effect will come about from this thesis project. I think about other amputees reading what I have written, and judging me as something weaker than they. It sounds strange, but I do not know very many people like me. I've interacted with every other amputee I've met and I catch myself quickly as I continue to write that I can count all of them with my fingers. I'm not perfect; I too will accidentally use language, mannerisms, stereotypes and assumptions that embarrass me from time to time. The difference is that with time came better understanding, and with awareness it happens less and less each day.

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