

Ethical Dilemmas and Digital Subcultures: Silencing Self-Starvers as Epistemic Violence

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Abstract: *This article argues that two non-profit national eating disorder advocacy groups, the National Eating Disorder Association (NEDA) and the National Association of Anorexia Nervosa and Associated Disorders (ANAD), play an integral role in censoring pro-anorexia (pro-ana) subculture on social media platforms. This article adds to the ongoing debate surrounding the censorship of pro-ana discourse by interrogating the erasure of digital forums due to fears that eating disorders are communicable through narratives written predominately by young women. In response to these ostensibly infectious narratives, the advocacy groups institute guidelines for crafting a singular recovery narrative that might be “useful” for others, eschewing much of the research pertaining to eating disorder treatment and recovery and the lived experiences of self-starving women. As I will demonstrate, viewing this erasure through the lens of epistemic violence reveals that a social discomfort with pro-ana content may speak to a general unwillingness to confront structural violence that influences some women to engage in self-starvation.*

Keywords: *epistemic violence, eating disorders, recovery, illness narratives, rhetoric*

For many, the moniker pro-anorexia (pro-ana) is perversely ironic: how can someone be for anorexia? What are the people who write in such spaces for, exactly? The promotion of eating disorders? The sharing of stories in a supportive space? In part due to its discomfiting tone, the term, adopted by female self-starvers¹ who write about their experiences in online forums, has been the locus of much dissension in recent years, and social media websites have particularly struggled to address the potential threats such narratives may pose. Pro-ana websites have proliferated since the early 2000s, and in 2012, Lewis and Arbuthnott found that more than 13,245,000 Google searches

1 I primarily refer to self-starvers as women in this article because, according to the Office on Women’s Health, 85-95 percent of anorexics are female (“Anorexia Nervosa Fact Sheet” n.p.). Also, I adopt the term self-starver rather than anorexic to avoid labeling those who grapple with eating disorders and to emphasize their agency.

for pro-eating disorder websites are conducted annually (202). The surge of pro-ana narratives and thinspirational images (thin-inspiration) in online forums provoked many to study what was happening in these spaces, and what the effects were on viewers.

Pro-ana communities are often considered dangerous because they offer support for disordered eating behaviors, prevent recovery, discourage users from seeking help, and function as a type of Online Negative Enabling Support Group (Codie R. Rouleau and Kristin M. von Ranson 526; Stephen M. Haas, Meghan E. Irr, Nancy A. Jennings, and Lisa M. Wagner 51). According to Rouleau and von Ranson, these websites are often shut down because of concerns surrounding the “alluring quality of pro-ED websites to young girls and the potentially deadly effects of promoting self-starvation to this vulnerable population” (526). In 2010, Scarlett Jett, David J. LaPorte, and Jill Wanchisn found a correlation between viewership of a pro-ED website and significantly reduced caloric intake for participants following exposure (413). Similarly, Jeannine Gailey explains that she had to limit her research on pro-ana websites, and seek help from colleagues and friends, because the content negatively affected her eating behaviors (97). In part due to such findings, researchers often refer to the effects that pro-ana websites might have on those who are experimenting with disordered eating behaviors as “contagion-like” and “exceptionally deviant and destructive” because it seems that pro-ana content itself can trigger eating disorders (Stephen P. Lewis and Alexis E. Arbuthnott 201, Krista Whitehead 621, Jessica Reaves n.p.). This metaphor of contagion is especially provocative, as many fear that anorexia might be transmissible—not through face-to-face contact or airborne germs, but through infection with a pro-ana narrative.

Kelsey Osgood’s *How to Disappear Completely* reifies this belief by explicitly labeling the women who compose pro-ana narratives in any forum (online or in print) irresponsible. She recalls that even materials intended for anorexia treatment or awareness became, for her, a how-to manual. She warns against the sharing of self-starving experiences, which she finds inherently dangerous because readers might “catch” an eating disorder by reading about it: “[a]norexia,” she writes, “is contagious . . . It is a behavior that can be learned through stories . . . [It is] communicable, like herpes, mumps, AIDS, or the flu” (26-7). While Osgood’s own experiences speak to the danger that pro-ana narratives can and do pose for those vulnerable to such content, her account also renders any narrativizing about eating disorders potentially unethical, a problem that needs further investigation.

Risk-of-transmission frames have led to the erasure of pro-ana narratives on the blog hosting platform Tumblr and on two photo sharing services, Instagram and Pinterest. These three websites have in fact authored policies

that threaten to erase self-harm content and redirect users who search for pro-ana discussions to professional organizations such as the National Association of Anorexia Nervosa and Associated Disorders (ANAD) and the National Eating Disorder Association (NEDA). More specifically, in 2012, Tumblr changed its policies to ban any content that might encourage users to “embrace anorexia, bulimia, or other eating disorders; or commit suicide rather than, e.g., seeking counseling or treatment” (“Community Guidelines”). In an attempt to be responsible about its hosted content, Tumblr took a public stand against pro-ana (Pinterest and Instagram quickly followed suite), threatening to delete any accounts that engaged in positive discussions of eating disorders. While of course such websites must have guidelines for what kinds of content are acceptable, I want to interrogate their response of erasure to what are oftentimes complex and multi-faceted narratives about eating disorder experiences.

This article attempts to theorize a discomfort with erasing female voices because they are considered “dangerous.” While I understand the need to protect minors and vulnerable viewers from potentially dangerous ideas, I also wonder about the implications of censoring the narratives of women in digital spaces—and what other stories might be banned using rubrics of “contagion” and “danger.” Furthermore, the metaphor of pro-ana “infection” that conceptualizes eating disorders as diseases that may be “caught” immediately obscures the complexity of these illnesses, which may stem from many causes and develop over long periods of time. I am also concerned with the way the infection metaphor potentially discredits the women who write (about) themselves and their experiences. Debra Ferreday argues that pro-ana forums are shared subversive spaces: “Pro-ana represents an attempt to facilitate communication between people with eating disorders and, in doing so, implicitly aims to subvert the medical model of anorexia, whose emphasis on recovery tends to isolate individual sufferers” (284). Ferreday remains committed to seeing pro-ana community members as just that—members of a community wherein they can share experiences outside of medicine’s purview. Is it so strange that the self-starver’s attempt to reclaim control of her body through an eating disorder might also drive her to reclaim control of a forum for speaking about it? She adds that while many pro-ana sites do in fact “contain medical advice together with links that refer anorexics who feel ready to seek recovery to relevant sources of information” they also “provide a forum for young women who do not feel able to take such a step to discuss their lives as anorexics” (290). For Ferreday, “It could be argued that this also constitutes support,” albeit the kind of support that allows for many different recovery trajectories (290).

Similarly, some feminist scholars have argued that pro-ana writers should not be punished (with erasure) for merely reproducing dangerous messages.

Although Gailey experienced personal difficulty while researching pro-ana websites, she urges researchers to blame “the cultural messages that we are inundated with daily” instead of self-starvers and their websites for the proliferation of eating disorders (107). This is an important point for a feminist approach to understanding self-starving women, since I suggest that self-starvers are oftentimes maintaining (and exaggerating) cultural scripts about female bodies² they have learned from society at large rather than generating dangerous ideologies themselves. And, generally, pro-ana writing is less focused on converting others to anorexia than on attempting to gain control over one’s otherwise chaotic life. In fact, feelings of inadequacy, needs for nurturance, and fear/mistrust of people tend to motivate eating disorders, not a desire to convert others (Michele Siegel, Judith Brishman, and Margot Weinschel n.p.). Those at high risk for eating disorders are also often victims of sexual abuse, domestic violence, or sufferers of PTSD, which further complicates the idea that such pro-ana writers are dangerous (“Trauma and Eating Disorders” n.p.). Perhaps self-starvers’ narratives instead reveal their responses to violence that has already been done to them. In particular, NEDA’s website notes that 30 percent of self-starvers have been sexually abused, and Jacqueline C. Carter, Carmen Bewell, Elizabeth Blackmore, and D. Blake Woodside found that patients with a history of childhood sexual abuse (CSA) reported “more severe eating disorder psychopathology” when compared with patients who had no history of CSA (“Trauma and Eating Disorders” n.p.; 264). Because many women’s self-starving narratives stress the degree to which experiences of abuse and trauma have contributed to their eating disorder, a response of erasure to all pro-ana content might encompass a refusal to interrogate Western culture’s disproportionate abuse of women. Overall, the erasure of pro-ana subculture represents a misplaced and shortsighted attack on those who propagate and exaggerate unattainable bodily standards and respond to abuse rather than a structural engagement with the many issues that lead to eating problems.

While these banning practices have been met with much positive reception—and some criticism—no previous research has considered the impetus for erasure in terms of the organizations that provoke it. More specifically, no previous research has examined the role that non-profit advocacy groups play in perpetuating the violent erasure of the digital self-starving subculture. Unless they have carefully examined press releases and social media policies, some might not realize the integral role professional eating disorder organizations play in waging the digital war against pro-ana. In a press release from 2012 on the National Eating Disorder Association’s (NEDA) website, the

2 For example, that women must be thin, toned, and without appetite.

organization explains that they have joined forces with Tumblr to combat the pro-ana subculture that haunts their forums:

NEDA is now working with Tumblr to assist them in flagging pro-ana/ mia (short for pro-anorexia/bulimia) websites and to create language for directing individuals . . . to resources and help. Tumblr expressed their dedication to removing content that could trigger those susceptible to an eating disorder or further entrench the illness for those struggling, stating that they want to 'do the right thing.' ("National Eating Disorder Association Partners with Tumblr" n.p.)

NEDA, then, has played and continues to play an integral role in determining the acceptability of eating disorder content on social media websites, and they have even helped such websites locate content that should be flagged for removal. Furthermore, NEDA has encouraged social media websites to redirect searches for pro-ana content to eating disorder treatment resources. NEDA argues that removing pro-ana content to protect other viewers represents a justifiable excuse for erasure, and they furthermore claim this is "the right thing" to do. NEDA also mentions that they have previously partnered with Facebook "to help the company establish policies regarding reporting, flagging and removing individuals or groups—as well as photos, wall posts or statuses—that promote unhealthy behavior related to body image and eating disorders" (n.p.). The slipperiness of NEDA's word choice—such as unhealthy behavior and dangerous media messages—and the moralistic stance they take to eliminating the pro-ana subculture as it ostensibly preys on innocent victims warrant further analysis in terms of erasure and ethics.

In what follows, I analyze the websites of the two most prominent non-profit eating disorder advocacy organizations, NEDA and ANAD, to interrogate some of the ways in which they define eating disorders and control the narratives that can be shared about self-starving experiences. In attempting to counter the pro-ana subculture, NEDA and ANAD oversee the erasure of marginal voices as they generate one "healthy" and "responsible" narrative that can be told about eating disorders—to the exclusion of countless others that fail to fit their parameters. I will argue that the erasure of pro-ana subculture grants NEDA and ANAD the authority to speak for the relationships that self-starving women and men should have with their bodies and their eating problems. In what follows, I will discuss epistemic violence in connection to eating disorder treatment and pro-ana subculture more generally.

Then, I will shift to an analysis of the NEDA and ANAD websites, considering the extent to which their practices may be seen as silencing an important set of experiences and voices that bring vital issues surrounding eating disorder treatment to the surface. To illustrate the narrative constraints that

NEDA and ANAD place on self-starving writers, I will incorporate some of the narratives shared on their websites, and I will consider how they do or don't "measure up" to the organizations' ideal anorexia narrative. I will finally argue that attempts by female self-starvers to bear witness to complex systems of oppression enacted upon their bodies warrants our careful response, and not our fearful silence.

Epistemic Violence and Pro-Ana Erasure

Gailey identifies pro-ana as a "subculture" within which self-starving women might engage in edgework, or "voluntary risk-taking" behaviors (94). Gailey locates the pro-ana subculture movement within a general shift towards community formation and aggregation in digital spaces. She also points out the rhetorical significance of the communication practices that happen in these communities when she argues that "the young women are bound together by specialized symbols, images, and language" through which they communally share experiences (94). Gailey, then, emphasizes the personal risks that self-starving women take in pro-anorexia (pro-ana) forums and the extent to which they rely on these specialized communication practices and symbols to confront and/or cope with the stigmatization they experience.

While the narrativizing of stigmatization, abuse, and eating problems have been characterized as dangerous, I want to take an alternative approach that in some ways engages in edgework itself. Instead of further blaming self-starving women, I want to instead ask how viewing the erasure of pro-ana narratives through the lens of epistemic violence might alter our ways of responding to the embodied stories they share. For Gayatri Chakravorty Spivak, epistemic violence is a concept that describes (1) the violent re-appropriation of subaltern epistemologies as oppositional to imperialist epistemology and (2) the reduction of subaltern ways of knowing into a coherent and unified epistemology. In "Can The Subaltern Speak?" Spivak explains that examples of epistemic violence are characterized by "remotely orchestrated, far-flung, and heterogeneous project[s] to constitute the colonial subject as Other" and "the asymmetrical obliteration of the trace of that Other in its precarious Subjectivity" (2115). Put another way, epistemic violence occurs when the representation of subjugated ways of knowing are assimilated into one coherent narrative that is then conceptualized as oppositional to the dominant way of knowing.

Of course, pro-ana discourses are not the same as anti-colonial discourses, and there are inherent differences in reifying the authority of a colonializing nation vis-à-vis professional eating disorder organizations. However, the concept of epistemic violence resonates with the way pro-ana subculture is reduced to a series of dangerous, devious, and disingenuous communication strategies in contrast to the (ostensibly) healthy, affirming, and honest

communication strategies espoused by NEDA and ANAD. This transaction involves a relation of power, too, one that denigrates self-starvers' ways of knowing their bodies as it applauds the official narrative generated by advocacy organizations. For the self-starver, the erasure of her story results in a form of violence against her identity—what Spivak describes as the “obliteration” of the Other’s subjectivity—because it discounts her ways of coping as deviant (2115). Also, as NEDA and ANAD attempt to generate one acceptable and “helpful” narrative about eating disorders, they hint that all other narratives are (conversely) threatening and dangerous. In an epistemic violence framework, there cannot be a spectrum of narratives; there can only be two, and only one can be acceptable. Through Spivak’s frame, it’s clear that obliterating an Other’s ability to speak on her own terms is always an act of violence, one that renders the authoritative speaker or narrative more powerful.

When self-starvers do speak, their narratives and bodies are notoriously misread. Spivak describes a different yet similar problem in her example of embodied epistemic violence when she reflects on a young woman named Bhubaneswari Bhaduri, who killed herself in 1926 because she was unable to complete a political assassination. She delayed her suicide until she was menstruating because she did not want her suicide to be attributed to an illicit pregnancy (2123). Bhaduri’s suicide, according to Spivak, “generalized the sanctioned motive for female suicide [sati] by taking immense trouble to displace (not merely deny), in the physiological inscription of her body, its imprisonment within legitimate passion by a single mate” (2123). The complexity of this suicide was later dismissed by a new generation of female family members, who misinterpreted Bhaduri’s body’s message: “Bhubaneswari attempted to ‘speak’ by turning her body into a text of woman/writing. The immediate passion of my declaration ‘the subaltern cannot speak,’ came from the despair that, in her own family, among women, in no more than fifty years, her attempt had failed” (Spivak 2124). The misreading of Bhaduri’s body is analogous to the misreading of self-starving women, whose bodies bear complex and often contradictory messages. While of course there are differences in what the bodies of Bhaduri and pro-ana writers say, the idea that women communicate messages through their bodies—and that these messages are often misread—should give us pause as we consider the erasure of the narratives that further articulate these messages. As Bhaduri’s family misread her suicide, we now risk the potential misreading of self-starvers when we silence their bodies.

The erasure of pro-ana websites, which discredits female ways of knowing, perpetuates a cycle of violence that is always already done to women’s ways of understanding and experiencing their bodies. As an extension of Spivak’s

concept of epistemic violence, I posit that self-starving bodies are subaltern to the extent that they are potentially able to speak but not be heard. I argue that the self-starver cannot be heard or read because her ways of knowing herself and her body are subjugated in favor of ostensibly more credible medical and professional discourses which claim to offer support to women with eating disorders, even as they authoritatively speak for and, perhaps unwittingly, commit violence against them.

Epistemic Violence and Treatment

Before I shift to an analysis of the non-profit organizations that influence the erasure of pro-ana subculture and position themselves as the authorities for speaking about eating problems, I will first briefly describe the inadequacy of traditional medical forums as spaces wherein self-starvers might speak. Despite the apparent logic of recommending that women seek professional help rather than support from a pro-ana community, given the barriers that make treatment for eating disorders ineffective and unaffordable, such directives might make many self-starvers feel hopeless. In such cases, the pro-ana writer is unable to be heard because she does not have a stable forum wherein she might speak.

First, treatment methods for eating disorders are largely ineffective, despite the fact that eating disorders have the highest mortality rate of any mental illness. More specifically, according to research compiled by the Eating Disorders Coalition, up to 20 percent of people with anorexia will die from the disease (often due to heart failure), and the rates of recovery indicate that “1/3 recover after [the] initial episode,” “1/3 fluctuate with recovery and relapse,” and 1/3 will die (Ellin n.p.). Many women who do seek treatment will be turned away due to high costs or subjected to failing treatment models and unbalanced power dynamics within treatment centers. Herzog et al. also found that forty percent of anorexic patients will relapse after completing treatment (834). Thus, overall, the treatment model for eating disorders is largely ineffective in the long-term, and the mortality rate (due to suicide or complications) remains staggeringly high.³ In part, the proliferation of pro-ana forums might be read as a response to the inefficacy of treatment methods and the need to find alternative ways to speak about eating problems.

Furthermore, it is worth noting that many have criticized healthcare professionals for the ways in which they infantilize and dominate self-starvers

3 According to their meta-analysis of 36 studies, Jon Arcelus, Alex J. Mitchell, Jackie Wales, and Søren Nielsen found that the “weighted annual mortality for AN was 5.10 deaths (95% CI, 3.99-6.14) per 1000 person-years, of which 1.3 deaths resulted from suicide” (726). They also found that mortality rates for anorexia are “much higher” than for other psychiatric illnesses (729).

(and self-starving young women, in particular). In *Biting the Hand that Starves You*, David Epston reflects on his years of practice and research and reveals that psychological treatment for female patients is often deplorable. He writes:

women described with uncanny repetition that the hospitals to which they had been admitted as a last resort were “no better than concentration camps.” Although they had physically survived the ordeals of hospitalization and the terror of their force-feedings, many felt that their spirits had been trampled upon in the process, making them even more vulnerable to a/b [anorexia and bulimia] upon discharge.
(5)

As Epston reveals, the lack of attention physicians pay to empowering and listening to patients during treatment may render any physical improvements that are made temporary—even futile if patients leave feeling more dedicated to their eating disorders than before. The “concentration camp” metaphor offers an extreme depiction of the powerlessness and psychological torture that patients may experience during treatment. Epston also characterizes physician attitudes towards patients as violent: “Over the years, I heard many professionals refer to [patients] as ‘prima donnas,’ ‘spoiled brats,’ and ‘manipulative attention-seekers,’ describing them as people deserving of disdain and even loathing. At the same time, they also feared these young women” (5). Not only are psychological treatment models for eating disorders potentially violent in the sense that they might physically intrude upon the woman’s body through force-feeding or mentally retrain her ways of seeing and valuing her body, the sentiments and motivations behind such treatment can be violent as well. Such violence is also gendered, as the language used to vilify patients reflects a paternalistic and sexist stance toward female self-starving women and their illnesses. Furthermore, the discussion of loathing and fear as rhetorical responses to self-starving women serves as a valid frame through which we might conceive of the erasure of pro-ana subculture. By reacting to self-starving women and their narratives with disgust and fear, rather than a willingness to listen, we again refuse to hear their bodies speak.

Furthermore, traditional treatment methods for eating disorders may be inaccessible to some self-starvers who experience social anxiety or stigmatization for their illness. For example, Renee D. Goodwin and Marian L. Fitzgibbon found that “social anxiety is associated with a decreased ability to engage in treatment among individuals with eating disorders” (105). They add, “It is logical that social anxiety, in which fear of humiliation and rejection is often coped with through avoidance, may inhibit eating disorder sufferers from entering therapy in which social fears of evaluation may be activated” (105). An extreme fear of others and the opinions that eating problems can engender

can itself be a deterrent to seeking treatment, as self-starvers may fear the judgment and sharing that treatment requires. Ironically, treatment models that emphasize extreme monitoring of eating behaviors can reinforce habits that patients already inflict upon themselves. Furthermore, fears that a psychiatric diagnosis will haunt them in the future may keep some patients from seeking treatment. In *Don't Shrink to Fit! A Confrontation with Dehumanization in Psychiatry and Psychology*, psychiatrist Eileen Walkenstein writes, "[a] psychiatric diagnosis is like a jail sentence, a permanent mark on your record that follows you wherever you go" (22). When self-starvers diagnosed with Anorexia Nervosa are required to disclose their diagnosis for life insurance policies, job applications, and other official documents, they may fear that the risk of being stigmatized for their eating problem outweighs the benefits of insurance coverage for treatment costs. A diagnosis may secure funding for their treatments (although even a diagnosis fails to guarantee this), but they might not get a job because of their diagnosis, an even more devastating financial blow.

Many women will never have to face such a conundrum at all, however, since only a select few can access treatment due to the high costs for both in-patient and outpatient care. The South Carolina Department of Mental Health, for example, estimates that "[t]reatment of an eating disorder in the US ranges from \$500 per day to \$2,000 per day. The average cost for a month of inpatient treatment is \$30,000" and "[t]he cost of outpatient treatment, including therapy and medical monitoring, can extend to \$100,000 or more" ("Eating Disorder Statistics"). They also explain that health insurance companies often do not cover treatment costs ("Eating Disorder Statistics"). Lack of coverage and high treatment costs, unsurprisingly, have negative consequences for many women with eating disorders who are told that they have a disease but cannot afford treatment. According to ANAD's website, only "1 in 10 men and women with eating disorders receive treatment" and "[o]nly 35% of people that receive treatment for eating disorders get treatment at a specialized facility" ("Eating Disorder Statistics"). Thus, the violent medicalization of female bodies also fails the women who are excluded from treatment due to their inability to pay.

As previously mentioned, the research pertaining to the violence surrounding eating disorder treatment and the erasure of pro-ana has increased in recent years due to the growth of the pro-ana subculture. However, I will now add to this ongoing discussion by considering the role that NEDA and ANAD play in this cycle of violence that involves the physical control over female bodies in treatment, the erasure of their voices in cyberspace, and the epistemic and narrative control over their experiences on the NEDA and ANAD websites.

Epistemic Violence and Defining Anorexia

The erasure of pro-ana narratives stems from a joint commitment on the part of healthcare facilities, social media websites, and professional eating disorder organizations to monitor and control what can be said about eating problems. While medical treatment models reify medicine's authority over female bodies, thereby silencing self-starvers in favor of healthcare providers, professional eating disorder associations raise awareness about eating disorder treatment, inform the public about eating disorders, and connect women who might be at risk to helpful resources. More specifically, NEDA explains that their mission is to "support individuals and families affected by eating disorders, and serv[e] as a catalyst for prevention, cures and access to quality care" ("Mission and Vision"). This mission speaks to the important role that professional eating disorder organizations play in connecting self-starvers to treatment options and information. However, when professional eating disorder organizations use inadequate definitions for eating disorders and provide exclusionary guidelines for "responsibly" sharing narratives about eating disorders, they propagate the epistemic violence that is sometimes committed by medical authorities.

One way in which professional eating disorder associations, and ANAD and NEDA in particular, risk enacting this violence is by defining eating disorders in rigid ways that exclude many women who may not meet the "official" criteria for an eating disorder. For example, ANAD's website defines anorexia as being "characterized by emaciation, a relentless pursuit of thinness and unwillingness to maintain a normal or healthy weight, a distortion of body image and intense fear of gaining weight, a lack of menstruation among girls and women, and extremely disturbed eating behavior" ("Anorexia Nervosa"). They also use terms such as "obsessions," "deteriorates," "battle," "illness," "deliberate," "irregular," "abnormal," "compulsive," "excessive," "continuous," "refusal," and "a very frightening experience [that] feels very real" to describe the symptoms associated with anorexia ("Anorexia Nervosa"). These definitions characterize anorexia in exclusionary ways, as they insist that anorexia is characterized by absolute physical conditions (i.e. "a lack of menstruation") and vague psychological conditions (i.e. "a distortion of body image"). The definitions are both too broad (who among us in Western culture *doesn't* have a distorted body image?) and too narrow (some self-starvers continue to menstruate). Further, in using terms such as "relentless," "distortion," "intense," and "extremely disturbed," which suggest extreme degrees of psychological illness, ANAD risks the potential alienation of women who know that they experience anorexia, but not to the extent that these singular definitions suggest.

These definitions are problematic because the extreme medicalization of female bodies, particularly in regards to weight management, dictates that an expert must diagnose women with an eating disorder before they can seek treatment and receive insurance coverage. When the criteria for defining an eating disorder is simultaneously this specific and vague, many women may be told that they are not “really” or “officially” anorexic when they nonetheless experience disordered eating behaviors or relationships with their bodies. Functioning self-starvers who find that they are “not anorexic enough” to meet this definition’s standards may not seek treatment if they feel that their experience of disordered eating does not meet the official criteria. This means that many women may not be able to seek treatment until their anorexia is very severe, at which point treatment is usually less effective.⁴ Defining eating disorders, particularly anorexia, in very specific and extreme ways, is an act of epistemic violence because it speaks for self-starving women by defining who they (officially) are and are not. Furthermore, such a practice casts all women with anorexia into one category, as if they share one unified experience with it and can be treated in the same way. Finally, such an exclusionary practice commits the violence of preventing many self-starvers from seeking treatment as it delegitimizes their eating problem as irregular or not “real” enough to warrant coverage.

Guidelines for Sharing

Professional organizations go beyond speaking for self-starving women; they also tell them how to speak. NEDA’s website provides a set of guidelines that encourage women to blog about their experiences, but only within specific parameters for sharing stories “responsibly.” The guidelines for responsible sharing inform women that they “are in a unique position to offer hope” to others, and they urge them to “present your story in a *useful* way while protecting your personal well-being” (“Guidelines for Sharing,” emphasis mine). The guidelines tell women that there are ways of sharing their stories that are dangerous to themselves and others. To mitigate the risks of sharing their narratives, they must follow NEDA’s directions and shape their stories in accordance with these guidelines. While this warning does clearly articulate the rules for participating in the websites’ forums, it also potentially places blame on female self-starvers (in advance) for negative responses readers might experience.

For example, in a section called “Remember your reason for speaking,” writers are told to “[m]ake sure [they] leave [their] audience with the message that there is hope” (“Guidelines for Sharing”). Women are also warned to

⁴ According to Mental Health America, “The earlier a person receives treatment, the greater likelihood of full recovery” (n.p.).

avoid “anorexia chic” and told to remind the audience that “eating disorders are illnesses, not choices” to be glamorized (“Guidelines for Sharing”). These guidelines tell women which forms of narrativizing about their eating disorder are acceptable, but perhaps more importantly, they also tell them how to think about their disorder. Whether or not they feel that they *choose* to engage in disordered eating behaviors, they are told that they do not—anorexia is an illness that infects them against their will. They are told that eating disorders are not glamorous, which assumes that the women feel that way to begin with, even though some actually find the daily realities of self-starvation to be quite ugly. Finally, being told to leave the audience with a message that there is hope may be akin to asking the women to lie when we remember that two thirds of self-starving women will not fully recover.

Narrative Control and Eating Disorder Stories

While the previously mentioned forms of narrative control enacted by ANAD and NEDA, in terms of what constitutes an eating disorder and how experiences with an eating disorder can be described, represent forms of epistemic violence by controlling the definition and conceptualization of eating disorders, perhaps the most troubling way in which they establish themselves as the authorities for speaking about self-starving comes from their recovery story collections. ANAD features a page called “RECOVERY—True, Inspirational Stories,” where they invite women who have recovered from an eating disorder to share their stories. However, a message at the top of the page clarifies their philosophy on eating disorder narratives:

ANAD believes that full recovery is possible for each individual, but we also know how difficult it can be to imagine what life in recovery looks like. Here are the stories of people from all walks of life who have found freedom, happiness, and renewal through their own paths to recovery! (n.p.)

This philosophy, of course, seems overly optimistic when we again recall the low recovery rate for eating disorders. Although ANAD stresses that the writers come from “all walks of life,” they mention that they have all had the same outcome: recovery, happiness, and even freedom. They also suggest that the stories provided will help readers visualize what recovery looks like so they can shape their own problem narrative to fit those that they see featured on the website. In generating one narrative of recovery for people from different walks of life, ANAD restricts what readers can expect from the recovery process, fails to account for a variety of recovery narratives, and rejects the fact that recovery may be impossible or ongoing for many self-starvers.

NEDA echoes ANAD's philosophy on their own "Stories of Hope" page, where they similarly note that recovery is possible for every "diverse" person who experiences an eating disorder. However, "[t]he path to recovery is different for everyone, and each person's experience with an eating disorder is uniquely impacted by their many identities, including race or ethnicity, age, ability, religion, gender, and sexuality" (n.p.). It is interesting that NEDA invokes diversity and intersectional identities to speak about recovery, because I would argue that intersectionality is precisely what makes eating disorders so difficult to treat and recovery so challenging for many women. Becky W. Thompson suggests that "eating problems begin as survival strategies—as sensible acts of self-preservation—in response to myriad injustices including racism, sexism, homophobia, classism, the stress of acculturation, and emotional, physical, and sexual abuse" (2). With this intersectional framework in mind, Thompson relabels eating "disorders" as eating "problems" to position them as "logical, creative responses to trauma" rather than psychopathology (2). Thus, while NEDA attempts to argue that intersectional identities will not prevent any person from recovering from an eating disorder (although they admit that recovery journeys may vary), Thompson reminds us that curing eating disorders must involve a structural mission to confront social injustice and violence against women just as it involves an interpersonal goal to help women embrace their bodies. Full recovery from an eating disorder may entail not just a personal triumph over illness, as ANAD and NEDA imagine, but also a commitment to addressing institutions that contribute to the powerlessness and hopelessness that drive women to self-starve in the first place.

ANAD: "True Inspirational Stories" and Recovery

Despite the problems associated with making universal claims about eating disorder recovery, 33 out of 33 stories on ANAD's Inspirational Stories page ultimately conclude with the message that recovery is possible (although, to be fair, this is a criteria for having a narrative posted in the forum). In general, the self-starving men and women who post their stories identify a few common factors that helped them recover such as their own resolution to do so, an experience of being shocked by the reality of their situation, effective treatment, finding friends or mentors to confide in, finding alternative hobbies/interests, or religion/God. However, many of the writers' narratives reveal tensions between their recovery experiences and the criteria for such narratives espoused by ANAD. For example, a woman named Courtney emphasizes the role that trauma played in generating her eating disorder; she explains, in particular, that her eating disorder served as a "distraction" from the painful memories of that experience (n.p.). She writes, "I'd heard the statistics before: that at least 30 percent of people with eating disorders have experienced

significant trauma, and that eating disorders are unhealthy coping mechanisms. But of course, my eating disorder convinced me otherwise" (n.p.). For Courtney, a "light bulb moment" allowed her to "break down the cage" of the eating disorder and achieve full recovery (n.p.).

It is important to note that Courtney is one of the few writers who never shifts to second person point-of-view in her writing. Within the 33 narratives, most begin with a first person, past tense narrative, and shift to a present tense, second person call to action for readers. Thus, in concluding that she is "bigger and stronger" than her eating disorder and trauma, Courtney ignores the rhetorical imperative from ANAD to explicitly articulate an inspirational message for readers. Instead, she chooses to reflect on her experiences and share this introspection with readers, thus implicitly preventing the adoption of her narrative as a model for others to follow.

While Courtney feels that she has broken free of her eating disorder and the trauma she faced, a writer named Cody Barnes seems slightly less sure of his ability to completely escape his eating problem. Barnes, too, speaks of a man who abused him, and he describes his experience with bulimia that ultimately led him to try to commit suicide at Disney World: "[i]t was a wakeup call. I kicked my butt in gear and I was ready to fight this. I was no longer going to let this destroy me. I began standing up for myself. I began talking" (n.p.). He adds that he was able to put the man who abused him "on a shelf," and that in terms of recovery, "I'm getting there" (n.p.). However, after this admission of an ongoing process towards recovery, Barnes shifts into second person point of view to assure readers, "You can beat this! Life is so beautiful, you are so beautiful and you should be able to see that" (n.p.). While I do not mean to suggest that Barnes has not recovered from his eating disorder, I hope to highlight the way in which his narrative moves from a moment of doubt, of personal reflection, to self-assured motivational speaking for readers. The dual purposes served within Barnes' narrative points to a project not endorsed by ANAD's story collection. Although ANAD intends for the stories to be inspirational for readers, Barnes, like Courtney, engages in personal introspection throughout the piece. Barnes' piece also reveals a moment of hesitation—a revelation that "I'm getting there"—but he quickly shifts into a positive affirmation for readers, telling them with certainty that they can "beat" their eating disorder for good.

A feeling of uncertainty about recovery can be more clearly witnessed in a post by Jessica, who explains that recovery has been an ongoing struggle for her. She writes, "Lately I've focused on my negativity pushing my thoughts into a downward spiral. My lifesaver is the comfort my OCD and eating disorder provide. I escape and go numb. My mind can't hurt me there" (n.p.). This phrasing makes it unclear as to whether or not Jessica still engages in self-starving behaviors. She also describes her eating disorder as an "addiction," which

presents an interesting contrast in terms of recovery; significantly, it suggests that recovery might be a constant state of active and willful resistance rather than an epiphanic moment that allows one to fully heal. Jessica's narrative also stands out because it is one of only a few that doesn't shift to past tense when describing her eating disorder at the end. She remains in present tense to say, "[i]t's so hard for me, and every day I need to practice. I need to try to tell myself that I can handle anything, that I am strong and everything will be OK" (n.p.). Jessica's portrait of recovery, then, is one of an unending and difficult struggle.

In contrast to Jessica's account, a writer named Lauren H. again adopts the metaphor of "beating" anorexia in discussing her perspective on recovery. She explains, "For me, finding the resolve to beat this illness was about learning to engage in life and finding happiness and pleasure in the simple things in life. I think that one of the most important aspects of recovering from anorexia, which is often overlooked, is creating a life for yourself that you want to live in" (n.p.). Lauren H. also invokes the idea that recovery can be quantified when she notes that "[a]fter suffering from Anorexia Nervosa for a terrible 15 years I can finally and honestly say that I am 100% free from it" (n.p.). In contrast to Jessica's account about eating disorders, addiction, and recovery as constant struggle, Lauren H. argues that she has beaten her anorexia and is now "free" of it. The metaphor of freedom is invoked 24 times in the 33 narratives in a variety of forms: free, freed, freedom. Despite the few tentative accounts that present recovery as extremely difficult, full of relapses, and ongoing, ANAD's argument that recovery is possible for everyone seems to have influenced the rhetorical moves made by those who submit narratives for their collection.

These true, inspirational stories present some interesting tensions in response to ANAD's call for narratives that will inspire others to recover. The tension between writing for oneself and writing for an audience of other self-starvers can be seen in many narratives, where writers commonly shift from a first person point of view to a second person point of view in the last paragraph. Writers also seem divided on the issue of the tense used when describing their self-starving experiences (past or present), which highlights a larger issue of whether or not full recovery can be achieved, or whether it must be constantly attempted. Overall, then, the writers reflect some of the very problems inherent in making sweeping claims about the possibility of recovery for each person who experiences an eating disorder. The variety of experiences reflected in the stories demonstrates the importance of a more encompassing discussion of recovery on the part of ANAD.

There are also, noticeably, stories that are missing: stories by self-starvers who couldn't afford treatment, stories that reveal the violence that treatment can enact, and stories that reveal the possibility that freedom from an eating

disorder is not always possible. There is a disconnect, then, between the statistics used to discuss eating disorder recovery, mortality, and treatment, and the narratives ANAD embraces, even requires, on their website.

NEDA: “Stories of Hope” and the Role of Others

While ANAD stresses that contributors should ensure their story inspires others to be hopeful, NEDA provides guidelines regarding the role other people (family members, friends, and care providers) should play in the anorexia narrative. They explain that self-starvers should clearly describe that they depended upon others throughout their recovery process, and that eating disorders cannot and should not be faced alone. NEDA writes, “Be careful about providing testimony of how you ‘bravely fought this illness alone’ (“Guidelines for Sharing”). This message presumes, first of all, that self-starvers will want to present themselves as brave heroes who have rescued themselves from eating disorders. NEDA also asks that such testimony, even if it is true, be withheld from anorexia narratives. As they clarify: “Perhaps you did [fight the illness alone], but most do not—the vast majority of those who recover from their illness do it only with the ongoing help of trained professionals. Remember that isolation is one of the most difficult aspects of eating disorders for many sufferers” (“Guidelines for Sharing”). Again, it is not productive to generalize about how “most” do or do not recover from an eating disorder, particularly when those claims are not substantiated with any evidence.

NEDA’s policy also implies that self-starvers should have access to treatment, that such treatment is actually helpful for patients, and that there are other people available (such as supportive family members or friends) who are willing to be involved in the recovery process. For many women, these supportive networks of family members, friends, and caretakers may not exist, or they may be unable to care for the self-starver for financial, physical, or other reasons. Also, while it may be true that “most” do not recover in isolation, this statement strips the self-starver of her sense of agency in suggesting that she probably did not play a significant role in her own recovery. Finally, NEDA explains that self-starvers should “[m]ake sure you reinforce that it is courageous and necessary to reach out for support and guidance during the recovery process” (“Guidelines for Sharing”). For the reasons previously mentioned, insisting that others should “reach out” for help is unfair given the financial and emotional restrictions, and the stigmatization, that keep many women from doing so.

On NEDA’s website, nonetheless, while self-starvers do generally discuss others as a positive, motivating factor in their recovery, their stories reveal some important tensions between the role that others play in the recovery process and the self-starver’s own agency. A contributor named Ericka reveals

that other people—particularly one child—ultimately led her to seek help. She explains, “It wasn’t until I became a preschool teacher that I even began to appreciate and understand what life is about. I watched one of my students battle (and survive!!) cancer. It was then that I realized that I had a critical choice to make. I could honor my body...Or I could continue to abuse it” (n.p.). Other contributors echo this narrative by revealing that other people’s illnesses, their near-death experiences, and interpersonal confrontations led them to realize the severity of their illness and seek help. For some, becoming responsible for another person in a crisis situation served as an epiphanic moment that reminded them of the importance of living. However, Ericka’s framing of her epiphany as suddenly “choosing” to recover is at odds with NEDA’s and ANAD’s own claims that eating disorders are not lifestyle choices but diseases. While they in some cases deny that self-starvers have agency in choosing to perpetuate their disorder, they also ironically demand that self-starvers should *choose* to recover, with the help of a supportive community.

Contributors also describe the role a supportive community played in helping them through the challenges of the recovery process. Another contributor, Meghan, writes that her family and a friend named Sam were her motivation for healing. She notes, “My family never judged. They just loved. They also worried. Learning of the worry my anorexia and bulimia were causing for the ones I loved most became a main motivator in my later recovery” (n.p.). In this case, other people motivate Meghan to the point that she feels guilty for her illness. Meghan seeks treatment when she realizes how her pain affects others, but it seems that this is due to a sense of obligation to family rather than for her own benefit. Meghan also shares her future plans as they relate to her health and the family she is creating with Sam: “A continuous motivator in beating this thing has been the hope for a happy, healthy family with Sam. I want happy, healthy children who never have to experience the horror of anorexia and bulimia” (n.p.). Even in describing the future, Meghan seems to hold herself accountable for being healthy enough to create a family and bear children. It is others—both present and potential—who motivate her health—but they also foster feelings of guilt and potential inadequacy.

Another writer, Debbi, describes the role her treatment facility played in her recovery. She explains that those who cared for her while she was in treatment became very important to her—so much so that her final day in their care was very emotional. She remembers that “Tears streamed down my cheeks as the therapists, staff members and other girls touched my heart when they told me how far I had come” (n.p.). She adds, “I’m so grateful for all the love and support I received from everyone—it truly showed me how lucky I was. There was even a mock funeral staged for me at the facility to prove how many people I’d be hurting if I let my disorder consume me entirely. Physically

and psychologically, I was torn apart by this" (Debbi). Like Meghan, Debbi experiences guilt at the thought of hurting her family and friends by potentially dying. Unlike Meghan, however, Debbi seems unnerved by the experience of the mock funeral, and a bit overwhelmed by the pressure to stay healthy for so many others. Also, the phrase "if I let my disorder consume me entirely" reveals that Debbi views the disorder as something that she can, and should, control. Her ethical obligation to not hurt others makes her feel (perhaps unfairly) a responsibility not to allow anorexia to control her. She insinuates that if she allows anorexia to control her, then she allows anorexia to hurt the people she loves. This undermines NEDA's claim that others should be included in the narrative because they have helped the self-starver recover. As Debbi's account reminds us, even well-intentioned family and friends can cause more harm than good when they respond to the eating problem by reinscribing feelings of inadequacy and guilt. Perhaps acting brave for others does not differ so much from rescuing oneself from a disorder.

Ultimately, NEDA's argument that self-starvers must stress the extent to which they rely on others to help them recover from their eating problems risks placing guilt on women, who may feel that they must maintain their health for others. While feeling responsible for others is not wrong, of course, it does seem important that a person suffering with an eating disorder not be unfairly burdened with ensuring the happiness of others as she fights to save her life. Furthermore, NEDA ignores the extent to which many women do face eating problems alone, and this loneliness can cause self-starvers to seek support in the very pro-ana forums that NEDA attempts to erase. An ugly but nonetheless true reality is that many women cannot afford professional support and cannot find emotional support for their eating problems. Thus, NEDA's narrative both unfairly imposes a particular narrative stricture upon writers and excludes women for whom this element of eating disorder recovery does not apply.

Conclusion

In the future, social media sites should reconceive of their role in the ongoing censorship and erasure that medical treatment centers and professional organizations engage in. Rather than focusing their efforts on banning pro-ana content, social media platforms should help democratize access to support groups and treatment and encourage more self-starvers to seek help—but on their own terms. Social media platforms hold unique benefits as spaces wherein self-starving narratives can be shared; for example, such spaces are much more readily available than expensive treatment options. Additionally, pro-ana forums and social media websites can provide anonymity that may encourage some self-starvers to feel more comfortable speaking out about

their experiences. Finally, such spaces can connect self-starvers who may otherwise never meet in person—especially for those who live in remote areas, for whom treatment can be more difficult. For some women who might not be able to travel to areas where support groups or treatment facilities can be found in abundance, online forums offer such communities at the click of a button. Social media websites constantly encourage both personal testimony and shared meaning making, so such spaces might also foster supportive engagements among self-starvers, who can assert the unique qualities of their experience even as they connect with others whose narratives overlap with their own.

As I conclude this alternative reading of the importance of pro-ana forums, and the violence of their erasure, I am struck by what might at first seem like a curveball analogy. However, I believe it has important implications for the way we respond to the framing of particular texts as dangerous. In early 2016, a new edition of Adolf Hitler's *Mein Kampf* was published, reigniting a fraught discussion among various stakeholders—within politics, education, and the media—about the ethical implications of reading Hitler's Nazi treatise. The scholarly publication, which features heavy annotations and contextualization, is now available for sale and purchase in Germany for the first time since World War II. The fear of Hitler's text inspiring a neo-Nazi revival in Germany—or perpetuating Germany's shame for having embraced Hitler as a leader—has led many to suggest that Hitler's text should continue to be banned. However, in "Does 'Mein Kampf' Remain a Dangerous Book?" Adam Gopnik argues that rather than fearing a text, we must fear and respond to the circumstances that allow such "dangerous" texts to be embraced. He writes that Hitler "didn't invent these arguments. He adapted them, and then later showed where in the real world they led, if taken to their logical outcome by someone possessed, for a time, of absolute power. Resisting those arguments is still our struggle, and so they are, however unsettling, still worth reading, even in their creepiest form" (n.p.). Gopnik's argument is twofold: first, Hitler wasn't himself the sole author of Nazism. Although he led the movement and actively participated in the murder of millions of Jews, social forces such as racism, nationalism, and even the devaluing of the arts⁵ contributed to the Nazi movement. Hitler's responsibility must be viewed within a system of violence and oppression that supported his message and helped him put it into action. Furthermore, Gopnik reminds us that we must read Hitler's narrative precisely because it is dangerous, since we cannot expect to respond to and prevent such tragedies from occurring in the future by simply pretending that they did not happen.

5 See Peter Ross Range's "Why 'Mein Kampf' is a Must-Read Now" for a fascinating account.

Of course, pro-ana narratives are a far cry from *Mein Kampf*. But the idea that narratives can be dangerous—and that they can transmit dangerous actions—fails to justify their erasure. As Hitler’s narrative must be read within a social context that allowed his ideas to take root and succeed, pro-ana narratives must be read within a social context that encourages eating problems, promotes extreme thinness and dieting, and generates troubling relationships between women and food. Similarly, just as we must engage with Hitler’s ideas precisely because they make us uncomfortable, we must also face the uncomfortable truths that pro-ana narratives reveal: that treatment is often ineffective, that women are disproportionately victims of abuse, violence, and rape, and that Western beauty ideals can have devastating effects on those who try to meet them, among others. Just as we have a social responsibility, as citizens of a global community, to actively prevent tragedies such as the Holocaust from occurring again, as digital netizens, we have a responsibility to actively respond to the social ills pro-ana discourse reveals.

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