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Running Head: UNDERSTANDING RECOVERY FROM ANOREXIA

Understanding the Changing Landscape of Client Perspectives
of Recovery from Anorexia Nervosa

by

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B.A., Wagner College, 2009
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DISSERTATION

Submitted in partial fulfillment for the degree of
Doctor of Psychology in the Department of Clinical Psychology
at Antioch University New England, 2014

Keene, New Hampshire



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The undersigned have examined the dissertation entitled:

**UNDERSTANDING THE CHANGING LANDSCAPE OF CLIENT PERSPECTIVES
OF RECOVERY FROM ANOREXIA NERVOSA**

presented on August 28, 2014

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Dedication

“Recovery feels like shit. It didn't feel like I was doing something good; it felt like I was giving up. It feels like having to learn how to walk all over again.”

- [Portia de Rossi](#)

For the 79 women who participated in this study; who did not give up; and for those who are learning to walk again. Sharing your stories provides others the chance to learn to walk—even run—again. Your journeys are invaluable and your voices matter.

This project was inspired by the incredible journey of a dear friend for without whose help, heart, perseverance and strength, this study would have never come to fruition. As you continue on, never lose hope. You have touched my life and my heart.

Thank you JW

Acknowledgements

*“No one who achieves success does so without the help of others. The wise and confident acknowledge this help with **gratitude**.”*

- Alfred North Whitehead

It is not every day I am given the opportunity to formally thank those who have supported me on this journey. I am going to take full advantage of it!

In the Contemporary Psychoanalytic course in the spring of 2013, Ted said that students often take this chance to thank a “laundry list” of people who helped make their dissertations possible. He commented that it did not make sense to thank everyone, as students are responsible for putting their “blood, sweat, and tears” into their work. For me this was an important moment because not only did I want to complete my dissertation so that I could have an Acknowledgement section all to myself, but I already had my laundry list read. And despite his opinion on who should and should not be thanked, Ted's name was up at the top of my laundry list.

Ted: without your support, confidence in me, patience, kindness, and knowledge, this document would not be what it is today. I likely could have written another dissertation, but not this one. In its current form. You have helped ground me in more ways than one and been a guide to help me navigate some dangerous surfs. You have impacted my life in ways that stretch from coast to coast. Thank you for taking the time to know me.

Two very strong and intelligent women—Marti Straus and Rachael Goren-Watts: You both inspire me. The opportunity to learn from you and be in your presence has been invaluable. You constantly remind me that life is not something to rush through, but rather to embrace. I aspire to one day possess your unmistakable courage and strength.

Vince—Probably the first Snapchat committee request ever. For all you do and for who you are, it is with so much respect that, I thank you a million times over. Your knowledge and generosity has never gone unnoticed.

“With a grateful heart, we are energized to move toward our desires, live creatively and give generously. In gratitude song and dance burst spontaneously.”

- Carol J. Adamski

This quote reminds me of Dean Hammer, who was one of the first professors I have ever had who challenged me and invited me to find and explore my voice. He created a space where students felt safe; a place where it was okay to speak without fear of negative judgment and critique. Dean: your open heart is contagious. Your compassion and ability to challenge me has expanded my lens wider than I thought it could go. There are many more doors I am now willing to walk through, as I seize opportunities for growth with less fear than ever before. You have helped me to understand the beauty and value of mistakes, and the many opportunities for growth that are constantly before me.

“When we become more fully aware that our success is due in large measure to the loyalty, helpfulness, and encouragement we have received from others, our desire grows to pass on similar gifts. Gratitude spurs us on to prove ourselves worthy of what others have done for us.”

- Wilferd A. Peterson

My parents have provided me with a great deal of support in all senses of the word. Mars and Padge: Your selflessness and generosity influences so much of who I am, and your kindness continues to astound me. You have created for me stepping stones (often bridges), to cross barriers I would have otherwise been stuck at. The trying moments have been some of the most important ones, as our relationship at all stages of my life have made me who I am today. I carry you with me.

“At times our own light goes out and is rekindled by a spark from another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us.”

- Albert Schweitzer

Kate & Laura—you know my story as much as I do. The countless hours reading, encouraging me, and brainstorming. You held and sat with me, allowed my tears to fall, and conquered many miles. Your voices are part of mine. My true friends. I share this with you.

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Abstract

Current research exposes the lack of a universal definition of recovery from Anorexia Nervosa (AN). Discrepancies in how the term is defined and used have created problems for clients, clinicians, and families; particularly around how insurance providers allot financial coverage for treatment. Additionally, there is a gap in the literature regarding the length of time clients consider appropriate for symptom abatement prior to being considered recovered. This dissertation utilized a mixed-methods approach to investigate how the term recovery had different meanings over the course of treatment for women previously treated for AN. Seventy-nine adult women participated in the web-based survey. Descriptive statistics and patterns of responding were identified using quantitative data. Content analysis was employed to analyze qualitative data that sought to gain insight into subjective definitions of recovery. Participant responses were coded and sorted into categories that were then used to establish a codebook of the major themes. All participants reported a shift in personal meanings of recovery over time, as they were asked to reflect on how they viewed recovery at the beginning and the end of treatment, as well as at the time of survey administration. Participants were also asked to report on symptoms they believe are important to address in order to consider one's self recovered, in addition to the length of time symptoms must be gone. This dissertation also attends to the unique nature of individual responses and explores suggestions to assist future research and clinicians who work with this population. Limitations of this study are also shared.

Keywords: anorexia nervosa, recovery, eating disorders, client perspectives of recovery

Understanding the Changing Landscape of Client Perspectives of Recovery
from Anorexia Nervosa

Chapter 1: Statement of the Problem

Research suggests that there is no consensual definition for *recovery* from Anorexia Nervosa (AN). Over the past 30 years, studies have found numerous discrepancies between how clinicians, treatment facilities, health care companies, and clients define recovery. Often researchers identify a definition in a research article or chapter which differs from those proposed in other works. Competing definitions impact the ability for people with AN to receive appropriate treatment, as different criteria for recovery impacts the needs assessments used by clinicians, treatment facilities, and insurance companies. In short, those who prematurely declare someone recovered may be ignoring the severity of other psychological, behavioral, or medical problems not considered in the narrow definition of recovery (Liu, 2008).

Little research exists to understand the impact of how length of time impacts definitions of recovery. This study sought to address how and if clients consider time as an important measure of declaring one recovered. Specifically, participants were asked to think retrospectively about how they prioritized various aspects of recovery at the beginning and end of treatment, as well as at the time of administration. Results from this study may be used to inform treatment providers about the various aspects of recovery that often go unattended due to financial limitations of treatment. This study may also help provide rationale for why insurance companies should comply with requests for financial coverage for intensive and long-term care, as many residential programs offer clients the time and resources necessary to battle this deadly disease. Attention is also paid to the importance of building an authentic therapeutic alliance with clients, and the impact of the alliance on outcome and effectiveness of treatment.

Chapter 2: Review of the Literature

The following literature review provides in depth definitions of AN, characteristics of the disorder, etiological proposals, relevant studies and research, and various definitions of what it means to be recovered. Such topics are also considered to explore the lack of clarity and understanding of what it means to be recovered, as well as to convey the foundation and rationale for the current study.

Why Study Eating Disorders?

AN is diagnosed in both men and women of all ages across the lifespan (“Anorexia Nervosa,” n.d.). The disorder is found in people from all socioeconomic, ethnic, and racial groups. Approximately 90% of clients diagnosed with AN are women between the ages of 12 and 25, with an average age of onset at 19 years old (Hudson, Hiripi, Pope, & Kessler, 2007). A common profile for a person diagnosed with AN is a female who works hard, presents as introverted, is resistant to change, is often highly self-critical, perfectionistic, and has low self-esteem.

In 2007, the first nationally represented study of eating disorders in the United States appeared in the February edition of *Biological Psychiatry* (Hudson et al., 2007) and brought to light the necessity of identifying and treating people struggling with eating disorders. The National Comorbidity Survey Replication (NCS-R) was administered to 9,282 English-speaking American adults over the age of 18. Results indicated that 0.6-4.5% of participants struggled with a lifetime prevalence of an eating disorder. Further, many participants who met criteria for AN had never been formally diagnosed nor had been in treatment. The study also showed several participants had been, at one time, diagnosed with at least one other mental health

disorder deemed unrelated to eating behaviors and thoughts (including, but not limited to, anxiety or depression; Hudson et al., 2007).

The 2007 study raised awareness about the number of Americans struggling with symptoms of AN at ages much younger than previously reported (as young as seven years old). Further, the study found that (a) 40-60% of high school girls diet, (b) 13% of high school girls purge, (c) 30-40% of junior-high girls worry about weight, (d) 40% of nine-year-old girls have dieted, and (e) that five-year-old girls have been found to be concerned about diet and weight (Hudson et al., 2007). Additionally, results indicated that eating disorders were increasingly found in diverse populations more than ever before.

AN is one of the most difficult psychiatric disorders to treat, as symptoms are typically chronic and persistent (Halmi et al., 2005). Clinicians and researchers frequently report that reduction in symptoms can take many years, even under the “best circumstances” (McHugh, 2007). Steinhausen (2002) compared data from 5,590 women with AN who participated in 119 studies published in both English and German literature. He looked at client outcomes between the years of 1950–1979, 1980–1989, and 1990–1999 and found that 50% of participants experienced a complete reduction in symptoms, 30% experienced some reduction, and 20% exhibited chronic symptoms. He concluded that AN did not lose its poor prognosis over time.

Further, AN has a higher mortality rate than any other psychiatric disorder (Hudson et al., 2007). Approximately 20% of clients diagnosed with AN die from symptoms of AN or health complications (this number varies by study). Clients with AN also have the longest average hospital stays and a greater chance of actually completing a suicide attempt compared to people with any other mental health illnesses (Greenblatt, 2010).

DSM Criteria for AN

Table 1 depicts the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text-Revision (DSM-IV-TR*; American Psychiatric Association, 2000) criteria for AN, which was considered when establishing the current study.

DSM-IV-TR criteria are not used or supported universally by all stakeholders when defining or diagnosing AN. Criticism of the *DSM-IV-TR* diagnostic criteria contributed to major revisions established in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5*; American Psychiatric Association, 2013). As the new criteria were published during the course of this project, criteria for AN from the *DSM-5* are explored and critiqued with regard to the findings of this study in Chapter 5. Table 2 shows the *DSM-5* criteria for AN.

Table 1

DSM-IV-TR Criteria for Anorexia Nervosa Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, IV-TR Edition*, (Copyright ©2000). American Psychiatric Association

A.	Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
B.	Intense fear of gaining weight or becoming fat, even though underweight.
C.	Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
D.	In postmenarcheal females, amenorrhea [i.e., the absence of at least three consecutive menstrual cycles]. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration.)
Restricting Type	During the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). Clients who engage in restrictive behaviors make conscious efforts to avoid gaining weight by skipping meals and excessively exercising (Bakker et al., 2011). Laxatives, self-induced vomiting, diuretics, and medications that promote weight loss are also used to maintain a low weight.
Binge-Eating/ Purging Type	During the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). The binge-eating/purging subtype is more commonly diagnosed in clients with histories of high weight or obesity and impulsive behaviors and ways of thinking (Bakker et al., 2011). Obsessions with thinness, fears of fatness, and negative thoughts motivate both restrictive and binge-purging behaviors.

Table 2

DSM-5 Criteria for Anorexia Nervosa Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, (Copyright ©2013). American Psychiatric Association

A.	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. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.
B.	Intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, even though at a significantly low weight.
C.	Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
Restricting Type	During the last 3 months, the individual has not engaged in re-current episodes of binge eating or purging behaviors (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise.
Binge-Eating/Purging Type	During the last 3 months, the individual has engaged in recurrent episodes of binge eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
<i>Specify if:</i>	<p>In partial remission: After full criteria for AN were previously met, Criterion A (low body weight) has not been met for a sustained period, but either Criterion B (intense fear of gaining weight or becoming fat or behavior that interferes with weight gain) or Criterion C (disturbances in self-perception of weight and shape) is still met.</p> <p>In full remission: After full criteria for AN were previously met, none of the criteria have been met for a sustained period of time.</p>
<i>Specify Current Severity:</i>	<p>The minimum level of severity is based, for adults, on current body mass index (BMI) or, for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used.</p> <p>The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.</p> <p>Mild: BMI (greater than or equal to) 17 kg/m²</p> <p>Moderate: BMI 16-16.99 kg/m²</p> <p>Severe: BMI 15-15.99 kg/m²</p> <p>Extreme: BMI < 15kg/m²</p>

DSM Criteria for Eating Disorder Not Otherwise Specified

The most common diagnosis given to clients with eating disorders is Eating Disorder Not Otherwise Specified (EDNOS). Prior to the publication of the *DSM-5*, EDNOS constituted 60% of diagnosed cases (Greenblatt, 2010). Clients with EDNOS commonly present with symptoms of AN, Bulimia Nervosa (BN), mixed features, or atypical eating behaviors not accounted for in the *DSM-IV*. The *DSM-IV-TR* does not provide diagnostic criteria for *EDNOS*, but rather lists examples of symptoms clients might present with that would qualify them for a diagnosis of EDNOS. Greenblatt states that, “this diagnosis tells clinicians little about the client except that he or she failed to meet the strict criteria of either AN or BN” (p. 25). Table 3 depicts how EDNOS is referenced in the *DSM-IV-TR*.

Table 3

DSM-IV Criterion for EDNOS. Reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, IV-TR Edition, (Copyright ©2000). American Psychiatric Association

A.	Meeting all criteria for anorexia nervosa except has regular menstrual cycles
B.	Meeting all criteria for anorexia nervosa except weight falls within the normal range
C.	Meeting all criteria for bulimia nervosa except they engage in binge eating or purging behaviors less than twice per week or for fewer than three months
D.	Purging after eating small amounts of food while retaining a normal body weight
E.	Repeatedly chewing and spitting out large amounts of food without swallowing
F.	Meeting criteria for binge eating disorder

Characteristics of AN

Many individuals with AN consider themselves overweight or fat, despite often being underweight and malnourished (Greenblatt, 2010). Food and caloric intake, as well as control over one's weight become obsessive, resulting in the engagement of checking behaviors such as frequently stepping on the scale, portioning and/or restricting food intake, and compulsive exercise habits. Obsessions with food and weight may dominate cognitive processes, making it difficult to concentrate on other tasks. Weight loss that results in compliments and positive attention from others often heightens feelings of competency and achievement, thereby reinforcing compulsive behaviors and masking underlying emotional pain (Bakker et al., 2011).

Physiological and medical symptoms. Physical and medical complications often accompany AN. Symptoms can include (a) chronic feelings of coldness; (b) blue lips and fingernails resulting from poor blood circulation; (c) dry skin and/or hair loss; (d) osteoporosis; (e) dehydration; (f) energy loss; (g) anemia; (h) gingivitis; (i) periodontal disease; (j) hyper-acute hearing; (k) yellowing of the palms; (l) hypertension; (m) seizures; (n) gastrointestinal problems and colon dysfunction, such as constipation; (o) bleeding; (p) abnormal pain; (q) kidney, urinary, pancreatic or renal dysfunction; (r) cerebral atrophy; (s) neurological abnormalities; (t)

reproductive and endocrine abnormalities; (u) hypothalamic-pituitary-adrenal axis dysfunction; (v) abnormal thyroid functioning; (w) metabolic acidosis or alkalosis; (x) stunted growth; and (y) long-term issues with bone strength or reproductive health (Bakker et al., 2011; Sargent, 1998). People with AN are also prone to an imbalance in electrolytes which can cause cardiac arrhythmia, heart complications, and fluid imbalances. Further, complications from AN can cause amenorrhea, irregular heartbeat, heart failure, kidney stones or kidney failure, and contribute to muscle atrophy (Hudson et al., 2007).

Chronic AN can increase the likelihood of onset for other psychological symptoms, such as anxiety, chronic depression, obsessions, compulsions, psychosis, insomnia, and social isolation. Neurological impairment may also result from persistent symptoms of AN and has been observed to impact personality functioning and cause thought regression (Anzai, Lindsey-Dudley, & Bidwell, 2002). Physiological effects, neurological symptoms, environmental positive reinforcement for weight loss, and a decrease in cognitive flexibility likely make it more challenging for a person with AN to shift disordered ways of thinking and viewing the self.

Etiology. Although the etiology of AN is not fully understood, several theories posit explanations that consider the role of genetics as well as familial, social, and cultural influences. This section explores the complexity of the etiological considerations of AN, as no single theory has yet to reach unanimous agreement to explain the high prevalence of the disorder.

Early psychoanalytic theories proposed that weight control pertained to one's unconscious fears and concerns regarding sexuality (Bakker et al., 2011). According to this paradigm, the individual used starvation during childhood and adolescence to prevent the mother from overwhelming the ego. Starvation was also used to manage anxiety associated with weight

gain, as well as fear around loss of control. Early theory suggested that restriction of nourishment symbolized the struggle for autonomy from parental figures. Recent literature has considered the etiology of AN as it relates to one's genetics, social, and cultural frameworks (Bakker et al., 2011).

Genetic research as it relates to AN is limited, although it is more commonly considered and researched with regard to onset of the disorder. Liu's (2008) research focused on the influence of genetics as he found that immediate family members of clients diagnosed with AN were 12 times more likely to develop the disorder than those with no family history. Results from the study suggest that similar personality traits, including (a) perfectionism, (b) extreme cautiousness, (c) rigid self-discipline, and (d) perceiving the self as inadequate, are commonly reported experiences of clients with AN.

Social values have also been suggested to contribute to the onset of the disorder (Way, 1993). Western culture often defines beauty by thinness and youth (Liu, 2008), and beauty is used to enhance one's popularity and/or status (Way, 1993). Such an idea is seen in the media, including outlets such as (a) magazines, (b) television commercials, (c) billboards, (d) movies, (e) cultural idolization of celebrities, and (f) the internet and other forms of social media. The "ideal body" so often portrayed is only naturally possessed by less than 5% of American females ("Eating Disorders 101 Guide," 2003). Claude-Pierre (1998) suggests that society's emphasis on appearance fosters motivation to engage in harmful and life-threatening behaviors; specifically related to food, weight, and body image. In one study, Levine (1998) found that 70% of participants over the age of 30 and of "normal" weight, noted feeling dissatisfied with their bodies and 39% of participants were willing to take three years off their lives if they could be at their desired weight (15% of participants were willing to take as many as five years off). Results

from this study are indicative of the value of thinness and the extremes women would consider to obtain this ideal.

In recent years, AN has been diagnosed in more culturally diverse and minority women than ever before. As a result, one's culture, race, ethnicity, and socioeconomic status have been proposed as necessary to consider when looking at the etiology of AN ("Anorexia Nervosa," n.d.). Historically, AN was more commonly diagnosed in middle to upper-class Caucasian women; however, the disorder is now diagnosed in people from diverse demographic populations. Important to note is that a discrepancy remains in rates of diagnosis when comparing minority groups to majority groups, as well as people from different social classes, which may be explained by limited access to treatment for those from minority and low income populations. Additionally, although rates of diagnosing AN in male populations has also increased, it is likely that many men go undiagnosed and without treatment, as men may be embarrassed they are struggling with a "women's" issue. Further, clinicians and physicians may not recognize AN for what it is in male populations, and may attribute the symptoms to other physical conditions or stress.

Frequency of AN in adolescence. A common profile of an individual with AN includes a diagnosis during adolescence. In one study, approximately 90% of female participants were diagnosed between the ages of 12 and 25, with an average age of onset at 19 years old (Hudson et al., 2007). Several theories exist to explain why adolescence is the most common time of onset. As adolescence is marked by puberty and natural physical transformation, biology has not been ignored or overlooked in how this time of life may impact the onset of symptoms. For females, the body may shift in ways that do not meet social and cultural expectations. Adolescents may become insecure about how their body grows, forms, and stores weight.

Adolescence also marks a time of changes in identity, shifts in personality, and alterations in brain functioning (Hudson et al., 2007). Such developments can create feelings of insecurity, embarrassment, shame, and other negative experiences of the self. Developmental changes may decrease feelings of control over the body, which is then compensated for as one strives for more “control” over one’s weight and appearance. This may occur through dieting, restrictive eating patterns, laxative use, rigid and excessive exercise routines, and other behaviors (Hudson, et al., 2007). Some adolescents try to “perfect” themselves and manipulate the body into matching an unattainable image derived from what they believe others want or what is socially acceptable. To gain acceptance and approval from others often becomes a goal, often ignoring the desires and needs of the self (Way, 1993).

Many researchers have also turned to the influence of media and social messages, as children have access to cell phones, internet, and more “adult content” at younger ages than ever before. One study found that 69% of girls between the fifth and 12th grades reported that the media, particularly pictures in magazine, influenced how they thought of a “perfect body shape” and enhanced the likelihood of desired weight loss (Levine, 1998).

Frequency of AN in adulthood. Although AN is most commonly diagnosed during adolescence, there has been a significant increase in clients first diagnosed after the age of 30 in the last 20 years (“Eating Disorders 101 Guide,” 2003). The Renfrew Center (a national eating disorder treatment facility) found that 20% of adult clients diagnosed with eating disorders for the first time were at least 30 years of age. Providers at Renfrew, in addition to other researchers, hypothesize that older clients are more likely to have experienced symptoms since adolescence and may present for help later in life (“Eating Disorders 101 Guide,” 2003). This may be explained several ways. First, adults with AN who have have lived with symptoms for

several decades may finally be able to come to terms with the severity of the disorder. One's experiences of symptoms as an adolescent, or how they managed or coped with stressors, no longer may be working. Further, symptoms may have temporarily gone away and resurfaced over time. Clients may also be experiencing negative physiological effects, such as reproductive challenges, physical pain, or dental problems ("Eating Disorders 101 Guide," 2003).

Additionally, shifts in mental health parity laws allow better access to medical care and services, specifically for lower income households, than ever before. Whereas previously individuals might have been denied coverage or even medical insurance, there is now greater access for people from multiple socioeconomic groups to obtain coverage.

Another explanation for the increase in the AN diagnosis of post-adolescent women is that societal pressure to be thin has intensified and is now also applicable to older populations where, historically, thinness has been most commonly associated with a youthful appearance. Post-adolescent clients report an increase in life stress related to the pressures to be thin and beautiful, and more often equate success with beauty than previously reported ("Eating Disorders 101 Guide," 2003). Since "youth" is associated with thinness and not simply one's age, more women strive to obtain or maintain a youthful appearance by controlling their level of physical activity and caloric intake (Liu, 2008). Women also pay for cosmetic surgeries and procedures to increase weight loss and rid the body of the undesirable effects of natural processes of aging.

Frequency of AN in men. Although women are diagnosed with AN ten times more frequently than men (American Psychiatric Association, 2013), symptoms of the disorder are increasingly seen in males. It is often assumed that AN is a disorder found only in females, which may cause men who suffer to remain quiet without support or treatment (Rader Programs, 2012). This is perpetuated by the DSM-IV-TR criteria for AN, which includes the loss of one's

menstrual cycle; seemingly not taking into consideration the potential of the diagnosis for men. The hesitancy several men have reported often emerges from fear of seeking support for a “female problem.” Men also report having a difficult time asking for help with anything, as many are socialized to feel they must do things independently and be “in control” of a given situation. Men may also internalize messages regarding masculinity, and believe that expressing feelings or challenges would be emasculating. Rigid expectations of the self, particularly ones that come from messages of the larger culture, can cause men to seek ways of coping with feelings of stress and anxiety, such as disordered behaviors, in order to feel more in control.

The under-diagnosis of eating disorders in men is not only attributed to the frequency of which men present with symptoms (Rader Programs, 2012). It is not uncommon for physicians and health care providers to overlook symptoms of AN, or explain them another way. When working with men, practitioners may first look for other causes of weight change prior to considering the possibility of an eating disorder. Research has shown that symptoms of AN manifest differently in males, and men may experience proportional drops in testosterone and libido (Rader Programs, 2012). Men with eating disorders have been found to be more concerned with body size and shape, whereas women are more concerned with weight. Thus, on average, it takes twice as long to diagnose eating disorders in men than in women, leaving more time for symptoms and behaviors to become more severe.

The etiology of AN in men has also been reported to be different than for females, as men and women face different challenges and expectations according to gender roles. Although similarly with females, family dynamics have been reported as playing a role in onset of eating disordered behaviors in men, how relationships and expectations are internalized may be different for men than for females (Rader Programs, 2012). For instance, fathers often relate

more with sons through physical activity, such as athletic activities, rather than through emotional outlets. If a son does not participate in sports or is not “good enough,” he may feel he has disappointed his father and lost the chance for connection. Additionally, men diagnosed with eating disorders report having difficulty attaining “socially appropriate” masculine traits, including competitiveness, aggressiveness, strength, athleticism and independence (Rader Programs, 2012). Those who develop eating disorders later in life tend to be more passive, less or non-athletic, and more dependent compared to a non-eating disordered male. Research also shows that many eating disordered men identify more closely with their mothers than with their fathers (Rader Programs, 2012).

Weight restrictions and requirements (for example, for certain sports) can also create a culture of disordered eating behaviors among athletic men (Rader Programs, 2012). As society continues to change its values and expectations of the “ideal” male body, issues pertaining to body image are no longer gender specific. Magazines that promote ideal looks, fitness, and “healthy” nutrition in men are more prevalent than they were previously. The media also is more likely to present the male body as a sex object, which contributes to men being more conscious about their aesthetic appearance. Interesting to note is that men comprise over a quarter of all cosmetic surgery patients, which clearly indicates that men are more invested in their appearance than ever before (Rader Programs, 2012).

Developmental factors also play a role in onset of eating disorders in men, as adolescence is also a crucial time with regard to physical and identity development in males (Rader Programs, 2012). Many eating disordered men cite adolescence as being a challenging time for several reasons, especially those who did not feel they met the increasingly high standards for what it means to be masculine. Further, some males reported using eating disordered behaviors to cope

with sexual impulses as a means to gain control over their bodies. Important to note is that starvation can actually reduce the production of testosterone, thereby reducing one's sex drive (Rader Programs, 2012).

The disorder is also diagnosed in males who identify as transgender and/or gay. Onset of AN may have been the result of a male individual's attempt to unconsciously deal with gender identity conflicts, particularly during adolescence (Rader Programs, 2012). Disordered eating behaviors may be used to avoid symptoms of anxiety and depression that result from feeling ashamed, different, unaccepted, or a perceived disappointment to others.

Treating AN

Due to the complex nature of the disorder, several forms of treatment have been established. Modalities include (a) individual outpatient, (b) family and/or group therapy, (c) partial or full-day treatment, and (d) inpatient or residential stays (Bakker et al., 2011). Further, care is often coordinated with numerous health professionals, as behavioral and psychological symptoms of AN can be accompanied by devastating health issues. For instance, complications with malnutrition (regardless of weight) constitute approximately two thirds of the number of deaths related to AN (Bakker et al., 2011). Thus, clients with AN are often seen by more than one health care professional, including (a) medical practitioners, (b) psychiatrists, (c) nutritionists, (d) exercise physiologists, (e) community support groups, (f) acupuncturists, and (g) massage therapists.

Despite only 33.8% of people diagnosed with AN present for treatment, the National Healthcare Systems reports that AN generates higher average costs for treatment and requires longer inpatient stays than any other psychiatric condition (Hudson et al., 2007; McKenzie & Joyce, 1992). Way (1993) posits that AN is egosyntonic in nature and that the disorder,

symptoms, and behaviors become fused with one's identity, making it difficult to recognize the profound physical and psychological costs of the disorder. Therefore, many people with AN deny behaviors and symptoms, have a distorted body image, enjoy the physical effects of restriction, and may not understand or will minimize the seriousness of their condition (Way, 1993).

Clients enter treatment through various ways. Those who acknowledge symptoms or have family members, medical practitioners, and/or friends who encourage them to seek help make up approximately one third of the clients who meet criteria (Hudson et al., 2007). This is particularly true for adolescents who are brought to treatment by family members. Many people are first approached by loved ones who express concern around dramatic weight loss or eating and/or exercise behaviors. Many initially resist help; particularly adolescents and those brought in and/or mandated to treatment (Hudson et al., 2007).

What is Recovery?

As previously noted, there is currently no universal definition for recovery from AN. The American Psychiatric Association (2000, 2013) acknowledges the importance of establishing standardized criteria for client discharge and recovery. For this to occur, the American Psychiatric Association encourages the creation of a comprehensive approach to assess client readiness for discharge and makes suggestions for how this can be accomplished. Specifically, the American Psychiatric Association suggests that clinicians and doctors observe a client's medical stability, assess for readiness for nutritional rehabilitation, observe a decrease in compensatory behaviors and co-morbid diagnoses, as well as a decline in psychological symptoms caused by AN (McHugh, 2007). The American Psychiatric Association also advocates that clients who enter treatment remain in treatment until meeting biopsychosocial

criteria for discharge following medical stabilization. Presently, standard biopsychosocial criteria for recovery do not exist and vary depending on the treatment setting, provider, and context, making it impossible for standards of discharge to be universally observed (McHugh, 2007).

An ongoing argument is that the term *recovery* is inhibited by narrow definitions that only refer to observable reductions in behaviors or thoughts (Aaserudster, 2007). Despite the American Psychiatric Association's (2000, 2013) recommendations, decisions pertaining to criteria for discharge often focus solely on physical measures of change, such as weight gain and stabilization and improved vital signs and heart rate. Strober, Freeman, and Morrell (1997) propose that the absence of physical symptoms of AN, an increase in weight, and discontinuing the engagement in restrictive eating behaviors does not equate to recovery from AN. Framing recovery as achieving the previously mentioned milestones ignores the subjective and individual experiences of the client who psychologically may be suffering which may not be seen by the eye of another (Lamourex & Bottorf, 2005).

Some researchers suggest that more complex and nuanced ways to look at recovery are needed. Bachner-Melman, Zohar, and Ebstein (2006) identify several domains of recovery that distinguish between behavioral recovery, cognitive recovery, and biological recovery. Castro, Gila, Puig, Rodriguez, and Toro (2004) found that some clinicians refer to recovery only when clients are at comparable risk for relapse as that of the regular population; however how this is determined is unclear. Tozzi, Sullivan, Fear, McKenzie, and Bulik (2003) advocate for a social constructionist view on recovery that allows flexibility and considers social and cultural practices. On the other hand, some researchers propose that limiting criteria for recovery is most practical, as many clinicians struggle when advocating for client care with insurance companies

(Jenkins & Ogden, 2012). Many agree that recovery can and should be evaluated according to (a) one's physical symptoms (heart palpitations, vitals, weight loss, etc.; Kordy et al., 2002; Pike, 1998), (b) behaviors, (c) nutrition, (d) Body Mass Index (BMI), or (e) one's thoughts.

Clinicians argue that observing behavioral changes, such as a reduction in restricting practices, makes the most sense, as it allows for measurable outcome-based methods to determine recovery (Way, 1993).

Recovery from the Perspective of the Client

A limited amount of research attempts to operationalize recovery from the perspective of clients diagnosed with AN (Darcy et al., 2010). This may be due to several reasons, as clients often have little input in their treatment; particularly those in fairly structured treatment centers or when clients are under the age of 18. Many clinicians and researchers tread lightly when considering client perspectives of recovery—talking about differences in how recovery is approached and considered is viewed as complex and too subjective (Treasure & Schmidt, 2003). This section focuses on exploring research from the perspective of clients.

Client perspectives explored in previous research. Layered and complex meanings of AN recovery are highlighted in Hardin's (2003) thematic analysis of clients who considered themselves recovered. In this study, many participants saw recovery as related to a shift in one's mental state, in addition to the observance of a change in one's physical and/or medical condition. Shifts in mood, emotional experiences, spiritual awareness, and social interactions were also reported as important components of recovery (Hardin, 2003). Further, some clients thought about recovery as having abandoned obsessions with food and weight, never feeling as if one has to engage in starvation strategies, having the strength to fight social pressures to be thin, having developed existential or spiritual meaning in life, and no longer feeling socially isolated.

In another study, Darcy et al. (2010) found that 65% of participants with AN defined recovery in terms of cessation of eating disordered symptoms, with the most frequent client sub-theme being the ability to engage in eating “comfortably.” In a later study, Darcy et al. (2012) reported that participants considered recovery to be a relational, social, and interpersonal process. Through this lens, recovery takes into account the ability for clients to develop and maintain loving and meaningful relationships, as well as experience an enhanced sense of confidence and assertiveness in relationships.

Jenkins and Ogden (2012) found that women defined recovery as putting an end to the “AN mindset” through changing negative cognitions into healthier ones. Participants spoke to the importance enjoying life, feeling comfortable with their bodies, and experiencing a decrease in obsessions with food and weight. Some identified recovery as no longer having “distorted” thoughts, experiencing an increase in self-esteem related to body image, noticing a reduction in negative thoughts related to body image, and feeling a general sense of healthier functioning. The majority of participants spoke about recovery from physical and psychological symptoms as separate. The belief that psychological recovery typically follows physical recovery was also noted by many participants.

Reflecting on qualitative research on client ideas of recovery, some researchers suggest that establishing a set of guidelines to determine whether a person is recovered from AN may underestimate the importance of individual psychological experiences (D’Abundo & Chally, 2004). The subjective nature of one’s personal meanings of recovery may be overlooked. Jacobson (2001) posits that clients recognize recovery as a unique process; clients acknowledge the importance of separating the illness from one’s self-concept and the necessity of learning how to manage the self as separate from symptoms, weight, and body size.

Exploring the Impact of Ambiguous Definitions of Recovery

Treatment. Bachner-Melman et al. (2006) argue that the multiple ambiguous definitions of recovery held by clients, clinicians, insurance companies, families, and medical professionals have significant implications for treatment outcome. The lack of well-understood, consistently applied, and agreed-upon criteria for recovery leaves clients, clinicians, treatment facilities, and parents on different pages and confused about the role of treatment. With minimal tangible “evidence” to support arguments for treatment, insurance companies easily create excuses to refuse treatment for clients, as they are the determiners of client eligibility for financial support. The criteria for eligibility vary drastically by and within each insurance company.

Liu (2008) proposes that increasing rates of relapse and higher rates of recidivism are a result of shifts in the focus of treatment. Whereas clinicians once had the time and financial recourse to challenge rigid patterns of thinking and expose underlying cognitive and psychological factors that contributed to the onset and maintenance of AN, medical complications and weight stabilization are now top priorities when treating AN.

Some argue that changes in the structure of treating clients with AN is in response to pressures to cut costs of treatment by providing the highest and most expensive levels of care only to clients who meet medical necessity standards. However such practices overlook research that demonstrates clients have a lower capacity to restore and maintain body weight following shorter lengths of stays compared to clients with longer stays. Although the “Statement of Intent” issued by the American Psychiatric Association asserts that “the ultimate judgment regarding a particular clinical procedure of treatment course be made by the physician in light of the clinical data and treatment options available,” this assertion often goes overlooked and overturned by insurance companies who refuse to pay for intensive and long-term treatment

(American Psychiatric Association, 2000). If a complete physical recovery were to be prioritized over a shorter length of stay, clients would have a greater chance of experiencing psychological improvement and long-term change (Fennig, Fennig, & Roe, 2002).

Research. The current practice of researchers often working independently has resulted in multiple definitions being proposed and operationalized (Noordenbos & Seubring, 2006). This abundance of proposed definitions also makes it difficult to understand rates of recovery. Hardin (2003) proposes it is likely that, with more criteria included in the definition of recovery, a lower percentage of clients will then be considered recovered. For example, if criteria are solely based on body weight, the percentage of recovered clients will be higher than if a set of psychological criteria were also factored into the equation. Even the slightest discrepancies in the definition of recovery contribute to the variance in rates of recovery among studies (Hardin, 2003). Additionally, researchers suggest that coming to a consensus regarding the term recovery also creates the ability to compare outcome data from research on various forms of treatment (Couturier & Lock, 2006).

The Impact of Financial Limitations on Recovery from AN

Financial constraints and limitations often prevent people from seeking or receiving the help needed to treat AN. Treatment can be complicated, time consuming, and costly, whether a person has insurance coverage or not. The lack of standardized criteria for recovery can be a challenge when clients seek financial assistance for treatment, as insurance companies often deny coverage for intense and longer-term services that are often needed to treat this disorder (Greenblatt, 2010). Further, insurance companies require concrete and tangible evidence when determining eligibility for reimbursement. Examples of commonly used measures of assessment include the *DSM* and BMI. BMI is obtained by dividing one's weight by height. The difficulty

with relying on strictly numerical information is that such methods alone do not take into account behaviors, thoughts, feelings, and other physiological markers of health. In addition, BMI makes no distinction between muscle and fat, and has proven to provide inaccurate information regarding actual body size and health risks (Aaserudster, 2007).

Insurance providers have been criticized for overemphasizing the importance of meeting *DSM-IV-TR* criteria and/or basing decisions purely on the reduction of observable symptoms that do not correlate with psychological or physical health. For instance, abatement of Criterion A in the *DSM-IV-TR* does not guarantee that relevant physical functions of the body are restored and can be considered healthy (Noordenbos, 2011). Generally, weight restoration and positive changes in behavior occur prior to and more frequently than psychological changes (Couturier & Lock, 2006). Meguerditchian et al. (2009) found that psychological functioning typically does not improve following “nutritional” or “medical recovery.” Clients discharged from a form of treatment that solely addressed physical symptoms, psychological symptoms persisted (Claude-Pierre, 1998).

Criterion B critics argue that there should be no stipulation that one must be underweight to meet the criterion, but rather it may be more appropriate to look at one’s intense fear of gaining weight or becoming fat, regardless of his or her size. Critics of Criterion D argue that physical consequences are not represented sufficiently in *DSM-IV-TR* criteria, as many medical issues other than amenorrhea may occur when the body lacks nourishment (Noordenbos, 2011). Additionally, weight restoration and the return of menses do not ensure the desired changes in a client’s cognitions and behaviors, such as the healthy acceptance of one’s weight and shape, or a reduction in the fear of gaining weight (Noordenbos, 2011). Criteria are also limiting in that they are not all applicable to naturally non-menstruating individuals, including pre-menstrual females,

pregnant, menopausal and post-menopausal females, transgender individuals utilizing hormone therapy, and males.

Researchers suggest that some insurance reviewers, perhaps due to a lack of understanding about the severity and complexity of the disorder, use their “discretion” when determining whether a client can receive or continue with treatment (Comerci, 1991). Although managed care companies report adhering to recovery standards as outlined in the *DSM-IV-TR* when reviewing treatment requests (Comerci, 1991), research has shown this is not always the case. Varying laws and standards of each state, in addition to the policies of the insurance provider, allow for the establishment of flexibility when it comes to determining coverage for services (National Eating Disorder Association, n.d.). Clients may be offered limited coverage or even denied reimbursement for treatment once a particular weight has been maintained, or after reaching other measurable and easily identifiable signs of physical health (e.g., regulated heart rate and normal vitals; Comerci, 1991).

Discharge prior to a full amelioration of symptoms not outlined in the *DSM-IV-TR* is not uncommon, as insurance companies are often firm in stating that once a client is medically stable, psychological, behavioral, and interpersonal symptoms can be addressed in less intensive (and less costly) forms of treatment such as in partial day treatment, intensive outpatient, or individual and group settings). Circumstances can pose great challenges for clients and their families, as decisions must be made around whether independently covering costs for treatment recommended by healthcare professionals is affordable if insurance companies refuse to pay. For some, the reality of incurring debt renders them unable or unwilling to seek treatment. It is not uncommon for clients to start treatment, maintain or gain weight, and suddenly no longer be considered eligible for services.

A diagnosis of EDNOS also creates complications with regard to billing and reimbursement, as many insurance companies do not reimburse for this diagnosis or will reimburse a fewer number of therapy sessions compared to other eating disorder diagnoses (Greenblatt, 2010). Even under mental health parity laws, insurance companies can refuse to pay for intensive treatment, resulting in premature discharge. Financial barriers often stand in the way of clients obtaining appropriate and sufficient care for eating disorders, as managed care companies deem individuals who do not meet all criteria for AN as “recovered enough” to refuse appropriate medical and mental health care (Greenblatt, 2010). By not reaching a point of “full recovery,” clients continue to suffer, and become vulnerable to relapse. Further, being denied coverage may enhance the client’s belief that he or she is not sick enough, thin enough, or even good enough at the disorder or in general. This experience of the self can further perpetuate a client’s engagement in restrictive and dangerous eating behaviors, thoughts, and actions.

Efforts to assist with coverage. Steps have been taken to assist clients in receiving coverage for treatment. The “Federal Response to Eliminate Eating Disorders Act,” (The FREED Act) is the first bill in the history of Congress to address eating disorder research, treatment, education, and prevention (Eating Disorders Coalition, 2011). The FREED Act will help people with Medicaid. Through this bill, treatment for eating disorders is made accessible to people of low income by including treatment in the services covered by Medicaid. This means that medical assistance, such as screenings, counseling, and pharmacotherapy (even for clients in an inpatient setting) will be provided to someone with an eating disorder who is Medicaid eligible (Eating Disorders Coalition, 2011).

Additionally, the Affordable Care Act (ACA) introduced in 2014, aims to be helpful to people seeking treatment for eating disorders (National Association of Anorexia Nervosa and

Associated Disorders, 2013). Prior to the ACA, more than 129 million people were denied insurance coverage due to a “pre-existing condition,” including an eating disorder. People with eating disorders were also finding their insurance providers eliminated benefits for treatment because of “an exclusion” in a policy. The ACA prohibits denying coverage because of pre-existing conditions, including eating disorders. Additionally, all children under the age of 19, regardless of their health condition, must be provided insurance benefits. Until the ACA, families who had group health insurance could not get coverage for children with pre-existing conditions. As females under the age of 19 are highly susceptible to the onset of symptoms for AN, the ability to seek early treatment is imperative. The ACA does not allow for “lifetime maximums,” which prohibits insurance companies from placing a dollar amount on how much treatment they will cover over a person’s lifetime (National Association of Anorexia Nervosa and Associated Disorders, 2013).

Seeking treatment can be both emotionally and financially devastating for clients and their families. Many organizations have emerged to support clients with this task by answering questions, being available for consultation, and assisting in requests for reimbursement. The Eating Disorders Coalition (a coalition of over 35 eating disorder organizations) works with advocates and members of congress to ensure ongoing conversations about funding for the treatment of eating disorders. Additionally, The National Association of Anorexia Nervosa and Associated Disorders (ANAD) provides information and guidelines to help clients and families advocate for treatment coverage; particularly in seeking funding for residential or inpatient stays (National Association of Anorexia Nervosa and Associated Disorders, 2013). The organization suggests that clients follow the recommendations of their treatment teams as opposed to insurance companies, who often deny the necessity of intense (and expensive) forms of care per

order of the treatment provider. ANAD encourages clients:

Do not let the insurance company dictate your recovery! We understand the cost of treatment is incredibly costly, and some families must go to extreme measures to keep a loved one in treatment. We also understand how frightening and chaotic this time can be. This is where we come in: we work with your insurance company and treatment facility after a denial to seek reimbursement of the benefits available under your policy. If your insurance denies coverage for treatment, we can only help you recover these benefits if you (1) have an insurance denial in writing and (2) have STAYED in treatment. Please note that we can help with any level of treatment denial—including PHP (Partial Hospitalization Program) and IOP (Intensive Outpatient Program).

ANAD also provides information about the Employee Retirement Income Security Act, (ERISA). ERISA states that clients have the right to file a lawsuit to recover unpaid benefits for expenses that were medically necessary. Further, several residential and inpatient treatment centers provide information on their websites to help clients learn about, obtain, and fight for reimbursement (see Appendix A; Mirasol Recovery Centers, 2013).

Development of the Current Survey

Project overview and purpose. The current study explored how participants define recovery from AN and how definitions of recovery change over time according to the stage of treatment. Current and former female clients with AN were asked to participate in a web-based survey that aimed to better understand the criteria considered necessary when defining recovery at the beginning and end of treatment, and at the time of survey administration. Participant perspectives on recovery were compared with existing definitions of recovery as proposed in the research, as well as in the diagnostic manuals. Results from the current study may be used to

inform treatment models, insurance company criteria for establishing coverage for care, and to enhance the therapeutic alliance. Results may also provide clinicians with information about how client ideas of recovery change over time, as well as the impact changes have on rates of relapse and recidivism. Participants were also asked to respond to questions that referred to the length of time symptoms must be gone prior to considering one's self recovered.

This study used an abbreviated version of Noordenbos and Seubring's (2006) measure in combination with open-ended questions designed to capture ideas about recovery from the perspective of clients with AN. Thirty-five of the 52 criteria used by Noordenbos and Seubring were incorporated in the current study, while items noted by fewer than 70% of participants in the original study were omitted. Items were omitted to maintain the brevity of the survey, as other items thought to be more pertinent based on the researchers literature review were added to the new survey. Additional items also took into consideration recommendations proposed by Noordenbos and Seubring.

Participants were also asked to think retrospectively about each of the criteria as an indicator of recovery at different points of treatment. Quantitative and qualitative questions captured the subjective experiences of each participant, as well as identified themes and variations in responses. Open-ended questions were derived from previous qualitative research that focused on understanding the meaning of recovery from the perspective of the client.

Rationale for the current study. Several obstacles frequently present themselves when working with clients suffering from AN. Many are treatment resistant and initially uninterested in change. As AN has the highest mortality of any psychiatric disorder, there is a strong need to improve treatment protocols and better understand the needs of this population. As criteria for recovery used by insurance companies (and treatment centers) continue to focus on the

restoration of weight and physical health, clients are not provided the time nor resources to truly help them battle AN. If insurance companies, families, clients, and medical professionals are to become more invested in the long-term outcomes of client physical and mental health, there needs to be a greater understanding of what the end-goal of treatment is, how to assess for it, and how it impacts the treatment being employed. Further, this study aimed to show that over time, client perspectives of recovery shift and must be taken into account in treatment. Additionally, data is needed to establish a basis to show why thorough, long-term, intensive care is a smart financial decision for insurance providers and worth investing in on behalf of clients and clinicians. Gaining a greater understanding of the needs of clients would also enhance the therapeutic alliance. Therapeutic alliance is one of the highest predictors of client outcome in therapy and plays an invaluable role in the client's process of change. Further, because of its powerful influence, the relationship has the greatest potential for dramatically decreasing the mortality rate, particularly with regard to suicidality.

Benefits of this study. In the work that largely informed the creation of the current study, Noordenbos and Seubring (2006) proposed that a reexamination of criteria for assessing recovery is essential to improve treatment success. Further, many researchers suggest treatment outcome will improve when clinicians prioritize and recognize criteria that address client needs and goals for treatment. One benefit of the current study is that by obtaining an increased understanding of what criteria clients prioritize, clinicians and treatment facilities can adjust their work as needed. Noordenbos and Seubring also suggest that not clarifying the goals of clients at the beginning of treatment was a limitation of their study. Thus, the current study takes into account retroactive responses of clients and encouraged participants to reflect on criteria they prioritized at three different points in time.

Chapter 3: Methodology

Research Questions

Given the findings of previous research on client perspectives of recovery, the current study explored the following questions:

1. How do women currently or previously in treatment for AN define recovery?
2. How does one's definition of recovery change over time? Specifically, how do women define and think about recovery at various points in time with regard to treatment (pretreatment, posttreatment, and at the time the survey was administered)?
3. How long do women with AN believe symptoms must be gone to consider someone recovered?

Participant Eligibility

To take the survey, participants were required to have a current or past diagnosis of AN, have received treatment for AN, and be at least 18 years of age at the time the survey was taken (although they may have been younger than 18 when diagnosed). Eighteen years of age is considered the legal threshold for adulthood and therefore was chosen as the criterion for study eligibility. Participants were also required to be female and have access to the Internet, as the survey was web-based. Although AN is also present in males, females constitute the majority (90%) of diagnosed cases. This study was intended to better understand females' beliefs around recovery and how to enhance therapeutic alliance and the effectiveness of treatment. Participants also had to be English speakers who were able to read at or above an eighth-grade reading level.

Recruitment

Participants were recruited primarily through electronic media. Organizations and eating disorder facilities that work with clients diagnosed with AN were contacted via e-mail and informed about the study (Appendix B). These facilities include but were not limited to the

(a) National Eating Disorders Association (NEDA), (b) NORMAL In Schools, Inc., (c) Monte Nido, (d) the UF Health Eating Disorders Recovery Center, (e) the Milestones Program, (f) Walden Behavioral Care, (g) the Renfrew Center, (h) the Institute of Living, (i) Center for Discovery New England, and (j) New England Eating Disorders Program. These treatment facilities were contacted for help recruiting participants and provided with the information to access the web-based survey and the letter of informed consent for participants (Appendix C). Organizations were asked to share the web link, which was often done through public media forums such as listservs, message boards, mass e-mails, and newsletters. Treatment providers were encouraged to contact me with questions.

Administrators and creators of Facebook groups established to support current and former clients diagnosed with AN, as well as groups that provide information on seeking treatment for AN were also contacted and provided information about the study. Permission was sought from leaders to either allow the link to the survey to be posted on group homepages or have creators share the link themselves. No member of any group was individually contacted during the recruitment process, and information about the study was not posted without the permission of the group creator. Participants were not forced or required to complete the survey on behalf of any group or organization. Contacting groups and organizations was solely geared toward making the survey available to those who were eligible and wanted to participate.

The desired minimum number of participants recruited for this study was based on the suggestions and previous research of Noordenbos and Seubring (2006). Although Noordenbos and Seubring recruited 41 participants for their study, they posited that a larger sample size would be beneficial to establish a more generalized understanding of client perspectives on recovery. Given this recommendation, a minimum of 41 participants were initially sought to

participate in the current study. However, I welcomed as many participants as possible to take the survey within the time constraints of the data collection. In all, 79 participants responded to the online survey used for the current study.

Instrument

The web-based survey (Appendix D) was used to collect qualitative and quantitative data about definitions of recovery. Web-based surveys provide freedom for individuals to participate on their own terms and time-frame. They also allow researchers to obtain large amounts of data without hiring interviewers or paying for paper and postage. Furthermore, web-based surveys allow data to be collected and downloaded into statistical software without additional data entry, potentially saving the researcher time when reviewing collected information. For this study, the Survey Monkey (surveymonkey.com) tool was chosen for its user-friendly nature and easy access for both the researcher and participants. A Survey Monkey membership was purchased for a nominal fee that allowed me to post the survey and review data.

As previously mentioned, items for the survey were generated after careful review of several previous qualitative and quantitative studies that have focused on recovery from AN. This survey incorporates 32 of the 52 dichotomous “yes or no” questions from Noordenbos and Seubring’s (2006) questionnaire. For this survey, questions were presented in several formats including “yes or no,” open-ended, and short-answer styles that asked participants to reflect on symptoms, treatment history, and their own perspectives on recovery. Open-ended and short-answer style questions helped to better understand participant’s unique and individual ideas about recovery.

The self as an instrument. Although research in general is always subject to researcher bias, the nature of qualitative inquiry is particularly subjective. Therefore, it was necessary to be aware of explicit assumptions, biases, and opinions, particularly while coding (Morrow, 2005).

The following section details how the perspective of the researcher was taken into account during data analysis.

First, I have a strong interest in the research topic and have worked with several female clients who met *DSM-IV-TR* criteria for AN. I also have personal experiences and relationships with people diagnosed with AN. Such women have often discussed their struggles to come to terms with ideas regarding what it means to be recovered and how one knows they are recovered. They also expressed feeling as though personal goals for treatment were not acknowledged or met, no matter what form of treatment they engaged in. Given these factors, it was important for me to “bracket” my opinions and continuously “monitor [my]self,” as described by Peshkin (as cited in Morrow, 2005, p. 9). This refers to a continuous process of attending to one’s subjectivity by consciously attempting to suspend one’s beliefs and allow data to speak for itself during the processes of data collection and data analysis. I was able to do this by also utilizing feedback from an additional collaborator regarding the impact of my subjectivity on data analysis, particularly with regard to thinking about how and why particular categories were maintained while others might not have made it into early versions of the codebook.

A Mixed-Methods Approach

The subjective nature of defining recovery, as discussed and explored in previous literature, influenced the research approach taken for the current study. While considering the strengths of both quantitative and qualitative research, incorporating a mixed-methods approach to the research questions served several purposes.

Quantitative data provides a basis for the generalizability of specific research observations and can be used to verify qualitative findings (Noordenbos & Seubring, 2006). Qualitative data has the capacity to richly depict and strategically compare data, thereby

overcoming the abstraction inherent in many quantitative studies (Noordenbos & Seubring, 2006). Qualitative analysis creates the opportunity to facilitate analysis by validating, interpreting, and clarifying quantitative findings, as well as strengthening and revisiting existing theories.

Although quantitative methods tend to be used more often when studying eating disorders, qualitative methodology is being incorporated more frequently in this research (Noordenbos & Seubring, 2006). Combining qualitative and quantitative research methods to establish a mixed-methods approach allows for the elaboration and development of a more thorough analysis, often leading to more precise and generalized results (Miles & Huberman, 1994). This approach also explores multiple dimensions of client perspectives of recovery. While analyzing results from qualitative-style research may be more time-consuming, the added narrative and detailed information on subjective experiences was important to supplement and enrich data derived from the other traditional methods of research.

Statistics and Analysis

This section explains how descriptive statistics and content analysis were used to better understand the collected data.

Descriptive statistics. Descriptive statistics were used to describe collected quantitative data. *Descriptive statistics* refer to the process of describing the main features of a collection of data (Trochim, 2006). This process of presenting and organizing statistics helps describe, show, or summarize data in a meaningful way. For instance, descriptive statistics can highlight patterns that emerge in an organized way using tables or graphs. This method is especially useful when presenting a great deal of data, such as in the current study, to minimize the reader's risk of becoming overwhelmed or challenged. Important to note is that descriptive statistics do not

allow researchers to draw conclusions beyond the scope of the analyzed data, but rather simply provide one way to describe data (Trochim, 2006).

Similarly to how Noordenbos and Seubring (2006) presented their research, tables were created to illustrate data collected in the current study. Tables are used throughout the results portion of this paper to illustrate how participants collectively cited criteria in terms of importance when asked to think about recovery.

Content analysis. The analysis of open-ended questions included in this study was conducted using conventional content analysis. Content analysis was chosen as it allows for the exploration and subjective interpretation of text through coding, as well as the identification of themes and patterns (Hsieh & Shannon, 2005). Additionally, content analysis has been identified as a flexible and effective way of organizing open-ended questions in research (Cavanagh, 1997). Content analysis emphasizes the integration of speech, texts, and context (Zhang & Wildemuth, 2005) and allows researchers to use data “to provide knowledge and understanding of the phenomenon under study” (Downe-Wamboldt, 1992, p. 314).

Content analysis begins during the early stages of data collection (Zhang & Wildemuth, 2005). Attending to analysis at the beginning of one’s research can help orient the researcher toward focusing on both concept development and data collection. As codes and themes are derived directly from the data to describe a phenomenon, categories emerge. This process is known as inductive category development (Hsieh & Shannon, 2005).

Content analysis can be labor intensive and time consuming, particularly if coding is complex (Kondracki, Wellman, & Amundson, 2002). It is not uncommon for key categories to be overlooked, increasing the risk of misrepresenting the data. The quality and trustworthiness of this type of research is largely based on how the researcher is able to explicitly relay the

process by which the study was conducted, as well as the way in which results are presented. For the current study, credibility was established through collaboration with peers, prolonged exposure to the data, and persistent observation. While it was important to account for the researcher's subjectivity, the goal of qualitative inquiry, including the current study, is to explore and describe something rather than to confirm and explain it (Chwalisz, Shah, & Hand, 2008).

The following steps provide a detailed explanation of how data was analyzed using conventional content analysis.

Step 1: considering the data. I began the analysis process by becoming fully immersed in the data (Zhang & Wildemuth, 2005). Immersion in the data involved repeatedly reading and analyzing participant responses in an active way, searching for meanings and patterns. To ensure a thorough and systematic review of the data, I read over a hard copy of each participant's completed survey several times.

Step 2: defining units of analysis. A unit of analysis refers to the most basic unit of classified text (Zhang & Wildemuth, 2005). Defining what constitutes a unit is fundamental (Weber, 1990), as discrepancies between how a unit is defined can impact coding decisions and the comparability of data (De Wever, Schellens, Valcke, & Van Keer, 2006). For this study, themes were used as units of analysis. An expression of an idea was considered a theme when it captured something important about the data and represented some level of patterned response (Berg, 2008). Themes emerged from single words, sentences, and phrases. Thought units were cut from hard copies of participant responses and placed into an envelope according to recurring and like-themes. This is known as the grounded theory method of "cutting and sorting," which involves "identifying quotes or expressions that seemed somehow important and arranging the quotes/expressions into piles that went together" (Ryan & Bernard, 2003, p. 94).

The prevalence of a theme, or how frequently a theme presented itself, was considered when continuing onto Step 3.

Step 3: generating codes. A code refers to an element of raw data that can be assessed in a meaningful way regarding a particular phenomenon (Tuckett, 2005). Coding is used to identify and retrieve meaningful content from the data (Hsieh & Shannon, 2005). Codes are also used to organize participant responses into similar or related clusters. Codes are not to be confused with units of analysis, as units of analysis are established prior to the development of codes. Units of analysis are then coded and organized into similar themes (Boyatzis, 1998).

There is no standard way to determine prevalence, as content analysis is flexible and allows for themes to emerge in a number of ways. This form of coding requires researchers to be consistent in how they determine how to code a unit of analysis (Saha, 2003). In the current study, codes were generated once the researcher was familiar with the data. An initial list of noteworthy and recurring ideas expressed by at least five participants was built. Codes were assigned to text that represented a single theme (or idea) relevant to the questions under study. A semantic approach was taken, meaning that themes were identified from responses explicitly provided by the participants as opposed to inferring and looking beyond explicit responses (Braun & Clarke, 2006). Each response was identified by participant number, question number, and code number.

Codes were constantly compared and consolidated throughout the analysis process to avoid redundancy. The constant comparative method was employed, which refers to the systematic comparison of each text assigned to a category to more fully understand the theoretical properties of each grouping. Further, to ensure consistency of coding, a codebook (Appendix E) was developed (Zhang & Wildemuth, 2005) and included (a) category names, (b)

definitions (or rules for how codes were assigned to specific categories), and (c) examples of data that fit each code (Weber, 1990).

Although assigning a particular text to a single category can be challenging, qualitative content analysis allows units of text to be considered in more than one category (Tesch, 1990).

Step 4: the development of categories. Categories are descriptive names for groups of data that highlight patterns expressed in text (Saha, 2003). They allow the researcher to better understand a particular phenomenon and can be organized several different ways (Hsieh & Shannon, 2005). However, researchers have strongly suggested that categories be grounded in repeated ideas that emerge from the data (Saha, 2003).

In the current study, categories were determined inductively from previously organized units of analysis grouped by code. The iterative process refers to moving between data immersion and category creation/consolidation. This process enhanced category development by allowing me to distinguish differences between and amongst ideas to accurately represent and reflect themes while, simultaneously, integrating categories and their properties. Categories were continuously reviewed, established, and combined throughout the analysis process as I became more familiar and immersed in the data. For example, the constant comparative method was used to develop new insights and make distinctions between each category (Glaser & Strauss, 1967, as cited in Zhang & Wildemuth, 2005). This method uses systematic strategies to compare responses not yet assigned to categories with ones that have been assigned.

The outcome resulted in a list of initial categories based on participant responses. Ryan and Bernard (2003) posit that initially, data analysis should consider as many categories as possible, while later phases can focus on identifying categories most relevant to the study. Thus, there were more categories in the earlier stages of analysis than are currently found in the

codebook (Appendix E). During the next phase, known as “axial coding,” (Corbin & Strauss, 2008) categories were refined, condensed, and synthesized based on the relevance of each initial category. This was done by reviewing each unit of thought and assessing whether categories were accurate expressions of the data. I avoided keeping categories that were too narrow by combining similar ideas and creating more detailed and explicit subcategories within the broader, overarching thoughts and was mindful that having too many categories could create challenges when sorting through and presenting data in an efficient and effective manner. Thus, subcategories were created to highlight different but related ideas of through within broader categories, as many have multiple and connected ideas. In this study, creating subcategories, or smaller groups, allowed for the meaning of participant responses to be retained and comprehensively captured.

By the end of this phase of coding, 16 categories had been established, many of which contained related subcategories. Definitions of each category and subcategory are presented in the codebook (Appendix E). The codebook also demonstrates how the researcher thinks about how each subcategory fits within larger category headings.

Step 5: testing the codebook. Upon preliminary completion of the codebook, steps were taken to validate the coding scheme to establish consistency. Toward this aim, another reader (and collaborator) was recruited to assess for overlapping or ambiguous inclusion criteria that made it difficult to distinguish between codes. This collaborator, familiar with content analysis and qualitative research, had been provided with the definition of each category and was asked to immerse herself in the codebook to assess whether examples from the data were appropriately sorted. Inconsistencies were noted, discussed, and resolved. The codebook was refined to incorporate feedback, and categories flagged as confusing were discussed, clarified, reworked, or

removed. Assigned codes were also revisited to ensure thematic accuracy, as category organization was continuously developed to reflect the researcher's changing understanding over time (Miles & Huberman, 1994). Finally, all previously coded text was reviewed and recoded (if necessary) to ensure consistency with the revised codebook.

Ethical Considerations

Confidentiality. Confidentiality of participant responses was safeguarded through the use of the survey tool, Survey Monkey. Participants remained anonymous, as they were not asked to disclose their names or contact information. The researcher had access to the data through a password-protected login. Data was shared with the investigator's advisor as needed during the analysis process. Once data was used, responses were cleared from Survey Monkey and the researcher's account was terminated.

Informed consent. The letter of informed consent was written at an eighth-grade reading level (Appendix D). Verification of understanding the informed consent was required before participants could access the survey. Participants were also informed that they could discontinue the survey at any point, but that information could not be removed from being included in the study once the survey was submitted.

The informed consent addressed the nature of the study, as well as the potential benefits and risks of participating. Potential adverse effects outlined in the informed consent included emotional discomfort or distress resulting from reflection on experiences in treatment or with regard to thinking about symptoms of AN. Although no adverse events were expected, participants were encouraged to discontinue the survey and seek professional help immediately if an adverse event or reaction occurred.

IRB approval. Prior to survey administration, this study was approved by the Institutional Review Board (IRB) at Antioch University New England on November 17, 2013. Data

collection was approved from December 16, 2013 until April 30, 2014. Data collection occurred from December 16, 2013 until January 1, 2014.

Chapter 4: Results

Seventy-nine participants completed some or all of the web-based survey. All responses were included in the analysis of the results. Participants were made aware via the informed consent that they could discontinue the survey or skip any questions they did not wish to answer. Therefore, some questions were not answered by all participants. Table 4 shows how many participants responded to and skipped each question. All questions were reported on and explored despite not having been responded to by all participants.

Descriptive Statistics

Respondent demographics. All participants were between the ages of 18 and 64. Of the 79 participants who responded to this question, 40 participants (50.63%) were between the ages of 18 and 24; 29 participants (36.71%) were between the ages 25 and 34; six participants (7.59%) were between the ages of 34 and 44; three participants (3.80%) were between the ages of 45 and 54; one participant (1.27%) was between the ages of 55 and 64; and no participants were over the age of 65.

Table 4

Number of Respondents to Each Question

Question	Number of Participants who Responded to Question	Number of Participants who Skipped Question
What is Your Age?	79	0
When Were you Diagnosed with anorexia?	79	0
How Long Did You or Have you had AN?	79	0
The following questions are about treatment and getting better. Please list all types of treatment you have received and how long you were in treatment. Examples of treatment include, but are not limited to: Residential programs (non-hospital setting), inpatient hospital-based program, outpatient individual therapy, partial day program (at a hospital or residential setting), group treatment (support peer-led, clinician-led, etc.), or psychiatric medication. Please write it as type of treatment followed by the start date) (example: Inpatient hospital-based program 1/12 – 4/12)	74	5
The next section asks you to think back to the beginning and end of treatment, as well as how you are doing now. Please check as many boxes as is true for you if the statement is part of how you defined “recovery” at 1) the beginning of treatment, 2) the end of treatment, or 3) now. If you are just starting treatment for the first time, please answer only answer in the “Beginning of Treatment” category.	79	0
Please think about how you responded to the above items. Are there other things not covered above you think show you got better?	72	7
Please Explain	40	39
Please Describe your Goals for Recovery at the Beginning of Treatment	72	7

Did you achieve these goals?	70	9
Please Describe your Goals for Recovery at the end of Treatment	70	9
Did you Achieve these Goals?	70	9
Was Treatment Helpful?	72	7
Please Explain	62	17
The Next Section asks you to Think About your Ideas of Recovery Now. Is it Possible to Recover from AN?	71	8
If you believe that recovery is possible, how long should symptoms be gone before you can be considered recovered? Please explain	58	21

Diagnostic information. Figure 1 depicts how participants responded to the question, “When were you diagnosed with anorexia?” The median was 17-19 years, as was the mode. Fifty of the 79 participants are represented in Figure 1, as some participants responded in such a way that was not sufficiently clear to determine the specific age in which they were diagnosed. For example, some reported, “when I was younger” or “I can’t remember not having AN.” Therefore, it was impossible to determine the age of diagnosis for 29 participants.

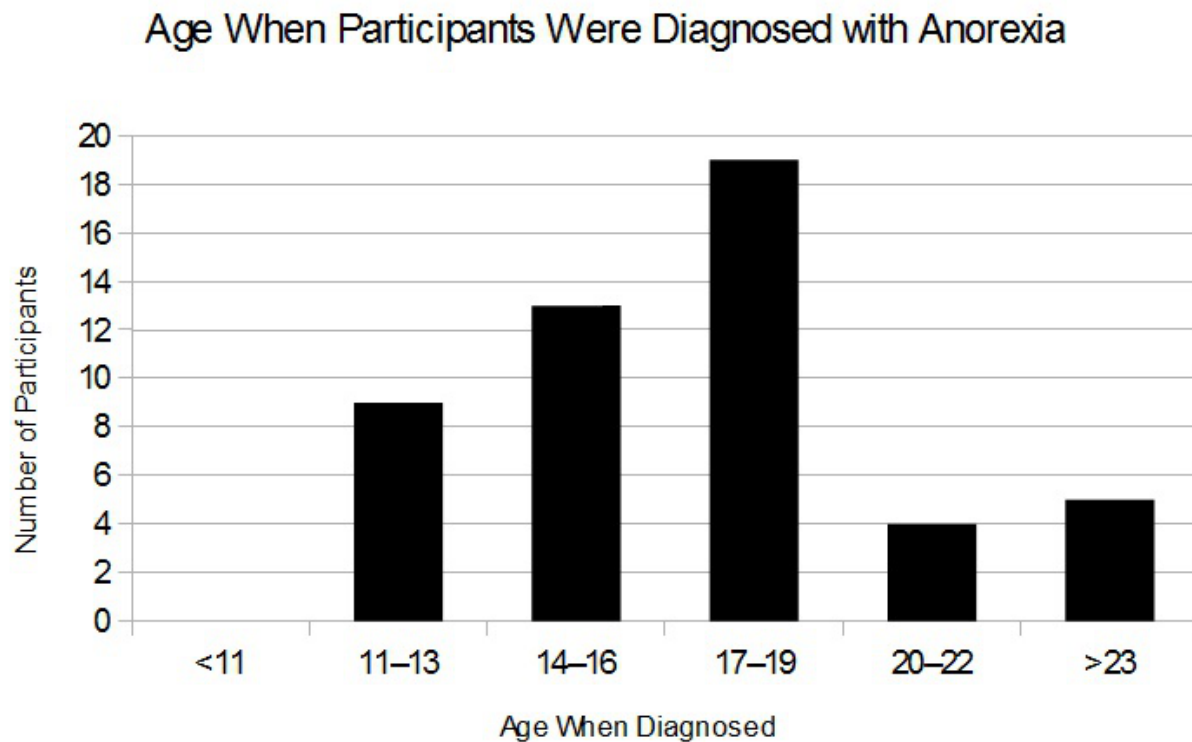


Figure 1. Age of diagnosis. This figure illustrates the age ranges of 50 participants when first receiving a diagnosis of AN

Figure 2 represents the length of time participants met criteria for AN. Seventy-five participants responded to this question. The median number of years was 7 and the mode was 11-20.

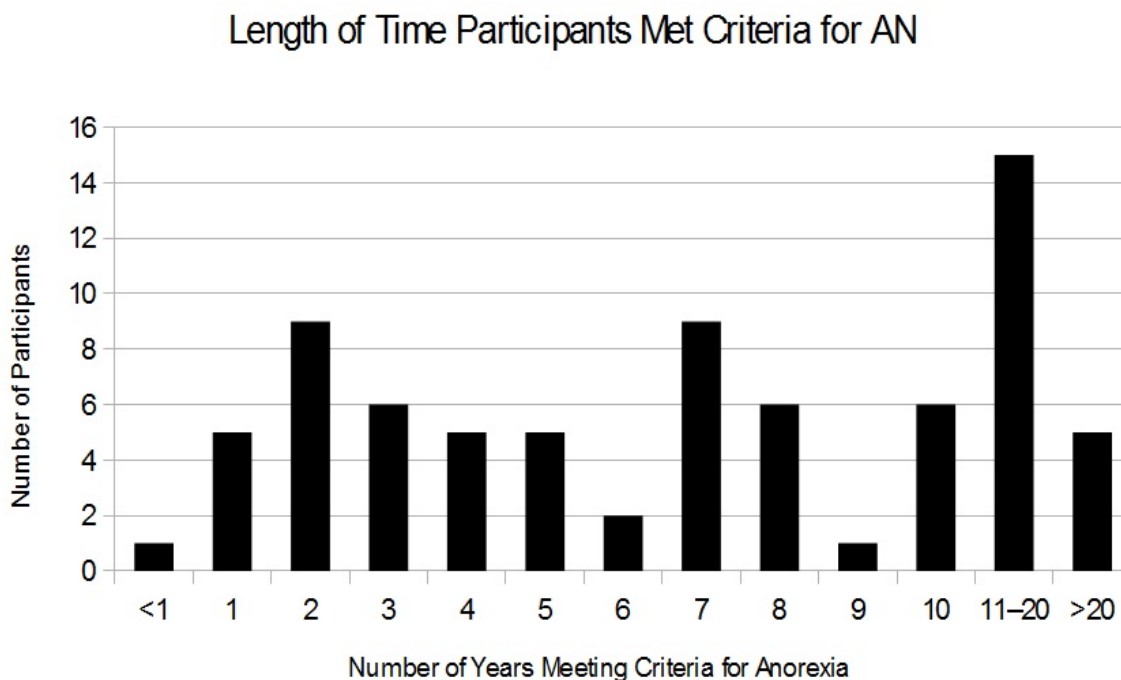


Figure 2. Number of years participants met criteria for AN.

Treatment. Seventy-four percent of participants responded to the question that asked them to list all forms of treatment they have received, as well as how much time was spent in each treatment setting. Overall ten different treatment modalities represented participant responses, including (a) residential programs (nonhospital setting), (b) inpatient hospital-based program, (c) outpatient individual therapy, (d) partial-day programs (in hospital and in residential programs), (e) group treatment (support peer-led and clinician-led), (f) psychiatric medication, (g) step-down programs following residential treatment programs, (h) intensive outpatient treatment, (i) individual psychotherapy, and (j) g-mail therapy. Participants also reported that they are or have been treated by doctors and nurses to monitor weight stability as well as having had received services from dietitians and nutritionists.

The majority of participants described having received multiple methods of treatment concurrently. In some cases, participants mentioned having received more than one method of

treatment at the same time. For example, some participants received simultaneous group and individual therapy, whereas another participant received simultaneous psychiatric services, nutritional counseling, and individual therapy. Alternately, others reported trying different methods of treatment sequentially.

With regard to the number of different forms of treatments in which participants were involved, seven respondents reported having been in one form of treatment; 17 respondents reported two forms; 18 respondents reported three forms; 17 respondents reported four forms; 11 respondents reported five forms; three respondents reported six forms; one respondent reported seven forms; and one respondent reported eight forms. Participants also provided information regarding how many times they were in each form of treatment. Twelve respondents reported having been in the same form of treatment once; 19 respondents reported twice; 16 respondents reported three times; six respondents reported four times; one respondent reported five times; and one respondent reported eight times.

Not all participants specified how long they were in each form of treatment (despite the question calling for participants to include dates of treatment). For instance, a participant may have considered being in outpatient psychotherapy consistently for eight years (even with different clinicians) as one form of treatment; whereas another respondent may have been in outpatient treatment intermittently over eight years with the same clinician and referred to it as having four different outpatient therapy experiences. For some participants, there was no way to differentiate between how they were defining a therapeutic experience/treatment.

Of the 72 participants that responded to the question “was treatment helpful?” 59 (81.94%) reported that it was, nine (12.50%) reported that they were unsure, and six (8.33%) reported that it was not helpful. Of the 70 participants that responded to whether or not goals

had been achieved at the beginning of treatment, 36 (51.43%) reported they had been, and 19 (27.14%) reported that they were unsure, and 20 (28.57%) reported that they had not been.

Participants were also asked whether they achieved their goals at the end of treatment. Of the 70 participants who responded, 37 (52.86%) reported they had achieved, 14 (20.00%) were unsure, and 24 (34.29%) reported that they had not. Important to note is that some participants responded with more than one answer.

Belief in recovery. Seventy-one participants responded to the question, “Is it possible to recover from AN?” Although the responses could have been “yes,” “no,” or “unsure,” a few participants responded more than once. This created 74 total responses to this question. Of the 74 responses, 40 (56.34%) believed recovery to be possible, 11 (15.49%) did not believe it to be possible, and 23 (32.39%) expressed feeling unsure about whether recovery was possible.

Figure 3 depicts the breakdown according to the percent of 65 participants who believe in recovery as a function of the length of time meeting diagnostic criteria. The percentage of participant belief in recovery is therefore not based on all 79 people who responded to the survey, but rather was established by the proportion of the total number of analyzable responses (65). Percentages of participants articulating each of the three options (believe in recovery, don’t believe in recovery, and unsure) add up to 100%. Important to note is that as this data is only representative of 65 participants. Interesting to note is that as time went on, participants did not note believing in recovery less, but rather the number of participants who were uncertain about whether recovery is possible had increased, which could explain why fewer participants were less certain about the possibility of a full recovery.

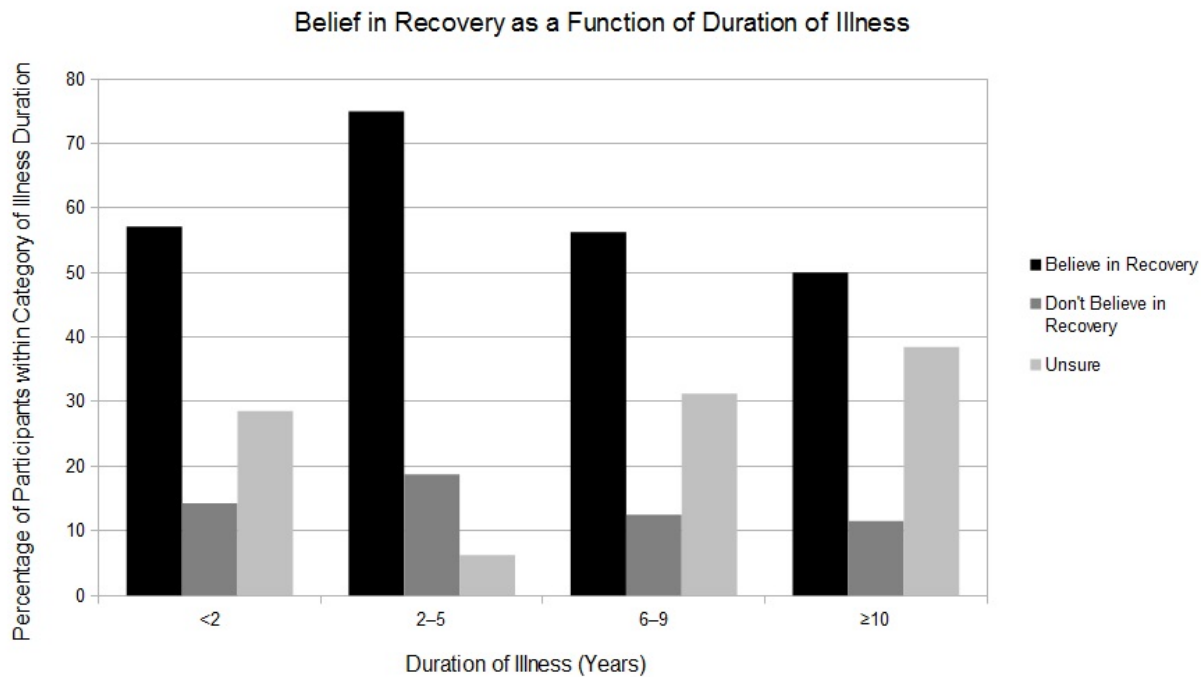


Figure 3. Belief in recovery as a function of duration of illness. This figure represents the responses of 65 participants with regards to their belief in recovery as a function of how long they have suffered with AN.

Domains of criteria. Noordenbos and Seubring's (2006) categories of recovery were adapted for the purposes of the current study. The researchers established criteria based on literature and criteria for recovery mentioned in other studies. Characteristics and consequences of eating disorders were split into the five domains: (a) eating behavior, (b) body experience, (c) somatic criteria, (d) psychological criteria, (e) emotional criteria, and (f) social criteria (see Table 5). Figure 4 depicts the percentages of participants who referred to categories of recovery criteria as important across time.

Table 5

Criteria for Recovery

Broad Categories of Recovery	Specific Criteria
Eating Behavior	I eat three meals a day I consume a normal amount of calories I do not binge I do not vomit after a meal I do not take laxatives I do not use diuretics I do not use diet pills I do not exercise excessively I do not use too much alcohol
Body Experience	I do not feel too fat I have a positive body experience I accept my appearance I do not need to be excessively slim I am not obsessed with food and weight
Somatic Criteria	My body temperature is normal My heartbeat is normal My sleep is normal I am not often tired
Psychological Criteria	I have adequate self-esteem My self-esteem is no longer dependent on my weight I am assertive I do not punish myself after a meal I am not extremely perfectionistic I do not have a strong fear of failure I have a realistic image of myself
Emotional Criteria	I am not depressed I am able to express emotions verbally and non-verbally I can handle negative and positive emotions I can express a different opinion and handle conflict
Social Criteria	I am in touch with my feelings I participate in social activities I have friends

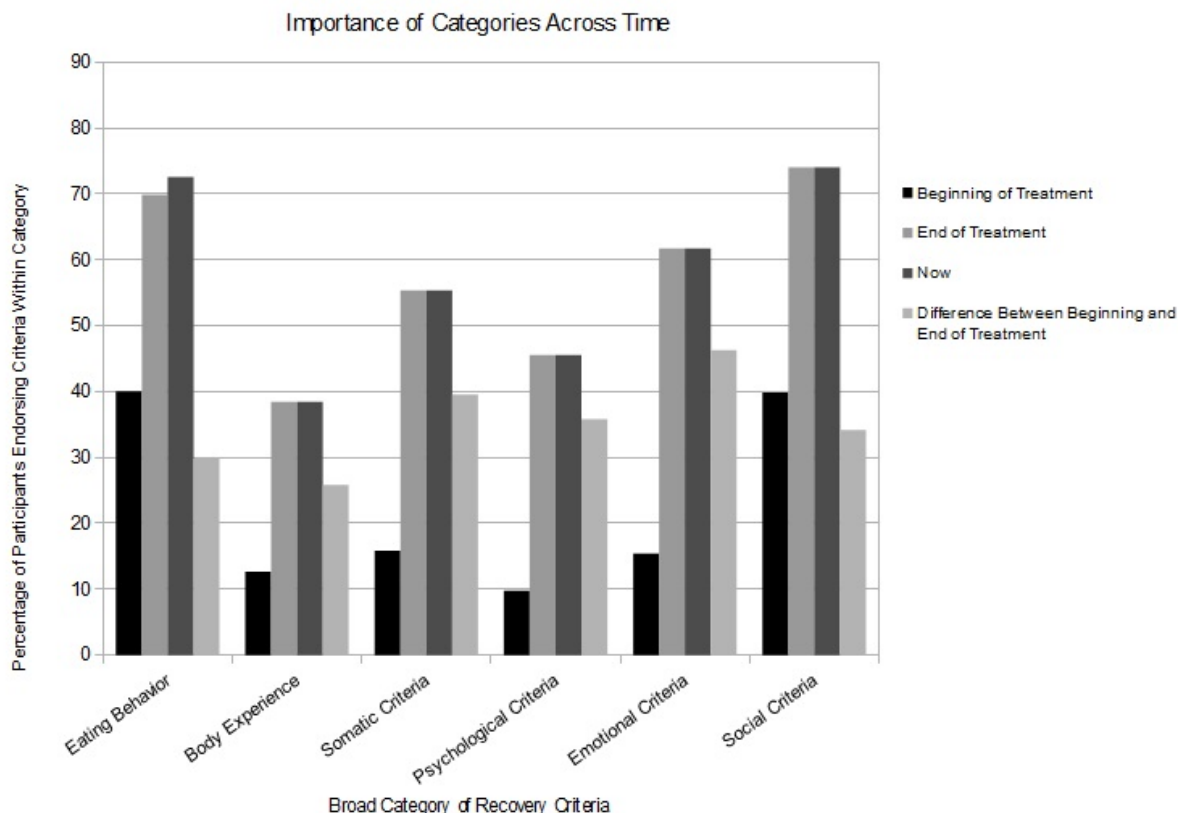


Figure 4. Importance in percentages of categories across time. The figure also highlights the changes in how participants thought about criteria that were important from the beginning to the end of treatment, as well as at the time of survey administration.

Figure 5 depicts a bar graph that highlights the percentage of participants who referred to each criteria within the five major categories based on their level of importance at the beginning and end of treatment as well as at the time the survey was taken.

Criteria within the eating behavior category were noted by the largest percentage of participants at the beginning and end of treatment, as well as at the time of survey administration. Also of note is that the following items in this category: “I do not use too much alcohol,” “I do not use diuretics,” “I do not use diet pills,” and “I do not take laxatives” remained the top five most articulated criteria at all stages of treatment.

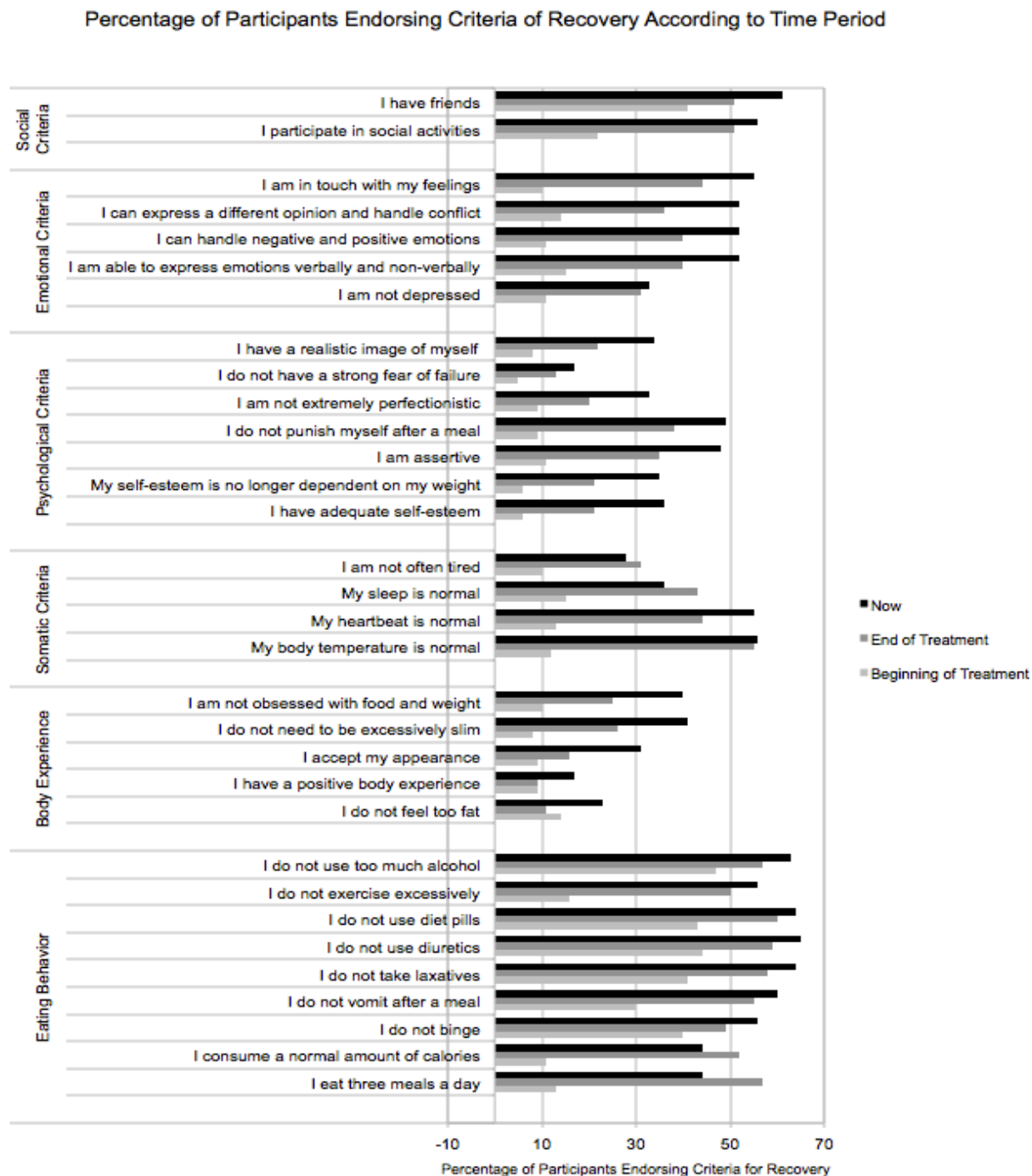


Figure 5. Percentage of participants citing criteria for recovery according to time in treatment.

Figure 6 shows the increase in frequency of citing all criteria from the beginning to the end of treatment with the exceptions being, “I do not feel too fat” (which decreased by 3.8%) and

“I have a positive body experience” (0% change).

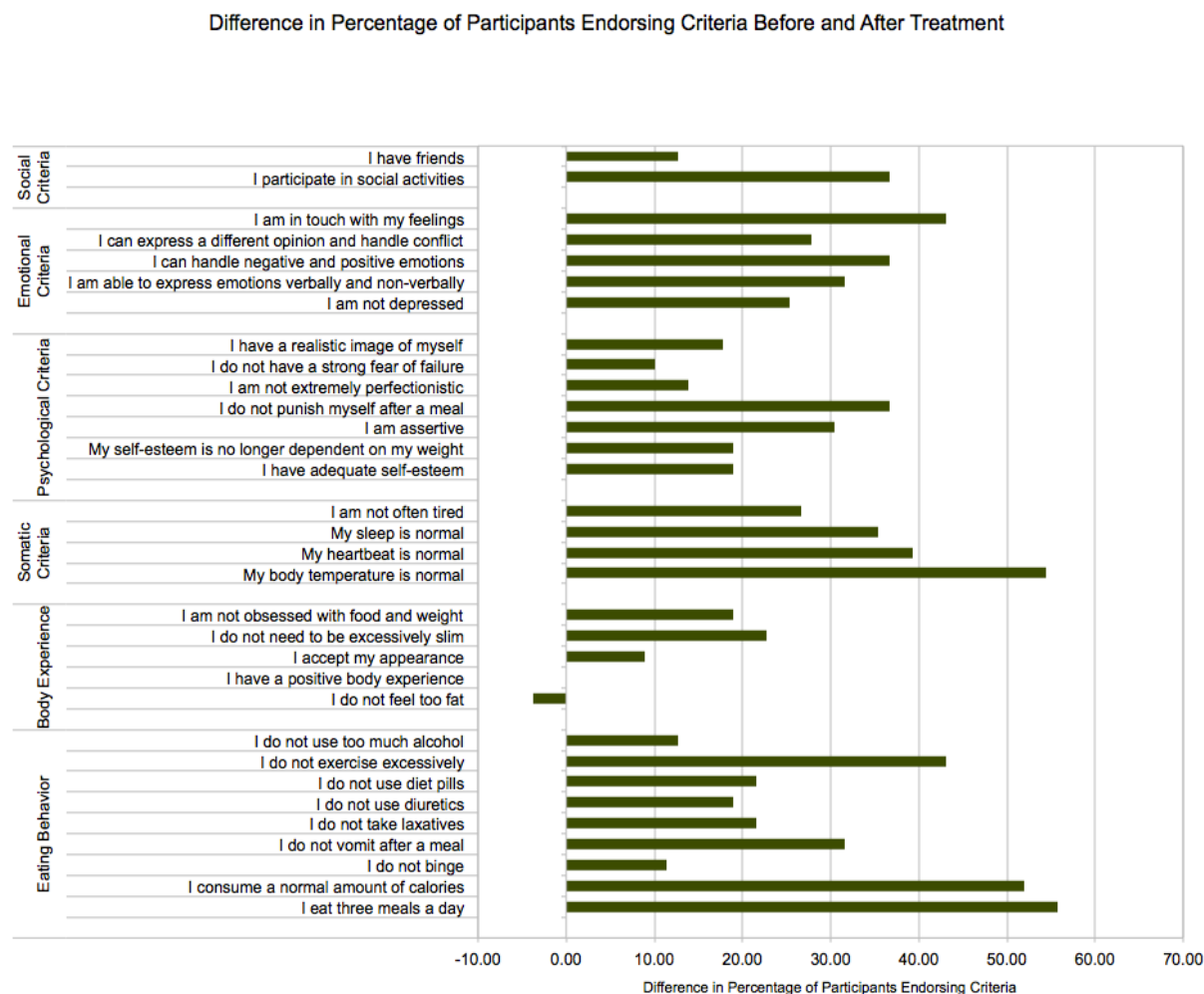


Figure 6. Difference in percentage of participants who cited criteria before and after treatment.

There was a shift in criteria considered most important (as reflected by frequency of mention).

At the beginning of treatment, “I do not use too much alcohol” was the most referenced criterion (59.49%) and “I do not have a strong fear of failure” was the lowest referenced criterion (6.33%). At the end of treatment, “I do not use diet pills” was the highest referenced criterion (75.95%) and “I have a positive body experience” was the lowest criterion (11.39%). At the

time of the survey (Now), “I do not use diuretics” was the highest referenced criterion (82.28%) and “I have a positive body experience” was the lowest (21.52%).

Figure 7 depicts how often criteria were mentioned based on point in time. The figure shows that none of the criteria were only noted at the beginning of treatment, one criterion was only cited at the end of treatment (“My sleep is normal”), five criteria were articulated at the time the survey was taken (for example, “I can express a different opinion and handle conflict”), five criteria were mentioned at the end of treatment and currently (for example, “I do not vomit after a meal”), and 11 criteria were named at all three points in time (for example, “I do not use diuretics”). No criteria were mentioned only at the beginning and end of treatment or at both the beginning of treatment and at the present time.

The current study used procedures set forth by Noordenbos and Seubring (2006) to determine the level of importance for each criterion. Noordenbos and Seubring established criteria as “very important” when noted by at least 80% of respondents, as “important” when noted by 50–79% of respondents, and as “not important” when noted by less than 50% of respondents. In the current study, participants named more criteria as important over time. For example, no criteria were “very important” at the beginning of treatment, whereas three criteria were cited as “very important” at the time of survey administration. Six criteria were considered “important” at the beginning of treatment compared to 18 considered “important” at the time of taking the survey. Finally, 26 criteria were noted as “not important” at the beginning of treatment, whereas only 11 as “not important” at the time of survey administration.

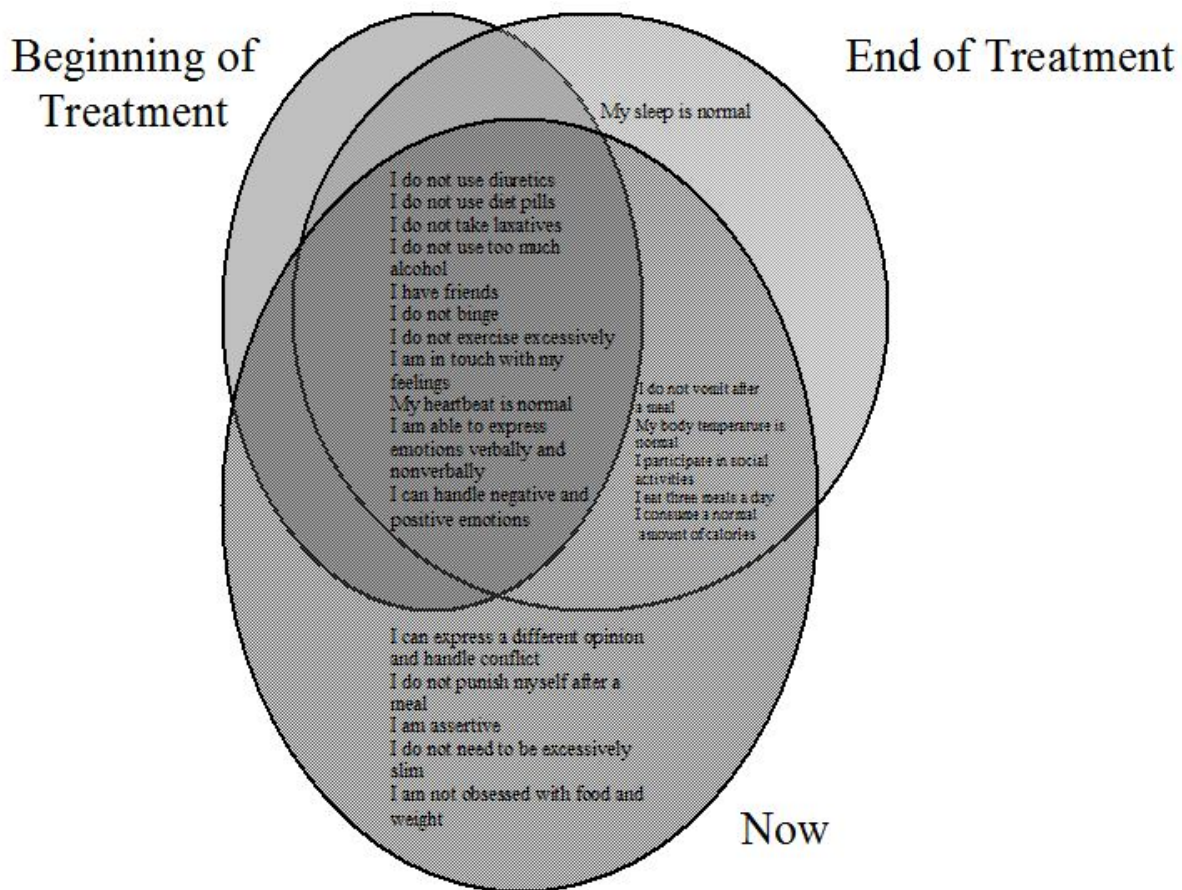


Figure 7. Venn diagram of criteria noted over the course of treatment.

Qualitative Results

On the basis of the content analysis of the five open-ended questions on the survey, 16 categories and several subcategories emerged. Categories included the following: (a) Shifts in Cognitions Related to Food, (b) Changes in Emotional Experiences, (c) Changes in Social Experiences, (d) Spirituality and Religion, (e) Changes in Physical Practices, (f) Medication, (g) Weight/Appearance, (h) Decrease in Negative Cognitions (Unrelated to Food), (i) Control, Time, (j) Changes in Experiences of the Self, (k) Viewing Treatment as Beneficial, Changes in Experiences of the Body, (l) Anger, Denial, and (m) Self-Defeating Goals. Each category is

discussed in greater detail in the following section of this study.

Shifts in cognitions related to food. Table 6 depicts the subcategories within “Shifts in Cognitions Related to Food.” I defined this category as “any reference to one’s changes in thoughts concerning food or eating behaviors.” The third column (as well as the third column of the subsequent 14 tables) shows the question from which the subcategories emerged.

The subcategory, “To Eat Without Judgment” included responses such as “treatment pushed me to realize food isn’t evil nor bad.” The “Decrease in Obsessions with Food” subcategory pertained to responses such as, “the amount of time spent thinking about food and calories. When I was sick I would spend all day thinking of what I was going to eat, and when. It consumed my thoughts,” and, “I think true recovery happens when food no longer dictates your life or encompasses the vast majority of your thoughts.” “No Longer Count Calories” is the subcategory that refers to responses that acknowledge not having or wanting to tend to caloric intake, such as one participant who wrote “stop counting calories.”

Table 6

Dimensions of Category One: Construct/Meaning of Shifts in Cognitions Related to Food

Category	Subcategories	Question Number in Which Response Was Provided For
Shifts in Cognitions Related to Food	1. To Eat Without Judgment	9, 11, 14
	2. Decrease in Obsessions with Food	9, 11, 14
	3. No Longer Count Calories	9, 11

Changes in emotional experiences. Table 7 depicts the subcategories within “Changes in Emotional Experiences.” This category was defined as “any reference to a shift or change in one’s subjective experience of a feeling or affect.” The category also refers to “changes in one’s ability to express emotion or changes in physical sensations related to emotion.”

“Decrease in Anxiety” was represented in responses such as to “be able to eat without anxiety.” Another subcategory, “Enhanced Ability to Describe/Disclose Emotions,” can be seen in responses such as, “I’m able to DESCRIBE my emotions. I’m more familiar and comfortable with the rises and falls in my emotions and feelings about life.” “Decrease in Shame” emerged from responses such as “decreased sense of shame” and “I don’t try to hide my body.” The subcategory “Decrease in Guilt” was captured by responses such as “eat more normally without extreme guilt or compensation.” Examples of the “Increased Hopefulness” subcategory included responses such as “at the end of that I wanted to find out who I was again, I wanted to live an actual life instead of pretty much waiting to die.”

Table 7

Dimensions of Category Two: Construct/Meaning of Changes in Emotional Experiences

Category	Subcategories	Question Number in Which Response Was Provided For
Changes in Emotional Experiences	1. Decrease in Anxiety	8, 9, 14
	2. Enhanced Ability to Describe/Disclose Emotion	9, 11, 14
	3. Decrease in Shame	11
	4. Decrease in Guilt	9
	5. Increased Hopefulness	9, 11
	6. Enhanced/Stabilized Mood	9, 11
	7. Enjoying Food	8, 11

A number of responses suggested clients with AN will experience “Enhanced/Stabilized Mood.” For example, one participant wrote, “I wanted to be happy.” Another wrote that “now I actually enjoy a fulfilled life with many activities and challenges.” Finally, participants also mentioned that “Enjoying Food” was important when thinking about recovery, which thus constituted a subcategory. A response that exemplified this includes “The ability to not just eat a wide variety of things, but to enjoy it.”

Changes in social experiences. Table 8 depicts the subcategories contained within “Changes in Social Experiences.” I defined this category as “any reference to changes in how one relates and participates in relationships with others and to the world, as well as to one’s engagement in social activities.”

“Participating in Healthy, Intimate Relationships” emerged from responses such as “to be able to make and sustain deep relationships with other people,” and “to be able to spend time with my family without being completely consumed by stress about food, and obsession over my body.” Another emergent subcategory subsumed under this category was “Engaging in Fun Activities,” exemplified in responses such as, “I find enjoyment in social activities and in

Table 8

Dimensions of Category Three: Construct/Meaning of Changes in Social Experiences

Category	Subcategories	Question Number in Which Response Was Provided For
Changes in Social Experiences	1. Participating in Healthy, Intimate Relationships	9, 11, 14
	2. Engaging in Fun Activities	8, 11
	3. Engaging in Developmentally Appropriate Activities	8, 9, 11
	4. Being Honest	8, 9, 11
	5. Speaking Openly About AN	11
	6. Repairing Relationships and Forgiveness	11

fulfilling work. I allow myself to do things for fun rather than only because I should or because it is productive or because I have to.” The subcategory “Engaging in Developmentally Appropriate Activities” came to light from participant responses including “my other goals were to become less preoccupied with food so that I could focus on building friendships, enjoying school and social activities, and basically being a normal teenager.”

The subcategory “Being Honest” surfaced from written comments such as, “to be open and direct with people.” “Speaking Openly About AN” references responses that specifically acknowledge honesty or openness regarding experiences with AN, rather than general openness with others. For example, responses that were captured by this subcategory included, “I can talk about my eating disorder experience openly. I can encourage others to get support.” The last subcategory included in this category is “Repairing Relationships and Forgiveness.” This subcategory included responses such as, “to be forgiving of myself and those around me, and to repair the relationships I had damaged through my eating disorder.”

Changes in spiritual and religious beliefs and/or practices. Table 9 depicts the subcategories contained within “Spirituality and Religion.” This category was defined as “any reference to spirituality and/or religious experiences, thoughts, or behaviors.” Although no questions specifically asked participants to comment on religious or spiritual beliefs, several spontaneous responses emerged as a function of discussing what it means to recover. Several participants referred to changes in spiritual beliefs. One participant reflected:

I had a significant spiritual experience that marked the end of my eating disorder so for me it was what happened before and after that. I am markedly better after that experience and I have no symptoms lingering since then and everything has improved since then. So is it my treatment that got me better? Yes. But I find that my spiritual experience brought more healing on many more levels than treatment ever did.

Table 9

Dimensions of Category Four: Construct/Meaning of Spirituality and Religion

Category	Subcategories	Question Number in Which Response Was Provided For
Spirituality and Religion	1. Changes in Spirituality	8, 14
	2. Dedication to Religious Beliefs	8

The subcategory “Religious Beliefs” contains responses specifically having to do with God or specific religious practices. One participant wrote, “With God’s grace.....recovery from anorexia is 100% possible!”

Changes in physical practices. Table 10 depicts the subcategories within “Changes in Physical Practices.” I defined this category as “any reference to physical activities that impact the body or behaviors engaged in that positively or negatively alter one’s physical self. It also refers to any reference to food or drink consumption as well as behaviors prior to or following food consumption.”

“Not Skipping Meals” included responses such as, “I had a goal to no longer skip meals.” “Eating Flexibly” emerged from responses such as, “I am flexible with what I eat,” and “to trust that I will be able to find something to eat wherever I am and not worry about whether it is the perfect thing, clean, pure, etc.” The subcategories “Drinking Less Alcohol,” “Following a Meal Plan,” and “Not Engaging in Purging Behavior,” incorporated direct references to these goals, such as, “drink less alcohol,” “to be able to follow my meal plan,” and, “I had a goal to no longer purge meals” (respectively).

The subcategory “Eating Intuitively” pertains to responses focused on participants eating when hungry and responding to bodily signals. An example of a response within this category is, “eat intuitively based on hunger and fullness cues.” “Not Exercising Excessively” refers to

Table 10

Dimensions of Category Five: Construct/Meaning of Changes in Physical Practices

Category	Subcategories	Question Number in Which Response Was Provided For
Changes in Physical Practices	1. Not Skipping Meals	8, 11
	2. Eating Flexibly	8, 11
	3. Drinking Less Alcohol	9
	4. Following a Meal Plan	9, 11
	5. Not Engaging in Purging Behaviors	9, 11
	6. Eating Intuitively	11
	7. Not Exercising Excessively	8, 9, 11, 14
	8. Decrease in Self-Harming Behaviors	9, 11
	9. Being Healthy	8, 9, 11

responses that reference exercising for reasons other than to maintain or lose weight. One participant wrote that she wanted to, “exercise when I want to vs. thinking I have to.”

“Decrease in Self-Harming Behaviors” contains both specific and generalized ideas about no longer causing harm to one’s self. Examples of responses for this category include, “I have a goal to no longer engage in self harm or suicidal fantasies,” and “decrease or cessation of self-injurious behaviors.” The last subcategory, “Being Healthy,” includes reference to wanting to change physical practices once considered unhealthy and focus on becoming physically well. Responses include, “I wanted to be in a good place physically—to be warm (not freezing all the time), not worry about losing heart muscle mass, and have the ability to have children one day.”

Medication. Table 11 summarizes the category “Medication.” There were no subcategories within this overarching category. “Medication” was referenced by some participant responses to question 8 of the survey. This category is defined as “any reference to the use of psychotropic medications to treat symptoms associated with AN.” For example, one participant wrote, “to me, real recovery also means not having to be on medication.”

Table 11

Dimensions of Category Six: Construct/Meaning of Medication

Category	Subcategories	Question Number in Which Response Was Provided For
Medication	NA	8

Weight/appearance. Table 12 depicts the subcategories within the category “Weight/Appearance.” The researcher defined this category as “any reference to a change in one’s ability/desire to gain or lose weight, changes in thoughts about weight, or changes in self-experience associated with weight.”

The subcategory “Maintaining a Normal Weight” includes examples of how participants think about the importance of weight and appearance with regards to recovery. Participant responses for this subcategory make reference to maintaining (normal) weight and wellness. For instance, one participant commented that an important aspect to recovery was to “maintain weight restoration.” Another participant wrote, “I could be a normal weight (BMI went from 18 to 20–21)” and a different participant disclosed, “I wanted to be able to maintain physical wellness.”

“Gaining Weight” is another subcategory which includes responses of participants who refer to increasing their weight or weight gain. One participant wrote that their goal was to “return to healthy weight.” Another subcategory, “Decrease in Obsessions Around Weight and Body,” includes responses such as, “focus less on my weight,” and, “I also wanted to stop hyperfocusing on my body itself.”

Table 12

Dimensions of Category Seven: Construct/Meaning of Weight/Appearance

Category	Subcategories	Question Number in Which Response was Provided For
Weight/Appearance	1. Maintaining a Normal Weight	8, 9, 11, 14
	2. Gaining Weight	9, 14
	3. Decrease in Obsessions Around Weight and Body	8, 11
	4. Self-Worth as Separate from Size	11

The subcategory “Decrease in Obsessions around Weight and Body” is comprised of responses of participants who wrote about or referred to recovery in terms of reducing the attention and mental energy spent on thinking about weight and body image. Examples of responses include, “Focus less on my weight,” and “I also wanted to stop hyper-focusing on my body itself.” The last subcategory, “Self Worth as Separate from Size,” includes ideas pertaining to thinking about one’s value as defined by more than weight, shape, or size. Participants expressed that it was important to, “stop having weight be the basis of self worth,” and, “create a sense of self independent of my body shape.”

Decrease in negative cognitions (unrelated to food). Table 13 depicts the subcategories within “Decrease in Negative Cognitions (Unrelated to Food).” The researcher defined this category as “any reference to a shift in one’s cognitive process of knowing, including aspects such as (a) [mental] awareness, (b) perception, (c) insight, (d) reasoning, (e) knowledge, and (f) judgment.”

Table 13

Dimensions of Category Eight: Construct/Meaning of Decrease in Negative Cognitions (Unrelated to Food)

Category	Subcategories	Question Number in Which Response Was Provided For
Decrease in Negative Cognitions (Unrelated to Food)	1. Decreases in Catastrophic Thinking	8
	2. Decrease in Suicidal Ideation	8, 9, 11, 14
	3. Mental Freedom	11, 14

The subcategory “Decrease in Catastrophic Thinking” highlights participant’s acknowledgement of a change in thinking unrelated to food and weight, specifically with regards to thoughts that are often “If/Then” or generalized fears in which the outcome has less of a chance to occur than it does to happen. Examples of responses include, “I have much less catastrophic thinking,” and:

If you walk out of treatment and after a day have absolutely no negative thoughts or behaviors, you are recovered. I believe when you no longer have any thoughts or behaviors or triggers or cravings to use behaviors, that is when you are recovered.

“Decrease in Suicidal Ideation” is the second subcategory that emerged and describes responses that refer to not wanting to die or engage in life-threatening behaviors. An example of this can be seen from one participant’s response: “I could be a normal weight and not want to die.” The last subcategory, “Mental Freedom,” includes responses in which participants referred to wanting to think through a lens other than one that focuses on food and negative behaviors, particularly AN itself. Examples of responses that fit into this subcategory include: “I also wanted to have my mind freed from the prison that is anorexia” and, “freedom from the

burden of an eating disorder.”

Control. Table 14 depicts the subcategories within the category “Control.” I defined this category as “any reference to one’s ability to take or have ownership over their thoughts, actions, and body.”

“Experiencing a Sense of Control” is comprised of responses that relate to participants feeling as if they have more choice and ownership of their actions, emotions, and decision making. An example of a response in this subcategory is, “to be more directly involved with my food (shopping, recipe planning and cooking).” “Choosing Health” is another subcategory under the overarching category of “Control” and refers to responses that address participant’s actively pursuing behaviors and steps towards caring for their bodies (physically and emotionally). An example of this includes, “my goals to improve myself are something I will work on throughout my life. If I didn’t go to treatment I don’t think I’d even be alive to even try to fulfill such goals.”

Table 14

Dimensions of Category Nine: Construct/Meaning of Control

Category	Subcategories	Question Number in Which Response Was Provided For
Control	1. Experiencing a Sense of Control 2. Choosing Health	8, 9, 11, 14 11, 14

Changes in experiences of the self. Table 15 depicts the subcategories within the category “Changes in Experiences of the Self.” I defined this category as “reference to positive changes or shifts in one’s experience of the self (with the exclusion of experiences of the body).”

The subcategory “Enhanced Positive Self Image/Identity” references responses that identify positive shifts in how participants view themselves, as well as identifying the need, importance, or desire to think differently about the self. Examples of participant goals that created this category include, “to have a positive view of myself,” and, “to begin rebuilding my self-esteem, identity, and assertiveness.” “Enhanced Self-Acceptance” is different than the last subcategory in that it includes responses that refer to feeling more secure with who one is, what one needs, and granting the self-permission to simply be. A response that falls into this subcategory is:

Having trust that I will be able to find something to eat wherever I am and not worry about whether it is the perfect thing, clean, pure, etc. The ability to nap when I am sick, to say yea to dessert, to be at a social event and not have to spare half, 90%, or in deed any of my focus and energy in the hypnotic, racing, cyclical vortex of food fear thoughts and the anxiety they generate. I don’t want to be unhealthy, but if can avoid a life like that, I don’t care what my body looks like.

Table 15

Dimensions of Category Ten: Construct/Meaning of Changes in Experiences of the Self

Category	Subcategories	Question Number in Which Response Was Provided For
Changes in Experiences of the Self	1. Enhanced Positive Self Image/Identity	11
	2. Enhanced Self-Acceptance	9, 11
	3. Feeling Normal	11
	4. Getting to Know the Self	9, 14
	5. The Self as Separate from the Disorder	9, 11

“Feeling Normal” includes participant responses such as wanting “to be able to live a normal life without all the negativity in my head,” and, “I wanted to be myself again, as vague as that sounds.” “Getting to Know the Self” is another subcategory that emerged from responses in which participants talked about being able to see themselves “more clearly, differently, or honestly.” One participant wrote,

It was as if someone wiped fog from a mirror and I could really see ‘me’ for the first time in a very long time. What I saw wasn’t pretty, and it was tough work, but worth it, and I’ve clung to that image ever since.

The fifth subcategory, “The Self as Separate from the Disorder” includes responses that highlight participants who are aware that AN does not define them. One participant wrote, “I do not identify myself as an eating disorder and recognize myself as separate.”

Treatment as beneficial. Table 16 depicts the subcategories within the category “Viewing Treatment as Beneficial.” I defined this category as “any reference to treatment environment as an opportunity for growth, change, and safety.”

Table 16

Dimensions of Category Eleven: Construct/Meaning of Viewing Treatment as Beneficial

Category	Subcategories	Question Number in Which Response Was Provided For
Viewing Treatment as Beneficial	1. Treatment as a Protective and Safe Space	14
	2. Treatment as Life-Saving	14
	3. Exploration of Underlying Issues of the Eating Disorder	9, 14
	4. Accepting Support from Others	8, 11
	5. Learning to Accept the Disease (AN)	14
	6. Learning to Manage Negative Thoughts, Urges, and Triggers	9, 11, 14
	7. The Learning and Implementation of Skills	11, 14

The subcategory “Treatment as a Protective and Safe Space” included codes that described treatment as more beneficial or less harmful than other environments. One participant wrote:

Getting away from my family and being in a new environment was very helpful. I needed to escape the traps that I had at home and take the time to focus solely on myself. Additionally the nutrition was helpful as I would have been unable to select the variety and amounts of food for myself.

“Treatment as Life-Saving” represents codes that refer to treatment as instrumental in preserving life. Examples of participant responses include: “treatment literally saved my life” and “treatment saved my life, I was very sick and I would not have lived without the help I received.”

The subcategory “Exploration of Underlying Issues of the Eating Disorder” highlights participant beliefs that recovery involves investigating the underlying factors contributing to eating disordered thoughts, behaviors, and emotions. Examples of responses coded in this

subcategory include, “they helped me realize and deal with underlying issues- clinical depression and family problems,” “to deal with trauma and depression and suicidal ideation,” and, “I learned a lot about myself and this disease.” The fourth subcategory, “Accepting Support from Others,” describes codes that mention receiving any form of help from those around them. Such responses include, “Keep appointments with therapist/dietician/etc.,” and, “I also met a lot of kind, helpful and inspiring people.”

Another subcategory, “Learning to Accept the Disease (AN),” encompasses codes that depict a change in how participants looked at, understood, or previously resisted acknowledging there was a problem (behaviorally, diagnostically, etc.). One participant disclosed that “at the beginning of treatment I was mostly forced into going but as I became a little more comfortable admitting I had a problem I started to set goals of wanting to get better and accepting myself.” Examples of the subcategory “Learning to Manage Negative Thoughts, Urges, and Triggers” include,

When things get tough—when a bout of depression hits, for example, I have thoughts of skipping meals, or restrictive eating. I do my best not to entertain them. I quickly remember what life with an eating disorder is like and realize my problem is with the thoughts behind the desire to control my life through eating. I may not deal with the physical trials of anorexia, but I deal with some preliminary thoughts.

The last subcategory, “The Learning and Implementation of Skills,” identifies responses that acknowledge having learned new behaviors or specifically reference gaining resources from treatment. One participant wrote that “it gave me the necessary tools to cope with the hardships

of life and the safety to talk about my feelings,” and another said, “I was able to identify the triggers and effectively recognize when they were happening and used coping skills.”

Changes in experiences of the body. Table 17 depicts the subcategories within the category “Changes in Experiences of the Body.” The researcher defined this category as “any reference to an enhanced degree of connection to the body or to the integration between one’s somatic, emotional, and cognitive experiences.”

“Embodiment” refers to coded responses that reflect participants’ desires or abilities to stay connected to their bodies and use somatic experiences to make meaning or inform the self. Examples of coded responses include: “some of my goals of recovery included becoming more embodied (particularly having a less alienated relationship with my body and feeling more connected/compassionate towards it),” “to stay in my body,” and “not experiencing my body as alien or ‘other,’ pathetically needy, or malevolent.”

“Acceptance of the Physical Body” does not specifically refer to one’s experience with regards to weight (as previously discussed in the category of “Weight/Appearance”) but instead captures participants’ beliefs about the importance of approving of one’s body. Examples of responses within this subcategory include, “to become more comfortable in my body,” as well as, “to come to love my body the way it is.”

Although this theme was not reported frequently enough (at least five times) to be its own category, several participants referred to engaging in mindfulness practices when talking about change. Participants described mindfulness as, “being able to maintain a moment-by-moment awareness of one’s thoughts, feelings, bodily sensations, and surrounding environment.” Another participant wrote, “mindfulness also involves acceptance of one’s thoughts and feelings without judgment.”

Table 17

Dimensions of Category Twelve: Construct/Meaning of Changes in Experiences of the Body

Category	Subcategories	Question Number in Which Response Was Provided For
Changes in Experiences of the Body	1. Embodiment	8, 11
	2. Acceptance of the Physical Body	11

Anger. Table 18 depicts the subcategories within the category “Anger.” The researcher defined this category as “any reference to client frustration or disapproval towards various aspects of treatment.”

“Anger with Professionals” is comprised of responses that expressed frustration, bitterness, or hostility towards professionals (clinicians, nutritionists, medical professionals, etc.) that participants worked with in treatment or are more generally in the field of medicine. One participant wrote that,

The only thing professionals care about is weight. My weight got better so they thought I was better...I was a little, but I have always been disordered and my thoughts are the same now as they were when I had a BMI of 15...

“Anger with the BMI as a Measure of Health” is another subcategory in which participants displayed frustration, bitterness, and hostility in responses; however this time towards numbers rather than people. One response was, “PS the BMI is fucking bullshit.”

The third subcategory, “Anger with Regards to Being in Treatment,” makes reference to responses of women who became frustrated, bitter, or hostile about having to attend treatment or about how they were treated while under the care of medical professionals, etc. Such

Table 18

Dimensions of Category Thirteen: Construct/Meaning of Anger

Category	Subcategories	Question Number in Which Response Was Provided For
Anger	1. Anger with Professionals	14
	2. Anger with the BMI as a Measure of Health	14
	3. Anger with Regards to Being in Treatment	14

responses within this subcategory include, “after two weeks of anger and fighting the program, I gave in (sometimes I think out of sheer exhaustion),” and:

My goals at the end of treatment were to maintain the goal weight that had been set for me so that I would never have to return to the hospital again, as it was an adult psychiatric facility and extremely scary for me as a twelve-year-old.

Denial. Table 19 depicts the subcategories contained under the category “Denial.” I defined this category as “any reference to not accepting the existence of recovery, diagnosis of an eating disorder, or treatment as beneficial.”

“Denial of the Existence of Recovery” pertains to responses reflecting the idea that recovery is not possible. Examples of responses within this subcategory includes, “it is a disease that you can never get rid of,” and “I think it is unlikely that symptoms will ever disappear completely.”

“Denial of Diagnosis of AN” refers to any participant response coded that references the notion that one does not suffer from AN (diagnostically or symptomatically). An example of such a response is, “I had no clue that it was truly a mental disease and there were a lot of layers underneath my eating habits that spoke more than just me not wanting to eat enough.”

Table 19

Dimensions of Category Fourteen: Construct/Meaning of Denial

Category	Subcategories	Question Number in Which Response Was Provided For
Denial	1. Denial of the Existence of Recovery	8, 14
	2. Denial of Diagnosis of AN	8, 9

Self-defeating goals. Table 20 depicts the subcategories within “Self-Defeating Goals.” This category is defined as “any reference to client goals that indicate that she would rather stay sick or continue engaging in unhealthy behaviors rather than work towards health and recovery.”

There were several examples of self-defeating goals particularly in responses to the question regarding goals at the beginning of treatment. “Not Having Treatment Goals” is exemplified by the response “I was a minor and was forced into treatment so I did not have any goals. I didn’t want to get better at the time.” “Wanting to Quit Treatment” was represented in codes that suggested participants did not see a reason for or did not have interest in receiving help. For example, one woman wrote that she “didn’t want to be in treatment” and “just wanted to get out.” “To Lose Weight” was also a common theme among those whose responses referred to self-defeating goals. For instance, one respondent noted that “when I left my last treatment center, I still didn’t want to be better/healthier. I wanted to lose more weight.”

“Wanting to Die” was another way in which some participants talked about not wanting to be in treatment, no longer struggle with AN, or escape emotional, physical, or relational distress. One participant wrote, “I wanted to get rid of my anorexia and be healthy. That went away through the years of treatment and even in my last treatment setting, I had absolutely no goals. I wanted to die as quickly as possible.”

Table 20

Dimensions of Category Fifteen: Construct/Meaning of Self-Defeating Goals

Category	Subcategories	Question Number in Which Response Was Provided For
Self-Defeating Goals	1. Not Having Treatment Goals	9
	2. Wanting to Quit Treatment	9, 14
	3. To Lose Weight	9, 11
	4. Wanting to Die	9
	5. Pleasing Others	9, 14

The subcategory “Pleasing Others” includes responses in which women discussed focusing on assisting others, as well as engaging in acts that would be more beneficial to those around them than themselves. For instance, one participant said:

During the first several years of my treatment I was not completely focused on recovery but wanted to please the people who were concerned about me. In all honesty my goals at the beginning of my treatment were primarily based upon pleasing others and killing myself to do that if necessary.

Time. Participants were asked to respond to the question, “If you believe that recovery is possible, how long should symptoms be gone before you can be considered recovered? Please explain.” Fifty-eight participants responded and most provided answers that referenced their experiences. The category of “Time” was defined as “any reference to being symptom free for a specific length of time.” Most commonly, participants responded to this question by stating how difficult it was to provide a specified length. Twenty-nine of the 58 respondents specified a length of time. Their responses are displayed in Table 21.

Table 21

Length of Time of Symptom Alleviation Required to be Considered Recovered

Length of Time	Number of Participants Indicating Time Length
1 month	2
6 months	2
18 months	1
1 year	9
2 years	4
2 – 3 years	4
3 years	1
5 years	3
5 – 7 years	1

In addition to specified lengths of time shown in Table 21, five subcategories emerged from the responses of the other 29 participants. Table 22 highlights the category as well as the five subcategories within it. This category was defined as “any reference to being symptom free for a specific length of time.”

The first subcategory, “Equal Length of Time as Course of Symptoms,” refers to participants who responded that symptoms must be gone for the same length of time in which they presented or persisted in order for one to be considered recovered. One participant stated that, “recovery would take place when the person was able to not have symptoms for approximately as long as they had had them.” Others referred to recovery as a “Life-Long Process,” which became a subcategory. Once again, a specified length of time for symptoms to be gone was not included. However, several participants identified a similar theme exemplified by the following, “My goals to improve myself are something I will work on throughout my life.”

Table 22

Dimensions of Category Sixteen: Construct/Meaning of Time

Category	Subcategories
Time	<ol style="list-style-type: none"> 1. Equal Length of Time as Course of Symptoms 2. Life-Long Process 3. Unspecified Amount of Time 4. Years 5. Specified Number of Years (see Table 18)

The “Unspecified Amount of Time” subcategory depicts that some participants felt unable to provide a more specific answer beyond that the time it takes to recover is based on each client’s case, circumstances, and means. One participant said, “I don’t think you can put a time frame on it,” and another disclosed, “I think it depends on the person and his or her situation.” The last subcategory, “Years,” refers to responses from participants that referred to acknowledging AN takes quite some time to recover from (years); however they did not specify any specific number of years in which symptoms had to be gone. An example of this includes one woman who wrote, “It takes most people several years before they can get to a point where they really don’t have any thoughts at all that are mired in food and body image.”

Noteworthy Results and Implications

Shifts in recovery over time. Responses to questions that asked respondents to cite criteria important at each phase of treatment demonstrate the unique nature of the progression of the disorder, treatment, and recovery. This was true of all participants, as no two women articulated the same criteria at any point of treatment, nor the same criteria at all stages of treatment. Results reiterate that, although there may have been an overlap in ideas and themes within participant responses, recovery is unique to each individual; priorities and goals within treatment and recovery process reflect the individual nature of AN.

Table 23

Criteria for Recovery Over Time as Noted by Participant 16

Criteria	Beginning of Treatment	End of Treatment	Now
I eat three meals a day		X	X
I consume a normal amount of calories		X	X
I do not binge	X	X	X
I do not vomit after a meal	X	X	X
I do not take laxatives	X	X	X
I do not use diuretics	X	X	X
I do not use diet pills	X	X	X
I do not exercise excessively			X
I do not use too much alcohol	X	X	X
I do not feel too fat			X
I accept my appearance		X	X
I do not need to be excessively slim		X	X
I am not obsessed with food and weight			X
My body temperature is normal		X	X
My heartbeat is normal		X	X
I am not often tired	X		
I have adequate self-esteem		X	X
I am assertive			X
I do not punish myself after a meal	X	X	X
I have a realistic image of myself			X
I am not depressed	X	X	X
I am able to express emotions verbally and nonverbally			X
I can handle negative and positive emotions			X
I can express a different opinion and handle conflict			X
I participate in social activities	X	X	X
I have friends	X	X	X

Table 24

Criteria for Recovery Over Time as Noted by Participant 77

Criteria	Beginning of Treatment	End of Treatment	Now
I eat three meals a day		X	X
I consume a normal amount of calories			X
I do not binge			X
I do not vomit after a meal		X	X
I do not take laxatives	X	X	X
I do not use diuretics	X	X	X
I do not use diet pills	X	X	X
I do not exercise excessively		X	X
I do not use too much alcohol		X	X
I am not obsessed with food and weight		X	X
My body temperature is normal		X	X
My heartbeat is normal		X	X
My sleep is normal		X	X
I have adequate self-esteem		X	X
My self-esteem is no longer dependent on my weight		X	X
I am assertive	X	X	X
I do not punish myself after a meal		X	X
I am not extremely perfectionistic		X	
I have a realistic image of myself		X	
I am not depressed		X	X
I am able to express emotions verbally and nonverbally		X	X
I can handle negative and positive emotions		X	X
I can express a different opinion and handle conflict	X	X	X
I am in touch with my feelings		X	X
I participate in social activities	X	X	X
I have friends	X	X	X

Additional Responses

Forty participants responded uniquely to open-ended question that looked at ideas or characteristics of recovery not included on selected items from the survey created by Noordenbos and Seubring (2006). Participants presented several ideas that do not fit or were not mentioned frequently enough to be considered as part of the previously listed categories. Such ideas include (a) a shift in one's focus on academics; (b) an increase in motivation to stay alive, (c) a shift in how one thinks and views the world, (d) learning to eat intuitively, (e) talking openly about AN, (f) making decisions that focus on the self rather than societal or familial norms, (g) learning to describe emotions, (g) and experiencing a higher level of comfort with emotions one perceived as "bad." Further, one participant wrote that she "gained the ability to cry. Increased ability to focus. Could be open and honest to those whom I trusted. Could trust. Could see a connection between my problems and other peoples [sic] problems." Another described a "real mental shift that happened when I finally fully recovered, but it is hard to explain." She went on to describe that she was, "eating and exercising normally before, but I was eating as little as possible of specific foods. It wasn't necessarily anorexia, but it wasn't NOT anorexia." For her, recovery was defined as being able to "eat whatever I wanted and not think about it. I could skip a day or a week of working out and not feel bad. I could be a normal weight (BMI went from 18 to 20–21) and not want to die."

Symptoms prior to diagnosis. Many participants cited having met criteria for AN prior to receiving a formal diagnosis. As the survey asked participants how long they had been formally diagnosed, it is important to consider that symptoms might have been present prior to receiving the diagnosis.

Age of diagnosis. The age in which participants were diagnosed is consistent with much of the literature that suggests that many clients are diagnosed during adolescence. Further, research shows that age of onset and/or diagnosis frequently occurs more during early adulthood as well as later in life (also demonstrated in the data).

Duration of illness. A duration of illness of less than two years was reported by the fewest participants (seven participants) while a duration of 10 or more years of illness was reported by 26 participants. This may contribute to supporting evidence for the poor prognosis and chronic nature of AN.

Chapter 5: Discussion

Overview

In this chapter, the major findings of the study are discussed and interpreted. Results are compared and contrasted with definitions of recovery established in the *DSM-IV-TR* and *DSM-5*. Implications for clinical practice and future research are addressed, and limitations of the study are also acknowledged, specifically with regard to how conclusions can be drawn from the data and interpreted results. Finally, I offer concluding remarks and provide a brief summary of the study.

Interpreting the Results

The primary and exploratory analyses are discussed in reference to the three research questions:

1. How do women currently or previously in treatment for AN define recovery?
2. How does one's definition of recovery change over time? Specifically, how do women define and think about recovery at various points in time with regard to treatment (pretreatment, posttreatment, and at the time the survey was administered)?
3. How long do women with AN believe symptoms must be gone to consider someone recovered?

Research question 1. Both qualitative and quantitative results provide a foundation that supports the notion that from the perspective of clients with AN, a singular universal definition of recovery does not exist: *there is no consensus*. As no two participants expressed thinking about recovery in the exact same way, results highlight the importance of recognizing and incorporating a client's subjective experiences into treatment goals. This can be done by obtaining a clearer understanding of criteria that clients consider to be necessary for their

recovery, as well as learning about how they make meaning of such criteria. These considerations are reflected in participant responses to open-ended questions that asked them to reflect on personal ideas of recovery and previous experiences in treatment history.

Several rationales may explain why results do not point to a singular or consensual definition of recovery. Since participants of the study were diagnosed at different stages of life (and therefore development), in addition to the fact that each participant referred to a different treatment trajectory in terms of length of stays and treatment modalities, influencing factors that shape one's experiences are versatile. For example, if someone is diagnosed during adolescence, initially they may be more resistant to treatment, have a difficult time not prioritizing weight loss due to social pressures, and therefore be less likely to recognize they have a problem. As they progress in treatment and developmentally mature, they may begin to more easily recognize the dangers of their eating behaviors and ways of thinking. This is further explored in the next section that discusses results related to the second research question; however, time of onset and treatment trajectory also influence how recovery is defined and the wide breadth of responses that emerged in the current study.

Each individual with AN has a unique social, cultural, and treatment experience that impacts their view of recovery. It is impossible to separate the impact and influence in which one's thinking is shaped by forms of media, social experiences, culture, family of origin, and previous relationships with food and the body. Participant responses also referred to how and why health care professionals (particularly for those who had been in multiple forms of treatment) impacted their view recovery. For example, participants believed some symptoms should be more prioritized than others, which was explained based on previously established goals encouraged by clinicians and treatment facilities. Such influences make it challenging to

determine whose voice (a participant or their health care professional) is speaking when referring to goals for recovery.

Research question 2. Results pertaining to the second research question highlight that, in one way or another, all participant views of recovery shifted over time. This idea was primarily explored by participant responses to the question where they were asked to cite items they believed to be important when defining recovery at the beginning and end of treatment, as well as at the time the survey was completed. For all participants, changes in views of recovery expanded to encompass more criteria over time. The following section details how individual criteria shifted over time in the current study, and offers possible explanations for why such changes may occur.

Most participants mentioned eating behavior and social criteria as important for recovery at the beginning of treatment. This may be explained as a result of both categories encompassing criteria commonly recognized and referred to when talking about eating disorders. Examples of such criteria include food intake, dieting, bingeing and purging, using diuretics or laxatives, and engaging in negative coping such as alcohol abuse or misuse. Although weight, nutrition, body image, and excessive exercise were noted as priorities for participants at the beginning of treatment, results also reflect that, in general, participants referred to a greater number of items within the six categories (eating behavior, body experience, somatic criteria, psychological criteria, emotional criteria, and social criteria) over time.

The differences between criteria mentioned at the beginning and end of treatment reflect changes in how clients prioritize and think about their symptoms. This may be explained by the psychological changes that often occur over the course of treatment and one's development. Participants reported a shift in their ideas about the broad and complex ways that AN had

affected their life, as illustrated in the increase in mention of psychological criteria such as, “I have a realistic image of myself,” “I am not extremely perfectionistic,” “I am assertive,” “My self-esteem is no longer dependent on my weight,” and “I have adequate self-esteem.”

Considering these criteria as more important by the end of treatment may also be explained by changes that occurred over time when exploring the ways that eating disorders affected the participants’ lives. Treatment can allow for reflection, new ways of thinking, and a greater understanding of one’s self and etiology of the disorder.

Social criteria were also commonly referred to as important to recovery at the beginning of treatment compared to other categories. This may be due to the fact that items within this category encompass observable behaviors that more clearly cause distress for both the individual and those around her. Changes in one’s social behaviors are often seen in women with AN as she decreases her engagement in social activities that were once important in order to accommodate disordered food-related thoughts and behaviors. Many times, withdrawal from others and the intense focus on symptoms or eating-related thoughts causes damage to relationships. Clients might also become upset at those around them when others express concern about changing weight, eating behaviors, and ways of socializing. The client may also feel pressured by others to seek help for a “problem” they do not consider challenging.

Emotional criteria was noted with the largest increase in percentage of participants in the beginning as compared to the percentage at the end of treatment. Specific criteria within the overarching emotional criteria category were only deemed important to recovery by 15.44% of participants at the beginning of treatment, and by 61.77% at the end of treatment. Similarly, psychological criteria had a large shift in the percentage of participants who cited them as important at the beginning of treatment compared to at the end of treatment. Psychological

criteria had 35.81% more participants citing them as important, from 9.76% at the beginning of treatment to 45.57% at the end of treatment.

There was a statistically significant shift in the percentage of participants who noted somatic criteria as important to recovery at the beginning (15.83%) compared to at the end (55.38%) of treatment; a difference of 39.55%. This may reflect participants learning to be more aware of their bodies and attuned to bodily cues such as hunger, fullness, or tiredness. The change may also reflect participants becoming less fearful or scared of being connected to physical experiences, as many clients may have initially ignored cues and sensations to avoid feeling, full, fat, ill, or physically uncomfortable as part of their eating disorder symptoms. This may explain the increase in the percentage of participants who referred to body experience as important at the beginning (12.66%) and at the end (38.48%) of treatment (an increase of 25.82%). The increase over time for somatic experience criteria (39.55%) was greater than the increase over time for body experience criteria (25.52%). At all points in time, somatic experience criteria were always cited as more important than bodily experience criteria.

Participants responded to open-ended questions asking them to consider how goals for recovery changed over the course of treatment. Results demonstrate no consensual response to this question; each was unique. Participants considered their experiences of recovery as having changed over time. One participant referred to different forms of treatment as being influential in shaping and reshaping her ideas of recovery. Another participant wrote of her comorbid diagnosis of OCD and said, “Once I was more nourished, in order to find a true and lasting freedom from anorexic thoughts and fears, I needed to address pretty intensively, the ways in which OCD and OCD style thinking interacts with anorexic thoughts and behaviors.” She went on to explain how she viewed recovery over time as a result of changes in weight restoration and

nourishment:

I needed not only to address weight restoration but challenge all of my ideas, fears, and judgments about food. I needed to see that I could eat anything without poisoning myself. I needed time and structured treatment that continued after weight restoration in order to experience true freedom from these fears, to completely release control and really have proof that not only does the world not implode, but expands and lightens, is safer and more desirable.

She also talked specifically about what she learned was important to recovery, which encompasses several aspects of functioning (e.g., psychological, behavioral, and physical).

Another participant illustrated the elusive nature of recovery and healing, and the difficulty in pinpointing “an honest answer for what finally clicked.” She wrote:

I’d like to think that parts of treatment along the way suddenly all compiled and made sense, or maybe I just finally felt too exhausted and was tired of living life that way. It definitely took time though and each treatment program helped in different ways.

Although the preceding participant had a difficult time understanding why change occurred, she recognized that it did, and that it likely had something to do with different forms of treatment at different times.

Additionally, another participant described her ongoing process of acknowledging and accepting that she had AN through her various treatment stays. She identified the positive aspects of each treatment, despite her struggle to be open and vulnerable with professionals. She recognized the importance of time, different forms of treatment, her own perceptions of recovery, and what she wanted when explaining why change occurred over time. She also

specifically noted what had changed for her and how it benefitted her overall recovery.

Of note is that all but two criteria experienced an increase in participant mention over time. When comparing the number of participants who identified each statement as important, “I have a positive body experience” had no change, and fewer participants noted “I do not feel too fat” at the end of treatment than at the beginning. The fact that the former statement did not increase in importance over time may be surprising. There are several reasons why this may be the case. The first is that perhaps clients do not believe it to be helpful to focus on assessing their bodies while in treatment; particularly when the focus of treatment is often on weight gain or stabilization. Another reason may be that when clients first begin treatment, often they are ambivalent or fighting change, particularly physical change, and experiencing their body in a positive manner may not even seem realistic or feasible.

At the time of survey administration, however, there was an increase in the number of participants who mentioned the item as being important to recovery. This may represent how one’s ability to appreciate the importance of positively assessing the body is something that develops over time. The equivalent amount of importance assigned to the second statement, “I do not feel too fat,” across time may be explained by effective treatment and/or shifts in how clients experience their bodies. As perceptions of the body transform, so might the emphasis on one’s attention to weight and self-criticism (for example, feeling “too fat”). As psychological, somatic, and other changes in experience occur, clients may become more accepting of the “fat” on their bodies and experience a more positive self-assessment, rather than seeing “fat” as something to be rid of.

Research question 3. The third research question examined how long participants believed symptoms must be gone prior to considering recovery. This section highlights the

varying responses provided by participants. Views regarding how participants noted achieving recovery are also discussed. Overall the data suggests that participants did not declare a consensual length of time one must not exhibit symptoms for to be considered recovered.

Some participants responded with a specific length of time (often suggested in month or year-long increments). The most common response was “1 year.” This response was provided by nine participants (15.5 % of the 58 participants who responded to this question).

There was no notable difference between the percentage of participants who believed in recovery based on duration of illness (<2 years: 14.28% believe in recovery; 2-5 years: 18.75%; 6-9 years: 12.5%; ≥ 10 years: 11.54%). A higher percentage of participants who met criteria for AN for longer than 10 years reported being unsure about whether they believe in recovery (38.46%); particularly when compared to participants who had symptoms for two to five years (6.25%). This may suggest that the longer one suffers from AN, the more likely they will question whether recovery is possible. The percentage of participants who do not believe in recovery did not change significantly according to duration of illness (18.75% for participants with AN between two and five years and 11.54% for those with AN for longer than 10 years).

Results also indicate that participants with AN for two to five years had the highest percentage of belief in recovery (75%) compared to other duration of illness clusters. This same group of participants also has the highest noted percentage of participants who did not believe in recovery (28.75%), at the time during which there was the lowest percentage of participants who were unsure whether or not they believed in recovery (6.25%). This group of participants was the most firm in their beliefs about recovery, whether or not they believed it to be possible, compared to other groups. Belief in recovery gradually decreased for participants who noted symptoms lasting between six and nine years (56.25%) and for longer than 10 years (50%).

Other participants had a difficult time clearly distinguishing a specific length of time.

For example, one participant wrote:

I've been told five years. I am currently 95% symptom free but I would not say I am fully recovered. I don't know if symptoms will ever disappear entirely, but I think once they stop consuming my thoughts for a year or so I will feel more confident in recovery. Five years sounds like a good foundation I guess.

One participant was hesitant to define a time frame and noted the subjectivity of what recovery looks like for others. She wrote, "I don't know. I don't think there's a timeline. I think it's different for everyone. For me personally, I would say 5 years with no symptoms would be recovered." Another participant recognized the influence of friends and treatment professionals on her belief in recovery, definition of recovery, and how long symptoms must be gone for her to be considered in recovery. She wrote:

I have two friends from ED treatment who now say that they are recovered, and a handful of friends who say they are recovering. I suppose then that I have to believe that recovery is possible if I know two people with EDs that are now recovered, by their own definitions. My treatment professionals tell me that it takes a minimum of 6 months to 1 year of being symptom-free and 100% meal plan compliant before the brain can re-wire itself and not automatically default to ED thoughts. At least one friend in recovery described her experience in accordance to this time-frame, so I believe my treatment team that this time-frame of recovery is accurate.

This comment illustrates how some clients may come to understand ideas about recovery, based on the experiences of others as well as information given by treatment providers. Not all

participants responded to this question by providing a specific length of time for which symptoms must be gone before being considered recovered. One participant wrote:

I don't think you can specifically define it [recovery] by time. Obviously, there has to be some length of time without eating disorder symptoms, but recovery isn't just about stopping the eating disorder behaviors. There were plenty of people I met in treatment that were still miserable years after stopping their eating disordered behaviors. Real recovery is learning to live and enjoy life, have relationships and be present for them. This can come quicker for some people and longer for others. I remember being told in treatment that anorexia was something I would have to learn to "manage" for the rest of my life. 100% not true. The more I acknowledged my progress (especially the really small steps) the quicker I began to take responsibility for my recovery.

Finally, some participants wrote that they do not believe recovery is possible at all. One woman said:

Although I am still relatively young, I have a hard time using the word "recovered." I think an eating disorder is something that I'll struggle with on and off for the rest of my life. It's not like other addictions, such as being alcoholic, where we can avoid the substance. Food is one of those things that we have to encounter every single day for the rest of our lives whether we like it or not. Instead, I like to think of it as being "stable." At this point in my life, I absolutely feel stable in the sense that I do not worry about every little thing I put in my mouth like I used to and I am much more confident in myself.

Similarly to what was found in the previous two research questions, participants did not come to a consensus for how long symptoms should be gone for when considering recovery, and recognized the individualized nature of the timeline of recovery.

Is Recovery Possible?

The current study addresses suggestions posed in previous research regarding the importance of defining recovery from AN. Hardin (2003) suggests that even the slightest discrepancies in definitions contribute to the variance between rates of recovery among studies, making it difficult to compare research and the efficacy of treatment. Although the rationale for universal guidelines is enticing, findings from this study suggest that making data more comparable may contradict empirical data that suggests recovery is subjective and variable in nature. Thus, attempting to establish a simple way to diagnosis AN and determine recovery may in fact be more harmful to clients, as clients have their own subjective experiences of what it means to recover. These experiences can vary based on individual values, stage of development, culture, and stage of change.

Hardin (2003) found that some clients reject the notion of recovery, claiming that the word is too final. Hardin (2003) shared that one participant considered herself “mostly well” and criticized the medical model that posits someone can be “cured” from AN. Other participants described the pressure of striving towards or viewing recovery as a goal or endpoint as triggering, as it becomes a negative reminder of internal needs of perfection. As some clients attribute the need to achieve perfection with onset of symptoms, one's expectations may perpetuate and exacerbate experiences of the self that focus on obtaining a specific outcome. Thus, there may be consequences to having universal expectations or definitions of recovery, as they may lead to a personal sense of failure of recovery.

In a study by Jenkins and Ogden (2012), participants expressed both believing and not believing in the existence of recovery, although it was more common for participants to think of recovery as an ongoing process or transformation, rather than an endpoint or destination.

Results from the current study indicate that many women consider recovery to be possible. Further, participants referred to working towards recovery as a protective factor; a goal to achieve that serves as motivating and a more positive experience compared to women who consider it to be another challenge they cannot meet.

Clinical Suggestions and Implications

The strength of therapeutic alliance refers to the quality of the collaborative relationship between client and therapist (Noordenbos & Seubring, 2006). This alliance is typically measured by how well the clinician and client agree on therapeutic goals, treatment tasks, and whether they are able to bond with one another (Bordin, 1976; Horvath & Greenberg, 1994). Clinicians are encouraged to attend to client attitudes, values, and context to enhance the therapeutic alliance (Wampold, 2006). The more clinicians are aware of how clients think about change and growth, the more they can monitor alignment of treatment goals.

The working alliance contributes significantly to the outcome of treatment. Without an alliance, the client and clinician face a difficult time achieving a positive outcome (Seligman & Reichenberg, 2012). By acknowledging client ideals, values, behaviors, social relationships, thoughts, and self-evaluation, clinicians and clients can maintain a positive working alliance. Research indicates that clients are more likely to engage in psychotherapy while in treatment that is consistent with their expectations, when they feel positively about treatment, and when they feel understood by the therapist (Wampold, 2006).

The therapeutic relationship can serve as a vehicle for assisting clients with AN out of the world of food and into the world of people through the establishment of a strong, authentic relationship with treatment providers; specifically his or her therapist. Clinicians are encouraged to spend time clarifying client objectives for treatment, despite preconceived knowledge or goals assumed should be the focused on when working with this population. Some researchers have written about the effectiveness of treating clients with AN from an interpersonal or relational lens, as interventions focus on the power of sharing one's self with another, providing a space for the client to feel known and understood, the art of story-telling (Bruch, 1985).

Bruch (1985) acknowledged the necessity of a strong therapeutic alliance to better understand the inner world of clients and to allow them to learn about themselves and grow in an authentic manner. When engaging in an interpersonal with a client with AN, Bruch (1985) proposes that clinicians listen closely to discrepancies in the client's stories, how he or she describes the past, and for any misperceived or misinterpreted events responded to inappropriately by others. According to Bruch, the therapeutic goal is to allow the client to discover his or her own inner resources and capacities for thinking, judging, and feeling. Bruch proposes clinicians take a "naive" stance by listening and guiding the client. Her work focuses on empowering clients to face the realities of their lives rather than providing them with insight about the symbolic significance of symptoms and behaviors.

Bruch's (1985) approach is appropriate given the responses of participants of the current study. As the results show, participant ideas of recovery change over the course of treatment. To maintain a relationship that allows clients to give voice to their changing goals, ideas they will not be held accountable for attaining goals that no longer apply to how they think, feel, and desire their lives to be. Ignoring developmental history, ways of making meaning and viewing

the world, etiology of symptoms, social interactions, family history, cultural values, and genetic predisposition, would likely be less effective in treatment, as a one-size-fits-all treatment is undesirable by this population (Petrucelli, 2004). Further, results from this study indicate that as clients view recovery as more than simply ridding themselves of negative cognitions and behaviors, providers are encouraged to intervene beyond the scope of simply addressing behavioral and/or cognitive interventions.

Considering the necessity of the therapeutic alliance, clients cannot be expected to recover or experience a reduction in symptoms when they are not in treatment. As many people are unable to afford treatment without financial assistance from insurance companies, the option of treatment no longer is an option. Similarly, removing clients from treatment as symptom reduction occurs may also be more harmful than helpful, as clients are forced to prematurely leave clinicians they are likely forming close relationships with and becoming attached to. On the other hand, clients may not have enough time to be establishing a strong therapeutic alliance at all if they are frequently switching to a new counselor as a result of stepping down their care due to the insurance company's assessment of health care needs. Clients with AN may therefore not receive what has repeatedly been shown to be one of the most important components of working towards psychological, physical, and interpersonal health and functioning.

Bruch (1974) refers to several behavioral interventions such as journal writing and maintaining a food diary when working with clients with AN. As some participants of the current study wrote, there are times when clients feel too overwhelmed that words do not come easily, nor do they know how to ask or express their needs to others. The process of journaling food and behaviors teaches self-monitoring, while serving as a transitional object providing the client who can then share their words with the clinician (Bruch, 1974). Writing also provides the

opportunity to access cut-off aspects of one's own self-experiences. An intention behind writing and self-monitoring outside the therapy office is to encourage the client to gradually feel safer opening up to learning about him or herself and later sharing this awareness with the therapist. Although initially revealing his or her words may cause feelings of shame or distrust, revealing one's secret world to the therapist can enhance feelings of safety and establish a place where the client feels grounded in something other than dangerous rituals, such as restricting or counting calories. Sharing experiences of shame, disgust, and self-loathing with the clinician can be powerful for clients with AN (Bruch, 1974). Thus, a seemingly individualized behavioral plan becomes interpersonal in nature, as the clinician can ask questions, gently challenge, and gain insight into the client's world.

Incorporating individual, group, family and marital, psychiatric services, nutritional counseling, and medical physicians, (including a dental consultation) has been found to enhance efficacy of treatment (Petrucelli, 2004). Many residential facilities incorporate a multimodal approach when treating clients with eating disorders. Such centers may also involve non-traditional forms of therapies and activities, such as yoga and other structured mindfulness exercises, psychodrama, animal and art therapy.

Once out of the environment that so often is closely tied with how and why the clients are in services to begin with, they are able to learn about themselves, new ways of coping and engaging in the world, and practice as well as strengthen such skills while outside of the home. Clients are able to be surrounded by others who struggle with similar thoughts and issues and who can provide support they do not get at home. Clients are provided with a space to create a new relationship with food, reconnect with their bodies, and learn about themselves outside of the world of their disorder. It is understood that clients will likely eventually return to the

environment (or a similar one), from which they first entered therapy. Thus, family therapy is an important component of residential treatment, as family members are able to meet doctors and learn how to be supportive and safely meet the needs of the client in a way that does not cause irreparable ruptures.

Different forms of treatment are appropriate and necessary, as client challenges vary according to personality, needs of the individual, symptom severity, readiness for change, one's relationship with AN as well as the word recovery developmental stage, and phase of treatment. It is necessary to tailor treatment according to the needs of the client. To further demonstrate this point, consider the voice of a participant of the current study. She wrote:

Treatment was very helpful in some ways but very detrimental in others. Getting away from my family and being in a new environment was very helpful. I needed to escape the traps that I had at home and take the time to focus solely on myself. Additionally the nutrition was helpful as I would have been unable to select the variety and amounts of food for myself. However, being surrounded by groups of girls who were in a variety of stages of recovery, proved to be a challenge. While some girls were focused on recovery and were positive role models others were focused on being “the sickest” which perpetuated the eating disorder. Seeing girls with feeding tubes and walking around in skin-tight leggings was very challenging to deal with. It was also triggering to see what one of the other patients did to trick the system in treatment—hiding food in all sorts of ways, hiding diet pills and laxatives, etc.

Due to the nature of the disorder, it may be challenging to fully help clients to fulfill their personal goals. This researcher does not suggest that clinicians and treatment providers comply

with every request of the client. For instance if a client is treatment rejecting, does not believe she or he has a problem, and is malnourished to the point of bodily or psychological harm, it is not recommended to comply with the wishes of the client. However clinicians are encouraged to still pay attention and listen to the client perspectives to maintain the therapeutic alliance.

Results and Diagnostic Manuals

When comparing results of the current study with the *DSM-IV-TR* and *DSM-5*, many items frequently cited as important to recovery are not found in either version. Such categories include Spirituality/Religion, Medication, Decrease in Negative Cognitions (Unrelated to Food), Control, Changes in Experiences of the Self, and Viewing Treatment as Beneficial. Subcategories also provide some insight into the phenomenology of AN and its potential relevance to diagnostic criteria. For example, the subcategories such as “To Eat Without Judgment” are not included on the survey or in *DSM-5* criteria. Within the category “Changes in Emotional Experiences,” several participants talked about a decrease in shame, guilt, and anxiety, none of which are included in the *DSM-5*. Categories that emerged from participant responses depict the multidimensional approach that goes unconsidered in the *DSM* manuals and by insurance companies when determining coverage for care.

At the beginning and end of treatment, as well as at the time of survey administration, participants recognized the importance of addressing Social Criteria and Eating Behaviors as the most important to recovery. Items within the Emotional Criteria category were also popularly cited at the time of survey administration. However several items within these categories go unacknowledged in the *DSM-5*. For instance, items contained within the Eating Behaviors category are somewhat represented in *DSM-5* criteria. The following criteria: (a) I eat three meals a day, (b) I consume a normal amount of calories, (c) I do not binge, (d) I do not vomit

after a meal, (e) I do not take laxatives, (f) I do not use diuretics, and (g) I do not use diet pills, are not specifically included but could potentially fall under Criterion B, which refers to engaging in persistent behavior that interferes with weight gain. One of the most frequent statements, “I do not use too much alcohol,” is not included in diagnostic criteria for AN. Research shows that many clients with AN receive additional diagnoses, such as mood disorders, anxiety disorders, and substance use disorders (Salbach-Andrae, et al., 2008). Whereas the *DSM-5* (and therefore all professionals who use the manual for diagnosis) consider AN to be separate from many other diagnoses, results from the study indicate that clients, particularly at the end of and following treatment, consider symptomatology that may fall under other diagnoses to be manifestations of their eating disorder rather than separate.

It is important that treatment facilities, clinicians, and other providers look beyond *DSM* criteria that focus on eating behaviors and bodily experiences, which include several components of *DSM-5* criteria for AN (also used by managed care companies to establish the need for treatment). Data suggests the importance of including more holistic ideas of recovery in working with clients with this disorder that also focus on somatic, psychological, social, and emotional criteria. By considering what clients may be struggling with beyond the scope of the *DSM-5* criteria, they may feel more understood. This creates a stronger working alliance and rapport with the clinician and potentially enhances treatment outcome and the chance of recovery.

The idea of treating the client holistically and focusing on more than weight restoration and maintenance is in line with the ideas of several researchers committed to enhancing treatment. Gordon (2010) proposes that for treatment to be most effective, a therapist must work within a multimodal, multidisciplinary clinical team and utilize additional resources when appropriate. In addition to the primary therapist, he proposes that the three most important

members are a psychopharmacologist, medical practitioner, and a nutritionist (Gordon, 2010).

The multifaceted disciplines involved in treatment that Gordon suggests are congruent with the current study's findings of the subjectivity and complexity of the experience of AN.

The *DSM-5* does not specify a period of time for which criteria must no longer be present for one to be considered recovered. However, criteria outline that a client is considered to be “In partial remission” when “full criteria for AN were previously met, Criterion A (low body weight) has not been met for a sustained period, but either Criterion B (intense fear of gaining weight or becoming fat or behavior that interferes with weight gain) or Criterion C (disturbances in self-perception of weight and shape) is still met” (American Psychiatric Association, 2013). “In full remission” is determined when “full criteria for AN were previously met and no criteria are met for a sustained period of time.” By not including a specified time frame for clients to not be experiencing or exhibiting criteria, clinicians have more freedom to diagnose (or not diagnose) as they see fit. This also allows for opportunities to collaborate with clients about what constitutes recovery, including both criteria they find important, as well as how long and if criteria must be gone in order for one to be considered recovered.

The Influence of Insurance

Companies

Some participants referred to the impact of insurance providers when reflecting on their experiences in treatment. One participant wrote, “Because of the limitations of insurance, I never received adequate treatment after my most recent hospitalization, and therefore I struggle on a daily basis with the same issues I was admitted for.” Another participant said, “My health insurance does not let me receive anything other than IOP, regardless of my medical stability or lack thereof.”

When

insurance companies deny requests for intensive treatment, a message is sent to the often perfectionistic client with AN that he or she is not “sick enough” or “bad off enough” to require treatment. Taking such messages one step further, a client may then begin to think that he or she is not “skinny enough,” “working hard enough,” or that other clients are starving “better” than them. How insurance companies, clinicians, family members, and treatment teams respond to a client weight gain may be invalidating and not match the client's internal experiences of the self. Similarly, if clients are prematurely released from intensive treatment facilities, they may interpret such an action as, “you are no longer sick enough to be here,” causing them to work to be better at being sick.

Additionally, previous research found that vulnerability to weight relapse is highest within the first 12–18 months after discharge (Carter, Blackmore, Sutandar-Pinnock, & Woodside, 2004). Such ideas highlight that attaining medical stability does not mean that clients no longer require treatment or are psychologically healthy. In fact, many remain in the trenches of the disorder as they struggle to come to terms with weight gain, changes in relationships, new ideas about the world, and a concept of the self that is constantly in flux. Thus, this is a fragile time in which the client is likely to suffer if forced to cope alone in a chaotic or unstructured environment, as several participants made reference to in the current study.

In a comparative study of clients who maintained recovery versus those who did not, Cockell, Zaitsoff, and Geller (2004) found clients with clinicians and/or medical providers who assumed treatment was complete upon weight restoration were less likely to stay in recovery compared to clients who stayed in treatment following weight restoration. The shift from round-the-clock care to weekly individual therapy, or for some, no treatment at all, is especially challenging and a difficult transition (Gordon, 2010). Gordon (2010) suggests that the frequency of weekly treatment will

unlikely be enough, as clients often require a higher level of containment and intense treatment to minimize risk of relapse, even upon weight restoration. This was confirmed in responses from several participants of the current study and is important for insurance companies to become aware of to prevent and decrease high rates of premature discharge from treatment.

Barriers of Progress

As participants, clinicians, and researchers suggest the necessity and value of taking a multidimensional approach to treating AN, it is difficult to understand why medical professionals, insurance companies, and those who establish regulations for diagnosing, including the *DSM-5* and insurance providers, do not advocate for the implementation of such changes. Although initially it may be less cost effective to allow clients the time and resources required to achieve and maintain both medical and psychological stability, lower rates of recidivism would seemingly help insurance companies cut costs over time.

However, it does not serve everyone's best interest if rates of recidivism or onset of AN were to decrease. Pharmaceutical companies would likely experience a decrease in revenue; nutritionists, clinicians, psychiatrists, and medical professionals may experience a decrease in the number of clients and patients they see; and hospitals, residential centers, and other inpatient facilities would not be making as much money. The media, including magazine advertisements and marketing companies in general, may have to find other ways to appeal to the public, as becoming as small sized as possible would not be a goal for the number of women it is today. For instance, manikins that display clothing in stores and air-brushed pictures of models selling products would have to be considered, as both images represent sized bodies that are not attainable to match by a person within the "normal" or "healthy" weight range. It would be

difficult to continue selling products when the advertising techniques used are actually undesired by women.

Who would benefit from a decrease in recidivism and lower accounts of clients presenting with AN? Potentially, farmers and food corporations could see a rise in sales of their products. Most importantly, allowing clinicians and clients to think individually and tailor treatment to needs of the clients would benefit the client directly.

Suggestions for Future Research

Participants of this study referred to different symptoms and ideas of recovery and struggled with the disorder at different stages of life. There was no indication in the results that would suggest that researchers should continue searching for a universal definition for recovery or a consensual length of time for which clients must not display symptoms.

Although results do not add to the argument that a universal definition of recovery would necessarily benefit treatment outcome, other suggestions for future research are provided. First, gaining more insight into the numerous different manifestations of AN may be better use of resources than research that aims to determine a consensus on definitions of recovery. To develop a more nuanced understanding of AN, researchers may wish to consider establishing subtypes. Subtypes could provide more flexibility for clinicians when diagnosing, as clients would fit a broader range of criteria than only treating clients who meet the narrow list in the *DSM-5*. Establishing broader diagnostic criteria for AN would widen the number of clients eligible for higher levels of care for longer periods of time, thus allowing for greater chances of recovery. Creating subtypes through continued qualitative research methods reflect more detailed subjective truths of participants who exhibited not only different symptoms, but also disparate ways of thinking about the disorder, themselves, and needs across time.

Future researchers may also wish to use cluster analyses to look at how individual characteristics (or potentially subtypes of AN) present differently, and under what circumstances certain forms of treatment may be beneficial. Such research has the potential to positively impact treatment outcome if researchers and clinicians can better understand how different interventions impact people presenting with different personality styles. Treatment outcome may also be improved if research continues to look at whether there are patterns in client ideas of recovery at given point in treatment. Although such research was beyond the scope of the current study, results lay the foundation that ideas of recovery do in fact shift over time and deserve attention and clarity to assist clinicians in making more informed decisions for how to proceed in treatment.

Limitations of the Study

Exclusion criteria. The present study was limited by the sampling method and population. The choice to use a convenient sampling method was intentional and served the purpose of accessing a small population quickly using a web-based survey. Only women with access to the Internet were able to participate in the current study. This may have excluded clients from low socioeconomic backgrounds or rural areas who do not own or have access to computers or the Internet. The resources of this study did not allow for surveying younger participants and obtaining corresponding parental consent. The drawback of this is that there was no opportunity to understand more about how younger populations make meaning of recovery, as onset of AN usually occurs during this period of life.

Further, the questionnaire did not ask for some information related to diversity. Such demographic information may be helpful to consider when working with diverse populations, as potential patterns and themes may emerge from responses of participants with similar

backgrounds. Participants were not asked to disclose their ethnic and cultural heritage or what part of the country they were from. Further, this survey did not look at demographic information pertaining to race, religious/spiritual beliefs and/or practices, or sexual orientation.

The American Psychiatric Association explains that low rates of service utilization may reflect an “ascertainment bias,” and that the presentation of weight concerns among this population varies depending on one’s cultural context. The American Psychiatric Association describes how “the absence of an expressed fear of weight gain appears to be relatively more common amongst Asian populations,” whereas for Latino populations in the US, women “may be more likely to express an intense fear of weight gain” (American Psychiatric Association, 2013). As the current study does not address or incorporate the role of diversity (specifically, how demographic information pertaining to cultural heritage, race, ethnicity, spiritual/religious beliefs, sexual orientation, and gender), an area for future study may be to look at how clients from diverse and minority groups who are diagnosed with AN think about recovery. As different cultures have varying values, ideals, and norms, understanding how ideas about recovery are impacted by cultural context may inform and improve client willingness to accept treatment, as well as treatment outcomes.

The survey was also limited by language, as it was only given in English, and AN is found in clients from culturally diverse backgrounds (American Psychiatric Association, 2013). The Diagnostic Features Commentary Section for AN of the *DSM-5* speaks to how “the prevalence of AN appears comparatively low among Latinos, African Americans, and Asians in the US.” The commentary encourages clinicians to be aware that mental health service utilization among ethnic groups is significantly lower than in Caucasian populations (American Psychiatric Association, 2013).

This study included participants affected by a disorder that is often viewed or experienced as desirable. Many people with AN downplay or hide symptoms, not always experiencing the disorder as distressing, harmful, or dangerous. Further, people with AN may be more optimistic than realistic when it comes to symptom severity (Noordenbos & Seubring, 2006). Although perhaps not a limitation of the study, relying on self-report measures from a population likely to minimize or under-report symptom severity was considered during analysis. However, an important part of this study aimed to gain a better understanding of client perspectives and needs, no matter how “accurate” they are.

Gender and the exclusion of men. Another limitation to the study was the exclusion of males. Providing information about and increasing attention towards addressing men with eating disorders is necessary to learn more about the appropriateness of treatment. As males experience different physical and psychological symptoms of the disorder and have perceptions of their bodies, needs, goals for treatment, and how ideas about the disorder, researchers are encouraged to tend to and consider both men and women as susceptible to eating disordered symptoms.

The survey. Surveys are also not without limitations, as participants may rush through questions, as well as misinterpret directions or phrasing of questions. This likely occurred in the current study with regards to some of how questions were phrased and/or interpreted by participants. For example, it may have been more useful for the purposes of analyzing data and understanding client perspectives to phrase questions 3 (“When were you diagnosed with anorexia?”) and 4 (“How long did you or have you had anorexia?”) in a way that more clearly established a way for the researcher to determine each participant’s length of illness. For instance, a way in which confusion around this could have been avoided was to ask the questions differently, such as “At what age were you diagnosed with AN” or “Please specify the length of

time (in months or years) that you had or have had AN.” It would have been potentially helpful or useful to look at trends regarding whether or not there was a particular age range stood out in which more participants were diagnosed with AN. Further, by clarifying length of illness and the age when participants received their diagnosis, more participants would have been able to be included in some of the trends and data looked at in the current study.

Important to note is that this researcher did not explore whether there were identifiable patterns as to why participants skipped some questions and not others. As this was a mixed-methods study and quantitative data was presented through the use of descriptive statistics, individuals who did not complete questions were not included in describing patterns of responding to those questions. Any future follow-up studies which are embedded in positivist or post positivist epistemologies may want to consider empirical investigations that look at the patterns for those who did not respond to particular questions.

Concluding Remarks

This study was conducted as a response to prior research by Noordenbos and Seubring (2006) as an empirical investigation into the premise of understanding participant perspectives of recovery. Results from this study come from the experiences of 79 women who recalled their personal stories to benefit the treatment of eating disorders.

As illuminated in the results of this study, a diagnosis of AN does not mean all clients express or experience symptoms in the same manner, nor do they have the same goals for treatment. Further, the course of AN is in constant flux, meaning that client needs and goals are also constantly in flux. Several researchers propose that clarifying the meaning of recovery is essential to enhancing collaborative interactions between clients, clinicians, treatment facilities, and insurance companies (Jarman & Walsh, 1999). The current study does not propose or

suggest removing the idea of recovery from treatment all together; but rather promotes the idea that recovery be considered a subjective experience on behalf of the client. By removing the idea of a “one size fits all” way of talking, thinking, and actively engaging in recovery, clients may have time and space they need to learn new, healthier ways of living.

Results ALSO speak to the need to consider a multi-faceted definition of recovery, with multiple “stages” or “levels.” Financially, it is unlikely clients can remain in hospitals or intensive treatment facilities until they are “fully recovered,” but perhaps there are benchmarks that can be met so that we can better treat each stage. (I.e. a medical stage that addresses the physiological needs of the client- why not just call it that and once that has been addressed, then address the cognitive aspects, familiar/environmental, and so on).

The following response provided by one participant gives voice to conclusions of this study. When asked to respond to how long one’s symptoms should be in remission prior to being considered recovered, she wrote:

I think this question is mistaken by ignoring the uniqueness of each person’s own ED. One person’s recovery may not be the same as another person’s, and may not even mean a lack of symptoms in the longer term, but merely the ability to accept where one is at when they are there and take care of themselves in that place to the best of their abilities.

Hopefully future research will continue to recognize subjective experiences of each client in order to best understand their goals and provide treatment in an individualized manner that respects the uniqueness of each person.

References

- Aaserudseter, K. (2007). *Defining recovery in anorexia nervosa—the importance of concept clarification*. (Unpublished doctoral dissertation). University of Oslo, Oslo, Norway.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- American Psychiatric Association. (2000). *Practice guideline for the treatment of patients with eating disorders* (3rd ed.). Washington, DC: American Psychiatric Association.
- Anzai, N., Lindsey-Dudley, K., & Bidwell, R. J. (2002). Inpatient and partial hospital treatment for adolescent eating disorders. *Child and Adolescent Psychiatric Clinic North America, 11*, 279–309.
- APA Task Force on Evidence-Based Practice (including B. Wampold). (2006). Evidence-based practice in psychology. *American Psychologist, 61*, 271–285.
- Bachner-Melman, R., Zohar, A. H., & Ebstein, R. (2006). An examination of cognitive versus behavioral components of recovery from anorexia nervosa. *Journal of Nervous and Mental Disease, 194*, 697–703.
- Bakker, R., van Meijel, B., Beukers, L., van Ommen, J., Meerwijk, E. & van Elburg, A. (2011). Recovery of normal body weight in adolescents with Anorexia Nervosa: The nurses' perspective on effective interventions. *Journal of Child and Adolescent Psychiatric Nursing, 24*, 16–22.
- Beresin, E. V., Gordon, C., & Herzog, D. B. (1989). The process of recovering from anorexia nervosa. *Journal of The American Academy of Psychoanalysis, 17*, 103–130.

- Berg, B. L. (2008). *Qualitative research methods for the social sciences: International edition*. Needham Heights: Allyn & Bacon.
- Bordin, E. S. (1976). The generalizability of the psychoanalytic concept of working alliance. *Psychotherapy: Theory, Research, and Practice*, 16, 252–260.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications, Inc.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Bruch, H. (1974). Perils of behavior modification in treatment of anorexia nervosa. *Journal of the American Medical Association*, 230, 1419–1422.
- Bruch, H. (1985). Four decades of eating disorders. In D. Garner & P. Garfinkel (Eds.), *Handbook of psychotherapy for anorexia and bulimia* (pp. 7–18). New York: Guilford Press.
- Carter, J. C., Blackmore, E., Sutandar-Pinnock, K., & Woodside, D. B. (2004). Relapse in anorexia nervosa: A survival analysis. *Psychological Medicine*, 34, 671–679.
- Castro, J., Gila, A., Puig, J., Rodriguez, S., & Toro, J. (2004). Predictors of rehospitalization after total recovery in adolescents with Anorexia Nervosa. *International Journal of Eating Disorders*, 36, 22–30.
- Cavanagh, S. (1997). Content analysis: Concepts, methods and applications. *Nurse Researcher*, 4, 5–16.
- Chwalisz, K., Shah, S. R., & Hand, K. M. (2008). Facilitating rigorous qualitative research in rehabilitation psychology. *Rehabilitation Psychology*, 53(3), 387–399.

- Claude-Pierre, P. (1998). *The secret language of eating disorders: How you can understand and work to cure anorexia and bulimia*. Random House, Inc.: New York, NY.
- Cockell, S. J., Zaitsoff, S. L., & Geller, J. (2004). Maintaining change following eating disorder treatment. *Professional Psychology: Research and Practice*, 35, 527–534.
- Comerci, G. D. (1991). Fasting girls: The history of anorexia nervosa. *Archives of Pediatrics & Adolescent Medicine*, 145(2), 146.
- Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- Couturier, J., & Lock, J. (2006). What is recovery in adolescent Anorexia Nervosa? *International Journal of Eating Disorders*, 39, 550–555.
- D'Abundo, M., & Chally, P. (2004). Struggling with recovery: Participant perspectives on battling an eating disorder. *Qualitative Health Research*, 14, 1094–1106.
- Darcy, A. M., Katz, S., Fitzpatrick, K. K., Forsberg, S., Utzinger, L., & Lock, J. (2010). All better? How former Anorexia Nervosa patients define recovery and engaged in treatment. *European Eating Disorders Review*, 18, 260–270.
- De Wever, B., Schellens, T., Valcke, M., & Van Keer, H. (2006). Content analysis schemes to analyze transcripts of online asynchronous discussion groups: A review. *Computers & Education*, 46, 6–28.
- Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. *Health Care for Women International*, 13, 313–321.
- Eating Disorders Coalition (2011, July 16). What is the FREED act? [Web log comment]. Retrieved from <http://eatingdisorderscoalition.blogspot.com/2011/07/what-is-freed-act.html>.

- Fairburn, C. (2007, March). *Functional impairment in ED and relation to outcome*. Presentation at the themed symposium: Outcome assessment for eating disorders. International Eating Disorders Conference, London.
- Fennig, S., Fennig, S., & Roe, D. (2002). Physical recovery in anorexia nervosa: Is this the sole purpose of a child and adolescent medical-psychiatric unit? *General Hospital Psychiatry*, 24, 87–92.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Aldine Publishing Company, Hawthorne, NY.
- Greenblatt, J. (2010). *Answers to anorexia*. North Branch: Sunrise River Press.
- Gordon, R. A. (2010). Outpatient treatment of anorexia nervosa following weight restoration: Practical and conceptual issues. In M. Maine, B. H. McGilley, & D. W. Bunnell (Eds.), *Treatment of Eating Disorders: Bridging the Research-Practice Gap* (pp. 181–196). New York, NY: Elsevier/Academic Press.
- Halmi, K. A., Agras, S., Crow, S., Mitchell, J., Wilson, G. T., Bryson, S. W....Kraemer, H. C. (2005). Predictors of treatment acceptance and completion in anorexia nervosa: Implications for future study designs. *Archives of General Psychiatry*, 62, 776–781.
- Hardin, P. K. (2003). Social and cultural considerations of recovery from Anorexia Nervosa: A poststructuralist analysis. *Advances in Nursing Science*, 26(1).
- Horvath, A. O., & Greenberg, L. S. (1987). Development of the working alliance inventory. In L. S. Greenberg, & W. M. Pinsoff (Eds.), *The psychotherapeutic process: A research handbook* (pp. 529–556). New York, NY: Guilford.
- Hsieh, H. F., & Shannon, S. S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277–1288.

- Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*, 61, 348–358.
- Jacobson, N. (2001). Experiencing recovery: A dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 248–254.
- Jarman, M., & Walsh, S. (1999). Evaluating recovery from anorexia nervosa and bulimia nervosa: Integrating lessons learned from research and clinical practice. *Clinical Psychology Review* 19(7), 773–788.
- Jenkins, J., & Ogden, J. (2012). Becoming 'whole' again: A qualitative study of womens' views of recovering from Anorexia Nervosa. *European Eating Disorders Review*, 20, e23–e31.
- Kondracki, N. L., Wellman, N. S., & Amundson, D. R. (2002). Content analysis: Review of methods and their applications in nutrition education. *Journal of Nutrition Education and Behavior*, 34, 224–230.
- Kordy, H., Krämer, B., Palmer, R. L., Papezova, H., Pellet, J., Richard, M....Treasure, J. (2002). Remission, recovery, relapse and recurrence in eating disorders: Conceptualization and illustration of a validation strategy. *Journal of Clinical Psychology* 58(7), 833–846.
- Lamoureux, M. M. H., & Bottorf, J. L. (2005). "Becoming the real me": Recovering from anorexia nervosa. *Health Care for Women International*, 26, 170–188.
- Levine, M. (1998, July). Prevention of eating problems with elementary children. *USA Today*.
- Liu, A. (2008). *Gaining: The truth about life after eating disorders*. Warner Books: New York, NY.

- Mirasol Recovery Centers, (2013). *Cover me! Getting your insurer to pay for eating disorder treatment*. Retrieved from <http://www.mirasol.net/treatment-programs/paying-for-treatment/insurance-coverage.php>.
- McHugh, M. D. (2007). Readiness for change and short-term outcomes of female adolescents in residential treatment for Anorexia Nervosa. *International Journal of Eating Disorders*, 40, 602–612.
- McKenzie, J. M., & Joyce, P. R. (1992). Hospitalization for anorexia nervosa. *International Journal for Eating Disorders*, 11, 235–241.
- Meguerditchian, C., Samuelian-Massat, C., Veléro, R., Corroller, A. B., Fromont, I., Mancini, J., & Vialettes, B. (2009). The impact of weight normalization on quality of recovery in Anorexia Nervosa. *Journal of the American College of Nutrition*, 28, 397–404.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- National Association of Anorexia Nervosa and Associated Disorders. (2013). *Q&A with Lisa Kantor: How to get coverage for the treatment of my eating disorder*. Retrieved from <http://www.anad.org/news/q-a-with-lisa-kantor-how-to-get-coverage-for-the-treatment-of-my-eating-disorder/>.
- National Eating Disorder Association. (n.d.). *General statistics*. Retrieved from <http://www.nationaleatingdisorders.org/general-statistics>.
- Noordenbos, G. (2011). When have eating disorders patients recovered and what do the *DSM-IV* criteria tell about recovery? *Eating Disorders*, 19, 234–245.

- Noordenbos, G., & Seubring, A. (2006). Criteria for recovery from eating disorders according to patients and therapists. *Eating Disorders: The Journal of Treatment and Prevention*, 14(1), 41–54.
- Petrucelli, J. (2004). Treating eating disorders. In R. H. Coombs (Ed.), *Handbook of addictive disorders: A practical guide to diagnosis and treatment*(312-349). Hoboken: John Wiley & Sons, Inc.
- Pike, K. M. (1998). Long-term course of anorexia nervosa: Response, relapse, remission, and recovery. *Clinical Psychology Review*, 18, 447–75.
- Rader Programs (2012). *Men & eating disorders*. Retrieved from <http://www.raderprograms.com/affected-groups/men-eating-disorders.html>.
- Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, 15, 85–109.
- Saha, P. (2003). *Principles of data analysis*. Great Malvern: Cappella Archive.
- Salbach-Andrae, H., Lenz, K., Simmendinger, N., Klinkowski, N., Lehmkuhl, U., & Pfeiffer, E. (2008). Psychiatric comorbidities among female adolescents with anorexia nervosa. *Child Psychiatry & Human Development*, 39, 261–272.
- Sargent, J. T. (1998). *The long road back: A survivor's guide to anorexia*. Massachusetts: North Star Publications.
- Seligman, L., & Reichenber, L. W. (2012). *Selecting effective treatments: A comprehensive, systematic guide to treating mental disorders* (4th ed.). Hoboken, NJ: Wiley.
- Steinhausen, H. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, 159, 1284–1293.

- Strober, M., Freeman, R., & Morrel, W. (1997). The long-term course of severe anorexia nervosa in adolescents: Survival analysis of recovery, relapse and outcome predictors over 10–15 years in a prospective study. *International Journal of Eating Disorders*, 22, 339–360.
- Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. London: Psychology Press.
- The Renfrew Center Foundation for Eating Disorders. (2003). Eating disorders 101 guide: A summary of issues, statistics and resources.
- Tozzi, F., Sullivan, P. F., Fear, J. L., McKenzie, J., & Bulik, C. M. (2003). Cause and recovery in Anorexia Nervosa: The patient's perspective. *International Journal of Eating Disorders*, 33, 143–154.
- Treasure, J., & Schmidt, U. (2003). Treatment overview. In J. Treasure, Schmidt & E. Van Furth (Eds.), *Handbook of Eating Disorders* (2nd ed., pp. 207–217). Chichester: Wiley.
- Trochim, W. M. K. (2006). *Descriptive Statistics*. Retrieved from <http://www.socialresearchmethods.net/kb/statdesc.php>
- Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse*, 19, 75–87.
- Way, K. (1993). *Anorexia nervosa and recovery: A hunger for meaning*. The Haworth Press, Inc.: Binghamton, NY.
- Weber, R. P. (1990). *Basic content analysis* (2nd ed.). Newbury Park, CA: Sage Publications.
- Zhang, Y., & Wildemuth, B. M. (2005). Qualitative analysis of content. *Analysis*, 1(2), 1-12.

Appendix A

Marisol Treatment Centers Information on Insurance Reimbursement

Getting Your Insurer to Pay for Eating Disorder Treatment

1. First, read your insurance manual. Don't rely on a treatment center to call and get your benefit information. You need to be the expert on your insurance policy.
2. When you call the insurance company, ask to speak to a manager of benefits. Then get the name and contact information for an individual case manager. If you're not satisfied, talk to your EAP or human resources department (if you have one), or speak with your insurance agent.
3. Keep your insurance card handy. Your insurer will ask for your policy number, group number, date of birth and maybe your social security number. At this time, you can also find out how many days of treatment are covered and ask if they would consider flexing benefits. For example, some companies will take one inpatient day and convert it into two residential days.
4. It's important to remember that the information you're getting is strictly about your benefits and is **not a guarantee of payment**.
5. Record everything—the day, date and time of call, the name of the person you spoke with, etc. This is extremely important!
6. Ask for a copy of the guidelines your insurance company uses to determine the level of care (they're required to give it to you).
7. Meet with your family member's treatment team to determine the appropriate level of care.
8. Request that the insurance company meet your family member's level of care, which is based on the accepted guidelines.
9. If the request is denied, insist that your insurance company take full responsibility—**in writing!**—for your child's life, noting that they are disagreeing with the qualified experts in the field and with the approved guidelines. Feel free to ask, “Are you willing to take responsibility for denying the care that my doctor has recommended?”

10. Ask for a list of professionals and facilities that are under contract with your insurance company. If that list does not contain your preferred therapist or facility, ask if the insurance company is willing to do a single case agreement. This is a one-time contract between the insurer and the treatment the facility specifically for you.
11. Start a notebook and keep records of all communications, letters and phone calls.
12. Remember you are not asking for anything you're not entitled to. You're entitled to get the health care benefits you paid for when you or a family member falls ill.
13. If treatment is denied, appeal! Be tough and persistent! The “Insurance Issues” article describes the appeals process.

Things You Need to Know

- Eating disorder diagnosis
- Other psychiatric diagnoses
- Physiological complications of the eating disorder
- Level of recommended care (outpatient, inpatient, partial hospital, residential or intensive outpatient)
- Anticipated duration of recommended treatment
- Professionals needed and their required expertise
- Tips for Fighting for Appropriate Insurance Coverage
- Record and document every phone call including names, dates, times, what was discussed and how you were advised. Put requests in writing if they are initially denied.
- Keep copies of everything.
- Be persistent in the appeals process. Many denials can be reversed.
- Call your state insurance commissioner.

- Write letters and send copies to your insurance company's CEO/President, State Attorney General, State Insurance Commissioner, US and State members of Congress, advocacy organizations, your attorney, etc. Be sure to include documentation, evidence and details.
- Get the media's attention if appropriate
- Ask your employer's Human Resources expert, your insurance agent, and/or your union representative to work on your behalf. Give them powerful statistics to prove your point.
- Know your state laws. Insurance company agents won't tell you what they are!
- Don't give up! Insurance companies want you to do just that. Be persistent!!

PERMISSION:

From: **Jeanne Rust** <jrust@mirasol.net>
Date: Fri, Sep 12, 2014 at 11:01 AM
Subject: Re: Mirasol: Do I Need Help Form
To: jleslie1@antioch.edu
Dear Jen,

Thank you so much! Yes, you may use Mirasol in your dissertation. I wish you great success in your work! If I can ever help, please don't hesitate to contact me.

Warmly,
Jeannie Rust, PhD
CEO/Founder
Mirasol, Inc.
www.mirasol.net
www.edrecovery.com
[888-520-1700](tel:888-520-1700)

Appendix B

Recruitment Letter

Participants needed for research on recovery from anorexia.

My name is Jennifer Leslie and I am a doctoral student in the clinical psychology program at Antioch University New England. I am looking for help recruiting people for my dissertation. My study looks at how former and current clients think about what it means to “recover” from anorexia. There is currently no single way to describe what “recovery” means. Little research has looked at how ideas of getting better change over time. A survey will be used to learn what people think about “recovery” and if their ideas change over time. The project is supervised by Dr. Theodore Ellenhorn, a professor in the Clinical Psychology Department.

I am asking you to please forward this message to any electronic list serves or message boards to which you have access. Potential research participants can access the survey by clicking on this link (insert hypertext link to survey). I am not asking that people be sought out or contacted.

The survey will last about 30 minutes. Questions will be in yes/no, open-ended, and short-answer format. Questions focus on symptoms, treatment, and what it means to get better.

To participate, people must:

- Have a current or past diagnosis of anorexia
- Have received treatment for anorexia
- Be at least 18 years of age (may have been younger than when diagnosed)
- Be a female
- Have access to the Internet

Names and identifying information will not be collected. Responses will be stored on SurveyMonkey.com and data will be erased at the end of the project. Data will not be shared. Participants may stop the study at any time. They can skip questions they do not wish to answer.

The survey asks people to think about body image, self-esteem, and eating. Thinking about these topics may make participants upset. If they feel uneasy, they will be told to stop the survey. They will also be informed to contact a therapist or seek help.

Participants may not directly benefit from this study. However, responses may help to understand client ideas on what it means to get better. Information from the study may also provide better treatment for anorexic clients.

Please contact Jen Leslie at jleslie1@antioch.edu or (860) 836-7980 if you have questions about this study. Please see the attached document that includes a copy of the informed consent for participants.

Thank you for your help!

Jen Leslie, MS
Doctoral Candidate
Antioch University New England

Appendix C

Informed Consent

Have you ever been treated for anorexia?

My name is Jennifer Leslie and I am a doctoral student in the clinical psychology program at Antioch University New England. I am currently working on my dissertation, which is a study of how current and former clients talk about what it means to “recover” from anorexia. Little research has looked at how client ideas of getting better from anorexia change over time. The project is supervised by Dr. Theodore Ellenhorn, a professor in the Clinical Psychology Department.

To participate, you must:

- Have a current or past diagnosis of anorexia
- Have received treatment for anorexia
- Be at least 18 years of age
- Be a female
- Have access to the Internet to take the survey

If you decide to participate, you will be asked to take an online survey. The survey will ask you to think about topics such as body image, self-esteem, eating, what it means to recover from anorexia, and whether your ideas about these things have changed over time. We estimate that completing the survey will take about 30 minutes of your time. Questions will be in yes/no, open-ended, and short-answer format.

I will protect your privacy. You will not be asked for your name or other information that could identify you. Responses will be stored on SurveyMonkey.com. Your survey will only be seen by the researcher and the advisor. Data will be erased at the end of the project.

Participating in this study is voluntary. You do not have to take the survey and you may stop it at any time. You may skip questions you do not want to answer. If you become uncomfortable while taking the survey, you can choose to stop. You may contact a psychotherapist or seek other help.

This study is not expected to result in any direct benefit to you. Your participation may help our profession to better understand what it means to get better from anorexia.

If you wish to participate in this study, I will ask you to first confirm that you meet all of the requirements listed above. Then you can click on the survey link below. Please respond to the survey as honestly as possible.

If you have questions about this research project, you may contact me at jleslie1@antioch.edu. If you have concerns about your rights as a research participant, you may contact Dr. Katherine

Clarke. She is the Chair of Antioch's Institutional Review Board and can be reached at (603) 283-2162 or kclarke@antioch.edu.

Thank you for your help!

Jen Leslie, MS
Doctoral Candidate
Antioch University New England

I certify that I meet all requirements and that I am eligible to complete this survey.

By "clicking here" and continuing to the survey, it will be assumed that you consent to participate in the survey (and research project).

Appendix D

Participant Survey

Age:

When were you diagnosed with anorexia?

0-1 years ago

2 – 3 years ago

4 – 6 years ago

7+ years ago

How long have you or did you have anorexia?

Less than 1 year

1 – 2 years

3 – 5 years

5 – 8 years

9+ years

The following questions are about treatment and getting better.

Please list all types of treatment you have received as well as how long you were in treatment. Examples of treatment include but are not limited to: Residential treatment program (non-hospital setting), inpatient hospital-based program, outpatient individual therapy, partial day program at hospital or residential setting, group treatment (including support peer-led groups as well as clinician led), psychiatric medication.

Type of treatment Date (month & year) treatment began Date treatment ended

1.

2.

3.

4.

5.

The next section asks you to think back to the beginning and end of treatment, and how you are doing now. Please answer each of the following statements by circling yes or no, if the statement is part of how you define recovery at 1) Beginning of Treatment, 2) End of Treatment, 3) Now.

Statement	Importance					
	Beginning of Treatment		End of Treatment		Now	
I eat three meals a day	Yes	No	Yes	No	Yes	No
I consume a normal amount of calories	Yes	No	Yes	No	Yes	No
I do not binge	Yes	No	Yes	No	Yes	No
I do not vomit after a meal	Yes	No	Yes	No	Yes	No

I do not take laxatives	Yes	No	Yes	No	Yes	No
I do not use diuretics	Yes	No	Yes	No	Yes	No
I do not use diet pills	Yes	No	Yes	No	Yes	No
I do not exercise excessively	Yes	No	Yes	No	Yes	No
I do not use too much alcohol	Yes	No	Yes	No	Yes	No
I do not feel too fat	Yes	No	Yes	No	Yes	No
I have a positive body experience	Yes	No	Yes	No	Yes	No
I accept my appearance	Yes	No	Yes	No	Yes	No
I do not need to be excessively slim	Yes	No	Yes	No	Yes	No
I am not obsessed with food and weight	Yes	No	Yes	No	Yes	No
My body temperature is normal	Yes	No	Yes	No	Yes	No
My heartbeat is normal	Yes	No	Yes	No	Yes	No
My sleep is normal	Yes	No	Yes	No	Yes	No
I am not often tired	Yes	No	Yes	No	Yes	No
I have adequate self-esteem	Yes	No	Yes	No	Yes	No
My self-esteem is no longer dependent on my weight	Yes	No	Yes	No	Yes	No
I am assertive	Yes	No	Yes	No	Yes	No
I do not punish myself after a meal	Yes	No	Yes	No	Yes	No
I am not extremely perfectionistic	Yes	No	Yes	No	Yes	No
I do not have a strong fear of failure	Yes	No	Yes	No	Yes	No
I have a realistic image of myself	Yes	No	Yes	No	Yes	No
I am not depressed	Yes	No	Yes	No	Yes	No
I am able to express emotions verbally and nonverbally	Yes	No	Yes	No	Yes	No
I can handle negative and positive emotions	Yes	No	Yes	No	Yes	No
I can express a different opinion and handle conflict	Yes	No	Yes	No	Yes	No
I am in touch with my feelings	Yes	No	Yes	No	Yes	No
I participates in social activities	Yes	No	Yes	No	Yes	No
I have friends	Yes	No	Yes	No	Yes	No

Please think about how you responded to the above yes/no items.

If you gave different answers to beginning, end, or now, why do you think they are different?

Are there other things, not covered in the above questions, that you think show that you got better? Yes No Unsure

Please describe:

Please describe your goals regarding recovery at the beginning of treatment.

Did you achieve these goals? Yes No Unsure

Why or why not?

Please tell us about your goals regarding recovery at the end of treatment.

Did you achieve these goals? Yes No Unsure

Why or why not?

Were your goals the same as the goals of the clinician(s) you were working with?

Yes No Unsure

Please explain:

Was treatment helpful? Yes No Unsure

Please explain:

The next section asks you to think about your ideas of recovery.

Is it possible to recover from anorexia? Yes No Unsure

Do you think women with anorexia think about recovery the same as you do?

Yes No Unsure

Please explain:

What does it mean to be recovered from anorexia?

Do you think symptoms should be gone for a certain length of time before someone is considered recovered? Yes No Unsure

If yes, how long?

Please explain:

Appendix E

Codebook**1. Shift in Cognitions Related to Food**

a. *Definition:* Any reference to one's changes in thoughts concerning food or eating behaviors.

b. *Subcategories:*

i. To Eat Without Judgment

1. Example: "Treatment pushed me to realize food isn't evil nor bad."

ii. Decrease in Obsessions with Food

1. Example: "The amount of time spent thinking about food and calories. When I was sick I would spend all day thinking of what I was going to eat, and when. It consumed my thoughts;" "I think true recovery happens when food no longer dictates your life or encompasses the vast majority of your thoughts."

iii. No Longer Count Calories

1. Example: "Stop counting calories."

2. Changes in Emotional Experiences

a. *Definition:* Any reference to a shift or change in one's subjective experience of a feeling or affect. Also refers to changes in one's ability to express emotion or changes in physical sensations related to emotion.

b. *Subcategories:*

i. Decrease in Anxiety

1. Example: "Be able to eat without anxiety."

ii. Enhanced Ability to Describe/Disclose Emotion

1. "I'm able to DESCRIBE my emotions. I'm more familiar and comfortable with the rises and falls in my emotions and feelings about life."

iii. Decrease in Shame

1. Example: "Decreased sense of shame"

2. “I don't try to hide my body.”

- iv. Decrease in Guilt

1. Example: “Eat more normally without extreme guilt or compensation”

- v. Increased Hopefulness

1. Example: “At the end of that I wanted to find out who I was again, I wanted to live an actual life instead of pretty much waiting to die.”

- vi. Enhanced/Stabilized Mood

1. Example: ““I wanted to be happy.”
2. Example: “Now I actually enjoy a fulfilled life with many activities and challenges.”

- vii. Enjoying Food

1. Example: “The ability to not just eat a wide variety of things, but to enjoy it.”

3. **Changes in Social Experiences**

- a. *Definition:* Any reference to changes in how one relates and participates in relationships with others and to the world, as well as to one's engagement in social activities.

- b. *Subcategories:*

- i. Participating in Healthy and Intimate Relationships

1. Example: “To be able to make and sustain deep relationships with other people.”
2. Example: “To be able to spend time with my family without being completely consumed by stress about food, and obsession over my body.”

- ii. Engaging in Fun Activities

1. Example: “I find enjoyment in social activities and in fulfilling work. I allow myself to do things for fun rather than only because I should or because it is productive or because I have to.”

- iii. Engaging in Developmentally Appropriate Activities

1. Example: ““My other goals were to become less preoccupied with food so that I could focus on building friendships, enjoying school and social activities, and basically being a normal teenager.”

iv. Being Honest

1. Example: “To be open and direct with people.”

v. Speaking Openly About AN

1. Example: “I can talk about my eating disorder experience openly. I can encourage others to get support.”

vi. Repairing Relationships and Forgiveness

1. Example: “To be forgiving of myself and those around me, and to repair the relationships I had damaged through my eating disorder.”

4. **Spirituality and Religion**

- a. *Definition:* Any reference to spirituality and/or religious experiences, thoughts, or behaviors.

- b. *Subcategories:*

i. Changes in Spirituality

1. Example: “I had a significant spiritual experience that marked the end of my eating disorder so for me it what happened before and after that. I am markedly better after that experience and I have no symptoms lingering since then and everything has improved since then. So is it my treatment that got me better? Yes. But I find that my spiritual experience brought more healing on many more levels than treatment ever did.”

ii. Dedication to Religious Beliefs

1. Example: “With God's gracerecovery from anorexia is 100% possible!”

5. **Changes in Physical Practices**

- a. *Definition:* Any reference to physical activities that impact the body or behaviors engaged in that positively or negatively alter one's physical self. Also refers to any reference to food or drink consumption as well as behaviors prior to or following food consumption.
- b. *Subcategories:*
 - i. Not Skipping Meals
 - 1. Example: "I had a goal to no longer skip meals."
 - ii. Eating Flexibly
 - 1. Example: "I am flexible with what I eat;" "To trust that I will be able to find something to eat wherever I am and not worry about whether it is the perfect thing, clean, pure, etc."
 - iii. Drinking Less Alcohol
 - 1. Example: "Drink less alcohol."
 - iv. Following a Meal Plan
 - 1. Example: "To be able to follow my meal plan."
 - v. Not Engaging in Purging Behaviors
 - 1. Example: "I had a goal to no longer purge meals."
 - vi. Eating Intuitively
 - 1. Example: "Eat intuitively based on hunger and fullness cues."
 - vii. Not Exercising Excessively
 - 1. Example: "Exercise when I want to vs. thinking I have to."
 - viii. Decrease in Self-Harming Behaviors
 - 1. Example: "I have a goal to no longer engage in self harm or suicidal fantasies."
 - 2. "Decrease or cessation of self-injurious behaviors."
 - ix. Being Healthy
 - 1. Example: "I wanted to be in a good place physically - to be warm (not freezing all the time), not worry about losing heart"

muscle mass, and have the ability to have children one day;”
“Learning how the body handles food and what it needs.”

6. **Medication**

- a. *Definition*: Reference to the use of psychotropic medications to treat symptoms associated with AN.
 - 1. Example: “To me, real recovery also means not having to be on medication.”

7. **Weight/Appearance**

- a. *Definition*: Any reference to a change in one's ability/desire to gain or weight, changes in thoughts about weight, or changes in self-experience associated with weight.

- b. *Subcategories*:

- i. Maintaining a Normal Weight

- 1. Example: “Maintain weight restoration;” “I could be a normal weight (BMI went from 18 to 20-21);” “I wanted to be able to maintain physical wellness.”

- ii. Gaining Weight

- 1. Example: “Return to healthy weight.”

- iii. Decrease in Obsessions Around Weight and Body

- 1. Example: “Focus less on my weight.”
 - 2. Example: “I also wanted to stop hyper-focusing on my body itself.”

- iv. Self-Worth as Separate from Size

- 1. Example: “When someone can believe that your value is not embedded in your body size.”
 - 2. Example: “Not base my self-worth on appearance.”
 - 3. Example: “Stop having weight be the basis of self worth.”
 - 4. Example: “Create a sense of self independent of my body shape.”

8. **Decrease in Negative Cognitions (Unrelated to Food)**

- a. *Definition*: Any reference to a shift in one's cognitive process of knowing, including aspects such as (mental) awareness, perception, insight, reasoning, knowledge, and judgment.
- b. *Subcategories*:
 - i. Decrease in Catastrophic Thinking
 - 1. Example: "I have much less catastrophic thinking."
 - 2. Example: "If you walk out of treatment and after a day have absolutely no negative thoughts or behaviors, you are recovered. I believe when you no longer have any thoughts or behaviors or triggers or cravings to use behaviors, that is when you are recovered."
 - ii. Decrease in Suicidal Ideation
 - 1. Example: "I could be a normal weight and not want to die."
 - iii. Mental Freedom
 - 1. Example: "I also wanted to have my mind freed from the prison that is anorexia;" "Freedom from the burden of an eating disorder."

9. **Control**

- a. *Definition*: Any reference to one's ability to take or have ownership over their thoughts, actions, and body.
- b. *Subcategories*:
 - i. Experiencing a Sense of Control
 - 1. Example: "To be more directly involved with my food (shopping, recipe planning and cooking)."
 - ii. Choosing Health
 - 1. Example: "My goals to improve myself are something I will work on throughout my life. If I didn't go to treatment I don't think I'd even be alive to even try to fulfill such goals."

10. **Changes in Experiences of the Self**

- a. *Definition*: Any reference to positive changes or shifts in one's experience of the self (with the exclusion of one's experiences of the body).

b. *Subcategories:*

i. Enhanced Positive Self Image/Identity

1. Example: “To have a positive view of myself,” “To begin rebuilding my self-esteem, identity, and assertiveness”

ii. Enhanced Self-Acceptance

1. Example: “Having trust that I will be able to find something to eat wherever I am and not worry about whether it is the perfect thing, clean, pure, etc. The ability to nap when I am sick, to say yea to dessert, to be at a social event and not have to spare half, 90%, or in deed any of my focus and energy in the hypnotic, racing, cyclical vortex of food fear thoughts and the anxiety they generate. I don't want to be unhealthy, but if can avoid a life like that, I don't care what my body looks like.”

iii. Feeling Normal

1. Example: “To be able to live a normal life without all the negativity in my head.”
2. “I wanted to be myself again, as vague as that sounds.”

iv. Getting to Know the Self

1. Example: “It was as if someone wiped fog from a mirror and I could really see 'me' for the first time in a very long time. What I saw wasn't pretty, and it was tough work, but worth it, and I've clung to that image ever since;” “Focus less on my weight and create a sense of self independent of my body shape.”

v. The Self as Separate from the Disorder

1. Example: “I do not identify myself as an eating disorder and recognize myself as separate.”

11. **Viewing Treatment as Beneficial**

- a. *Definition:* Any reference to treatment environment as an opportunity for growth, change, and safety.

b. *Subcategories:*

i. Treatment as a Protective and Safe Space

1. Example: “Getting away from my family and being in a new environment was very helpful. I needed to escape the traps that I

had at home and take the time to focus solely on myself. Additionally the nutrition was helpful as I would have been unable to select the variety and amounts of food for myself.”

ii. Treatment as Life-Saving

1. Example: “Treatment literally saved my life.”
2. Example: Treatment saved my life, I was very sick and I would not have lived without the help I received.”

iii. Exploration of Underlying Issues of the Eating Disorder

1. Example: “They helped me realize and deal with underlying issues - clinical depression and family problems.”
2. Example: “To deal with trauma and depression and suicidal ideation.”
3. Example: “I learned a lot about myself and this disease.”

iv. Accepting Support from Others

1. Example: “Keep appointments with therapist/dietician/etc.”
2. Example: “I also met a lot of kind, helpful and inspiring people.”

v. Learning to Accept the Disease (AN)

1. Example: “At the beginning of treatment I was mostly forced into going but as I became a little more comfortable admitting I had a problem I started to set goals of wanting to get better and accepting myself.”

vi. Learning to Manage Negative Thoughts, Urges, and Triggers

1. Example: “When things get tough - when a bout of depression hits, for example, I have thoughts of skipping meals, or restrictive eating. I do my best not to entertain them. I quickly remember what life with an eating disorder is like and realize my problem is with the thoughts behind the desire to control my life through eating. I may not deal with the physical trials of anorexia, but I deal with some preliminary thoughts.”

vii. The Learning and Implementation of Skills

1. Example: “It gave me the necessary tools to cope with the hardships of life and the safety to talk about my feelings.”

2. Example: “I was able to identify the triggers and effectively recognize when they were happening and used coping skills.”

12. **Changes in Experiences of the Body**

- a. *Definition*: Any reference to an enhanced degree of connection to the body or to the integration between one's somatic, emotional, and cognitive experiences.
- b. *Subcategories*:
 - i. **Embodiment**
 1. Example: “Some of my goals of recovery included becoming more embodied (particularly having a less alienated relationship with my body and feeling more connected/compassionate towards it).”
 2. “To stay in my body.”
 3. “Not experiencing my body as alien or “other,” pathetically needy, or malevolent.”
 - ii. **Acceptance of the Physical Body**
 1. Example: “To become more comfortable in my body.”
 2. “To come to love my body the way it is.”.

13. **Anger**

- a. *Definition*: Any reference to client frustration or disapproval towards various aspects of treatment.
 - i. **Anger Toward Professionals**
 1. Example: “The only thing professionals care about is weight. My weight got better so they thought I was better...I was a little, but I have always been disordered and my thoughts are the same now as they were when I had a BMI of 15...”
 - ii. **Anger with the BMI as a Measure for Health**
 1. Example: “Example: “PS the BMI is fucking bull shit.”
 - iii. **Anger with Regards to Being in Treatment**
 1. Example: “After two weeks of anger and fighting the program, I gave in (sometimes I think out of sheer exhaustion).”

2. “My goals at the end of treatment were to maintain the goal weight that had been set for me so that I would never have to return to the hospital again, as it was an adult psychiatric facility and extremely scary for me as a twelve-year-old.”

14. **Denial**

- a. *Definition:* Any reference to not accepting the existence of recovery, diagnosis of an eating disorder, or that treatment as beneficial.

- b. *Subcategories:*

- i. Denial of Existence of Recovery

1. Example: “It is a disease that you can never get rid of;” “I think it is unlikely that symptoms will ever disappear completely.”

- ii. Denial of Diagnosis of AN

1. Example: “I had no clue that it was truly a mental disease and there were a lot of layers underneath my eating habits that spoke more than just me not wanting to eat enough.”

15. **Self-Defeating Goals**

- a. *Definition:* Any reference to client goals that indicate that she would rather stay sick or continue engaging in unhealthy behaviors rather than work towards health and recovery.

- b. *Subcategories:*

- i. Not Having Treatment Goals

1. Example: “I was a minor and was forced into treatment so I did not have any goals. I didn't want to get better at the time.”

- ii. Wanting to Quit Treatment

1. Example: “Didn't want to be in treatment. I just wanted to get out.”

- iii. To Lose Weight

1. Example: “When I left my last treatment center, I still didn't want to be better/healthier. I wanted to lose more weight.”

- iv. Wanting to Die

1. Example: “At the very beginning of treatment, I wanted to get rid of my anorexia and be healthy. That went away through the years

of treatment and even in my last treatment setting, I had absolutely no goals. I wanted to die as quickly as possible.”

v. Pleasing Others

1. Example: “During the first several years of my treatment I was not completely focused on recovery but wanted to please the people who were concerned about me. In all honesty my goals at the beginning of my treatment were primarily based upon pleasing others and killing myself to do that if necessary.”

16. Time

a. *Definition*: Any reference to being symptom free for a specific length of time.

b. *Subcategories*:

i. Equal Length of Time as Course of Symptoms

1. Example: “Recovery” would take place when the person was able to not have symptoms for approximately as long as they had had them.”

ii. Life-Long Process

1. Example: “My goals to improve myself are something I will work on throughout my life.”

iii. Unspecified Amount of Time

1. Example: “I don't think you can put a time frame on it.”
2. “I think it depends on the person and his or her situation.”

iv. Years

1. Example: “It takes most people several years before they can get to a point where they really don't have any thoughts at all that are mired in food and body image.”

Appendix F
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