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Weighing In: Therapeutic Benefits of Online Communities for Individuals with Eating  
Disorders

Cheri L. Greenfield

A research project submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

for the degree of

Educational Specialist

Department of Graduate Psychology

November 2014

## WEIGHING IN

### Dedication

This project is dedicated to my dear friend, SaraLisa. Our time was too short. I miss you.

### Gretel

*Andrea Hollander Budy*

A woman is born to this: sift, measure, mix, roll thin.  
She learns the dough until it folds into her skin and there is  
no difference. Much later she tries to lose it. Makes bets  
with herself and wins enough to keep trying. One day she begins  
that long walk in unfamiliar woods. She means to lose everything  
she is. She empties her dark pockets, dropping enough crumbs  
to feed all the men who have ever touched her or wished.  
When she reaches the clearing she is almost transparent—  
so thin the old woman in the house seizes  
only the brother. You know the rest: She won't escape that oven. She'll eat  
the crumbs meant for him, remember something of his touch, reach  
for the sifter and the cup.

"Gretel" is from *House Without a Dreamer* (Story Line Press, 1993). Copyright © by  
Andrea Hollander and reprinted with her permission.

## WEIGHING IN

### Acknowledgements

I'd like to acknowledge the following individuals for their support and assistance with this research project:

My partner, John McNaught, without whom this process would have looked much differently. Thank you for your encouragement and honest feedback, reading after reading.

My mentor, Nancy Webb. I want to be you when I grow up!

My advisor, Dr. Jack Presbury—thank you for your open and accepting approach, for encouraging me to write from my heart, and for your patience throughout this process.

Table of Contents

Dedication Page.....	ii
Acknowledgements.....	iii
Abstract.....	v
Introduction.....	1
Background: Diagnostic Criteria and Treatment Contrasts.....	2
Telling Our Stories: A Narrative Approach to Recovery.....	7
Media Influence and the Evolution of a Virtual Audience.....	10
Eating Disorder Websites: A Brief Introduction.....	14
Elements of Recovery: Rigidity vs. Personal Power.....	18
Online Resources and Eating Disorder Communities Explored.....	19
General Method.....	22
Results.....	25
Discussion.....	28
A Personal Narrative.....	30
Conclusion.....	38
References.....	41

Abstract

The treatment of eating disorders involves a complex approach. In recent years, a number of websites have developed in an attempt to meet the needs of individuals struggling with this set of disorders. Some of these websites are nationally recognized organizations dedicated to improve treatment and provide educational resources, while other websites have been authored by individuals with eating disorders in an attempt to create a safe community of support. This project explores various components found in online communities, examines characteristics of eating disorders, and evaluates the worth of such resources, even when in perceived contrast with traditional treatment. Rather than work against one another, this study looks at ways in which varying approaches to treatment might co-exist in a complementary manner, to provide a more comprehensive set of resources for clients with eating disorders.

*Keywords:* pro-ana, eating disorders, anorexia nervosa, bulimia nervosa

## Weighing In: Therapeutic Benefits of Online Communities for Individuals with Eating Disorders

Eating disorders have long existed as a secretive set of illnesses, with ambiguity surrounding the causes, diagnostic criteria, treatment, and recovery. Individuals who struggle with this disorder often express their symptoms as existing undercover, hidden from family and friends. This guarded position complicates relationships and creates confusion among those who do not have eating disorders.

As an individual who has experienced recovery from an eating disorder, I can attest that while the journey to recovery is quite personal, certain forms of treatment can be completely ineffective and can potentially perpetuate or exacerbate symptoms of the eating disorder. While a medical approach places high priority on weight gain as the immediate treatment goal, this focus can unintentionally ignore the emotions beneath the eating behaviors, often leaving the client/patient feeling disconnected and powerless over treatment (Noordenbos, Oldenhave, Muschter, & Terpstra, 2002).

The purpose of this paper is to explore available online resources for individuals with eating disorders based on current literature regarding treatment directions as well as narrative feedback from individuals within existing online communities, and to compare specific features of existing eating disorder websites in order to identify the general methodology and components of an online forum. At the core of this project is the idea that “weighing in,” a practice included in the medical approach to eating disorders treatment, focuses on the numbers and physical aspects of the disorder, rather than on the human, emotional implications. I propose that a metaphorical use of “weighing in” might have broader and more therapeutic benefits—that belonging to a community and

contributing words of encouragement and support are more likely to result in successful recovery, and at the very least, are involved in reducing the harm caused by an eating disorder.

### **Background: Diagnostic Criteria and Treatment Contrasts**

While eating disorders have undoubtedly been known about for some time, they have only recently surfaced in terms of significance and widespread public awareness. Anorexia nervosa and bulimia nervosa officially joined the ranks of psychological disorders in 1980 when they were added as categories in the Diagnostic and Statistical Manual of Mental Disorders (3<sup>rd</sup> ed.; American Psychiatric Association, 1980). More than thirty years later, the most recent edition of this publication (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association, 2013) includes several changes that impact the field of eating disorder treatment and research. A total of eight categories are listed within the “Feeding and Eating Disorders” section: Pica, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder, Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Other Specified Feeding or Eating Disorder, and Unspecified Feeding or Eating Disorder. This paper will focus mainly on anorexia nervosa and bulimia nervosa, the two disorders most often identified by individuals using online resources.

Definitions of both anorexia nervosa and bulimia nervosa were revised in the DSM-5, with clarifications regarding specific behaviors. Diagnostic criteria for anorexia nervosa include:

- “Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health,”

- “Intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain,”
- “Disturbance in the way in which one’s body weight or shape is experienced.” (pp. 338-339)

The definition goes on to list specific subtypes (restrictive vs. binge-purge), as well as identifying factors regarding severity of anorexia. The revised category no longer requires the amenorrhea criterion, which refers to the cessation of menstrual cycles often accompanying long-term anorexia, and removes the word “refusal” in regards to eating, focusing instead on restrictive behaviors that limit caloric intake (American Psychiatric Association, 2013).

According to the DSM-5, a diagnosis of bulimia nervosa include:

- “Recurrent episodes of binge eating”
- “Recurrent inappropriate compensatory behaviors in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise,” and
- “Binge eating and inappropriate compensatory behaviors both occur, on average, at least once a week for 3 months.” (p. 345)

Many individuals who self-identify as bulimic or anorexic exhibit associated behaviors without meeting specific diagnostic criteria. Until 2013, specific weight criterion was still required for a formal diagnosis of anorexia, excluding many individuals who presented with weights in a normal or slightly below normal range (Pearson, 2013), and the definition of bulimia includes terminology, such as “excessive exercise” or “misuse of laxatives, diuretics or other medications” that are not easily measured

(American Psychiatric Association, 2013). This ambiguity impacts diagnosis and prevents individuals from receiving necessary treatment. While the recent changes in the DSM-5 have addressed some of these factors, there exists a great deal of misconception regarding what constitutes an eating disorder. This confusion adds an additional complexity to diagnosis and treatment, and deserves further discussion within the counseling community as our understanding continues to evolve. As diagnoses more accurately reflect behaviors and thought patterns, treatment should be expected to improve.

However, a contrast exists in what the treatment community considers best practice versus what individuals with an eating disorder perceive as effective. A study by Agras and Robinson (2008) described the evolution of evidence-based treatment over a period of four decades, and found that research fails to identify a consistent direction in which anorexia nervosa is treated. This study also suggested that individuals with anorexia are inherently resistant to treatment efforts, and that treatment often fails due to their reluctance or refusal to gain weight. Ninety-three percent of clients surveyed in another study (Noordenbos, Oldenhavé, Muschter, & Terpstra, 2002) described initial medical treatment as ineffective, claiming that such attempts were often threaded with advice from physicians “not to diet anymore and to gain weight” (Noordenbos, et al., 2002, p. 22). More current studies by Pearson (2013) and Penny (2011) suggested that many individuals slip through the cracks, not meeting criteria for diagnosis or treatment. This can be for several reasons—the former definition of anorexia included amenorrhea and specific weight criteria (formerly fifteen percent below “normal”) for diagnosis, while the current definition views recovery as an absence of all symptoms, including

negative body perceptions. Most professional approaches to treating anorexia involve weight management, interpersonal therapy, cognitive behavioral therapy, and family therapy for children and adolescents, with growing support for therapy combined with medication management (Brown & Keel, 2012). However, some research suggested that an “anti-medical” view exists among anorexic individuals (Davies & Lipsey, 2003), and that certain approaches might actually manifest symptoms and behaviors of the illness, including repeated unsuccessful attempts at treatment in which recovery becomes associated with potential failure. In their 2002 study, Noordenbos et al. described experiences of individuals for whom recovery seemed a hopeless fantasy:

The more often the respondents experienced a therapy as unsuccessful, the less motivated they became for new treatment. They were often afraid of another failure and lost hope of improvement. They learned to see themselves as incurable. (p. 23)

Individuals with other types of eating disorders show slightly better outcomes in terms of treatment potential. Cognitive behavioral therapy or some variation is most often used in treatment of bulimia nervosa and binge eating disorder, while family and group therapies have yielded mixed results (Brown & Keel, 2012; Cook-Cottone, Beck, & Kane, 2008; Fairburn, et al, 2009). Dialectical behavior therapy combines elements of a traditional cognitive approach with mindfulness-based strategies and has been successfully used in treatment of individuals with bulimia (Federici, Wisniewski, & Ben-Porath, 2012). Interpersonal therapy, often in combination with an antidepressant, and practices like yoga and Pilates, which encourage a mind-body connection, have also

found success in the reduction of bingeing and purging behaviors (Brown & Keel, 2012; Neimark-Sztainer, Eisenberg, Wall, & Loth, 2011; Cook-Cottone, Beck, & Kane, 2008).

In fact, a recurring idea in research actually suggests inadequacy in treating an eating disorder medically. Unless they specialize in this type of treatment, medical doctors do not comprehensively train on the complex emotional implications of an eating disorder. In their study, Noordenbos and colleagues (2002) estimated over ninety percent of participants first sought help from their general practitioner, whose approach naturally focused on medically relevant techniques. While health implications of eating disorders are quite important to consider, ignoring psychological and emotional elements misses the mark. Traditional medical healing focuses on restoring the body to physical health, its main purpose to eliminate unhealthy behaviors rather than explore emotions that lie at the foundation of the eating disorder. With this view of recovery, relapse seems highly probable, and as research has shown, many treatment attempts are indeed unsuccessful. In the mind of an individual with an eating disorder, repeated failed attempts at recovery establish the eating disorder as an impenetrable force, creating a barrier in regards to recovery potential.

Noordenbos et. al. (2002) found:

The treatment of chronic patients with anorexia and bulimia nervosa leaves much to be desired. It often takes a long time before patients with EDs find any specialized treatment...As a rule, they get psychological treatment only after weight gain and medical intervention. However, gaining weight is often very threatening for them. After gaining weight some of these patients become severely depressed and think about suicide. They develop negative feelings

towards their therapists, and feelings of distrust about any new treatment. After several unsuccessful treatments they become afraid that they are incurable; some therapists also see them as incorrigible. (p. 26)

Not only is this a challenge for the individual who seeks treatment, this commonly described experience challenges the entire treatment community. When a client enters the counseling relationship with a solid foundation of examples where trust in others and even themselves has failed them, this impacts their success with even the most experienced and empathic therapist. If treatment specialists modify therapy practices and perceptions regarding recovery, we might see an evolution toward more effective eating disorder treatment.

### **Telling Our Stories: A Narrative Approach to Recovery**

The concept of recovery is complex. Generally, recovery can be viewed as a process that ends in return to a former state of health and wellness. However, while the body is resilient and often emerges from illness with unexpected strength and renewed energy, other examples suggest that recovery is not an absolute issue. Broken bones are often vulnerable to future breaks, and even when one's body is healed from the original injury, a scar remains. In this way, recovery from an eating disorder often varies according to personal experience, and it can be a long and lonely road. As Noordenbos et al. (2002) describes above, when multiple attempts at treatment have offered little relief or change, and at times have negatively impacted self-concept, our concept of recovery must be re-examined.

A feminist approach suggests that individuals with eating disorders use abnormal or dysfunctional eating behaviors to demonstrate personal control and autonomy

(Eastland, 1997), and to give a voice to conflicting or suppressed emotions. Empirical evidence supports the use of narrative therapy in eating disorders treatment (Tillman, 2009; Robbins & Pehrsson, 2009; Lock, Epston, Maisel, & deFaria, 2005). In “Body and Bulimia Revisited,” Lisa Tillman (2009) gave an emotional account of her experience with bulimia. While in graduate school, she read Christine and Julie Kiesinger’s paper, “Writing it Down: Sisters, Food, Eating, and Our Bodies,” and saw parallels between their experiences and her own. She began to record some of the memories resurfacing in her course journal, and her professor shared pieces with one of the authors, Christine Kiesinger. This was the beginning of a collaborative relationship in which Tillman found emotional support along with a writing partner who helped her navigate the tumultuous aspects of her eating disorder. Tillman (2009) wrote:

Christine and I continue delving beneath surface meanings of bulimia (e.g., as merely a means of achieving or maintaining thinness) and exploring its dialectical tensions: between fullness and emptiness, control and chaos, expression and secrecy. A binge not only can fill the body but also the spirit with nourishment and comfort; (over)eating in Western cultures is a common means of self-soothing. A bulimic purge expels not only food but also rage and pain. (pp. 106-107)

In this paper, Tillman described the change that took place when she began filling herself not only with food, but also with understanding and empathy for the experience of other women. As she found ways to express her emotions through her words, committed to changing the culture that encourages unhealthy body ideals for so many women, she began to heal. In 1996, she published “A Secret Life in a Culture of Thinness: Reflections

on *Body, Food, and Bulimia*,” and thought she had put her eating disorder to rest.

However, when her marriage began to fail ten years later, she spiraled into a depression in which she became dangerously close to relapse and finally entered therapy.

One of the themes that accompany Tillman’s work and account of her long and involved recovery is a feminist perspective. As a scholar and an educator, she acts as a mentor to her students, mostly young women. Her commitment to creating an improved environment for a younger generation of women includes responsibility not only to herself, but to those around her in how she addresses herself, how she describes her body, and even how she perceives her weight. For her, recovery involved exploring her story, its themes, and the elements that have contributed to her illness, recognizing which of those characteristics she continues to harbor. Writing and revising her story not only gave voice to her experience, it also allowed her to own and reshape that experience—to change its course.

Tillman isn’t alone in her support of a narrative approach. In their study, “Anorexia Nervosa: A Synthesis of Poetic and Narrative Therapies in the Outpatient Treatment of Young Adult Women,” Robbins and Pehrsson (2009) followed the treatment of a young woman named Amanda, who sought recovery from anorexia. As an outpatient client, Amanda worked with her counselor in a collaborative treatment plan that included using poetry to explore and metabolize painful emotions. At the beginning of this therapy, Amanda described the difficulty involved in simply entering treatment and revealing an eating disorder, accompanied by the fear of potential weight gain as a result of effective treatment.

In Amanda's treatment, poetry allowed her to explore pain from another's perspective, ultimately encouraging her story to surface and eventually bringing the concept of resolution to the table. In this way, the eating disorder is given an identity separate from the client, externalizing the disorder, which allows the client to recognize behaviors and thought processes with more clarity. As Amanda progressed through therapy, her poetry began to include statements of possibility, and she gradually began to view her body as her own. Through narrative and poetic therapy, the client is given a voice in her treatment, allowing a sense of control, as well as the opportunity to express the emotions that had previously held her captive.

### **Media and the Evolution of a Virtual Audience**

Personal control issues arise when the opinions and needs of others are emphasized more than an individual's personal perceptions. The tripartite model of influences identifies three central factors: parents, peers, and media (Hardit & Hannum, 2012; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). Given our culture's propensity toward imagery along with the thin ideals held by the fashion industry, it might seem that media influences would significantly impact body image development. However, some research findings suggest that among the general population of women, peer influences are most influential in perpetuating body dissatisfaction, while media images may have a greater impact on individuals with eating disorders (Hardit & Hannum, 2012; Suisman, et al, 2012). In a recent article in *The Guardian*, Laurie Penny described her experience as an adolescent in the early stages of anorexia:

... at age 12, I didn't care about celebrities. I stopped eating because I was desperately unhappy and wanted to disappear. It was only much later that I started

reading glossy magazines, which I found full of approving articles describing the starvation diets reputedly pursued by successful women in the public eye.

(Penney, 2011)

A 2011 study found women with below normal Body Mass Index (BMI) as more unhappy with their bodies than women with normal BMI, suggesting physical wellness might positively impact body satisfaction (Ferguson, Munoz, Contreras, & Velasquez, 2011). Likewise, maintaining a thin ideal correlates with increased body dissatisfaction, linked to a less fulfilling life overall (Munoz & Ferguson, 2012). These findings imply a cyclical nature—negative body image promotes unhealthy eating patterns, which perpetuates negative body image.

In recent years, individuals with eating disorders have faced an additional challenge with the vast world of visual imagery available and imposed on our computer desktops. Since its first emergence as a strange and mysterious underground information system, present day internet use has all but replaced our most basic sources of information. Communication increasingly relies on electronic transmission, and this virtual world has become part of our everyday reality. Advertising sidebars and pop-ups align with personal browsing history. Shopping online for women's exercise apparel or swimwear becomes an invitation to lose weight faster, get flatter abs, and look younger, sexier, thinner. The recent "Thigh Gap" phenomenon is not strictly an issue of disordered eating (Salter, 2013). Measuring the space between the thighs—dubbed the "thigh gap"—has in recent years become a trend among adolescent and emergent adult women. This practice is treated as a fitness goal similar to obtaining flat abdominal muscles. In reality, it exists more closely to the idea of changing one's eye color, as the absence or presence

of a space between the thighs is largely dependent upon genetically determined bone structure. In a recent online article, editor and blogger, Lindy West wrote:

For most women, a thigh gap is a physiological impossibility, not a goal that's attainable through some magic combination of Pilates and willpower. But that doesn't stop the young women of Tumblr from fawning over one another's thigh gaps, trading tips on how to 'get' one, and excoriating themselves for 'failing' to achieve the unachievable. (West, 2013)

The idea that a gap between one's thighs will make a woman more valuable or desirable is not a new concept. Media images have long exploited the female body with "ideals" in shape and size, which perhaps over time have led women to expect such treatment and to ultimately impose those expectations on other women.

There is an undeniable pressure to be thin in our society, especially for women, and when an individual doesn't meet that standard, it impacts self-esteem and confidence. Goals such as attaining a "thigh gap" or fitting into a size zero are unreachable for many women, in any way that maintains physical and emotional health. However absurd, the "thigh gap" challenge exists, and all over this country, girls measure themselves according to this unrealistic and potentially unattainable standard. The underlying problem is that young girls and women judge themselves and each other so harshly. Along with the constant bombardment of images from fashion magazines, social media, and advertising, it is the individual's inner voice who becomes her biggest critic.

The difference between what our society views as "normal" dieting and eating behaviors and what constitutes an eating disorder can be confusing. In their article, "A Story of Being 'Normal,'" Rance, Moller, and Douglas (2010) interviewed seven

counselors who have personally recovered from eating disorders. The concept of normality—the idea that weight and body image are struggles experienced by many women—is a dominant theme in this article. The authors suggested:

Given that arguably all women (eating disordered, recovered or ‘normal’) engage to some extent in the kinds of behaviors the participants distance themselves from, this puts female eating disorder practitioners with an eating disorder history into the impossible position of claiming normality in a world where the norm is not “normal.” (p. 387)

The article went on to explore the idea of normalcy and the stigma felt by individuals with eating disorders to fit within a culture’s prescribed behavioral norms along with acceptable standards of shape and health. The counselors interviewed discussed the pressures felt by many women—with and without eating disorders—in regards to body image. Such high cultural standards toward thinness promoted by media and fashion industries create unattainable expectations for healthy body image and skew perceptions of what is normal. This way of thinking places the opinions of others over an individual’s self-perception, inhibiting the development of self-esteem and encouraging unhealthy eating behaviors. One of the counselor’s interviewed, Sophie, described the struggle that many women experience:

... We scrutinize and examine our own bodies, we scrutinize and examine, other women’s bodies whether we like to admit it or not, it is always there . . . it’s all part of this whole bigger picture about women’s relationship with their bodies and food, umm, that we all have to live with. (p. 388)

These statements both reflect previous findings (Suisman et al, 2012) that place peer perceptions as more influential to body image than media projections of an idealized shape. While these perceptions may not directly impact the self-concept or body image of healthy women, it might significantly impact individuals with eating disorders.

A counselor who has personal experience with an eating disorder offers an exclusive perspective of the thought processes accompanying eating behaviors, and recognize that these thinking styles often impact an individual's life as much as dysfunctional eating patterns. Personal experience provides an understanding of both the logistics of the disorder, including the high potential for relapse, as well as practices that promote healing. While transference and countertransference inevitably come into play when a counselor and client share common struggles, personal understanding of such a complex and confusing set of disorders seems highly beneficial toward building a foundation for successful treatment and recovery.

### **Eating Disorder Websites: A Brief Introduction**

With the growth of the global community, our circle of peer influences grows. Along with the surge of information and advertising that has characterized the growth of the Internet are online resources that offer support, information, and a sense of community for individuals with a variety of challenges. Over the last decade, a crop of websites has appeared which host forums specifically composed of individuals with eating disorders. Among eating disorder websites, a few varying approaches exist. Several websites focus on providing informational support and treatment resources. They feature educational toolkits, information on treatment localities, and links to hotlines and support groups. Most of the forums on these recovery-based websites are limited to

individuals in active recovery seeking help and support from other individuals in recovery. Participants are encouraged to share personal stories of recovery, or in some cases, experiences involving a personal tragedy that might persuade others to recover. Other recovery-based websites offer non-judgmental support for individuals with eating disorders, with forums that maintain a positive focus, but do not require active recovery for participation and welcome some honest discussion regarding the struggle involved with an eating disorder.

Still another category exists: the pro-eating disorder website. These websites, referred to as pro-ana (pro-anorexia) and pro-mia (pro-bulimia), are often viewed negatively in the treatment community. In their 2012 study, Yeshua-Katz and Martins explored online blogs of individuals identifying as pro-ana. Through interviews with 33 bloggers, Yeshua-Katz and Martins looked deeper into the pro-ana community in order to better understand their perceptions and experiences. One blogger reflected:

I wanted a voice. There was no one in my life that I could speak to openly about what I was feeling and experiencing. I wanted to have a voice that I didn't have to censor for fear of upsetting people I knew or having them judge me. For me, writing my blog was the only way I could have a shoulder to cry on or a way to celebrate my successes. (p. 2)

This study not only illuminates the stigma that exists for individuals who live with these disorders, but also highlights the benefits and motivation behind the pro-ana community. Within these blogs and forums, individuals express emotions and share ways of coping with their disorders, creating a supportive social network of individuals with similar struggles.

While pro-ana blogs and websites are mostly managed by individuals with eating disorders in an attempt to provide a safe community and talking forum for others with eating disorders, their content varies. Some websites take a position against the idea of “disordered eating,” viewing anorexia and bulimia as lifestyle choices. They celebrate strength of character and provide the opportunity to be a part of an accepting community of other like-minded individuals. Others offer strategies to hide weight loss from family members and friends as well as guidelines and motivating images to promote weight loss. Some websites maintain forums that offer both strategies toward healthier body image as well as weight loss strategies.

Understandably, these ideas are not embraced by the larger public eye. Much controversy surrounds pro-ana and pro-mia websites, and it seems that a divide exists even among eating disorder communities. Some websites appear militant about maintaining boundaries against those who do not share in their experiences. However, other sites offer a softer approach, and while they continue to receive backlash regarding their ambivalence around the subject of recovery, it seems that at the very root of their existence is the theme of acceptance. While such sites may be viewed as inherently destructive, membership in these communities continues to grow in spite of efforts to shut them down, and research suggests that there are beneficial and potentially therapeutic effects to be found within the pro-ana and pro-mia communities, especially in terms of support and belonging (Csipke & Horne, 2007).

The idea of supporting an approach whose focus is not primarily on recovery seems confusing and contradictory. However, current research exploring this emerging online resource reveals potential therapeutic benefits existing in a community where

individuals are accepted and encouraged, no matter where they stand on their path to recovery (Yeshua-Katz & Martins, 2012). Other professionals view them to be dangerous, claiming they promote weight loss and perpetuate eating disorders by viewing them as lifestyle choices rather than a form of mental disorder. Specific concerns have been noted regarding the age of the viewer, noting that young people are especially vulnerable to the attaching to a community to find a sense of belonging (Smith et al., 2011). The London-based online newspaper, *The Times* quoted Steve Bloomfield from the Eating Disorders Association (UK) as saying, “We are very concerned about the danger these sites pose to young people who may be in the early stages of anorexia and could be misled into believing that it is an acceptable lifestyle (Kemp, 2002). This is a genuine fear, and certain websites identifying as pro-eating disorder do indeed include information and dialogue that may influence individuals to engage in unhealthy behaviors. However this same danger exists elsewhere, offline, in schools and on university campuses—even within treatment facilities. As one forum user suggested: “There is a sense of competition when speaking with offline friends about the ED’s, as it can often be a case of who is ‘thinnest’ or most ‘disordered’” (Yeshua-Katz & Martins, 2012).

The support offered by online forums in pro-ana and pro-mia communities is vast. Users are given the opportunity to “speak” freely, in a somewhat anonymous setting. There is safety in this anonymity, and freedom in finally being allowed a voice for the emotions and habits that accompany an eating disorder. To have not only the voice but also understanding and acceptance of these behaviors can be healing in itself. Removing pressure toward recovery places the decision in the hands of the individual, while

offering support and encouragement necessary for healing to occur. The emphasis, placed on the individual, becomes an empowering connection to others, rather than support with strings, as might be the experience when recovery is demanded.

### **Elements of Recovery: Rigidity vs. Personal Power**

When viewed as a finite, rigid concept, recovery can be discouraging, especially when research suggests that many individuals take multiple attempts before experiencing success (Noordenbos et al., 2002). In a recent *Jezebel* article, writer Emily Ansar (2013) described her personal recovery with anorexia:

Anorexia is like alcoholism. You never fully beat it. I still have those dark thoughts...Just the other day I ate three slices of pizza and had to stop myself from immediately looking up the caloric information. I can't join a gym because the likelihood that I'll grow obsessive about the amount I run or elliptical is just too terrifying. My boyfriend, bless him, still has to tell me some days that I'm attractive—and then has to work hard to make me believe it.

Recovery is highly individualized. What works for one individual may not work for another, and indeed, there are situations where medical treatment and even hospitalization are necessary. One seemingly universal aspect of eating disorders is the concept of individual control. In general, eating disorders are often characterized by controlled, ritualistic behaviors with food, as a way to cope with difficult situations or relationships in which the individual experiences little personal power. This complicates recovery, especially with a medical model, where an individualized approach is lacking (Noordenbos et al., 2002), due to the focus on restoration to physical health. When personal control is relinquished in order to achieve this goal, the individual faces

increased pressure to regain a sense of power. For a person with anorexia, restrictive behaviors represent resilience—the ability to exist without food and the skill of hiding it from others become a source of personal strength, as well a secret that must remain hidden from others. When a person is not able to talk about the issues that cause pain, she faces them alone, reinforcing these behaviors as a source of comfort and stability. And herein lies the danger implicit in an unsupervised community of individuals—that they will communicate about specific strategies used to lose weight and maintain their eating disorders. They will acknowledge the strength it takes to sustain such behavior. And finally, that they will encourage each other in this struggle. Encouragement, without insistence on recovery, can be a frightening idea. However, without encouragement and an authentic recognition of the struggle that exists among individuals with eating disorders, recovery seems highly unlikely. Is it possible, then, that the risks associated with belonging to such a community might be outweighed by the potential benefits?

Perhaps the issue is not as simple as defining a website as safe or dangerous, helpful or harmful, good or bad. Unfortunately, humans crave this type of absolute categorizing—it gives the illusion of safety and security, and it helps to make sense of things not easily understood. In this same way, giving voice to the struggle helps individuals with eating disorders make sense of their everyday realities, in a setting that allows them to feel supported and validated as humans.

### **Online Resources and Eating Disorder Communities Explored**

Online resources for eating disorders vary greatly in focus, depth, and content. The vast genre includes recovery-focused informational services as well as websites that some believe promote disordered eating behaviors. Within this spectrum of approaches

are resources as varied as the individuals who access them. Most websites feature an online community where members can express conflicting thoughts and emotions while accessing support from others with similar challenges—these are most often referred to as a forum or discussion board. It is impossible to gain an accurate perspective regarding website content without participating in a forum—they exist as the pulse of the website. All else is simply informative and superficial. Forums are the human component of a website.

Upon becoming a member of a website forum, participants are asked to provide an introduction, which can include any relevant information about the applicant, most often focusing on eating disorder experience. Some websites request that a specific eating disorder be identified as part of this process. This categorization can be challenging, since many individuals have not been formally diagnosed, and those who have sought treatment sometimes fluctuate between various eating behaviors and diagnoses. Diagnostic criteria have also fluctuated, and even with more accurate representation of symptoms reflected in recent revisions of the DSM, diagnosis depends on human perception, which carries with it the possibility for error. Prior to 2013, the DSM-IV held strict diagnostic criteria for anorexia nervosa, shuffling many individuals with highly restrictive behaviors into the ambiguous category of EDNOS: Eating Disorder Not Otherwise Specified (American Psychiatric Association, 2000). In the DSM-5 revisions, the restrictions for anorexia were broadened to include a less rigid set of symptoms, clarified by severity, and the category of EDNOS was eliminated (American Psychiatric Association, 2013). This diagnostic inconsistency not only leads to misdiagnosis, which

impacts the effective potential of treatment, it also perpetuates a general lack of understanding and seriousness in the face of this struggle.

By definition, eating disorders involve behaviors with food that often appear bizarre to others. A closer look beneath these behaviors reveals even more confusing thought patterns from a brain that processes differently from a normally functioning brain. In 2013, Walter Kaye and colleagues published their research on the neuroscience of individuals with eating disorders, titled after a quotation by the British model, Kate Moss: “Nothing Tastes as Good as Skinny Feels” (Kaye, Wierenga, Bailer, Simons, & Bischoff-Grethe, 2013). The authors studied brain scans of individuals with anorexia and explored differences in chemical processes correlated with pleasure and reinforcement. Their findings suggest the brain of an individual with anorexia regulates the release of dopamine and serotonin differently than non-anorexic brains, causing emotional reversals in response to food stimuli. For example, when shown a slice of chocolate cake, the control group (composed of individuals without eating disorders) experienced pleasurable sensations, establishing a connection between eating chocolate cake and feeling positive emotions. In contrast, when shown the same images, individuals with anorexia experienced adverse reactions in response to food. The same study suggests that people with anorexia use restrictive behaviors to relieve negative emotions, and that restriction might even bring a sense of pleasure or calmness to the individual.

These thought processes are difficult to understand without personal experience with an eating disorder—how deeply it impacts one’s functioning is not easily described or explained. Although I have been in remission for over a decade, I still experience symptoms of anorexia. My brain is the brain of an individual with anorexia, and my

eating disorder will always be part of me. This is a strange thought to grasp—the concept of recovery as a fluid process. According to the DSM-5, for an individual to be in “partial remission” of anorexia nervosa, criteria relating to low body weight must not be met for a sustained period, while other symptoms might continue. These symptoms include an “intense fear of gaining weight or becoming fat or behavior that interferes with weight gain” or “disturbances in self-perception of weight and shape” (American Psychiatric Association, 2013, pp. 338-339). To be considered in “full remission,” an individual must be free of all symptoms. These criteria seem both unrealistic and unfair, as many women, with and without eating disorders, experience a struggle toward perfection and thinness. The idea that a negative perception toward one’s body image might indicate an eating disorder appears contradictory, since this behavior is often promoted and idealized in our culture through women’s magazines and the weight loss industry. Changing the way eating disorders are defined as well as perceived greatly impacts the potential of recovery. While online communities in no way replace treatment, they do provide a space for individuals with eating disorders to be heard and understood, as well as the chance to belong to a supportive group of people where their experiences are validated and normalized. They also present an opportunity for treatment professionals for more open communication with clients regarding their experiences online, offering increased awareness of what their struggle entails, as well as a stronger counselor-client bond.

### **General Method**

For confidentiality and ethical reasons, I have left out information obtained from forums or other sources not intended for online publication. Descriptions of such material are kept intentionally vague to reflect content in a general sense, without identifying

confidential material. Direct quotations have been included only when found on pages that are publicly accessible, and names or identifying information have been kept anonymous. I have also refrained from identifying many websites by names or web addresses. This is in part due to the transient nature of the Internet—websites come and go, dependent upon their human moderators. This anonymity also protects specific communities of individuals who depend upon each other for support. In the recent past, media attention has negatively impacted certain websites identifying as “pro-ana,” regardless of the interpretation of how this term might be perceived or defined by a given website, and without respect to the individuals most significantly affected. In some cases, websites have been shut down for this association. This argument stems from the idea that adolescents looking for a place to belong might stumble upon a pro-ana website and develop an eating disorder as a result of their online interactions, or that such online behavior perpetuates eating disorder symptoms. There seems to be a misconception regarding the vast amount of information available online, as well as the individualized content that varies among the spectrum of available resources. Rather than advertisements for an eating disorder, pro-ana websites and eating disorder forums might be recognized as communities of humans, each struggling with a disorder only truly understood by others with a similar struggle. To disengage such a group cuts off a system of support where individuals are safe to explore the emotions connected to their disorders without fear of judgment or misunderstanding. For this reason, protecting the anonymity of these groups seems only ethical.

In exploring relevant websites for this project, the combination of terms used in a web search significantly influenced the type of websites generated. Keywords such as

“eating disorder website,” “eating disorder support,” or “eating disorder forum” brought predictable results: widely recognized and reputable organizations such as Eating Disorders Anonymous, National Association of Anorexia Nervosa and Associated Disorders (ANAD), and National Eating Disorders Association (NEDA), who present a textbook view of eating disorders with a recovery-directed theme. These websites provide comprehensive informative resources as well as some degree of opportunity for discussion.

Recovery-focused websites often have more restrictions on what members can post and incorporate frequent feedback and censorship from administrators and moderators. Some websites require posts to be submitted for approval before they are posted on the website, and occasionally these submissions are edited by an administrator prior to posting. Rules and guidelines on recovery-based sites strive to keep content suitable for younger viewers, with specific restrictions on language and numbers. Among recovery-focused websites, some, more than others, offer opportunities for honest discussion. Eating Disorders Anonymous operates like Alcoholics Anonymous and provides online support through regularly scheduled meetings, as well as immediate support through online chat groups and hotlines. These meetings and chat groups are closed to the public—only members can participate and view content. This protects sensitive information and promotes sharing in a confidential and safe environment. In contrast, on the more popular recovery-focused websites, NEDA and ANAD, all forum discussions are publicly accessible and may be read by anyone. Only members of NEDA and ANAD can submit posts on their forums, but all posts are available for public view. This open format increases the vulnerability of the person submitting the post with the

understanding that anyone who accesses the website can read all content. Limited privacy and censored content on these websites create an environment that seems unnaturally monitored rather than a safe space used for genuine expression.

A web search using keywords “pro-ana,” “pro-mia,” or “pro-ED” also generated an unsurprising collection of homogenous blogs, websites, and several Tumblr pages dedicated to personal journeys with anorexia and bulimia, along with a handful of articles describing the dangers of visiting or belonging to “pro-ana” websites. Many of the smaller websites lacked both content and activity, with some appearing as virtual ghost towns. Some sites are strictly used for weight loss, and operate similarly to MyFitnessPal or WeightWatchers, where members track daily calories and create weight loss and fitness goals. A few “pro-ana” or “pro-mia” websites seem representative of a sensational approach to an eating disorder, with links to documents such as the “Thin Commandments.” One such commandment reads: “Being thin and not eating are signs of true willpower and success,” while another asserts: “Thou shall not eat fattening food without punishing afterwards.” This representation views Ana (anorexia) as a deity or higher power, who serves as a reminder of the strength and courage it takes to attain perfection. As one might imagine, this approach has generated much negative media attention regarding pro-ana websites, although in reality, these militantly thin-focused websites deviate significantly from other pro-ana communities.

### **Results**

Among online communities, some clear differences emerged. Many recovery-based sites exist to provide information to parents and families, with links to approved treatment centers, and the exclusive goal of physical and emotional wellness. Sometimes

along with its positive focus, this message carries an implied pressure toward recovery that can seem judgmental, especially to individuals who have attempted recovery and relapsed. To some, the idea of recovering from an eating disorder is overwhelming, in the same way that running a marathon might be intimidating for a person who has never run a mile. Part of the appeal of pro-ana websites is that they present an alternative to the traditional treatment model—not by ruling out treatment, but by recognizing all levels of emotional functioning and identifying recovery as a personal decision involving an individualized process.

Forums on most of the nationally recognized, recovery-focused websites are heavily moderated, with administrators weighing in frequently. Most of the recovery-based sites reviewed for this project explicitly state that forums and support groups do not replace professional help from a doctor or mental health professional, and forums found on these websites seem to involve a lot of advice from moderators, most often directing the individual to a hotline or treatment resource. This directive approach, while perhaps helpful to some individuals, seems to lack the energy and opportunity to connect found in other, non-recovery-focused communities.

In contrast, the forums found on many websites without a strong recovery focus include dialogue with more authentic personal experience. These communities include website administrators and moderators who facilitate dialogue while offering encouragement and resources as needed, but without the heavy censorship utilized in the nationally recognized recovery-focused websites. The support in these forums largely comes from other members, and while their approach does not always explicitly include recovery, it is not excluded as an option. Members also have the option of keeping an

online journal or blog where they can express thoughts and emotions in an ongoing diary. Within these journals, individuals report personal challenges, daily food intake, struggles with body image and mental illness, as well as personal victories. There is an overwhelming sense of respect and empathy expressed by members, and posts added to these journal entries are thoughtful and validating. This suggests an understanding among individuals with eating disorders—that sometimes recovery is a valid option, while sometimes the individual is not yet ready to recover, and regardless of one's recovery status or intent, support is essential. Rather than viewing such websites as a threat, they might be considered as a group of humans at a common meeting place, exploring and supporting each other through common experiences.

Out of the eighteen websites reviewed during this research, a few clearly identify as functioning communities—these communities exist in a few recovery-focused websites, but the most active communities were found within websites that have been associated with the pro-ana movement. The forums in these sites include fluid and authentic communication among members and function much like psychotherapy or support groups, with elements similar to the counseling relationship—empathy, understanding, and validation. Even when recovery is not the explicit focus, forums often include a recovery thread, where discussion topics specific to various stages of recovery are explored. In all the forums explored for this research, a high level of integrity and respect existed among members, as well as a basic acknowledgement of the strength it takes to maintain any level of health in relation to disordered eating. Discussions found in most areas of these websites are overwhelmingly accepting and focus on supporting the individual.

A significant issue among forums is the issue of privacy. Websites with more active forums often maintain a public forum thread where non-members can learn more about the community before joining, while all other forum threads and posts are closed and inaccessible except by members. This protects the individual's anonymity and provides a safe space to explore and express the struggles common with eating disorders. No matter where an individual exists in relation to recovery, they deserve acceptance. Communities that nurture communication and emotional support create a safe environment where recovery is allowed the space to become a possibility.

### **Discussion**

Weight loss and maintenance is tricky for individuals with eating disorders, and there is not a lot of dialogue regarding this topic outside of online communities or support groups. However, it's a human condition—weight fluctuates, and there is a lot of outside pressure to conform to cultural standards of beauty. American culture and media, while explicitly encouraging an unrealistic ideal toward thinness, does little to support maintaining a healthy weight. Weight management is often treated as a reactionary response to overindulgence, rather than normal maintenance of physical health.

Within some eating disorder forums, the category “tips and tricks” exists as a collection of posts discussing weight loss—sometimes these tips share a recent experience with a specific diet, and sometimes they discuss the emotional, physical, and psychological impact of fasting, dieting, and weight loss. Sometimes the category seems to cross a line, sharing information that might perpetuate an eating disorder, such as strategies on how to hide eating disordered behavior, although many websites have rules that restrict this type of sharing. The idea of having such information readily available is

sometimes thought to exist in contrast to recovery. These issues of recovery, support, and censorship are complex. The stigma of having an eating disorder encourages the hiding of one's behaviors—having a place to safely discuss one's experience helps render the stigma powerless, allowing honesty to surface. Such honesty is essential for recovery.

While defined remission requires an absence of negative body perceptions, actual recovery involves a more advanced synthesis of such distorted thinking, the ability to maintain a realistic stance in the face of irrational perceptions. Unrealistic body images exist as part of our culture, especially for women, and negative thought distortions are a reality for many twenty-first century women. These perceptions don't always develop into diagnosable eating disorders, but their existence suggests a cultural problem that impacts a much larger percentage of the population. Failing to recognize these culturally imposed ideals creates an impossible set of criteria surrounding recovery and ultimately promotes a greater potential toward relapse.

Belonging to a support group is both comforting and potentially triggering. The safety of being surrounded by others who are struggling in a similar way also involves risk. However, the human condition involves suffering. To deny the expression of suffering or to rush the process of recovery impedes honest dialogue and detracts from the healing potential of connecting with others. While having the opportunity to talk openly about one's experience is freeing and cathartic, it also has the potential to dredge up old emotions. Reading the struggles of others in a forum can be difficult, as well, and the concept of "trauma by proxy" is a relevant fear. However, triggering is not limited to online focus groups, and in fact, the act of being triggered by emotionally charged content is a reality continuously experienced by those involved in the recovery process.

Recovery does not guarantee healthy weight maintenance. Eating disorders involve an incredibly complicated relationship between food and emotions. This complexity does not dissolve upon recovery, but can instead create a general sense of tension around activities involving eating or physical vulnerability. In many forums, moderators and members regularly encourage other members to seek treatment when their eating behaviors are threatening their physical or mental health. These communities exist to provide a safe, supportive space where members don't have to explain every bizarre thought or behavior, a place to escape judgment and misunderstanding that often accompany other relationships. The act of talking about this tension, acknowledging its existence, can help individuals find a healthy mind-body balance, and can ultimately help forge a healthier relationship with one's body.

### **My Story: A Personal Narrative**

As long as I can remember, I have dieted. I don't think I ever needed to lose weight—in fact, I was always quite thin and bony. I remember uncles jabbing at my ribs, telling me I needed more *meat on those bones*, while my cousins threw me into the air and caught me, again and again, as I begged them for more. I loved the feeling of being weightless, near flight. My diminutive size brought me a lot of attention and gradually became part of my identity. Sometimes I hated this and felt that I was treated unfairly because of it. I was the last chosen for any team in gym class, the slowest runner, and I looked as if I belonged among younger peers. And then, eventually, the rules of the game changed. My first memories of actual body consciousness came later in fifth or sixth grade when others expressed envy at the size of my waist, a jealousy that felt good coming from the girls I looked up to. I could be the center of attention—the girl with the

smallest waist, the girl who scaled to the top of cheerleading mounts, seemingly weightless.

I dieted some in those days, but usually as an add-on to my mother and her sister. They were fond of the diets that involved eating one food consistently—usually bananas or some concoction involving cabbage and a chicken bullion cube. These brief near-fasts never lasted for more than a few days. I would join in for a meal or two, eating nothing but a banana for breakfast and lunch, opaque broth for dinner. Hunger pangs came to imply pride and accomplishment.

Fresh into adolescence, I took my first diet pill, out of curiosity more than any desire to actually diet. That day remains clear in my memory—wearing baggy jeans and my mother's red graduate school jersey, I cleaned compulsively for hours. I installed a new wooden toilet seat and attacked the linoleum with ammonia and a razor blade. My energy was unstoppable, limitless. I felt supreme. I consumed caffeine all day long and marveled at my lack of hunger, my stamina.

Productivity was part of my personality long before I developed anorexia. I came from a hardworking family of farmers, ministers, educators, and factory workers. My father worked for General Motors, and spent long hours in a filthy, hostile environment. My mother spent equally long hours as a kindergarten teacher, with afternoons spent teaching older children, sometimes adults, to play the piano. Saturdays were for shopping—groceries, clothing, anything, really. Sundays were for God. My mother oversaw the music program at our small congregation, taught Sunday School, organized funerals and fundraisers, and acted as the unofficial director of the summer Vacation Bible School program. With all of these unpaid responsibilities rolling themselves into an

additional full time position, my mother's life was punctuated by details—snapshots of a bigger picture. She stayed busy enough to avoid any of the less pleasant pieces of her life, including an actively shrinking daughter. Looking back, it's difficult to decipher whether or not my family was aware of my condition, or if they just didn't notice. My bizarre behavior with food was just one more way I had become unrecognizable to them.

I didn't begin serious calorie restriction until high school. My eating became a way to define myself, my size something I sought to preserve and control. In ninth grade, I went through a serious depression and lost all interest in food—in everything, really. I ate a package of peanut M&Ms for lunch every day and hoarded the extra lunch money. I took diet pills, but only occasionally, because I really didn't need them—I wasn't hungry. My depression eventually lifted, but my appetite never fully returned. Certain foods began to repulse me, and I gradually began drawing lines, creating boundaries around what I allowed into my body.

The simple truth is that I was good at losing weight. I trained my body to ignore hunger, crave emptiness. I loved my jutting hipbones, angular and concave, and abhorred the parts of my body that threatened to emerge as soft, curvaceous. The less I consumed, the stronger I felt. Of course, I was in truth becoming weaker, my identity shrinking along with my physical presence, but I didn't recognize it. I willed my body to shrink, and it did. To me, that felt incredible and accomplished.

When I began college, I sank deeper into periods of anxiety and depression, and my weight plummeted. I began weighing obsessively and charting food consumption, and I retreated into my own little cocoon. The university cafeteria both repulsed and terrified me. I hated the smell—industrial dishwashing spliced with week-old tomato sauce,

alongside overcooked canned green beans. More than anything, I hated being around other people. I felt immense social pressure and struggled to feel comfortable in my body. I skipped meals and consumed copious amounts of caffeine to keep myself awake and help ward off hunger. It worked. My weight dropped yet again, and my friends started to notice. I recognized their concern as compassionate, but confrontation wasn't what I needed. Although I was beginning to realize I was sick, in reality, I was simply functioning.

Eventually, I encountered another girl in my dormitory who had an eating disorder. I don't remember how we ended up connecting, but once we had discovered each other, we were immediately forged together by our common experience. She was one of the few people who understood my behavior and who didn't judge me. She grasped what it was like to be in my skin. Even now, as I try to recall some of those early conversations between us, I have no recollection of my own admission regarding my anorexia. I didn't really feel anorexic—I just appeared symptomatically so. I had no reference for this piece of myself, and no idea of how healthy might feel, nor how to get there. Like many individuals who develop eating disorders in adolescence and early adulthood, my life in my early twenties was rife with developmental change and existential longings. I was beginning to work through parts of my history, and my emotional response was overwhelming. Fasting and obsessing became ways to cope with all of the areas in my life beyond my control. However, as my weight continued to drop, so did my grades, friends, self-esteem—everything. I was slipping.

Having one friend who understood me was a significant factor in my eventual road to recovery. Her story differed from mine in many ways, but we shared common

emotions and ways of coping. And we shared them in secret—it was not socially acceptable to speak openly about actions that seemed so bizarre to others. My personal boundaries were compromised in many areas of my life at this time, but my anorexia existed as its own set of rules and restrictions—a barrier between me and the rest of the world put up for my protection. And I felt safe, wrapped in my own little world, until it became clear, even to me, that I needed help. My past experience with counseling had been largely unsuccessful, but when my friend decided to give therapy another shot, I shrugged my shoulders and followed her lead.

My treatment involved medication—antidepressants, benzodiazepines, and a tiny blue pill that helped alleviate my anxiety in a tremendous way. Anxiety and depression had accompanied my life since early adolescence, and my restrictive behaviors with food progressed as a way of coping with this anxiety. I remember awakening one morning shortly after beginning treatment, and I felt as if my brain had returned to me, that my mind was finally my own again. It was as if I had finally slipped into gear after grinding and shifting continuously for years. Prior to this, my anxiety had existed as a constant drone in my brain, a consistent underlying dissonance, indicating that some unidentified problem needed solving. Sometimes this buzzing became so loud, so pronounced that it drowned out all other thought, and I could barely function. I hadn't felt normal in my brain for years, and this change was like finally breathing after being underwater for so long.

Research has suggested that counseling individuals with eating disorders is difficult, challenging, and often questionable in terms of effectiveness (Federici, Wisniewski, & Ben-Porath, 2012; Rance, Moller, & Douglas, 2010; Noordenbox,

Oldenhave, Muschter, & Terpstra, 2002). My own experience with counseling varied. My first therapist had no idea what to do with me. My second saw me twice before referring me to a psychiatrist who could assist with medication management as well as offer counseling. During the year I spent with my third therapist, I chipped away at some of my early experiences and began looking more deeply into myself. However, I never felt a connection with her—I didn't really feel that she understood me, or even that she wanted to. Often, others project judgment and confusion attached to disordered eating, which only reinforces the sense of being misunderstood. It's uncomfortable to discuss having an eating disorder, and being weighed weekly often triggered the same behaviors and emotions for which I was seeking relief. I strongly resisted identifying as a person with anorexia, even when I was actively starving myself. I tricked my brain into thinking that my behavior was normal, and I was proud of accomplishing something so extreme. Every woman around me expressed dissatisfaction with her body and wanted to lose weight. I could finally achieve something nobody else around me could—I could be the skinniest. I just wasn't allowed to talk about it.

Of course, these emotional responses contradict emotional health. The desire to continue restricting one's diet, even in the face of eventual starvation—it's completely irrational, and on some level, I understood this. But the urge to restrict, the urge to be thin, to lose just a few more pounds, enough to give me a cushion—these urges superseded rational thought. The contrast between the two worlds is one of the true struggles. Although I was actively involved in my therapy, there seemed to be no space for me to safely express how normal and right these behaviors felt to me—no understanding of what made such perfect sense. Online communities did not exist yet—

the internet was still in its toddler stages, and Courtney Love was screaming, *I fake it so real, I am beyond fake... some day you will ache like I ache*. After hiding for so many years, it was next to impossible for me to even recognize myself, let alone introduce myself to my therapist.

It was feminism and poetry that ultimately saved me from my self-destructive path. It took looking outside myself at who I most wanted to become, and whom I most wanted to help. It involved recognizing that women have struggled with self-acceptance and body image for as long as can be imagined, and reading, absorbing the struggles and triumphs of other women. This process took years and continues even now. I am still evolving in relation to how I conceptualize my experience and my place in this world, as well as how I develop and reinforce a healthier self. I still experience anxiety, and I still struggle with self-perception. This progress ebbs and flows.

Although I have been in remission for over a decade, my brain is the brain of an individual with anorexia. To effectively maintain recovery, I have to recognize my limits, which exist in real time as well as online. My personal strategy has been to communicate with others in a way that seems relevant to my experience, participating in forum threads that encourage a possibility-focused mindset, while remaining open to personal struggles. Both online and offline, I avoid individuals whose focus consistently contradicts my own. In real life, this can be much more challenging, as we don't always get to choose the company we keep. Maintaining emotional health involves active participation, as well as active withdrawal from potentially triggering situations. Both websites in which I am most involved maintain forums focused solely on recovery. The discussion groups in

these forums encourage sincere dialogue among individuals and offer legitimate support with various struggles common in recovery.

I have not experienced recovery as a finite concept, but rather as existing on a spectrum. There are days and weeks when I focus on my health and my strengths. And there are many days when I see my reflection in the mirror and obsess about how much I've eaten or how little I've exercised. Sometimes this negative perception impacts me more significantly than the positive self-image I'm striving to create. I've learned to define my recovery as a greater number of good days, and most importantly, a desire for those good days. I try to practice mindful eating and self-affirming thoughts, but the truth is, I live in the same busy, thin-obsessed society as every other American woman. Maintaining a positive focus can be hard work.

When I initially joined a forum, I realized that I had not before experienced this level of camaraderie, that even among my closest friends, I had not felt safe talking about my eating disorder. I was ashamed to admit that at times it felt amazing to lose weight, and at the same moment shameful to have succumbed to old destructive behaviors. Online communication is faceless, anonymous, and there is a comfort in this—the absence of identity not only encourages more honest and open dialogue, it also promotes connections. For individuals who have spent large parts of their lives in isolation, opening up to a room full of strangers can be intimidating. Online sharing presents fewer risks, as one's identity is anonymous, and emotional vulnerability is minimized.

For me, joining this community has opened my mind—it has validated my experience and encouraged my recovery. Conversely, it has also triggered negative responses at times, and I have revisited some unhealthy thought patterns while

conducting this research. That being said, many experiences in life are similarly triggering, and part of recovery involves maintaining emotional health in response to what one encounters. When surrounded by a small village of others with similar struggles, these triggering moments don't seem quite as threatening—there's a space to take those thoughts. While this community does not replace my closest friends, they offer me something that I don't often experience—understanding of what drives me, what the inside of my brain feels like. Being part of a community like this feels safe. It feels necessary.

### **Conclusion**

My initial approach to this research was to identify components of a successful online resource for individuals with eating disorders, with the idea that I might eventually create a website of my own. However, my project led me to an unexpected conclusion. While I had previously focused on the informative aspect of a given resource, in doing so, I underestimated the power of human contact. Joining and participating in online communities overwhelmingly changed the way I approached my own experience with anorexia and continues to change the way I view recovery. The very definition of recovery as a finite condition—existing with no remaining trace of symptoms—suggests an impossible task and encourages a level of dishonesty from all involved. Emotional healing is complex, with many levels and layers, and any absolute expectation falsely simplifies this process. If we truly expect treatment outcomes to improve, we must improve our understanding of this experience, and this can only occur if we begin listening, as fellow humans who understand struggle, rather than as researchers studying from behind the glass.

Except for the single 12-step meeting I attended while in college, I had no personal experience with support groups prior to this research project. When I initially heard of online support groups and pro-ana websites, I lacked context for such a resource and did not know what to expect. I suspected there was more to the pro-ana movement than the controversy and criticism reported in mainstream publications. The tone and content in these articles only underscored a vast misunderstanding regarding eating disorders in general.

Ultimately, through this research project I discovered that there is little need to create yet another online resource. One reason for this is that several efficiently functioning communities exist, which include multiple vehicles for self-expression, forums and chat groups, as well as comprehensive lists of resources, from treatment facilities to more immediate support. Throughout this process, one message has come through consistently: as diversity exists among humans, so it exists in their disorders. And as this requires a variety of approaches for individual treatment, variety also exists in the resources available. Support sometimes presents itself in an unexpected fashion, and if we eliminate potential sources of help due to our own misperceptions or judgments, we essentially limit our effectiveness as therapists and negatively impact treatment outcomes.

A more thoughtful approach toward recovery involves recognizing growth as a fluid process that functions most efficiently when unconfined by measurements and conventional systems. Relationships exist on this level, and while a website design can attract and recruit members, the phenomenon of human connection cannot be created. Through developing relationships, whether online or in real life, we learn tolerance. We

learn to love and forgive. By communicating and listening to others regarding their struggles, not only do I have the opportunity to encourage others, but I also might learn to be more tolerant of my own struggle, allowing myself to hear the encouragement voiced by others. Weighing in is optional, yet within this process is the potential for healing.

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