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Erin Nicole Harrop

“Maybe I Really Am Too Fat to Have an Eating Disorder”: A Mixed Methods Study of Weight  
Stigma and Healthcare Experiences in a Diverse Sample of Patients with Atypical Anorexia

Erin Nicole Harrop

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Reading Committee:

Taryn P. Lindhorst, Chair

Megan Moore

Janell L. Mensinger

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**Abstract**

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Erin Nicole Harrop

Chair of the Supervisory Committee:

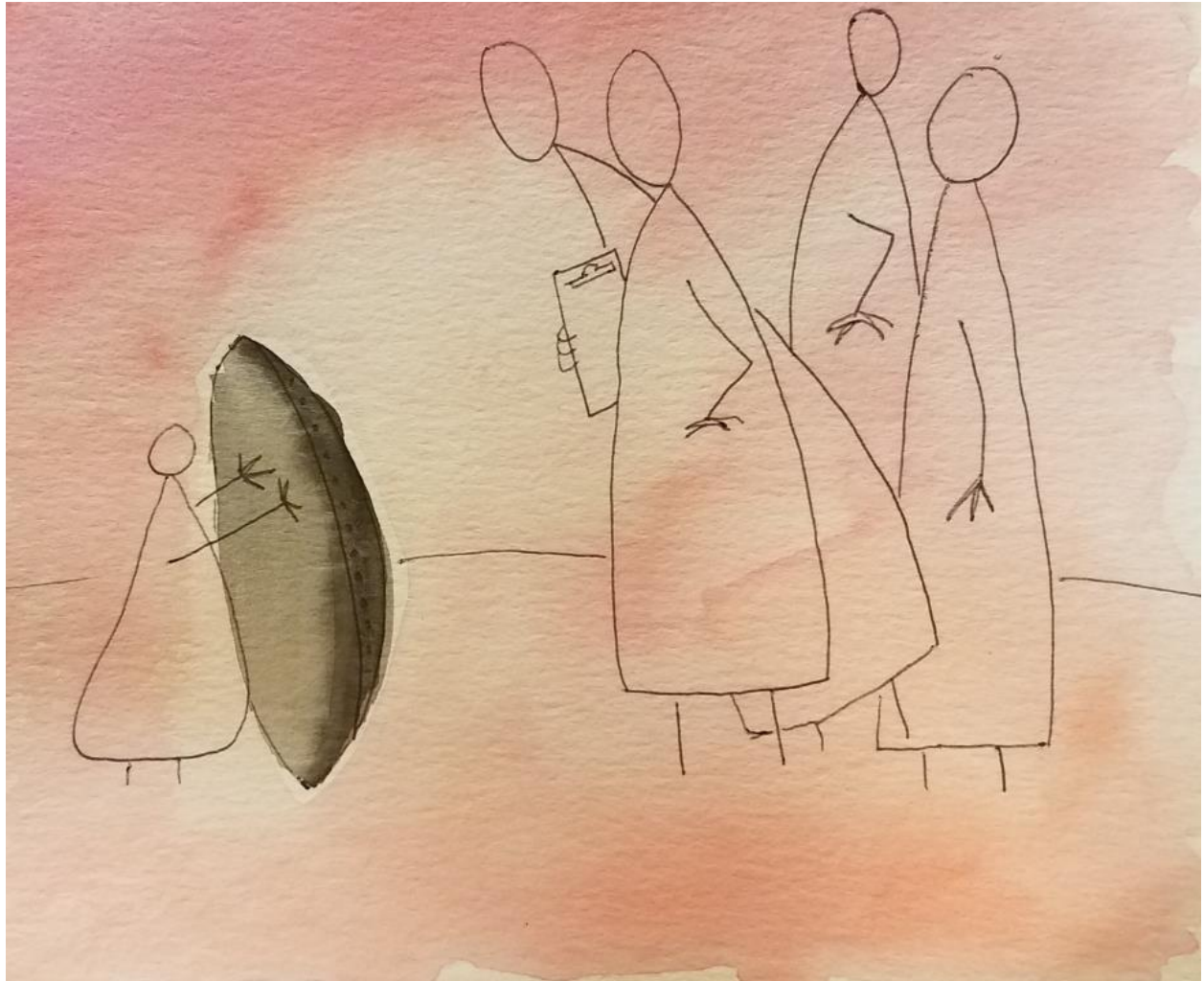
Professor Taryn Lindhorst

School of Social Work

Within mental disorders, anorexia nervosa (AN) has the second highest mortality rate, second only to opiate addiction; additionally, AN patients experience impairments in multiple spheres including psychological, social, physical, employment, and overall quality of life. “Atypical anorexia” (AAN) is an eating disorder (ED) describing those who meet all criteria for AN except being underweight. Further, by having larger bodies, AAN individuals are more likely to experience weight stigma. Currently, no literature has systematically reviewed published findings on AAN, and the extent to which AAN individuals experience physical consequences commensurate with AN, and the extent to which their healthcare experiences are impacted by their higher weight status are unknown. The present study used multiple methodologies to explore the AAN experience, focusing on how weight and weight stigma affect access to ED treatment and

healthcare. *Methods:* Study 1 utilized a systematic review of 42 articles to determine the weight history and medical complications of AAN compared to AN. Study 2 utilized in-depth semi-structured arts-based qualitative interviews with 38 AAN patients to describe their experiences of weight stigma in healthcare. Study 3 utilized correlations to determine associations between weight-related variables, treatment delay, and level of care received. *Results:* The review revealed that AAN patients experienced life-threatening medical complications (electrolyte imbalance, bradycardia, hypothermia, orthostasis) at commensurate rates to AN patients, despite AAN weights being higher. However, AAN experienced lower rates of amenorrhea and bone density loss compared to AN. Qualitative findings demonstrated that across the illness trajectory (risk development, pre-treatment, treatment, relapse prevention), patients reported that provider weight stigma contributed to initiation and persistence of ED behaviors, complicating illness trajectories. Quantitative results corroborated the impact of weight-related variables on treatment receipt and delay. Participants experienced a mean weight loss of 28.4% ( $SD = 10.0$ ) of their premorbid weight and a treatment delay of 11.6 years ( $SD = 11.7$ ) from the time patients believed they had an ED until receiving treatment. In correlation analysis, lower minimum BMI was associated with less treatment delay, and higher maximum BMI was associated with lower levels of care received. *Discussion:* These findings demonstrate that 1) AAN is a serious illness with similar medical comorbidities as AN, 2) higher weight patients were counseled to lose weight despite the presence of ED cognitions and behaviors that created health risks, 3) healthcare providers generally failed to recognize AAN in normal and higher weight patients, and 4) consequences of provider weight stigma included longer periods of living with undiagnosed, untreated EDs and instances of providers triggering (or re-triggering) ED behaviors, leading to increased health risk. These findings suggest several needed steps. First, transitioning to a

spectrum model for AN diagnosis (wherein weight is one severity indicator, but not the predominant focus) may facilitate faster diagnosis and treatment. Second, training is needed for transdisciplinary healthcare providers to increase recognition and screening of EDs in normal and higher weight patients. Third, conversations are needed between obesity and ED professionals to ensure that universal health promotion efforts do not cause unintended harm. Addressing weight stigma in these ways could enhance treatment receipt, quality of care, and healthcare engagement for ED patients, particularly those at higher weights.



Artwork by Joanna, Participant 5

“It makes it more difficult not being a smaller-sized person and going into any visit with any doctor and not having your guard up instantly.” –Veronica,<sup>1</sup> Participant 28

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<sup>1</sup> All participant names in this dissertation are pseudonyms.



Artwork by Molly, Participant 6

“I’m like a body. That’s all they see is a body. And they don’t approve of the body.”

--Cabaletta, Participant 21

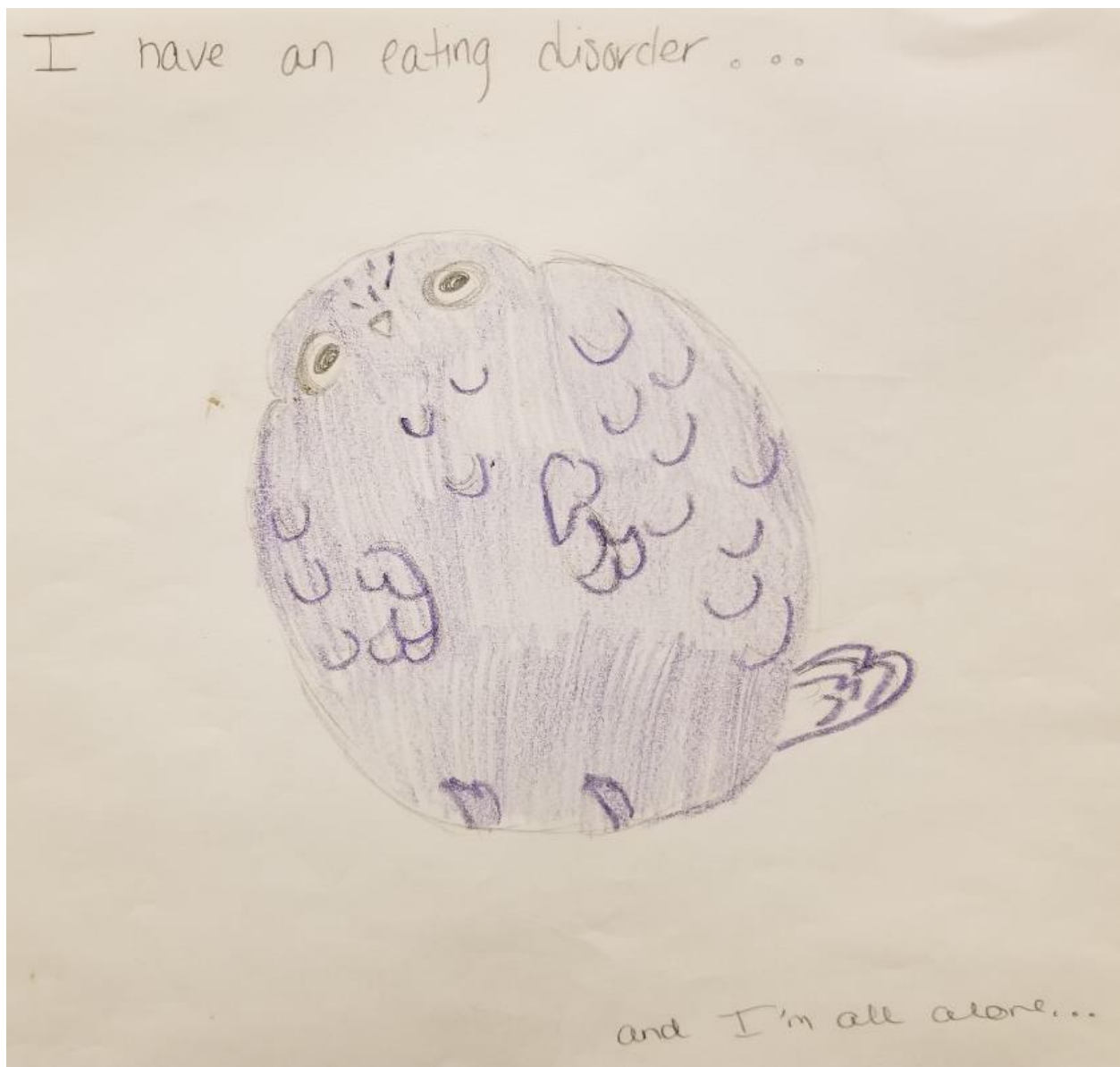
## TABLE OF CONTENTS

	Page
List of Figures .....	xi
List of Tables .....	xiii
List of Artwork .....	xv
List of Abbreviations .....	xvii
Acknowledgements .....	xxii
Dedication .....	xxiv
Introduction .....	1
References .....	23
Chapter 1: Weight History across the Lifetime and Medical Complications in Individuals with Atypical Anorexia Nervosa: A Systematic Review .....	31
References .....	63
Chapter 2: Introduction to the WINTER Study .....	82
References .....	93
Chapter 3: “You Don’t Look Anorexic:” Enacted and Internalized Experiences of Weight Stigma in Medical Care for Patients with Atypical Anorexia .....	98
References .....	126
Chapter 4: Weighting for Treatment: Linking Weight History, Disorder Severity, Weight Stigma, and Treatment Delay for Patients with histories of Atypical Anorexia .....	139
References .....	164
Chapter 5: Conclusion .....	176
References .....	193



## Appendices

Appendix A: Checklist for Authors of Review Articles .....	195
Appendix B: Baseline Interview Guide and Art Prompt .....	197
Appendix C: Sample Participant Symptom and Diagnostic Timeline (Carly) .....	198
Appendix D: 6-Month Interview Guide and Art Prompt .....	199
Appendix E: Coding Guide .....	200
Appendix F: 12-Month Interview Guide and Art Prompt .....	202
Appendix G: Sample Participant Art from Participant (Molly) .....	205
Appendix H: “thank you for acknowledging,” a Research Poem .....	207
Appendix I: Informed Consent Document .....	209
Appendix J: Sample Participant Portrait Summary (Charlie) .....	218
Appendix K: Themes with Evidence and Representative Artwork .....	222
Appendix L. Data Dictionary and Data Cleaning and Validation .....	226
Glossary .....	233
References .....	255
Curriculum Vitae .....	260

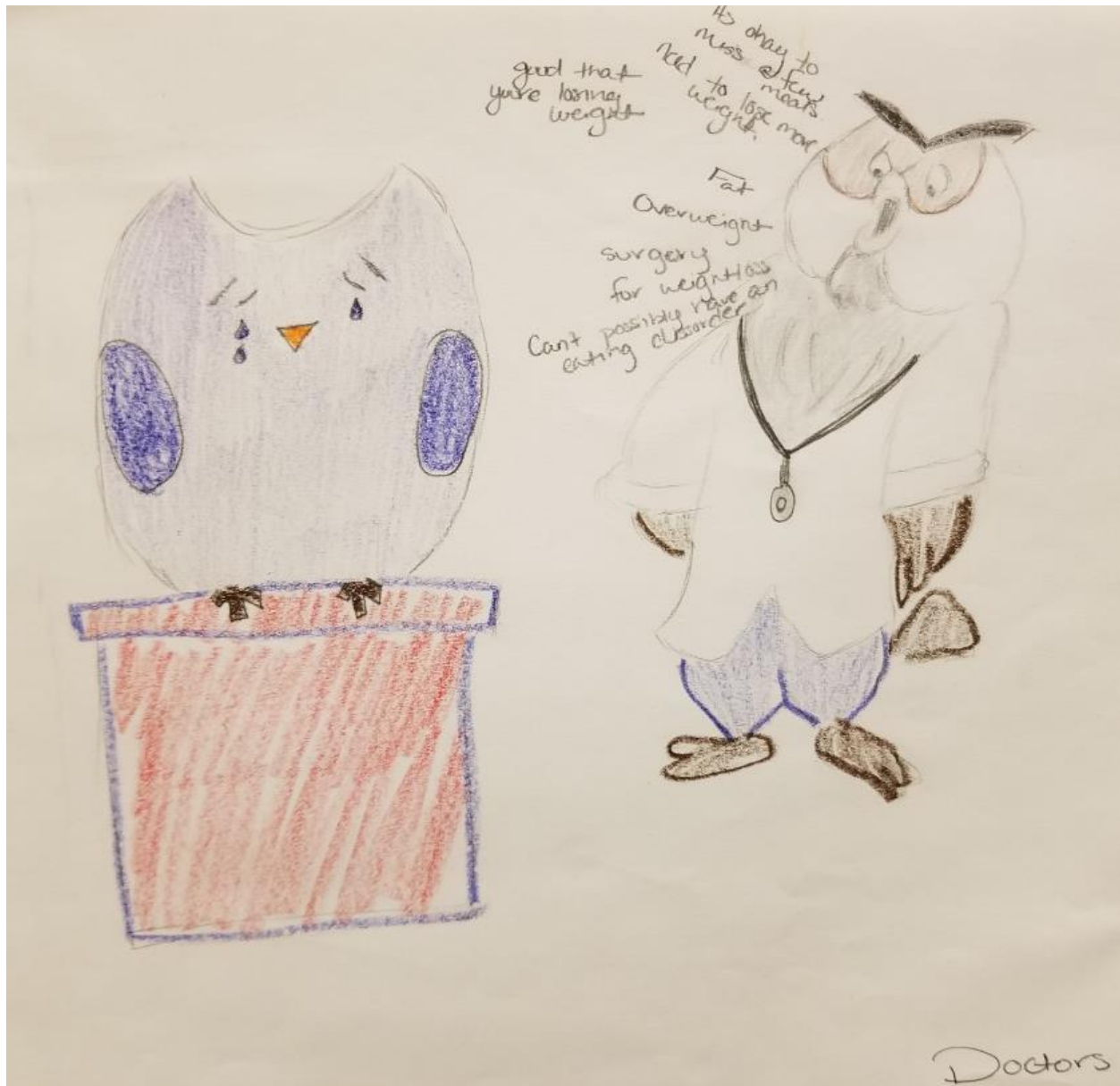


Artwork by Tori, Participant 7

“She was full on trained in eating disorders and that was the main component of the people that she saw. But she said, ‘Most of what I’m trying to do is get people to eat more, so I’m not sure if that really helps you.’” –Layla, Participant 23

## LIST OF FIGURES

Figure Number	Page
1. Proposed Model of Weight Stigma, ED Symptoms, and Outcomes in AAN .....	29
1.1. PRISMA Flow Diagram .....	70
2.1. Winter Study Design.....	95
3.1. Qualitative Themes of Weight Stigma Across Illness Trajectory .....	130
4.1. Recruitment, Screening, and Enrollment Flow Enrollment Diagram .....	170



Artwork by Tori, Participant 7

“All of the tears that I cried from shame from medical professionals and family, because I’m fat. So, there’s been lots of tears before and after doctor’s appointments.”

--Carly, Participant 9

## LIST OF TABLES

Table Number	Page
1.1. Demographics Summary and Quality Summary Scores.....	71
1.2. Quality Assessment of Included Articles.....	73
1.3. Mean BMI, Weight History, and Weight Suppression Data. ....	75
1.4. Rates of Amenorrhea and Other Findings Regarding Menstruation. ....	78
1.5. Rates of Bradycardia, Orthostatic Instability, Hypothermia, Additional Medical Findings.	79
2.1. Study Measures: Timing, Setting, Length, and Number of Items. ....	96
3.1. Demographic Characteristics of Participants.....	131
3.2. Themes of Weight Stigma During ED Risk and Development. ....	134
3.3. Themes of Weight Stigma Pre-Treatment for ED. ....	135
3.4. Themes of Weight Stigma in ED Treatment.....	136
3.5. Themes of Weight Stigma Post-Treatment (Relapse Prevention) ....	137
4.1. Demographic Characteristics of Sample.....	171
4.2. EDE-Q, CIA, WBIS Scores of WINTER Study Sample, Community Norms, and Clinical ED Samples.....	172
4.3. Weight-Related Variables and Treatment Delay. ....	173
4.4. Correlations between Weight-Related Variables, Treatment Delay, and Level of Care. ....	174



Artwork by Cabaletta, Participant 21

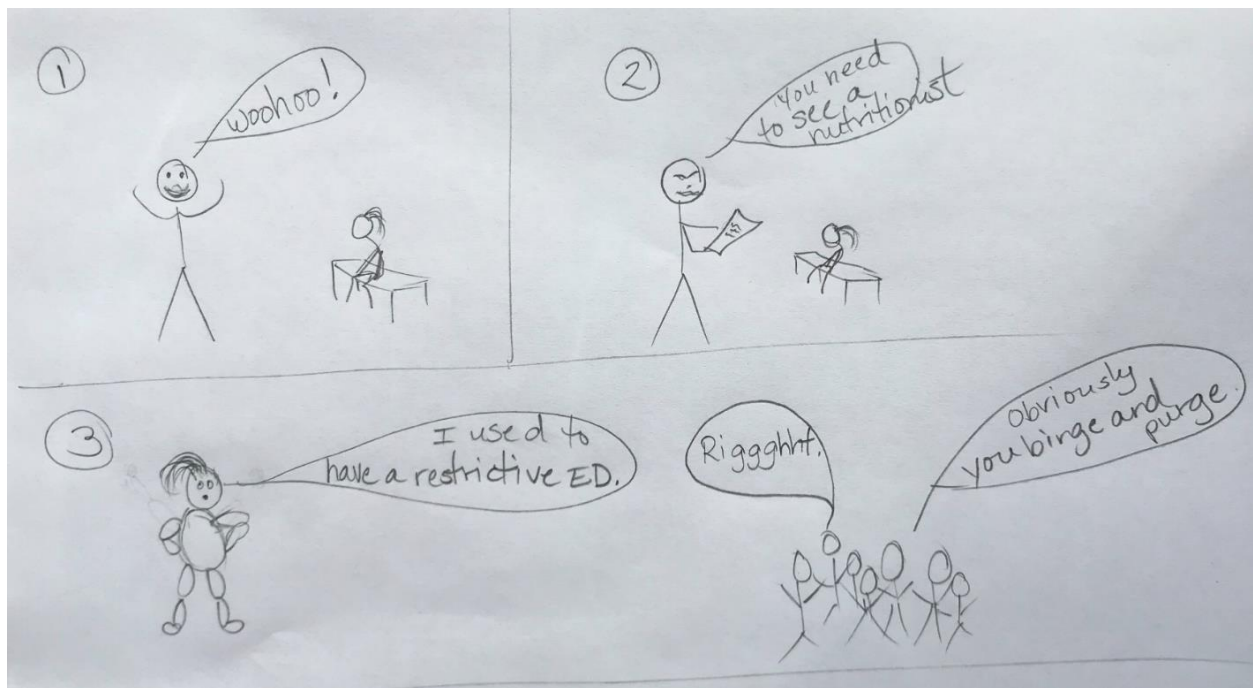
“Everything comes from somehow being in a body that is oversized, and it’s a self-worth feeling... I have been treated terribly because of what I look like and my size... I finally just had to tell people that I needed to be treated the way a person of an apparently acceptable size would be treated.”

--Gretchen, Participant 4

## LIST OF ARTWORK

Artwork with Pseudonym	Page
Artwork by Joanna, Participant 5.....	vi
Artwork by Molly, Participant 6.....	vii
Artwork by Tori, Participant 7.....	x
Artwork by Tori, Participant 7.....	xii
Artwork by Cabaletta, Participant 21.....	xiv
Artwork by Jen, Participant 24 .....	xvi
Artwork by Amanda, Participant 3 .....	xx
Artwork by Uki, Participant 11.....	xxi
Artwork by Candy, Participant 20 .....	xxiii
Artwork by Erin Harrop, Author .....	xxiv
Artwork by Marie, Participant 36 .....	xxv
Artwork by Grace, Participant 12 .....	30
Artwork by Mary, Participant 17 .....	81
Artwork by Carly, Participant 9.....	97
Artwork by Abby, Participant 8.....	99
Artwork by Gaia, Participant 30 .....	125
Artwork by Layla, Participant 23.....	138
Artwork by Jessie, Participant 37 .....	163
Artwork by Sisu, Participant 39.....	175
Artwork by Joanna, Participant 5.....	194

Artwork by Arati, Participant 16 .....	232
Artwork by Gretchen, Participant 4 .....	254
Artwork by Tori, Participant 7 .....	258
Artwork by Eli, Participant 14 .....	259



Artwork by Jen, Participant 24

“I’ve had a doctor say, ‘Well, you don’t look anorexic. You don’t look underweight... Do you want to look like someone who is anorexic?’ I was like, ‘I have no idea why you’re asking this or how to answer this question.’”

—Lexi, Participant 15



## LIST OF ABBREVIATIONS

- %ile:** percentile
- %mBW:** percent median body weight
- 17OHP:** 17-hydroxyprogesterone
- AAN:** atypical anorexia nervosa
- AFAB:** assigned female at birth
- AN:** anorexia nervosa
- ANbp:** anorexia nervosa, binge/purge subtype
- ANr:** anorexia nervosa, restrictive subtype
- APA:** American Psychological Association
- ARFID:** avoidant or restrictive food intake disorder
- AUDIT:** Alcohol Use Disorders Identification Test
- BAS:** Body Appreciation Scale
- BCBS:** Broad Conceptualizations of Beauty Scale
- BED:** binge eating disorder
- BMD:** bone mineral density
- BMI:** body mass index
- BN:** bulimia nervosa
- BP:** blood pressure
- bpm:** beats per minute
- C:** degrees Celsius
- CARE:** Consultation and Relational Empathy Measure
- CIA:** Clinical Impairment Assessment
- CINAHL:** Cumulative Index of Nursing and Allied Health Literature
- DHEA-S:** dehydroepiandrosterone-sulfate
- DSM:** Diagnostic and Statistical Manual
- DSM-5:** Diagnostic and Statistical Manual Edition 5
- DSM-IV:** Diagnostic and Statistical Manual Edition IV

**DUDIT:** Drug Use Disorders Identification Test

**E2:** estradiol

**ED:** eating disorder

**EDA-5:** Eating Disorders Assessment for DSM-5

**EDE-Q:** Eating Disorders Examination Questionnaire

**EDNOS:** eating disorder not otherwise specified

**F:** female

**FSH:** follicle-stimulating hormone

**FT4:** free thyroxine

**GAD-7:** Generalized Anxiety Disorder-7

**HAES®:** Health at Every Size®

**HIV:** human immunodeficiency virus

**IES:** Intuitive Eating Scale

**IQR:** interquartile range

**IRB:** Institutional Review Board

**kg:** kilograms

**LGBTQ:** lesbian, gay, bisexual, trans, queer

**LH:** luteinizing hormone

**M:** male

**Max:** maximum

**mBMI%:** median BMI percentile

**mBMI:** median BMI

**med:** median

**Min:** minimum

**mo.:** months

**NA:** not applicable:

**NR:** not reported

**OB:** obese BMI

**OSFED:** other specified feeding and eating disorders

**OW:** overweight BMI

**PD:** purging disorder

**PHQ-9:** Patient Health Questionnaire – 9

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**PRL:** prolactin

**PsycINFO:** APA database

**PubMed:** PubMed database.

**QAS:** Quality Assessment Scale

**QTc:** Q-T corrected interval

**RED:** restrictive eating disorder

**RedCap:** Research Electronic Data Capture

**RES:** Rosenberg Self Esteem Scale

**RSH:** unknown abbreviation used by Academy of Eating disorders in funding

**sAN:** subthreshold AN

**SD:** standard deviation

**SDS:** SD score

**STIPS:** Stanford Trust in Provider Scale

**T3:** triiodothyronine

**TL1:** Translational Science Fellowship

**TSH:** thyroid-stimulating hormone

**tx:** treatment

**Under-Wt:** underweight

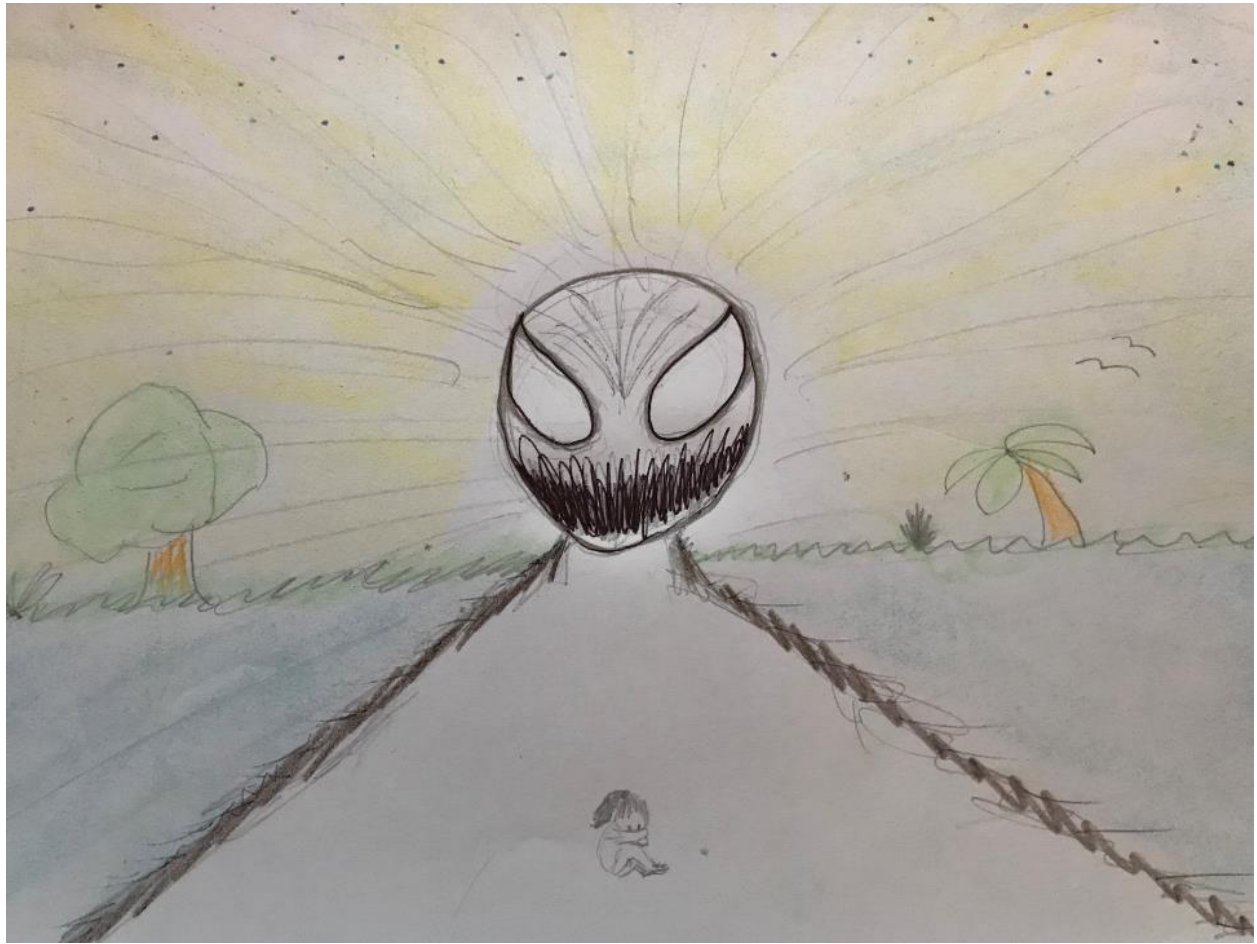
**VS:** vertebral strength

**WBIS:** Weight Bias Internalization Scale

**WHOQOL:** World Health Organization Quality of Life Brief Measure (WHOQOL-BREF)

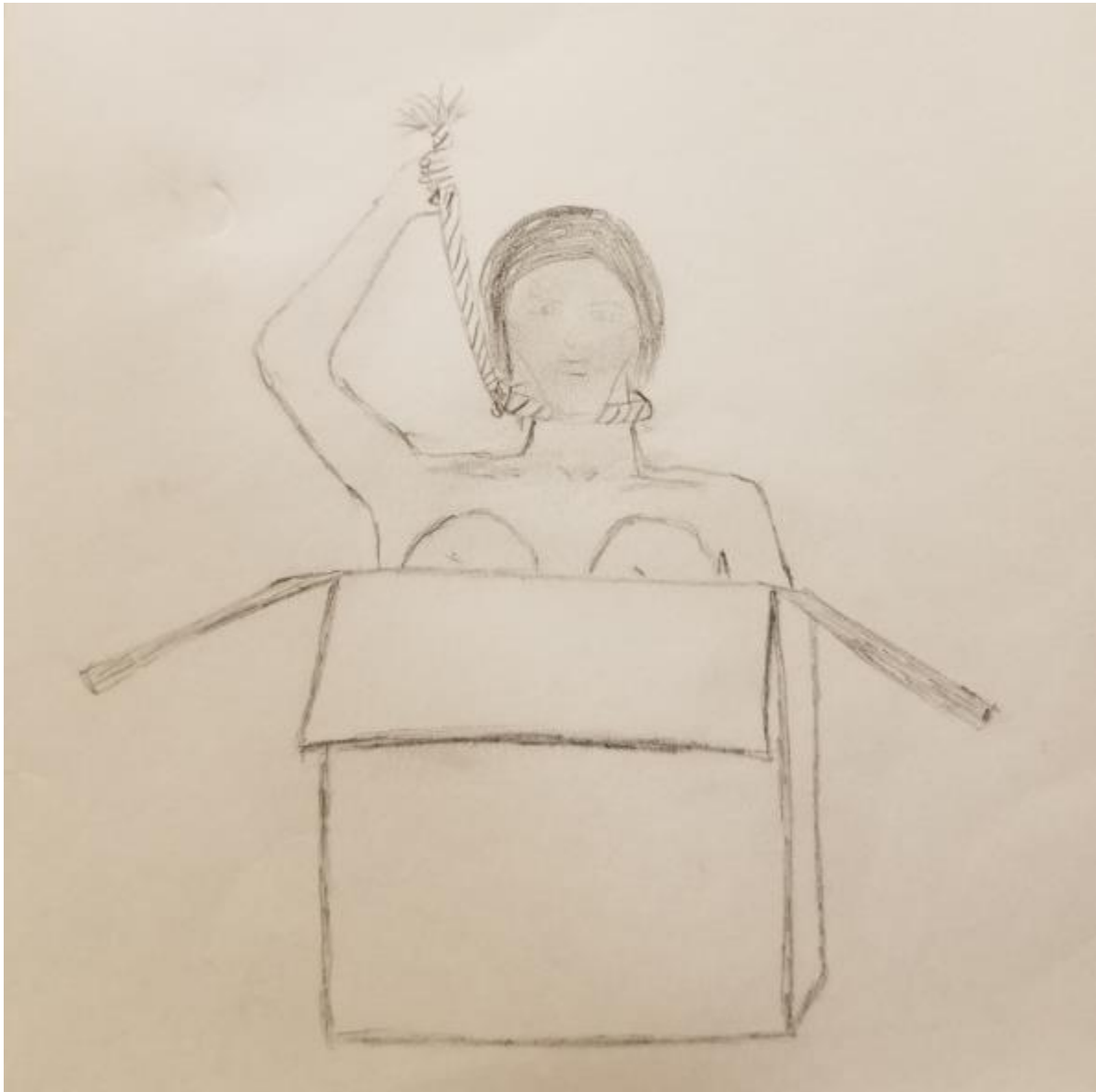
**WINTER:** Women’s Illness Narratives Through ED and Remission

**WL:** weight loss



Artwork by Amanda, Participant 3

“I felt more and more like I was taking up space [in treatment] that they really intended for someone else.” –Elizabeth, Participant 2



“It feels like people are trying to shove me in this box, and this box is the definition of whatever eating disorder label I had at the time. Or even just the label of ‘eating disorder.’ And I obviously don’t fit. Like teenage white girl, adult native woman. They are very different.”

Artwork and quote by Uki, Participant 11

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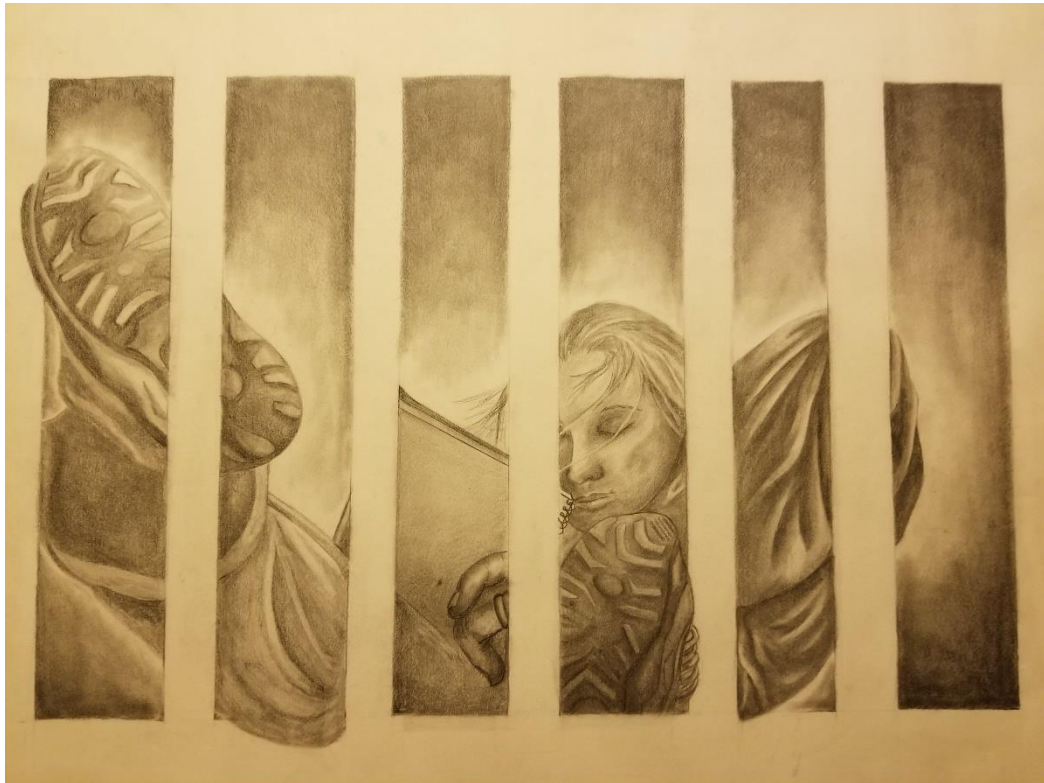
Artwork by Candy, Participant 20

“I was talking to the doctors about it, and that’s when they told me that ‘I don’t meet the numbers.’ And I couldn’t be a part of the [eating disorder] group, even though they said I had an eating disorder... they just said basically, it wasn’t bad enough for me to meet with that group.”

--Carter, Participant 29

## DEDICATION

This dissertation is lovingly dedicated to Jinah and Meaghan. Here's to fighting another decade.



Artwork by Erin Harrop, Author

“I was exercising HOURS every day, eating just enough to fly below radar... [I had] All these opportunities to notice disordered eating, disordered relationships with my body, exercise, and food, and no one even ASKED. Their actions tell me that they saw an overweight/obese woman complaining about her cycle, so they blamed her, blamed her weight, and washed their hands of her... she's fat, nothing else is to blame for her symptoms... amenorrhea due to undernutrition isn't a possibility when she looks like that.... What if ANYONE would have asked?! What if I didn't have to fight another decade...? What could my life be like now, had someone noticed, asked, or even just suggested my behaviors were problematic?” –Uki, Participant 11





Artwork by Marie, Participant 36

“I’m also invisible. But, like they don’t care, and I’m not really, not really sick enough for anybody to really give a shit... Even... when I was going inpatient... it’s just this dichotomy of like feeling like, ‘well, I have to get even more sick to be seen.’” –Marie

## INTRODUCTION

Anorexia nervosa (AN) is a serious psychiatric illness characterized by severe caloric restriction, significant weight loss, an overvaluation of weight and shape, body image disturbance, and a body mass index (BMI<sup>2</sup>) “less than minimally normal” or “expected,” which is often interpreted by clinicians as a BMI less than 18.5 (American Psychiatric Association; APA, 2013, p. 338). AN cognitive and behavioral symptoms manifest in “intense fear of gaining weight or becoming fat,” leading to strange eating behaviors (e.g. compulsive, time-consuming food rituals; mental obsession with food; obsessive calorie counting; secretive eating; eliminating “fear foods” from a diet) and dangerous compensatory behaviors (e.g. compulsive exercise and/or restless movement, self-induced vomiting, laxative/diuretic abuse, among others). Additionally, individuals with AN place high value on their weight and shape, such that their sense of identity and worth is “highly dependent on their perceptions of body shape and weight” (APA, 2013, p. 340); this overvaluation is doubly damaging, as AN individuals often experience significant body distortion, a phenomenon in which a person’s perception of their own body size and shape is grossly inaccurate. This combination of overvaluation of weight and shape and body image disturbance often results in time-consuming body checking rituals, such as frequently weighing, measuring, pinching, mirror-checking, or examining oneself. These behaviors often become all-consuming as affected individuals engage in obsessions around food and body, while also becoming medically compromised due to the physical effects of malnutrition. As a result, AN has

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<sup>2</sup> BMI refers to a mathematical ratio of a person’s weight and height and is represented by the formula: weight (kg) / [height (m)]<sup>2</sup>. While typically used as a measure of “fatness,” this measure does not measure *composition* of body mass (lean mass, bone mass, fat mass, etc.) and is not sensitive to racial, gender, or age differences. For adults, current Centers for Disease Control define BMIs under 18.5 as “underweight,” BMIs between 18.5 and 24.9 as “normal,” BMIs between 25.0 and 29.9 as “overweight,” and BMIs over 30.0 as “obese.” Childhood obesity is defined slightly differently, such that children and adolescents scoring above the 95<sup>th</sup> percentile of the BMI in the US population between 1963-1994 are considered “obese.”

one of the highest mortality rates of any psychiatric illness (second only to substance abuse), with deaths resulting from complications of malnutrition (e.g. cardiac arrest, organ failure) and suicide (Beumont & Touyz, 2003; Chesney, Goodwin, & Fazel, 2014; Harris & Barraclough, 1998; Smink, Van Hoeken, & Hoek, 2012).

### **The Disproportionate Impact of EDs**

EDs disproportionately impact women, adolescents, and young adults (Hudson, Hiripi, Pope, & Kessler, 2007; Smink, Van Hoeken, & Hoek, 2012). LGBTQ individuals, including transgender individuals of all genders, gay/bisexual men, and bisexual/lesbian women, have also shown increased risk for eating disorders (EDs; Bell, Rieger, & Hirsch, 2019; Calzo, Blashill, Brown, & Argenal, 2017; Diemer, Grant, Munn-Chernoff, Patterson, & Duncan, 2015; Feldman & Meyer, 2007; French, Story, Remafedi, Resnick, & Blum, 1996; Mustanski, Garofalo, & Emerson, 2010). Populations previously thought to be at lower risk for EDs have shown the highest rates of ED behavior increases in recent years, including men, those above age 44 years, and women of color (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001; Mitchison, Hay, Slewa-Younan, & Mond, 2014).

### **Atypical Anorexia Nervosa—A “New” ED**

“Atypical anorexia” (AAN) is an ED category designating those who meet all criteria for AN except their weight is maintained in a normal or above-normal BMI range (APA, 2013). Research on AAN is limited. Several prevalence studies have shown that AAN is at least as common as AN in community settings (Hammerle, Huss, Ernst, & Bürger, 2016; Hay et al., 2017; Isomaa, Isomaa, Marttunen, & Kaltiala-Heino, 2010; Stice, Marti, & Rohde, 2013), though AAN appears less represented in ED treatment settings (Harrop, Mensinger, Moore, & Lindhorst, under review). Individuals with AAN are also included in and make up a significant portion of the Other Specified Feeding and Eating Disorders (OSFED) category (Kennedy et al., 2017; J.

Månsson, Parling, & Swenne, 2016; Peebles et al., 2017; Swenne, 2016). In recent years, studies have reported that rates of AAN individuals entering treatment has been increasing (Whitelaw, Gilbertson, Lee, & Sawyer, 2014).

AAN has received relatively little attention as a separate and important ED experience. Much of the research examining AAN has focused on thin (but not underweight) or normal weight patients, rather than people with BMIs greater than 25. This focus is problematic as individuals of different BMIs may experience healthcare differently. For instance, a person with a BMI of 19.5 could be diagnosed with AAN, as well as a person with a BMI of 45.0, yet the perceptions of the bodies of those two people would be markedly different. One would be seen as having a “normal” (or possibly low) weight, while the other would be labeled “morbidly obese” by the medical system. According to the 5<sup>th</sup> Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) nosology, they have the same diagnosis (OSFED, AAN type). Yet, these differences in weight may result in different experiences of the healthcare system, especially in terms of ED risk screening, quality of care, and suggested treatments.

Our understanding of AAN is limited in several other ways. While research sometimes includes AAN participants in mixed diagnostic groups (e.g. all OSFED categories combined in one subgroup), this research practice obscures the distinct characteristics of the AAN group, as they are combined with other diagnoses with different cognitive and behavioral symptoms (e.g. subthreshold binge eating disorder, etc.). Additionally, because most samples within AAN literature show limited diversity in terms of age, gender, and race, mostly featuring white, young populations with few including adults over age 30, and gender minorities (Harrop, Mensinger, Moore, & Lindhorst, under review), the full diversity of AAN experiences is unknown. As such, research that focuses on increasing sample diversity is warranted in order to understand how this

disease manifests across the lifespan, across the weight spectrum, and for people with multiply marginalized identities (e.g. people of color, sexual, and gender minorities).

Preliminary research suggests that individuals with AAN face similar health-related consequences to patients with low-weight AN, such as increased rates of bradycardia, electrolyte imbalance, hypothermia, and medical instability (Peebles, Hardy, Wilson, & Lock, 2010; Sawyer, Whitelaw, Le Grange, Yeo, & Hughes, 2016). The extent to which these similarities manifest has yet to be fully assessed. Though symptoms of AN manifest across the weight spectrum (Swenne, 2016), people with AAN at higher weights demonstrate equivalent levels of caloric restriction to those at lower weights (Coniglio et al., 2017). While the similarities in clinical presentations between AAN and AN samples are notable (Davenport, Rushford, Soon, & McDermott, 2015; Eddy, Doyle, Hoste, Herzog, & Le Grange, 2008; Whitelaw et al., 2014; Schorr et al., 2017; Stice et al., 2013), it is also important to consider that individuals with AAN may have unique ED or health-related experiences due to the higher weight presentation of these patients and the challenges of weight stigma. Within this dissertation I seek to expand current understanding of AAN by using multiple methodologies to interrogate the breadth of the AAN experience, while also examining how patients with AAN are impacted by weight stigma.

## **Theoretical Underpinnings and Approaches**

### **Metatheory**

In this dissertation, I take a largely interpretivist approach focused on explaining behavior by “rendering it meaningful or intelligible” (Rosenberg, 2016, p. 25). An underlying assumption of the interpretive framework is that there is no objective, absolute truth. According to interpretivists, “what we might identify as universal or true or optimal in our beliefs, values, and institutions is really parochial, local, and merely convenient for some of us” (Rosenberg, 2016, p. 27).

As such, interpretivist approaches view knowledge progress as further interpretations that help social scientists understand the actions of others and ourselves, such that we learn to “place our own society in perspective” (Rosenberg, 2016, p. 27). Finally, interpretive approaches also introduce deliberate engagement with the “moral dimension of social science” which may be absent from more naturalistic empirical approaches (Rosenberg, 2016, p. 27).

### **Theorizing Stories and Narratives**

Within this dissertation, I utilize multiple methods (e.g. systematic review of previous literature, narrative analysis of interviews, and examining correlations) to deepen understanding of the AAN experience. Within this work, stories are an important source of data. As opposed to viewing stories as diametrically opposed to “truth” in a naturalistic sense, story-theorizer Stone-Mediatore takes an interpretivist approach, arguing that stories (especially from marginalized voices) are integral to understanding a more complete picture of reality, as understood from different political positionalities. Storytelling is situated within a critical feminist paradigm, in which storytelling is a means of resistance and a tool for countering dominant narratives that reinforce established power structures. Personal narratives (e.g., “stories”), particularly stories from marginalized groups, add more voices to traditional histories and have the power to tell a transformational story about society (Stone-Mediatore, 2003). Thus, she asserts that social scientists should include experientially-based stories in other forms of research in order to avoid alienating our work from practical struggles (Stone-Mediatore, 2003). An important innovation of this dissertation rests in how I elicited the patient perspective of a marginalized group (higher weight participants) with restrictive EDs that has been largely ignored in the literature.

Within the context of this dissertation, I apply the definitions of stories and narratives as described by Stone-Mediatore (2003). According to Stone-Mediatore (2003), stories are

composed of “narrated experiences,” which involve some level of interpretation as they are told by the author. A narrative is “a pattern of identifiable actors and action-units that are qualified through metaphor and other poetic devices and that are related together within a coherent structure of beginnings and endings” (Stone-Mediatore, 2003, p. 3). Within this approach to narratives, coherence is not necessarily organizational, as in a linear structure, as many stories may lack this form for a variety of reasons, including the experience of trauma, and the way that difficult stories are embodied and lived. Rather, narrative theory is more influenced by phenomenological philosophers who think of narratives as how we “experience events in terms of beginnings and endings, how we meaningfully communicate life events by recounting patterns of actors and actions, and how we consider the significance of possible actions by imagining them within narratives” (Stone-Mediatore, 2003, p. 4). Central to this interpretation of narrative is the concept of the simple hermeneutic—that we tell stories with lenses that interpret meaning, from the first utterance of the story, the person is already interpreting their own experience through storytelling. It is then the job of the interpretive scientist to analyze and interpret the various narratives (the double hermeneutic – the researcher interpreting the interpreting subject) and determine how these narratives influence our perspectives (Stone-Mediatore, 2003).

### **Illness Stories as Narratives**

Regarding medical and illness stories specifically, I draw on Kleinman’s (Kleinman, 1988) work which centers patient *illness narratives* and patient explanatory models. Kleinman argued that the “incorporation of ‘clinical social science’ was essential if physicians were to understand, respond to, and help patients deal with the concerns they bring to the doctor (A. Kleinman, Eisenberg, & Good, 1978, p. 252). To Kleinman, understanding the patient illness experience was critical to a physician’s understanding of their illness in addition to their treatment of the disease. Thus, to best understand and treat AAN, Kleinman would argue that providers

first need to understand the patient's understanding of their own illness. Kleinman also drew a distinction between the patient's illness (which refers to the lived experience and perception of symptoms and disability from the patient's perspective) and disease, which is the practitioner's interpretation of the illness (as they have been trained to see and understand the patient's problems). Alternatively, Stone-Mediatore might call the illness of AAN the simple hermeneutic (e.g. the patient's story), while disease is the double hermeneutic (the physician's understanding of the patient's story within the physician's framework of understanding).

### **Clinical Theory: Theorizing Stigma**

Stigma is the process in which some identities are systemically devalued or disadvantaged within societies, while others are systematically valued. For instance, racial stigma may manifest in white bodies being safer, preferred, or privileged compared to black and brown bodies; similarly, class stigma manifests in those with higher education and economic resources having advantages over those who have less education and fewer resources.

### **External Manifestations of Weight Stigma**

In the case of weight stigma, higher weight, "fat,"<sup>3</sup> bodies are systematically devalued, with associated experiences of discrimination, fewer economic and educational opportunities (Morris, 2007; Puhl & Heuer, 2009), and other forms of systemic abuse and mistreatment interpersonally and in healthcare (such as microaggressions, marginalization, and violence; Puhl & Heuer, 2009). It is important to note that weight stigma research converges with other literature around prejudice and discrimination when examining how some groups experience differential societal treatment and access. Stuber, Meyer, and Link (2013) summarize the relationship

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<sup>3</sup> "Fat" is used here in line with fat liberation communities who use the word "fat" as a neutral descriptor of body size and shape in an effort to reclaim stigmatizing language. See Meadows and Daníelsdóttir (2016) and Saguy and Ward (2011).



between these terms explaining that “research in the prejudice tradition grew from concerns with social processes driven by exploitation and domination, such as racism, while work in the stigma tradition has been more concerned with processes driven by enforcement of social norms and disease avoidance” (Stuber, Meyer, & Link, 2013). In the case of weight stigma, it may be that fat bodies have been devalued for both social and “disease avoidance” reasons, as higher weight bodies have become increasingly pathologized. Weight stigma carries consequences for fat bodies across multiple realms, with higher weight individuals paid lower wages, having less access to education, paying higher premiums for healthcare, and facing more weight-based bullying compared to thinner people (Puhl & Heuer, 2009). Weight stigma is a pervasive and growing phenomenon in much of the world (Brewis, SturtzSreetharan, & Wutich, 2018; Charlesworth & Banaji, 2019; Puhl, Andreyeva, & Brownell, 2008), including the global south and in countries where severe undernutrition still presents a major public health challenge (Brewis, SturtzSreetharan, & Wutich, 2018).

Weight stigma is particularly problematic as it is largely a socially acceptable form of discrimination (Puhl & Heuer, 2009). While not the only socially acceptable form of discrimination, the degree to which social leaders, the media, and the general public readily accept weight-stigmatizing beliefs makes combating weight stigma challenging. Within this lens, Puhl and Heuer (2009) point out that evidence of the acceptability of weight stigma is demonstrated through media representations of fatness, which frequently involve unkind, mocking, or derisive portrayals of large-bodied characters, news reports pathologizing fatter bodies, and advertisements for a plethora of products aimed decrease, prevent, hide, fix, disguise, or transform fatness.

## **Internalized Weight Stigma**

Weight stigma also manifests *internally* (i.e. internalized weight stigma), wherein higher weight individuals feel judgement and shame towards themselves (rather than from others or society) due to their higher weight (Durso & Latner, 2008). With internalized weight stigma, fat individuals adopt discriminatory attitudes towards their own bodies, mirroring the prejudicial attitudes of society, such that higher weight individuals may believe themselves to be bad, unattractive, lazy, unhealthy, or unmotivated due to their weight, regardless of their actual characteristics. This internalized weight stigma also interacts with the AN weight-based cognitions described above, wherein individuals with AN internalize shame about their bodies and have an intense fear of being fat and gaining weight, and negatively evaluate themselves based on their weight (which they perceive to be “too high” or “fat”). While AN individuals may not actually be fat, many have internalized messages that their weight is too high and therefore, unacceptable.

Higher weight individuals with AAN may face a compounded dose of weight stigma. Their higher weight bodies are systemically devalued by both society and their EDs. Thus, their ED symptoms of weight- and shape-overvaluation and body image disturbance may amplify experiences of internalized weight stigma that higher weight individuals experience (Durso, Latner, & Ciao, 2016). Given that internalized weight stigma has been found to moderate multiple eating and health behavior related outcomes (Mensinger, Calogero, & Tylka, 2016; Mensinger & Meadows, 2017; Mensinger, Tylka, & Calamari, 2018), understanding the extent and role of internalized weight stigma is warranted, particularly in regard to how AAN patients may have different illness experiences compared to their thinner counterparts with AN.

## **Theorizing Weight Stigma**

Weight stigma is a form of social identity threat theory (Dickerson, Gruenewald, & Kemeny, 2004), which hypothesizes how threats to the “social self” impact health and wellbeing.

Our social self is that aspect of a person that reflects a person's social value, status, esteem, and worth as perceived *by others* in society. As such, a person may have high self-esteem (and consider themselves to be valuable), yet still have low social esteem, if they are viewed by others as less worthy, important, valuable, or acceptable. According to social identity threat theory (Major, Eliezer, & Rieck, 2012; Major & O'Brien, 2005), threats to the social self involve situations in which there is a potential for the loss of social esteem, status, or acceptance (Dickerson et al., 2004). Threats to the social self involve rejection (whether explicit or potentially) due to a stigmatizing condition, uncontrollable characteristic, or unwanted identity (Dickerson et al., 2004). Relatedly, theorists argue that shame, a self-conscious emotion that involves both negative self-evaluation and witnessed judgments from others, enhances threats to the social self (Dickerson et al., 2004). Examples of identities which involve threats to the social self include HIV+ status and substance abuse. In both cases, a stigmatizing condition leads to potential social rejection. Central to social identity threat theory is the tenet that the stigma a person experiences as a result of the undesirable identity increases physiological stressors, which worsens health outcomes (Dickerson & Kemeny, 2004). Individuals who internalize shameful messages about their identity suffer worse health outcomes than those with the same identities who do not internalize shame to the same extent (Dickerson et al., 2004).

Social identity threat theory offers a useful lens when theorizing about higher weight people as a stigmatized group. In general, higher weight status is a stigmatized, socially undesirable status in Western cultures, and is largely perceived as something under a person's control (Puhl & Heuer, 2009). Additionally, higher weight persons tend to have high levels of internalized stigma believing themselves to be responsible for their higher weight status and the discrimination they experience (self-blame). To wit, in one study, believing oneself to be at an unacceptable

weight was more predictive of adverse health outcomes than actually being at a higher weight (Muennig, Jia, Lee, & Lubetkin, 2008). Further, the protective aspects of positive group identity such as those created by groups like recovering alcoholics or cancer survivors are less salient for higher weight people, as they often avoid group identification, and may avoid acknowledging their fat identity (Saguy & Ward, 2011). Other stigmatized groups, such as racial groups or queer communities, may gain protective factors (e.g., a sense of belonging) from group identification. One potential conclusion is that the stigma of higher weight status may contribute more to adverse health outcomes than the actual adipose tissue itself.

Within this dissertation, I approached weight status as a salient aspect of a person's social self which facilitated either social advantage (as in the case of low or "normal" weight persons, according to current BMI standards) or social threat (as in the case of higher weight persons). According to social identity threat theory, this social threat manifests in increased physiological stress responses and experiences of discrimination, thus worsening health outcomes. For patients with AAN, the shame of higher weight status (manifesting as internalized weight stigma), may be magnified compared to those without EDs, as overvaluation of body weight and shape is a defining characteristic of AAN.

## **Social Justice Considerations**

### **Incorporating Weight Stigma into a Social Justice Framework**

Weight stigma is an important part of social justice framework, because higher weight individuals systematically encounter discrimination from medical providers, insurance companies, family members, friends, and society due to their weight (Brownell, Puhl, Schwartz, & Rudd, 2005; Nutter et al., 2016; Puhl & Heuer, 2009). Though not a major focus of social work advocacy to date, theorists and social welfare scholars alike have argued for body weight to

become a greater focus of social justice advocacy work, as weight-based oppression is pervasive and significant, particularly in the global north, but with increasing impact in the global south as well (Brewis, SturtzSreetharan, & Wutich, 2018; Friedman, 2012; Nutter et al., 2016).

### **Weight Stigma as an Intersectional Social Justice Issue**

Within this discussion of weight stigma, it is important to note that weight stigma does not exist within a vacuum of other sources of discrimination. Racism, colorism, sexism, homophobia, transphobia, classism, ableism, healthism, ageism, xenophobia, and multiple other forms of discrimination intersect with weight stigma, such that individuals with different identities experience weight stigma differently. For example, in terms of age, a chubby (“obese”) baby with a round belly and dimpled legs may elicit expressions of delight and amusement, whereas an (“obese”) child may be viewed with pity, anxiety, or disappointment, and a chubby (“obese”) adult viewed with disgust, blame, or anger. Thus, it is not a person’s weight status *alone* that impacts stigma; it is their confluence of identity factors.

### **Weight Stigma as a Proxy for Other -Isms**

As with other forms of oppression, those embodying multiple marginalized identities face compounded challenges (Craig, 2006; Crenshaw, 1991). For example, women and femmes (those expressing or assigned more traditionally “feminine” gender aesthetics) experience weight stigma in different ways than men, because they are held to different aesthetic standards by society (Murnen, Smolak, Mills, & Good, 2003). Similarly, some racial and cultural groups have more protective cultural views about body size and weight, which impact how weight, food, and eating behaviors are perceived in these communities (Chin Evans & McConnell, 2003; Gordon, Castro, Sitnikov, & Holm-Denoma, 2010; Grabe & Hyde, 2005; Watson, Ancis, White, & Nazari, 2013; Wildes, Emery, & Simons, 2001). Other cultures have narrower views of what body sizes are appropriate or aesthetically pleasing, resulting in potentially more risk for these

groups (Chin Evans & McConnell, 2003). Some researchers have also argued that weight stigma is a proxy for other forms of prejudice that are less socially acceptable. For example, some racial groups, such as African Americans, are more likely to have higher BMIs (Heymsfield, Peterson, Thomas, Heo, & Schuna, 2016). In this case, where it is socially less acceptable to express racial gender, or class-based discriminatory beliefs, it is more socially acceptable to comment on body size, thus obscuring these other forms of discriminatory beliefs (Strings, 2019). As oppressed identities overlap, people may experience multiple forms of compounding oppressions, such as higher weight persons in marginalized communities with fewer economic resources, who may also experience illness and disability at higher rates (Ernsberger, 2009; Månsson & Merlo, 2001).

### **Liberatory Stance**

This research was undertaken from a liberatory stance (Freire, 1970), incorporating knowledge of privilege and oppression, while focusing on the social justice issue of weight stigma. A liberatory stance is built on the assumption that research is not (and cannot be) neutral; a primary goal of liberatory research is to ameliorate social inequities and injustices (Sandoval & Davis, 2000; Smith, 2012). Thus, I have approached this research from an explicit stance of exploring weight-based harm to learn how best to create a more equitable world for people of all sizes.

### **Amplification of Fat and Multiply Marginalized Voices**

In addition to choosing a topic which centers the voices of people in larger bodies, I also intentionally sought to represent diverse voices from people with multiple marginalized identities to increase our understanding of experiences currently missing in AAN literature. Participants with AAN were asked to speak from their own experiences and speak back to a scientific literature, which has largely ignored or pathologized them. A major goal of this research was to

amplify patient voices. I approached this research from a fat-liberation perspective, in the belief that fat bodies represent a normal form of human body diversity, and are inherently political, deserve to exist, and deserve equitable, respectful healthcare that is free from violence and coercion. Purposive sampling was utilized within this dissertation to explore the breadth of AAN experiences, intentionally sampling individuals with diverse identities, including those at normal and higher weights, nonbinary and trans individuals, patients presenting across the age spectrum, and participants with various sexual orientations and socioeconomic statuses.

### **Integration of Patient-Centered Approaches**

In an effort to magnify the voices of people with marginalized identities within the ED community, I designed this dissertation using elements of patient-centered research methods (Domecq et al., 2014; Sacristán José, 2013). This approach emphasizes the importance of individual patient's perspectives and experiences, beyond aggregate data aimed at the "average patient" (Sacristán José, 2013). In so doing, I sought to explore the breadth of the patient experience, with specific attention to those with diverse identities who may have different experiences than the "average patient" (Sacristán José, 2013). I included the following specific elements of patient-centered approaches: patient interviews, patient stakeholders giving input into the design of the interview guides, participant validation of the final transcripts, member-checking study results, and participant feedback on quantitative measures. Finally, to further integrate patient-centered methods into the qualitative analysis, I utilized narrative inquiry and phenomenological methods, focusing on understanding how patients understand their own experiences. This approach was informed by Kleinman's (1988) theory of patient explanatory models, which posits that a clinician must understand how a patient understands their own illness experience in order to best treat their disease. By eliciting patient explanatory models of their own illness experiences, I sought to better understand how ED providers can best support them.

## **Strategies to Reduce the Researcher Power Differential**

A final social justice consideration within this dissertation involved addressing the potential power differentials between myself (the researcher) and the participants (the researched). I implemented the following strategies to decrease the power differential, amplify patient voices, and to allow participants greater input into the research process: 1) Participants signed a consent form with five levels of consent to designate to what degree they would like to participate in the research, 2) Participants picked their own pseudonym unless they preferred not to (including their own first name if they wanted more ownership over their stories), 3) Participants could elect to either have their audio recordings used in public teaching and presentation forums or to have their audio destroyed instead, 4) Participants received all of their transcripts from the interviews, and were permitted to make any corrections that they wished, including deleting portions of the transcript, if, in retrospect, they wish they had not divulged certain information; participants were also permitted to add anything to their transcript in an effort to express their ideas most completely, 5) At the close of the interviews, participants were asked to share anything else pertinent to the topic that they wanted researchers and clinicians to know about their experience, in case there was a fundamental aspect of their story that was not specifically elicited in the interview protocol, 6) Participants were invited to “speak to healthcare providers” in the second interview (and provide insight about the kind of treatment they wish they had) with a question asking, “How might health providers be more supportive of your recovery?” 7) With participants’ consent, participants were invited to review papers prior to their publication, and offer feedback on the drafts (this was a form of member-checking, and was also an opportunity for participants to help shape the form and message of the research that was published about them, and 8) Participants were invited to give feedback on each of the quantitative measures, which, though validated scales, may have been imperfect at capturing the experiences of marginalized groups.



### **A Brief Note on Researcher Identity**

In the spirit of critical feminist scholars, I would like to situate myself in relation to this research. My identities as a white, nonbinary, assigned female at birth, queer, educated, fat (small-medium fat) individual necessarily shape my lens. I have experienced poverty, religious fundamentalism, and disability; I have benefited from generations of colonialism (societally and in my family's legacy). I have been fascinated by illness narratives from patients with EDs (how people develop, recover, change through illness) and peoples' evolving relationships with their bodies throughout these experiences (e.g. surveillance, control, medical gaze, autonomy, dissociation, acceptance, respect, affirmation, celebration, constriction, enlargement, healing). My approach is rooted in an intersectional standpoint (Crenshaw, 1990); I am committed to the work of body liberation.

My personal experiences with EDs were briefly documented in a recent article (Harrop, 2018). Having a personal history entwined with the questions this dissertation poses entails both insight and vulnerability. Having dealt with an ED for 25 years in various states of illness, relapse, and remission, I am an expert on my own experience and perspective—but not on others'. I have embodied an “underweight,” “normal,” and “obese” body within that time. I have reflected on my illness and remission, completed more than 40 journals, decades of therapy, and engaged in artistic and embodied practices. I have experienced outpatient, partial hospitalization, inpatient, and residential care, and both weight-centric and weight-inclusive (Tylka et al., 2014) treatment approaches. I have experienced discrimination due to poverty, homelessness, addiction, and body size, and I embodied privilege (race, size, education, social capital, nationality) that facilitated treatment access. I am also a mother, artist, athlete, student, coach, and meditator. These experiences have necessarily shaped my views.

In my clinical work, I bear the identities of clinician and patient simultaneously. As a medical social worker at a pediatric hospital, I witnessed traditional weight-centric approaches to ED care firsthand. I assessed adolescents with EDs and completed in depth interviews with their caregivers. From these experiences, I learned: 1) I could not accurately anticipate the degree of eating pathology by looking at the BMI of the person presenting with eating distress, 2) As medical providers, we often recommended dieting behaviors in higher weight children/adolescents that we considered pathological in lower weight children, 3) Adolescents did not appear to receive high enough levels of care until their weight fell to a certain point, 4) Patient perspectives seemed to diverge significantly from clinicians, and 5) it felt philosophically untenable to hold some Health at Every Size: HAES® tenets (e.g. body acceptance, intuitive eating, joyful movement, health equity), while maintaining a weight-centric approach to ED conceptualization and care. These clinical conundrums spurred me toward patient-informed research and advocacy.

This research and clinical work is grounded in advocacy. ED advocacy led me to fat activism, and fat activism led me to body liberation. Initially, I was afraid. I embodied a thin body and fat activism necessarily confronted some of my deepest, core, anorexic fears. As in any process of unlearning privilege, I had to confront my assumptions and internalized oppressions; I had to identify, digest, and understand my own weight stigma—and that of others. Loved ones did not want me focusing on the painful issue of “fat.” Some denied that fat was an oppressed identity; others argued it was a choice. Most in my life ignored the issue altogether.

Academically, a major part of my journey has been developing an academic “homeplace” (hooks, 2001) where I could safely explore these concepts of HAES®, fat-activism, and body liberation. Doing this work in community offered me a place to explore, connect, create, challenge, and develop. This dissertation is built on that homeplace, and from that homeplace of

personal experience, patient narratives, clinical practice, and ED advocacy, I have come to believe that fat-acceptance is a necessary component of the ED recovery movement. Weight stigma threatens not only fat individuals who bear the brunt of this stigma, but it also creates an environment which cannot promote wellbeing even for privileged bodies (Aphramor, 2005). Through storytelling, and retelling, we cocreate new narratives. Through listening to marginalized voices and witnessing these narratives, we cultivate empathy and compassion—and we realize we are not so separate. This is the heart of body liberation, and, I believe, only in this spirit can we truly promote health and wellbeing for all.

## **The Current Study**

### **Weight Stigma, Medical Care, and EDs**

Medical care and ED treatment are among the many realms impacted by weight stigma (Phelan et al., 2015; Puhl, Latner, King, & Luedicke, 2014). Although no research has yet directly assessed the effects of weight stigma on the care of people with AAN, it is likely that weight stigma may impact AAN individuals' experiences in treatment seeking and care for their EDs. A recent study by Puhl and colleagues demonstrated that ED professionals demonstrated weight stigma in their attitudes towards patients, with up to a third of professionals endorsing the belief that ED professionals are uncomfortable treating individuals at higher weights and have negative stereotypes of them (Puhl et al., 2014). Phelan and colleagues (2015) extended this work on negative provider stereotypes. These authors reviewed and synthesized literature on weight stigma and medical care, positing a theoretical model of stigma to explain relationships between obesity and adverse health outcomes. Drawing on research related to each theoretical link, the authors suggest the following: healthcare providers have strong negative attitudes towards heavier patients, leading to negatively stereotyping larger patients, and influencing

provider judgments about the types of care they recommend, how providers perceive patients, providers' interpersonal behaviors with patients, provider decision-making, and ultimately quality of care (Phelan et al., 2015).

Mensing, Tylka, and Calamari (2018) directly demonstrated the effect of weight stigma on healthcare avoidance in higher weight women. They showed how high BMI linked to increased weight stigma (both internalized and experienced firsthand). They went on to link weight stigma to body shame, body shame to healthcare stress, and finally, healthcare stress, to healthcare avoidance. Taken together, these complimentary theories suggest that healthcare provider weight stigma may lead to increased maladaptive patient behaviors such as healthcare avoidance, mistrust of providers, and less healthcare engagement on the part of heavier patients (Mensing et al., 2018; Phelan et al., 2015).

Given that some patients with AAN present at weights considered overweight or obese by current BMI standards, it is likely that these processes of weight stigma—stereotyping, physician and patient expectations, body shame, healthcare stress, and reduced quality of care—may also be impacting AAN treatment trajectories. Understanding how weight stigma functions for patients with AAN may provide useful insight into potential interventions at the provider and patient levels. If AAN providers had more knowledge of higher weight EDs, fewer weight stereotypes, more efficient screening and diagnosis practices, and better collaboration with higher weight AAN patients, it may increase quality of care, patient engagement, decrease health risks, and ultimately improve AAN outcomes.

### **Towards a New Theoretical Model for Weight Stigma and Higher Weight AAN**

Building from the theory work proposed by Mensinger, Tylka, and Calamari (2018) in addition to the work by Phelan and colleagues (2015), I propose an adapted theoretical model for higher weight patients with AAN engaging the healthcare system, which is shown in Figure 1. In

brief, similar to Mensinger and colleagues (2018), I propose that higher weight status leads to internalized weight stigma directed toward the self, as well as experiences of discrimination due to weight status, including discriminatory medical care. Diverging from Mensinger et al.'s model, I incorporate the ED cognitions and behaviors of AAN, theorizing that both forms of weight stigma (internalized and experienced discrimination) contribute to cycles of ED cognitive and behavioral symptoms. These ED experiences, in combination with discriminatory experiences based on weight then contribute to increased stress related to healthcare, which manifests in maladaptive patient behaviors, including healthcare avoidance, denial or minimization of ED symptoms, and reduced engagement. Finally, these maladaptive patient behaviors, in combination with weight discrimination experiences lead to poorer patient health and ED outcome. This could be hypothesized a final step further, by suggesting that the poor health and ED outcomes may create a negative feedback loop with the beginning of the model, strengthening stereotypes and discriminatory beliefs about the pathology and unhealthiness of fat persons.

As reviewed earlier, little research has directly addressed the AAN experience in depth, the health consequences of AAN, and the potential impacts of weight stigma on the course of illness in AAN. In this dissertation, I addressed these knowledge gaps in two major ways. First, I examined previously published studies on AAN in a systematic review, to determine what was known about the medical consequences of AAN and how they compared to AN. Second, I conducted a mixed methods study of a diverse sample of people with AAN to characterize the diversity and breadth of the AAN experience. Within this dissertation, multiple sources of data were each examined through the lens of weight stigma theory.

My approach makes several important contributions. First, a major strength of this study was the recruitment of AAN patients who presented across the age and weight spectrums, while

incorporating other aspects of diversity, including race, gender, and sexual orientation. Thus, a major contribution of this work is not how it compares the AAN experience to previously published studies of low-weight AN, but how it utilized mixed methods to better understand the *variation in the AAN experiences*, and how weight (and thus weight stigma) could impact differential experiences of the disease. Given the current state of AAN literature which has included mostly small, white, thin, young, cisgender female samples, describing this more diverse sample and testing to see how weight-related variables were associated with treatment delay and receipt is an important contribution. Primary data collection focused on patients with marginalized (and sometimes multiply-marginalized) identities in an attempt to capture greater sample diversity than is currently represented in AAN literature. Additionally, because the sample included those in both the “normal” range of BMI and the “overweight/obese” range of BMI, it is possible to apply a social identity threat lens to this data and compare the potential social “advantages” and “threats” experienced by participants based on their weight status. A final contribution is the utilization of weight stigma theory to more deeply understand AAN experiences that manifest across the BMI spectrum, as it provides a theoretical basis for why lower BMI individuals with AAN may have a different experience than higher BMI individuals with AAN.

### **Three-Paper Format and Research Questions**

Using a three-paper dissertation format, Paper One is a review of current published peer-reviewed literature, focusing specifically on the medical consequences and weight findings for people with a history of or currently experiencing AAN. Paper Two highlights the medical and weight stigma experiences of individuals with AAN with analysis of patient narratives of healthcare, treatment seeking, and ED treatment experiences. Qualitative interviews with patients with AAN were conducted and patient experiences of weight stigma were examined, specifically in regard to healthcare and treatment provider interactions. Paper Three presents the experiences

of this sample of patients with AAN quantitatively: the sample is described in terms of weight suppression, treatment delay, treatment history, ED severity, and ED-related functional impairment, while also examining the association between treatment delay and weight-related variables. To this end, I posed the following research questions:

**Paper 1: Systematic review of weight histories and medical consequences in AN and AAN populations.**

1. How do AAN individuals present in regard to current BMI, weight history, and weight suppression? How do AAN patients compare with AN patients in this regard?
2. What medical complications do AAN patients experience and at what rates? How do these rates compare to those with AN?

**Paper 2: Qualitative experiences of weight stigma in AAN patients' healthcare experiences.**

- 1) How do patients with a history of AAN report experiencing weight stigma in healthcare settings?
- 2) What are the patient-perceived impacts of these experiences?

**Paper 3: Characterizing the extent of AAN ED severity, ED-related impairment, and internalized weight stigma; Associations between weight-related variables, level of care, and treatment delay.**

1. To what degree do people with AAN in this sample experience ED severity, ED-related functional impairment, internalized weight stigma, weight suppression, and treatment delay? What percentage had received ED treatment, and what level of care did they receive?
2. What are the associations between weight-related variables (maximum BMI, minimum BMI, largest percent weight loss), highest level of care received, and treatment delay?

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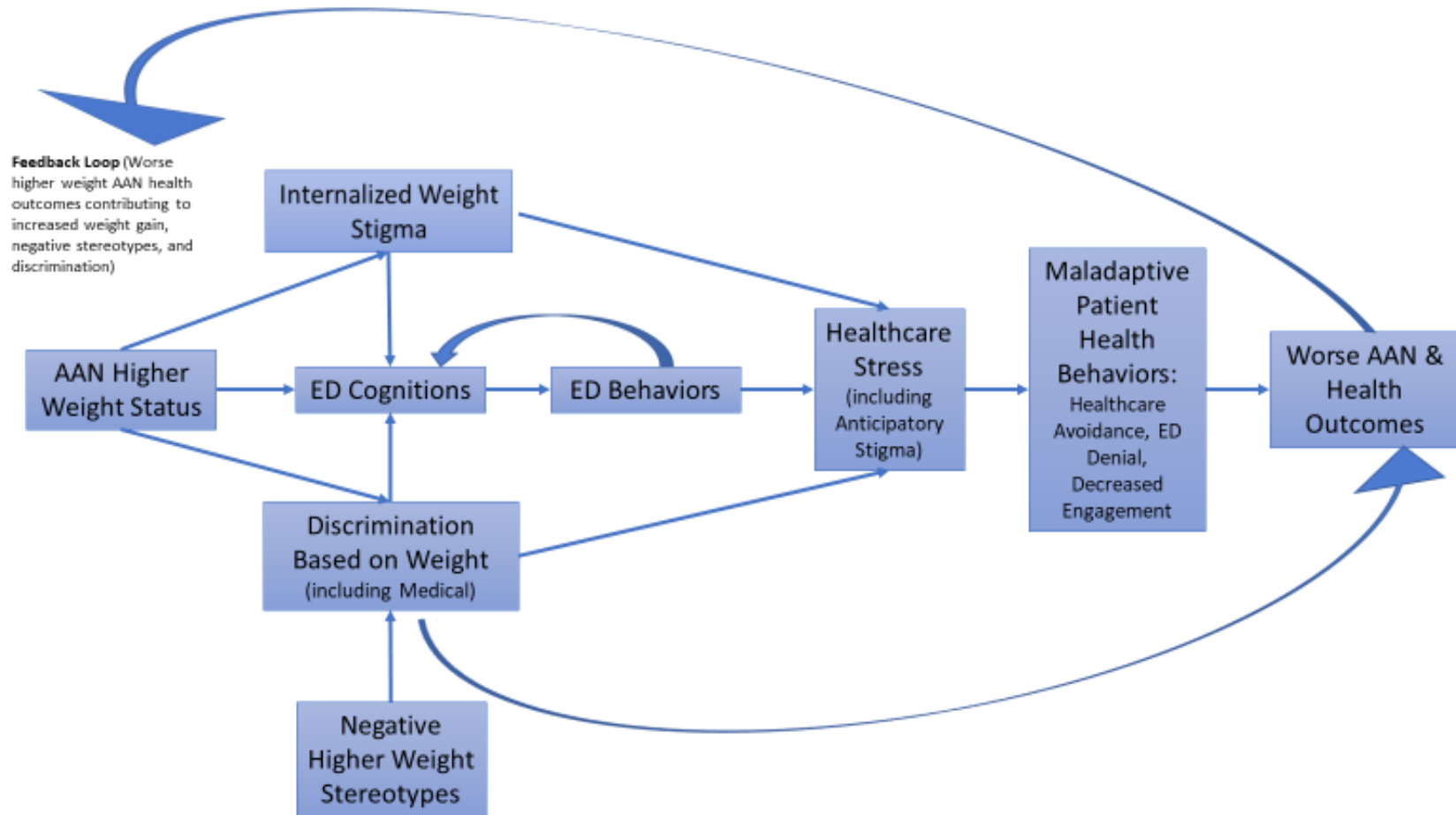


Figure 1. Proposed model showing how weight stigma may facilitate ED symptoms and poor healthcare outcomes for higher weight AAN patients.



Artwork by Grace, Participant 12

“A teenager loses over half their body weight in two years and it’s essentially ignored? [I was] eating under 800 calories a day and usually exercising twice that... it was all rendered invisible because I was a previously fat person who had become the “correct” size. I was a success story.”

--Mary, Participant 17

# CHAPTER ONE:

## WEIGHT HISTORY ACROSS THE LIFETIME AND MEDICAL COMPLICATIONS IN INDIVIDUALS WITH ATYPICAL ANOREXIA NERVOSA: A SYSTEMATIC REVIEW

### Abstract

Individuals with “atypical anorexia nervosa” (AAN) have cognitive and behavioral symptoms of anorexia nervosa (AN), except their body mass indices (BMI) are over 18.5. Though there are similarities between AN and AAN, debate persists regarding how patients with AN compare to patients with AAN in regard to weight history and medical complications. **Aims:** This systematic review of AAN literature from 2007 to 2018 investigates 1) the weight history and weight suppression of patients with AAN, 2) what medical complications patients with AAN face, and 3) how these symptoms compare with lower weight patients with AN. **Methods:** This report followed PRISMA procedures for systematic reviews, and searched three data bases (PsycInfo, CINAHL, and PubMed). The search strategy yielded 42 eligible articles which were coded for 18 data variables and assessed for quality using the Quality Assessment Scale. **Results:** Overall, AAN patients had higher current BMIs, lifetime nadir BMIs, and lifetime maximum BMIs, and experienced more weight loss prior to treatment. AAN samples tended to experience serious medical complications at levels commensurate to AN groups yet waited longer for medical care. Two additional gaps in studies reviewed were a lack of racially diverse samples and a lack of articles featuring patient perspectives or qualitative reports. **Discussion:** Similarities between AN and AAN in weight suppression and medical complications suggest that viewing AN and AAN as occurring on a spectrum (with BMI as but one severity indicator) may be more useful than viewing these disorders separately. Possible implications of a spectrum approach to AN include



facilitating faster diagnosis and access to life-saving treatment, particularly for those at higher weights, whose early stages of disease appear to be missed by healthcare providers.

**Keywords:** Atypical Anorexia Nervosa, Other Specified Feeding and Eating Disorder, Eating Disorder Not Otherwise Specified, Weight Suppression, Amenorrhea, Weight Stigma

## CHAPTER ONE:

### WEIGHT HISTORY ACROSS THE LIFETIME AND MEDICAL COMPLICATIONS IN INDIVIDUALS WITH ATYPICAL ANOREXIA NERVOSA: A SYSTEMATIC REVIEW

Eating disorders (ED) are complex biopsychosocial disorders with a plethora of serious medical consequences, including increased mortality and risk of death (Arcelus, Mitchell, Wales, & Nielsen, 2011). Of particular concern, anorexia nervosa (AN) has been found to have the highest mortality rate of all EDs (Arcelus et al., 2011), with mortality rates exceeding those of all other mental health disorders, except for opiate and methamphetamine disorders (Chesney, Goodwin, & Fazel, 2014). The physical consequences of EDs include weight cycling, malnutrition, amenorrhea, fertility concerns, bone density deterioration, overuse injuries, dental problems, impacts on brain matter, and life-threatening consequences such as cardiac arrhythmias, orthostatic instability, bradycardia, hypothermia, electrolyte imbalance, and Refeeding Syndrome (Bachmann et al., 2017; Beumont & Birmingham, 2004; Eynde et al., 2012; Galiger-Dobos & Túry, 2018; Gaudiani, 2018; Peebles, Hardy, Wilson, & Lock, 2010; Redgrave et al., 2015). While many of these physical effects are alleviated with nutritional rehabilitation and treatment, some medical consequences endure (Gaudiani, 2018).

When considering the medical consequences of EDs, weight-related consequences are prevalent and include weight loss and suppression, weight gain, and weight cycling (Murray et al., 2017; Serdar et al., 2011). Weight suppression (the difference between a person's highest and lowest past weights) is particularly concerning in EDs as it has been linked with ED severity (Bodell, Racine, & Wildes, 2016). For example, Bodell and colleagues (2016) found that weight suppression was associated with ED symptom persistence for individuals with higher BMI. These researchers found an interaction effect such that those with higher levels of weight

suppression and higher BMIs (i.e., those with higher BMIs who were still below their body's previous highest weight), experienced increased ED severity as noted by purging frequency and Eating Disorder Examination Questionnaire (EDE-Q) scores, and exhibited ongoing ED symptoms when followed longitudinally (Bodell et al., 2016). The researchers suggested that these individuals may have had a history of overweight or obese BMIs, which may have fueled fears of returning to higher weights, thus, resulting in higher weight participants engaging in more extreme or dangerous weight loss behaviors such as purging (Bodell et al., 2016, p. 761). Additionally, weight suppression correlates with future ED onset, such that those experiencing highest weight suppression were most at risk for EDs (Stice, Rohde, Shaw, & Desjardins, 2020).

Weight cycling (losing and then regaining weight) has also been identified as an area of concern in regard to weight consequences of EDs (Bacon & Aphramor, 2011). Weight cycling is commonly associated with weight loss attempts and disordered eating (Neumark-Sztainer et al., 2006), and has been found to be associated with cardiac disease (Rasla et al., 2016), insulin resistance (Oh et al., 2019), and overall mortality (Cologne et al., 2019; Zou et al., 2019). A study examining epidemiologically-ascertained data from the National Health and Nutrition Examination Survey found that weight cycling accounted for all excess mortality associated with obesity (Diaz, Mainous, & Everett, 2005). Weight-cycling has also been associated with psychological and behavioral consequences, such as lower self-esteem, lower health satisfaction, more frequent dieting, and higher rates of lifetime depression, anxiety, and EDs (Serdar et al., 2011).

While the medical complications of EDs such as AN and bulimia nervosa are well-documented, less is known about the physical consequences of atypical anorexia nervosa (AAN). AAN is an ED in which individuals meet all of the cognitive and behavioral criteria of AN, including caloric restriction, significant weight loss, fear of weight gain or behavior interfering

with weight gain, and disturbance in self-perceived weight or body shape or undue influence of weight or shape (American Psychiatric Association, 2013; APA). However, these individuals are usually not given an AN diagnosis as their weight has not yet reached a weight considered “less than minimally normal” or “expected,” which clinicians often interpret as a body mass index (BMI) less than 18.5 (APA, 2013, p. 338). AN is currently the only disorder in the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> Edition, DSM-5) that requires BMI criteria for diagnosis in addition to cognitive and behavioral symptoms (APA, 2013). Despite common assumptions that starvation only manifests in thin bodies, “average” or “fat” bodies (e.g. normal or high BMIs) can also become medically compromised due to malnutrition (Gaudiani, 2018). In addition to the physical effects of caloric restriction, AAN individuals also experience a variety of impairing cognitive and behavioral symptoms which may include obsessive calorie counting, compulsive food rituals, time-consuming exercise regimens, repeated body checking behaviors, and a variety of other common comorbid psychiatric conditions including depression, anxiety, self-harm, and suicidality (Koutek, Kocourkova, & Dudova, 2016; Ulfvebrand, Birgegård, Norring, Högdahl, & Von Hausswolff-Juhlin, 2015).

In regard to the clinical presentation of AAN, there is currently debate in the literature pertaining to how AAN patients compare to typically presenting underweight AN patients. As part of the Other Specified Feeding and Eating Disorders (OSFED) category, the AAN category is considered “subthreshold” or a “partial syndrome.” Due to this designation, some researchers argue that patients with these partial disorders fare better than those with typical AN (Bachmann et al., 2017; Bacopoulou et al., 2017; Swenne, Parling, & Salonen Ros, 2017). However, other researchers have shown that individuals with AAN present with similar sequelae of symptoms, psychiatric comorbidities, courses of treatment, severity, and levels of impairment as compared

to typically presenting individuals with lower BMIs (Fairweather-Schmidt & Wade, 2014; Sawyer, Whitelaw, Le Grange, Yeo, & Hughes, 2016; Thomas, Vartanian, & Brownell, 2009; Wade & O'Shea, 2015). Thus, the degree to which AAN produces physical impacts (e.g. weight changes, medical complications) commensurate with other full threshold ED diagnoses is as yet undetermined.

Finally, some researchers have also argued that individuals with AAN may present with distinct clinical challenges which may complicate illness trajectories and medical outcomes when compared to their lower weight peers (Peebles et al., 2010; Sawyer et al., 2016). For example, Sawyer and colleagues (2016) reported that compared to AN, groups with AAN experienced longer treatment delays, longer durations of symptoms, greater levels of weight loss, and increased distress related to body image. For higher weight patients with AAN, bias against higher weight bodies could contribute to delay of care if medical providers fail to recognize symptoms of AN in the absence of emaciation (Sawyer et al., 2016). Additionally, some AAN individuals considered overweight or obese by BMI standards, may be lauded by healthcare professionals for weight loss resulting from ED behaviors (self-starvation, purging, compulsive exercise) if providers do not question how such weight loss occurred; if left untreated, these behaviors could lead to bradycardia, electrolyte imbalance, hypothermia, and even death (Gaudiani, 2018).

### **The Current Study**

Despite ongoing debates regarding the clinical presentation of AAN, we are not aware of any reviews that synthesize AAN literature, making it difficult to ascertain what is known and what future research is needed. Currently, an area of debate in AAN research centers on the extent to which individuals with AAN experience physical consequences of EDs commensurate with those with typical low-weight AN. In order to better understand the physical consequences of AAN, this research posed the following questions: 1) How do patients with AAN present in

healthcare settings in regard to current weight, weight history, and weight suppression, and how do they compare to patients with AN in this regard? and 2) What medical complications (e.g. amenorrhea, bradycardia, hypothermia, electrolyte imbalance, losses in bone mineral density) do AAN patients experience and at what rates, and how do these rates compare to patients with AN?

## **Methods**

This systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Metanalyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009). An adapted PRISMA Review Checklist can be found in Appendix A.

### **Eligibility Criteria**

To be selected for the review, the article had to be written (or translated) in English and published in peer reviewed publications between January 1, 2007 and January 1, 2018. Though literature on higher weight restrictive eating disorders appears prior to 2007, this literature uses more heterogenous definitions of these disorders. The APA workgroup dedicated to the DSM-5 category of AAN began meeting in 2007, and so 2007 was selected as the lower limit for included articles. To be eligible, all articles needed to contain empirical data (or secondary data analysis) pertaining to a group that appeared to meet criteria for DSM-5 AAN (discussed below). Additionally, all articles needed to include some data pertaining to the weight history of patients with AAN (including any of the following: current BMI, lifetime maximum BMI, lifetime minimum BMI, weight suppression, rate of weight loss, BMI at amenorrhea, level of weight restoration), and/or medical consequences faced by individuals with AAN.

In accordance with DSM-5 criteria, all potential AAN samples were required to meet all of the following criteria: 1) energy restriction, 2) fear of weight gain or behavior interfering with weight gain, 3) disturbance in self-perceived weight or shape or undue influence of weight or

shape, and a BMI > 18.5. Articles operationalizing higher weight AN samples using diagnostic criteria from earlier editions of the DSM were included as long as the corresponding criteria capturing food restriction, fear of weight gain, and body image disturbance were met. AAN samples were required to experience clinical levels of distress, such that “subclinical,” and “prodromal” patient groups who failed to meet DSM-5 behavioral and cognitive criteria for AN were excluded.

Regarding weight-loss requirements for the AAN sample, various weight guidelines have been proposed to demarcate the boundary between typical and atypical AN (APA, 2013; Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017; J. J. Thomas, Roberto, & Brownell, 2009), with proposed diagnostic criteria (for AN) changing with evolutions of the DSM. For this review, we followed criteria outlined by Kandemir and colleagues (Kandemir et al., 2017), such that AAN included those with BMI > 18.5. Ambiguous AAN samples wherein all AAN individuals were between BMI 18.5 and 19.0 were excluded to more clearly delineate AAN. AAN samples using the DSM-IV cut off (BMI > 17.5) were included as long as some participants in the sample had BMI > 19.0, and no patients in the AAN group had BMI < 17.5. Finally, articles which combined AN and AAN participants for data analysis were included in this review, provided some results were reported which pertained to the AAN group specifically.

### **Information Sources**

PsycInfo, CINAHL, and PubMed databases were searched, with the final literature search completed through January 1, 2018. Articles were also located through back-citations and direct contact with study authors.

## Search

Search syntax for the databases was developed iteratively with all syntax trials and search results documented. Additionally, the author consulted with health science librarians and nutritional eating disorders experts to refine search terms. This process resulted in the following search term:

“(“partial anorexia”) or (“partial syndrome” and “anorexia”) or (“subthreshold” and “anorex\*”) or (“anorexia spectrum”) or (“DSM-5” and “anorexia”) or (“prodrom\*” and “anorex\*”) or (“higher-weight” and “anorex\*”) or (“sub-clinical” and “anorex\*”) or (“atypical” and “anorexia”) or (“higher weight” and “restrictive eating disorder\*”) or (“subclinical” and “anorex\*”) or (“sub-threshold” and “anorex\*”) or (“subsyndromal anorex\*”) or (“higher-weight anorex\*”) or (“EDNOS-wt”) or (“weight suppression” and “anorexia”) or (“weight suppression” and “restrictive eating disorder”)”

## Study Selection

The PRISMA (Moher et al., 2009) chart detailing the screening process and reasons for exclusions is found in Figure 1.1. During prescreening, articles prior to 2007, articles not in English, and ineligible publication formats (e.g. books, dissertations, etc.) were excluded. The author then reviewed the titles of all remaining articles, removing duplicates, and excluding clearly unrelated articles. The remaining articles were reviewed in full text form to assess for inclusion criteria. Due to the relatively recent classification of AAN, few articles focused on AAN specifically; thus full-text review was required to fully assess for potential eligible articles. For articles with questionable inclusion criteria, author Erin Harrop discussed these cases with author Janell Mensinger until consensus was reached to either include or exclude the article. If eligibility was still unclear after discussion, the original study authors were contacted to provide additional information regarding eligibility. If authors failed to respond, articles were excluded.



## **Data Collection Process, Data Items, and Summary Measures**

Eligible articles were reviewed and coded into five topical matrices which included: 1) Study Identification, 2) Methods, 3) Sample Characteristic Variables, 4) Outcomes Variables and 5) Implications. Two series of summary measures were recorded. Pertaining to aim one: investigating the weight history of individuals with AAN and AN: presenting BMI, maximum lifetime BMI, minimum lifetime BMI, BMI when patient reached amenorrhea, percent weight suppression, rate of weight loss, history of overweight and obesity, history of underweight, and weight restoration information. Pertaining to aim two: investigating the medical consequences faced by patients with AAN and AN: percent of sample with amenorrhea, duration and lifetime duration of amenorrhea, percent of sample with irregular menses, hypothermia, bradycardia, orthostatic instability, and electrolyte imbalance, and other medical symptoms or consequences (e.g. findings related to bone mineral density and vertebral strength).

## **Synthesis of Results**

This review followed the protocol outlined by Garrard for health science literature reviews, utilizing the matrix comparison method (Garrard, 2014). This protocol follows the following steps: 1) Read through all articles chronologically while coding each article according to a matrix of variables, 2) Compare results across studies (matrix rows) by examining each coded variable (matrix columns), 3) Analyze comparison matrices for themes, and convergences (similarities in variable columns) and divergences (disparate information in variable columns) of findings. Following step one of this process, articles were also coded for quality and rigor (as described in the following section). For quantitative findings, (rates of medical complications, BMIs, etc.), data were extracted from included studies and tabulated accordingly. Descriptive statistics (e.g. percent of studies reporting particular findings) were also calculated to summarize

main findings. For additional qualitative descriptive findings, brief summaries were recorded in data tables under the heading “Other Medical Findings” and “Other Menstruation Findings.”

### **Risk of Bias in Individual Studies and Across Studies**

This review utilized the Quality Assessment Scale (QAS; Kmet, Lee, & Cook, 2004) scored by a single reviewer (Harrop). The QAS is a quality assessment measure designed to assess rigor of scientific studies across a variety of study designs and methodologies and includes 14 areas of assessment, which has been cited by 943 scientific papers (for sample QAS application, see Ekelund et al., 2016). The QAS includes 14 areas of assessment including: 1) question and objective sufficiently described, 2) study design evident and appropriate, 3) method of subject and comparison group selection or source of information input variables described and appropriate, 4) subjects and comparison group characteristics sufficiently described, 5) if interventional, random allocation reported, 6) if interventional, blinding of investigators reported, 7) if interventional, blinding of subjects reported, 8) outcome measure well defined and robust to misclassification bias with means of assessment reported, 9) sample size appropriate, 10) analytic methods described, justified and appropriate, 11) some estimate of variance reported for main results, 12) controlled for confounding variables, 13) results reported in sufficient detail, and 14) conclusions supported by results (Kmet et al., 2004).

Each of these elements was scored as present (2), absent (0), partially present (1), or “not applicable.” Elements judged “not applicable” (for instance interventional blinding if no intervention was performed) were excluded from summary scores. Summary scores were calculated by taking the mean of all items, and dividing by 2, per QAS scoring conventions. Final QAS scores ranged from 0 to 1.0, with a score of 1.0 representing the presence of all quality elements and therefore minimal bias, and a score of 0 representing the absence of all elements, or maximum bias.

Factors impacting study quality were noted in each of the five matrices in a “Reflections” column. After scoring each article using the QAS, reasons for low or partial scores were listed in a “comments” column of the QAS matrix. This author re-reviewed their prior scoring of articles (and reasons for lower scores given) every ten articles, to increase consistency in scoring throughout the process. Following QAS scoring of all articles, the author assessed for common themes in the data (e.g. where studies frequently showed higher or lower scores) to assess for strengths and limitations across included articles as a whole. All studies were included in results synthesis, regardless of QAS score.

## **Results**

*<Insert Figure 1.1 here>*

### **Study Selection**

The search strategy yielded 2,175 articles for possible inclusion (See Figure 1.1 for PRISMA Flow Diagram). Of those, 1,428 articles were automatically excluded based on year, article type, or duplicates. An additional 198 were excluded during the title search, as they were unrelated to study aims. Following this, 549 full text articles were assessed. Of the 549 articles assessed, 17 studies contained research methods or samples with unclear eligibility, necessitating author contact to clarify eligibility criteria. Six authors failed to respond and were excluded by default, eight studies were deemed ineligible based on author response, and an additional three studies met inclusion criteria following author clarification of study sample and methods. All reasons for exclusion for the remaining articles are fully described in Figure 1.1. Ultimately, 42 articles reviewed met criteria for inclusion.

<Insert Table 1.1 here>

### **Study Characteristics and Risk of Bias**

Of the 42 articles, 6 utilized epidemiological samples, 24 utilized consecutive clinical admissions or referrals samples (in which participants were enrolled by selecting all consecutively referred or admitted patients to an institution), and 12 utilized convenience samples. Demographic characteristics of included studies are shown in Table 1.1 and organized by type of study sample (epidemiological, consecutive referral/admission, and convenience). All 42 studies defined gender in a binary fashion. Additionally, studies commonly featured female participants, with the majority of studies (86%,  $n = 36$ ) having at least 85% of their sample as female. In general, most studies focused on adolescent age 13-17 (71%,  $n = 30$ ) and young adult populations age 18-30 (79%,  $n = 33$ ). Roughly a third of studies included children up to age 12 (36%,  $n = 15$ ) and adults age 30 and older (31%,  $n = 13$ ). Fewer than a third of studies (31%,  $n = 13$ ) reported race as a demographic variable, but among those who did, the majority (77%,  $n = 10$ ) reported at least 85% of the sample as being white or Caucasian.

<Insert Table 1.2 here>

All studies were scored using the QAS measure, with scores ranging from .50 (highest bias) to .96 (lowest bias) ( $mean = .79$ ) on a scale from 0.0 to 1.0. Scoring for each study can be found in Table 1.2. Six studies assessed interventions (Gledhill et al., 2017; Hughes, Le Grange, Court, & Sawyer, 2017; Peebles et al., 2017; Redgrave et al., 2015; Smith et al., 2016; Swenne et al., 2017), relying heavily on quasi-experimental designs and rarely using control groups or

blinding, as studies were mainly assessing for feasibility. Within epidemiological studies, three utilized cross sectional designs (Forney et al., 2017; Hay et al., 2017; Zimmerman, Francione-Witt, Chelminski, Young, & Tortolani, 2008), while the remainder followed individuals longitudinally (Allen, Byrne, Oddy, & Crosby, 2013; Stice, Marti, & Rohde, 2013; Wade & O'Shea, 2015). Six studies reported on single cases or a small case series (Bayes & Madden, 2011; Berman, Boutelle, & Crow, 2009; Sim, Lebow, & Billings, 2013; Conceição et al., 2013; Harrison, Balasubramaniam, Robinson, & Norris, 2017; Wolter, Schneider, Pfeiffer, & Lehmkuhl, 2009). Three studies utilized age-matched designs (Bachmann et al., 2017; Parling, Cernvall, Stewart, Barnes-Holmes, & Ghaderi, 2012; Schorr et al., 2017), one study used a small convenience fMRI sample (Olivo et al., 2018), and two additional samples utilized convenience based internet or community samples (Cooper & Kelland, 2015; Davenport, Rushford, Soon, & McDermott, 2015). All remaining studies ( $n = 24$ ) utilized consecutive admission or referral samples with a wide range of study designs.

### **Findings regarding Weight, Weight History, and Weight Suppression**

Findings regarding mean BMI, weight history (e.g. lifetime maximum BMI, lifetime minimum BMI, percent with history of underweight BMI), and weight suppression (e.g. percent with history of overweight and obese BMI, percentage of weight loss, duration of weight loss) are presented in Table 1.3.

*<Insert Table 1.3 here>*

**BMI at presentation.** By definition, individuals with AAN present with higher BMIs compared to AN, which was represented in the findings of Table 1.3. Without exception, all studies comparing BMI at presentation found AAN samples to have higher BMIs compared to

AN samples. All studies (100%,  $n = 18$ ) reporting current BMI for individuals with AN reported mean BMI's falling between 15 and 18. For studies reporting mean BMI for AAN samples, the majority reported BMI's in the "low normal range" (BMIs approximately 18.5-22). Forty-eight percent ( $n = 15$ ) reported mean BMIs between 18 and 21, 39% ( $n = 12$ ) reported mean BMI's between 21 and 24.9, and 13% ( $n = 4$ ) reported mean BMI's at 25 or higher. For studies reporting AAN mean BMI's above 25, one involved a bariatric sample (Conceição et al., 2013), and the remaining involved adult epidemiological samples in the US and Australia (Forney et al., 2017; Hay et al., 2017).

**Weight history.** To assess weight history of AN and AAN samples, lifetime minimum and lifetime maximum BMIs, with standard deviations, were recorded ( $n = 12$  studies). Studies reporting weight history information for AAN individuals also reported that AAN patients had higher lifetime maximum BMIs (Davenport et al., 2015; Peebles et al., 2017; Rockert, Kaplan, & Olmsted, 2007; Santonastaso et al., 2009; Whitelaw, Gilbertson, Lee, Gilbertson, & Sawyer, 2014) compared to AN individuals. Compared to AN, AAN also had higher lifetime minimum BMIs (Davenport et al., 2015; Rockert et al., 2007; Santonastaso et al., 2009; Schorr et al., 2017).

**History of overweight and obesity.** Across all studies reporting, AAN patients were also more likely to have been previously (or currently) classified as overweight or obese according to current BMI standards. For instance, Whitelaw and colleagues' study of adolescents with Restrictive Eating Disorders (REDs), found that 17% of AAN individuals had been previously overweight and an additional 29% had been classified as obese, compared to 11% and 7% of AN patients (Whitelaw et al., 2014). Sawyer and colleagues found even higher rates, with 71% of AAN individuals presenting with a history of overweight or obesity, compared to 12% of AN

(Sawyer, Whitelaw, Le Grange, Yeo, & Hughes, 2016). Hughes and colleagues (2017) found similarly high rates of overweight/obesity in AAN (64%), though 6-9 months after treatment, only 7% had returned to this category (Hughes et al., 2017). Kennedy et al. (2017) found similar rates of history of overweight/obesity in their AAN sample (66.3%)—double that of the AN sample (33.7%). Of note, these researchers also found that 7.9% of previously overweight/obese patients with REDs were still overweight or obese when requiring medical stabilization at an inpatient facility (Kennedy et al., 2017). Overall, in all but two studies reporting history of overweight/obesity, at least 40% of the participants in AAN samples had a history of overweight/obese BMIs. Except in cases of bariatric samples, AN samples tended to have lower rates of history of previous overweight/obese BMIs.

**History of underweight BMI in AAN.** Despite higher minimum BMIs compared to AN individuals, a significant portion of AAN individuals had previously been underweight during their lifetimes, meeting criteria for typical AN diagnosis (Rockert et al., 2007; Schorr et al., 2017). For example, Santonastaso and colleagues (2009) found a mean lifetime minimum BMI of 17.8 for AAN individuals, suggesting that many would have previously met AN criteria during other periods in their lifetime. Similarly, 54% of Rockert and colleagues' (2007) sample, 80% of Bachman's sample (2017), 82% of Davenport et al.'s sample (2015), and 83% of Schorr and colleagues' (2017) AAN sample had previously met low BMI criteria for AN earlier in their lifetimes. By contrast, Swenne's (2016) sample, which examined only adolescents, found that only 1.6% had a history of a BMI Z-score less than -1, suggesting that few AAN participants in this study had a history of underweight as adolescents.

**Weight suppression and rates of weight loss in AAN.** There are multiple ways of measuring weight suppression, including measuring the difference between a person's highest

and lowest weight, measuring the percent body weight lost, measuring total BMI points lost, or measuring an absolute amount (e.g. 4.2 kg); this heterogeneity of definition makes cross-study comparison difficult. With the exception of one bariatric sample (Conceição et al., 2013), studies reported that individuals with AAN presented with percentages of weight loss on par with or exceeding the weight loss of AN patients (Kennedy et al., 2017; Peebles et al., 2010; Santonastaso et al., 2009; Whitelaw et al., 2014; Sawyer et al., 2016; Swenne, 2016). While two studies (Santonastaso et al., 2009; Whitelaw et al., 2014) reported equivalent levels of percent of weight loss between AN and AAN, most studies reported that AAN weight loss exceeded AN (Kennedy et al., 2017; Peebles et al., 2010; Sawyer et al., 2016; Swenne, 2016). In Peebles and colleagues' (2010) study of AAN and AN inpatients, AAN patients had lost an average of 34% of their body weight prior to admission, compared to 23% weight loss experienced by AN adolescents; AAN patients had also lost weight at a faster rate.

In some cases, AAN patients presented with significantly elevated BMI initially (Sim et al., 2013; Conceição et al., 2013; Wolter et al., 2009) and subsequently lost large amounts of weight prior to treatment. Some of highest weight suppression evidenced involved patients in a bariatric sample (Conceição et al., 2013) who lost an average of 26.4 BMI points, ranging from 14.5-45.4 BMI points. In another study, which measured weight suppression with percent of premorbid body weight lost, a teen lost 39% of her body weight in four months, prior to receiving care (Wolter et al., 2009); in Sim's (2013) case studies of two adolescents with AAN, one adolescent lost 45% of her body weight (the second lost a greater percentage, but the exact percentage was not recorded). These results are contrasted with two adolescent-based samples with lower levels of weight suppression, with AAN samples losing on average a total of 6.7 kg and 6.3 kg, respectively (Olivo et al., 2018; Swenne et al., 2017). In assessing these findings, Swenne



and colleagues concluded that adolescents in the sample with higher weight suppression experienced more severe EDs. Additionally, weight suppression often persisted throughout treatment (Berman et al., 2009; Hughes et al., 2017; Wolter et al., 2009) and levels of persistent weight suppression predicted worse outcomes for AAN individuals as measured by EDE-Q global scores (Swenne et al., 2017).

**Weight restoration findings.** Five studies reported on weight restoration with patients with AAN in case studies (Berman et al., 2009; Wolter et al., 2009) or larger samples (Hughes et al., 2017; Peebles et al., 2017; Santonastaso et al., 2009), with two additional studies featuring results of refeeding protocols in regard to medical symptoms, without mentioning information specific to AAN weight restoration (Redgrave et al., 2015; Smith et al., 2016). Two case studies reported minimal changes in weight, with AAN patients averaging a mean increase in BMI of 0.2 BMI points (Wolter et al., 2009) and 0.4 BMI points (Berman et al., 2009). Hughes and colleagues reported no statistically significant changes in BMI for patients with AAN, with one patient worsening and developing AN, and another experiencing an unusually large increase in BMI. Santonastaso and colleagues (2009) reported an increase in BMI post-treatment for patients with AAN from 19.0 to 20.2 (compared to patients with AN, 15.7 to 18.4). Finally, Peebles' (2017) report of an inpatient refeeding protocol included the most robust weight restoration, with clinicians explicitly aiming for higher levels of weight restoration.

While not including any specific data on amount of weight restoration for AAN participants, Smith and colleagues (2016) and Redgrave and colleagues (2015) concluded that weight restoration protocols that “start high and advance fast” were safe and tolerable for AAN patients in their studies. Of importance to these weight restoration studies, restoration and estimated energy requirements were sometimes based on universal guidelines for all participants (AN and

AAN alike), such as restoring to a BMI of 20 regardless of individual weight suppression (Redgrave et al., 2015; Smith et al., 2016).

### **Findings Related to Medical Complications of AAN**

Findings regarding rates of amenorrhea, lifetime duration of amenorrhea, and menstrual irregularity are shown in Table 1.4. Findings regarding other medical consequences of AAN including rates of bradycardia, orthostatic instability, hypothermia, electrolyte imbalance, and impact on bone mineral density (BMD) are shown in Table 1.5.

*<Insert Table 1.4 here>*

**Findings regarding amenorrhea and irregular menses.** Though never exceeding the rates of AN (unless studies required amenorrhea for a classification of AAN), instances of amenorrhea were common in AAN samples (Sim et al., 2013; Damiano, Reece, Reid, Atkins, & Patton, 2015; Forman et al., 2014; Hughes et al., 2017; Sawyer et al., 2016; Swenne, 2016; Swenne & Ros, 2017; Wolter et al., 2009). Menstrual irregularity tended to occur in over half of AAN cases (Forman et al., 2014; Hughes et al., 2017) and amenorrhea was noted in about a third of AAN cases (Bachmann et al., 2017; Olivo et al., 2018; Sawyer et al., 2016; Schorr et al., 2017; Swenne & Ros, 2017) with one epidemiological study finding lower rates of amenorrhea ranging between 4-6% (Forney et al., 2017). When statistical differences between AN and AAN groups were noted, AN always had higher rates of amenorrhea (Bachmann et al., 2017; Forman et al., 2014; Sawyer et al., 2016). AAN patients also reported higher BMI at amenorrhea (Sim et al., 2013; Forney et al., 2017; Santonastaso et al., 2009; Wolter et al., 2009) with 4.5% of AAN participants experiencing amenorrhea with as little as a 5% weight loss (Forney et al., 2017). Santonastaso and colleagues (2009) found that AAN groups experienced amenorrhea at higher

BMI (mean = 19.3, SD = 1.8) than groups with AN (mean = 17.9, SD = 1.9). Of note, instances and durations of amenorrhea were correlated with more severe medical complications including decreased bone mineral density (BMD) and volumetric strength (VS) (Bachmann et al., 2017; Bacopoulou et al., 2017).

*<Insert Table 1.5 here>*

**Rates of serious medical complications.** As shown in Table 1.5, multiple articles noted the presence of clinical signs of malnutrition in AAN individuals and life threatening symptoms (Bachmann et al., 2017; Bacopoulou et al., 2017; Bayes & Madden, 2011; Sim et al., 2013; Peebles et al., 2010; Peebles et al., 2017; Whitelaw et al., 2014; Sawyer et al., 2016; Swenne, 2016; Swenne et al., 2017; Swenne & Ros, 2017). Most studies found few or no differences that reached statistical significance in the rates of serious medical complications between AAN and AN groups (e.g. bradycardia, orthostatic instability, hypothermia, electrolyte imbalance), indicating that these groups had similar rates of medical problems.

Whitelaw and colleagues (2014) found no differences in rates of acute medical complications between AN and AAN individuals, including no differences in rates of bradycardia, low body temperature, or incidence of hypophosphatemia, hypomagnesemia, or hypokalemia. However, AN patients were noted to have lower prone position systolic blood pressure. Similarly, Sawyer and colleagues (2016) also found no difference in rates of low pulse rate, hypothermia, frequency of bradycardia, marked orthostatic changes, or medical need for inpatient hospital admission, but did find AAN individuals to have higher systolic blood pressures, higher body temperatures, and less hypotension. Peebles and colleagues (2010) also found no differences in rates

of hypothermia, orthostatic hypotension, or hypokalemia. However, they did find differences between AAN and AN groups, with AAN individuals faring worse in regard to rates of bradycardia and orthostasis, but better in regard to rates of hypotension and shorter QTc intervals (a measure of irregular heart rhythms). Similar to Sawyer and colleagues, they also found AAN had lower rates of hypotension.

## **Discussion**

The reviewed literature on the weight and medical consequences of AAN suggest that AAN presents as a significant, impairing, dangerous psychiatric disorder, manifesting across the lifespan and across the weight spectrum. Regarding weight-related findings, on the whole, AAN patients consistently reported higher presenting BMIs, lifetime maximum BMIs, lifetime minimum BMIs, and BMIs at amenorrhea, compared to patients with AN. AAN groups were also more likely to have a history of overweight or obese BMI compared to AN groups; often well over half of AAN samples reported histories of overweight and obese BMIs (Hughes et al., 2017; Kennedy et al., 2017; Whitelaw et al., 2014; Sawyer et al., 2016). Interestingly, a large portion of AAN groups also had histories of previous underweight BMIs, with at times up to half of the sample reporting previous underweight, and therefore a likely past AN diagnosis, whether they received treatment for this or not (Bachmann et al., 2017; Davenport et al., 2015; Rockert et al., 2007). Taken together, these findings suggest that patients with AAN may experience significant weight shifts (ranging from underweight to obese ranges of the BMI) and hence experience the health consequences of weight cycling (Zou et al., 2019). Such notable diversity of bodily presentation for AAN patients (with significant proportions experiencing underweight BMI, normal BMI, and elevated BMI within their lifetime), indicates that body size and BMI status are

likely poor indicators for when further ED screening is needed. As such, clinicians need to rely on other behavioral and medical cues to prompt screening.

Second, since a significant portion of AAN individuals experienced both elevated and underweight BMIs, this highlights the concern for sizeable weight suppression occurring in many individuals with AAN. Indeed, weight suppression findings revealed that patients with AAN tended to have levels of weight suppression meeting or exceeding the weight suppression exhibited by those with AN (Peebles et al., 2010; Sawyer et al., 2016). Previous research has found weight suppression to predict AN severity and prognosis, independent of BMI (Goodman, Berner, Shaw, Witt, & Lowe, 2013), and this may also be the case in AAN. Identifying weight suppression also represents an important intervention opportunity, as case reports of higher-weight adolescents experiencing high levels of weight suppression (e.g. 45% and 38.8% weight loss, respectively), show adolescents presenting for care with sentinel symptoms of starvation (e.g. rapid weight loss, amenorrhea, orthostatic changes) months to years before an ED was identified (Sim et al., 2013; Wolter et al., 2009). In one case, Sim and colleagues note that while the patient's weight "was a focus of discussion at all medical appointments throughout his childhood... during the 13 medical encounters that took place while he was losing weight [45% of his body weight], there was no discussion of concerns regarding weight loss" (Sim, et al., 2013, p. e2). While these case studies of multiple "medical misses" paint a sobering picture, they also highlight an important opportunity; when patients present with rapid weight loss, even in the context of elevated BMI, screening for ED symptoms and behaviors (and co-occurring medical comorbidities) could prevent or ameliorate further medical deterioration.

Finally, given that many AAN individuals presented with histories of underweight AN, this prompts the question for how to classify these individuals. For individuals with a recent

history of AN, the DSM-5 instructs clinicians to diagnose individuals no longer meeting the weight criterion of AN with a diagnosis of “AN, in partial remission” (APA, 2013, p. 339). However, for those patients for whom the AN diagnosis is a more distant event, it is unclear if these individuals should retain the AN diagnosis (due to past history of the disorder) or be categorized as OSFED, type AAN (due to present characterization of symptoms). Such classifications have significant implications for the type of treatment an individual may then receive, in addition to affecting how such cases are counted epidemiologically, providing the basis for understanding disease burden. Additionally, the finding that the AAN group has a history of underweight BMIs is also important as lifetime history of underweight has been linked with worsening long-term consequences of AN, such as decreased bone mineral density and volumetric strength; for patients suspected of having AAN with histories of low BMI, additional screening or intervention may be indicated (Bachmann et al., 2017; Schorr et al., 2017).

A final weight-related finding worth further examination involves the mean presenting BMIs for AAN samples. In this review, the mean BMIs (and weight ranges) of included participants was within the normal weight range, potentially truncating AAN samples by rarely including heavier patients. AAN samples commonly had mean BMIs in the low end of the normal BMI range, with only 13% of studies having AAN BMI means above the normal range ( $BMI \geq 25$ ). However, given that the largest epidemiological study of AAN found a mean BMI of 27.8 ( $SD = 6.3$ ), it is unlikely that people above a BMI of 25 simply failed to develop this disorder. Thus, it is not clear how many AAN individuals at the higher end of the weight spectrum may be missing from current literature and clinical samples, so the full scope of the problem of AAN in higher weight populations is as yet unknown. However, evidence from ED researchers evaluating those

with a history of elevated BMI indicates that AAN is a significant and underrecognized problem in higher weight populations (Kennedy et al., 2017; Sawyer et al., 2016; Swenne, 2016).

Regarding medical complications, studies reported similar levels of acute medical complications between AAN and AN samples, including similar rates of low pulse rate, bradycardia, hypothermia, orthostatic changes, and electrolyte imbalance (Peebles et al., 2010; Whitelaw et al., 2014; Sawyer et al., 2016). Even when testing across many variables, few differences in medical presentation reached statistical significance, and Sawyer and colleagues (2016) note that even if lab markers were statistically different between AN and AAN samples (e.g. a lower temperature in AN vs. AAN), AAN levels were still *clinically* significant, in that they warranted intervention or monitoring, despite being potentially less impaired than the levels of AN groups. Similarly, Peebles (2010) noted that while AN and AAN groups presented with similar rates of medical concerns, patients with AAN seemed to fare slightly better in some areas (e.g. rates of hypotension, length of QTc interval), and in other areas patients with AAN seemed to fare slightly worse (e.g. rates of bradycardia, orthostasis) than low-weight AN, leading her to conclude that, those with AAN presented as “more compromised than... patients with AN in some medical outcomes. This is the case despite being at a significantly higher, near ‘ideal’ body weight, reminding us that malnutrition is a complex disease with manifestations at multiple weights” (p. e1198). Similarly, Whitelaw and colleagues (2014), when reflecting on their more than fivefold increase of adolescents with AAN in the preceding six year period, concluded that “Despite not being underweight, [AAN] patients experienced a similar profile of life-threatening complications of weight loss as patients who have AN” (p. e758). Sawyer and colleagues (2016) echoed this sentiment, concluding that, “Many adolescents with AAN are physically unwell and have psychological morbidity as severe as underweight adolescents with AN” (p. 1).

Regarding findings pertaining to menstruation, there was a trend toward AAN experiencing amenorrhea, BMD deterioration, and hormonal disruption at lower rates compared to AN, but with a sizeable proportion of AAN individuals still experiencing clinical levels of impairment, and at higher rates compared to normal controls (Bachmann et al., 2017; Bacopoulou et al., 2017; Forman et al., 2014; Sawyer et al., 2016; Schorr et al., 2017). Rates and durations of amenorrhea are particularly concerning as they are associated with more severe long-term outcomes, such as bone density loss (Bachmann et al., 2017; Schorr et al., 2017). Typically, in treatment samples, about of third AAN groups were amenorrheic, with rates never exceeding those of AN patients (Bachmann et al., 2017; Hughes et al., 2017; Olivo et al., 2018; Sawyer et al., 2016; Swenne et al., 2017; Swenne & Ros, 2017). In community samples, amenorrhea rates for AAN were lower (Forney et al., 2017; Zimmerman et al., 2008). However, Forney and colleagues also found that individuals with AAN could present with amenorrhea with as little as 5% weight loss.

Finally, this review also suggests that in addition to experiencing greater levels of weight suppression during the ED (Kennedy et al., 2017; Peebles et al., 2010; Sawyer et al., 2016), AAN individuals may also experience sustained weight suppression after treatment, particularly when uniform weight restoration goals are set for all patients receiving nutritional rehabilitation, regardless of premorbid BMI. For example, several authors reported uniform target BMIs for all patients on weight restoration protocols (Redgrave et al., 2015; Smith et al., 2016), with target BMIs set at 20 or 21, a weight at which many AAN patients start treatment. This weight goal also posed problems in analyses of some studies, wherein if remission from ED was defined as reaching a uniform BMI, some AAN individuals were considered “remitted” prior to even beginning treatment (Forman et al., 2014; Hughes et al., 2017). For example, in one study (Hughes et al., 2017), though 64% of AAN patients had been classified as overweight or obese premorbidly,



only 7% were classified this way post treatment, suggesting sustained weight suppression. Furthermore, despite this sustained weight suppression, many AAN were classified as recovered due to meeting the uniform weight cut-off. Notably, in this sample, nearly a fifth (19%) of patients continued to be amenorrheic post-treatment, suggesting that additional weight restoration may be necessary for full medical recovery.

This pattern was also noted in other studies where AAN patients were considered “in remission” having achieved little (if any) weight restoration, and while still experiencing amenorrhea and ongoing cognitive symptoms of AAN (Berman et al., 2009; Wolter et al., 2009).

Swenne (2017) suggested that because “high weight suppression was independently associated with persistence of the ED, [w]eight recovery thus needs to be aimed at the premorbid growth trajectory of the adolescent rather than a weight standardized for gender, age, and height” (p. 7). Similarly, Peebles concluded that in AAN, weight restoration should be considered in the context of individual patient trajectories, not simply aiming for ideal or median BMI ranges (Peebles et al., 2010; Sawyer et al., 2016; Swenne et al., 2017). However, Peebles tempered this recommendation, citing the need to aim lower than past trajectories if patients were “extremely overweight” (Peebles et al., 2017, p.12); others suggested weight management of AAN should in some cases include weight loss if individuals remain overweight after treatment (Hughes et al., 2017). Thus, there is little consensus regarding weight restoration in AAN.

## **Limitations**

Though this literature review used a rigorous synthesis process to critique AAN research, there are several notable limitations. First, this review employed a single coder when coding data and assessing article quality. Second, though the category of AAN has existed within clinical research for decades, this review limited the search to articles post-2007, the year in which the APA workgroup which formalized the AAN category for DSM-5 began to meet. Third, in an

effort to obtain a more comprehensive picture of AAN literature, this review did not limit inclusion to only one type of study methodology, so identification of effect sizes via meta-analysis were not possible. Fourth, studies utilized multiple operational definitions for AAN, so measurement bias exists between samples. Finally, while this review utilized broad inclusion criteria, permitting any articles with any combination of medical or weight history findings for individuals with AAN to be included, the depth of findings specific to AAN was often lacking, as AAN was often not necessarily the focus of these studies (e.g., it was one of many included diagnostic categories). As such, results of this literature review should be viewed as preliminary groundwork in hopes of paving paths for more robust research on AAN.

### **Clinical Implications**

First, similarities between AAN and AN (in regard to diagnostic criteria, medical consequences, weight suppression, etc.) suggest that viewing AN and AAN as occurring on a spectrum (versus separate diagnoses) may facilitate diagnosis and access to life-saving treatment. Considering that weight loss levels as low as 5% were associated with clinically significant impairment (Forney et al., 2017), defining AAN, a psychiatric disorder, on the basis of cognitive, behavioral, and impairment symptoms *alone* could be sufficient. Viewing AN as occurring on a spectrum, with weight being just one factor affecting severity (in addition to other biological and psychiatric markers), may also enhance clarity between AAN and other disorders, including Purging Disorder (PD; an ED wherein individuals purge in absence of binges) and a residual RED. At minimum, the field should consider clarifying diagnostic hierarchy for residual ED diagnoses to aid in furthering ED nosology and standardizing diagnostic practices. However, multiple authors noted how similarities between AN and AAN individuals, point toward potentially overlapping constructs, suggesting that a more transdiagnostic approach (Ekeroth, Clinton, Norring, & Birgegård, 2013; Forman et al., 2014) may be warranted, or that AN and AAN may exist on “a

continuum of the same spectrum of restrictive ED” (Olivo et al., 2018). A spectrum approach would also resolve questions for how to categorize current AAN individuals with a previous history of low-weight AN. These diagnostic conceptualizations must also be balanced with concern for the natural stigmatization that occurs when people are “diagnosed” or considered “diseased” (Griffiths, Mond, Murray, & Touyz, 2015). However, in the case of obese individuals with AAN, additional harm may be minimized as their bodies are already treated as abnormal or ill (Star, Hay, Quirk, & Mond, 2015).

Second, some studies showed that AAN patients presented with sentinel symptoms of malnutrition (e.g. weight loss, low heart rate, orthostatic changes, menstrual irregularity) months or years before providers screened them for EDs, resulting in even more severe medical complications (Sim et al., 2013; Sawyer et al., 2016; Wolter et al., 2009). This is likely particularly pronounced for fatter patients for whom weight management strategies have been recommended. The AAN case studies reviewed here suggest that weight loss may be one of the first noticeable indicators that a person is engaging in ED behaviors (fasting, purging, compulsive exercise). If weight loss resulted in a brief provider intervention to screen for ED behaviors and cognitions (as opposed to automatic praise), this could interrupt further ED development and medical complications in ED-vulnerable individuals. Particularly for children and adolescents who experience normal and escalating weight gain with developmental changes, noting deviations in growth trajectories and universally screening those individuals for body dissatisfaction and ED behaviors could facilitate the early identification of these “less visible” AAN patients.

Third, if ED cognitions or behaviors are discovered in a primary care context, it is important that individuals receive psychosocial follow-up with consistent, comprehensive medical monitoring given the potential for severe medical consequences to go unnoticed (See Gaudiani,

2018 for a provider overview). Among psychiatric disorders, mortality rates of AN are second only to opiate and methamphetamine disorders (Arcelus et al., 2011; Chesney et al., 2014). Given the similar life-threatening complications found in AN and AAN, treatment for AAN individuals should be a priority. Forman (2014) summarizes this sentiment, asserting that “it is hoped that the seriousness of the percentage of body weight lost and the impact of extreme weight loss behaviors on the individual will be viewed by health care providers and insurers as just as important for those with AAN as for AN” (p. 753-4).

Fourth, given that AAN has been noted to occur in normal weight, overweight, and obese populations (Forney et al., 2017; Hughes et al., 2017; Kennedy et al., 2017; Sawyer et al., 2016), it is important to consider the potential impacts of weight stigma on this patient population, which is, by DSM-5 definition, acutely attuned to issues of weight. A large proportion of AAN individuals present with a history of overweight or obesity (Whitelaw et al., 2014; Sawyer et al., 2016), and for these individuals, psychiatric symptoms of fear of fatness may be exacerbated by lived experiences of weight stigma and discrimination (Sawyer et al., 2016). Wade and O’Shea (2015) also caution that given the tendency for AAN individuals to present as overweight, ED “behaviors may in fact be encouraged rather than highlighted as a cause for concern” (p. 373). Clinical interventions aimed at decreasing internalized weight stigma, and interventions at the societal and provider level aimed at decreasing weight stigma may benefit this population. Additionally, screening for ED symptoms, behaviors, and cognitions should occur prior to any clinical recommendation for weight loss, given the rising rates of these underdiagnosed and dangerous EDs, particularly in populations previously thought to be at lower risk for EDs (Hay et al., 2017; Mitchison, Hay, Slewa-Younan, & Mond, 2014).

Lastly, in the context of AAN, defining successful outcomes needs to be reconsidered. The issue of if and how much weight restoration is needed in AAN is hotly debated (Nagata, Garber, & Buckelew, 2018). In the absence of clearly delineated target weights for higher weight individuals, many patients with AAN have experienced limited weight restoration (if any) in the context of nutritional rehabilitation (Berman et al., 2009; Hughes et al., 2017; Swenne et al., 2017; Wolter et al., 2009). Given that many patients continued to experience cognitive ED symptoms and amenorrhea with limited weight restoration (Berman et al., 2009; Hughes et al., 2017; Wolter et al., 2009), it may be that higher levels of weight restoration are needed for full remission of symptoms. Additionally, definitions of recovery which rely on absolute measures of BMI as opposed to individualized weight trajectories may systematically discount ongoing symptomatology of higher weight individuals (as in studies where AAN individuals meet criteria for “recovery” before beginning treatment).

### **Research Implications**

The findings of this literature review suggest several steps to improve research on AAN. First, due to the various weight presentations of AAN individuals, standardly including measures of weight suppression and percent of weight restoration, in addition to absolute BMI measures, will provide greater clarity for AAN ED severity and outcomes. Second, reporting separate scores for each category of OSFED (e.g. reporting AAN scores separately from subthreshold binge eating disorder) would facilitate more nuanced understandings of heterogeneous residual categories.

Second, in some cases, AAN individuals presented for medical care months or years before an ED was diagnosed (Sim et al., 2013; Kennedy et al., 2017; Swenne et al., 2017; Wolter et al., 2009). This suggests the need for research regarding interventions at the provider level to improve recognition of these disorders, in addition to research addressing the potential impacts of

weight stigma and other factors that could influence lower levels of diagnosis, referral, or quality of care.

Finally, two other important gaps noted were the lack of racially diverse samples with only 31% ( $n = 13$ ) reporting racial demographics, and a complete lack of articles featuring patient perspectives or qualitative reports. Building robust understanding of AAN will require examining patient and caregiver perspectives to more accurately conceptualize and treat this illness.

## **Conclusion**

This review of AAN literature revealed that AAN patients present with higher weights and weight histories, higher levels of weight suppression, lower or equivalent rates of amenorrhea and BMD loss, and commensurate levels of serious medical complications of malnutrition, compared to full threshold AN. However, though AAN individuals were experiencing clinically impairing disorders with medical complications commensurate with AN, fewer were receiving care, and care was sometimes delayed when providers failed to recognize salient signs of malnutrition in non-emaciated bodies. Given the similarities of psychological symptoms, and the similar sequelae of physical impacts, reconceptualizing AN (and behaviorally similar disorders) as a “restrictive ED spectrum diagnosis” may be indicated. Looking forward to the DSM-6, this approach could have multiple benefits, including alleviating the need to distinguish between AAN and other overlapping categories (e.g. AN in partial recovery, RED, PD), introducing additional ED prevention opportunities when individuals first present with risk factors (dieting, weight loss), facilitating greater recognition of AN symptoms across the weight spectrum, facilitating faster diagnosis and treatment, and leading to the use of other, more clinically-based indicators of severity (aside from weight, which is current DSM-5 practice), such as lifetime duration of amenorrhea, level of weight suppression and caloric restriction, presence of purging behaviors,

comorbid diagnoses, and severity of cognitive symptoms. Perhaps, with such an approach, individuals across the AN spectrum would find increased levels of awareness, screening, and treatment referral to address this dangerous psychiatric disorder.

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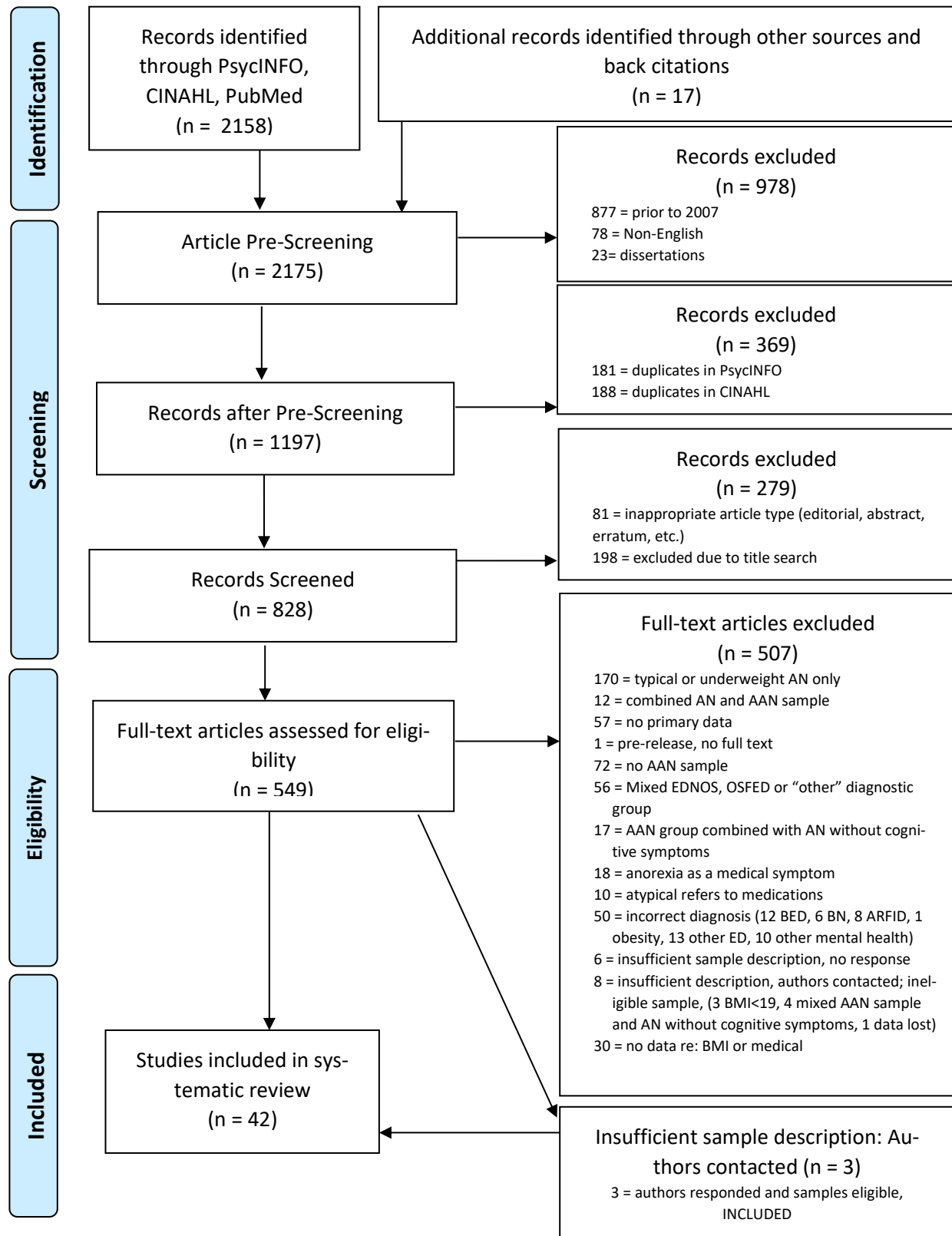


Figure 1.1. PRISMA Flow Diagram

Table 1.1

*Demographics Summary and Quality Summary Scores for Included Articles*

	Article	N	Sex	Age of Sample in Years						Race	% Sample		Quality		
	Year	Authors	Sample N †	% Fe- male	Mean (SD) †	Range †	5-12 years	13- 17 years	18- 19 years	20- 30 years	31+ years	% White	% AAN	% AN	Summary Score
Epidemiological Samples	2008	Zimmerman	2500	60.6	38.3 (12.8)	NR	?	?	?	?	✓	87.6	0.4	0.0%	0.77
	2013	Stice, et al.	496	100	13 (NR)	12-23	✓	✓	✓	✓		68	2.8	0.8%	0.91
	2013	Allen	1383	51	14.0 (.2); 16.9 (.2); 20.0 (.4)	14-20		✓	✓	✓		NR	M: 0.3, 0.0, 0.3; F: 0.9, 0.0, 0.1	M: 0.0, 0.0, 0.0; F: 0.3, ?, 0.6	0.86
	2015	Wade & O'Shea	699	100	14.0 (NR); 15.1 (NR); 16.9 (NR)	12.7- 19.8	✓	✓	✓			100	1.9 AAN; 4.7 RED	2.0	0.82
	2017	Forney, et al.	2464	67.8	35.3 (11.8) F; 32.4 (12.3) M	NR				✓	✓	67	2-13	0.0	0.82
	2017	Hay, et al.	5737	49.8	43.5 (16.3) AAN	15+		✓	✓	✓	✓	NR	2.5	0.5	0.91
Consecutive Clinical Referrals	2007	Rockert, et al.	1449	97	28.5 (8.9)	15-70		✓	✓	✓	✓	NR	11.8 + 10.0 PD	24.5	0.82
	2008	Eddy, et al.	281	92.2	16.0 (2.0)	12-19	✓	✓	✓			87.9	10.7	20.3	0.82
	2009	Santonastaso, et al.	569	100	21.2 (5.0) AAN	NR		?	✓	✓	?	NR	35.9	64.1	0.87
	2010	Ricca, et al.	103	100	29.9 (8.9) sAN	16-45		✓	✓	✓	✓	NR	34.0	51.5	0.82
	2010	Thomas, et al.	76	100	18.7 (1.5)	16-23		✓	✓	✓		97	NR	32.9	0.95
	2010	Peebles	1310	100	15.4 (2.0)	8-19	✓	✓	✓			75.3	3.5	25.2	0.91
	2011	Bayes & Madden	10	0	12.8 med	14-18		✓	✓			NR	40.0	30.0	0.61
	2013	Ekeroth, et al.	2233	100	25.7 (7.8)	18-67			✓	✓	✓	NR	13.9 AAN +8.2PD	29.5	0.91
	2013	Conceicao, et al.	12	100	46.8 (16.6)	23-69				✓	✓	NR	58.3	25.0	0.56
	2013	Ornstein et al.	215	88.6	15.4 (3.3)	8-21	✓	✓	✓	✓		NR	22.3	40.0	0.87
	2014	Forman, et al.	700	86.3	15.3 (2.4)	9-21	✓	✓	✓	✓		87.6	33.9	53.6	0.82
	2014	Whitelaw, et al.	99	87.0	15.2 (1.5)	12-19	✓	✓	✓			NR	26.3	73.7	0.91



	Article	N	Sex	Age of Sample in Years							Race	% Sample		Quality	
	Year	Authors	Sample N †	% Female	Mean (SD) †	Range †	5-12 years	13-17 years	18-19 years	20-30 years	31+ years	% White	AAN %	AN %	Summary Score
Convenience Samples Consecutive Clinical Referrals/Admissions	2015	Damiano, et al.	39	100	15.6 (1.5)	13-18		✓	✓			NR	74.4	25.6	0.87
	2015	Silen, et al.	47	91.4	14.6 (1.2)	NR		✓	?			NR	2.1	97.9	0.68
	2015	Redgrave, et al.	361§	91.70	NR	11-78	✓	✓	✓	✓	✓	92.80	22.1	77.9	0.54
	2016	Sawyer, et al.	256	88	15.5 (1.4)	14-16		✓				NR	16.4	46.1	0.87
	2016	Hughes, et al.	42	88	15.4 (1.4)	12-18	✓	✓	✓			NR	100.0	0.0	0.62
	2016	Swenne	275	100	15.3-18.8 (1.3-1.4)‡	18 and under	?	✓				NR	86.9	9.8	0.87
	2017	Bacopoulou, et al.	37	100	14.7 (NR)	12-20	✓	✓	✓	✓		NR	13.5	48.6	0.64
	2017	Swenne, et al.	201	93.5	15.0 (1.7)	9.4-17.8	✓	✓				NR	100.0	0.0	0.79
	2017	Swenne & Ros	339	100	15 (1.7)	10-17	✓	✓				NR	84.7	13.5	0.87
	2017	Nagata, et al.	1083	88.7	15.6 (NR)	10-19	✓	✓	✓			NR	7.8	71.4	0.87
	2017	Kennedy, et al.	522	88	15.6 (2.3)	NR		✓	?			81.4	39.5	60.5	0.91
	2017	Peebles, et al.	215	88	15.3 (NR)	5.8-23.2	✓	✓	✓	✓		86	18.0	64.0	0.75
	2009	Wolter, et al.	1	100	15 (0)	15		✓				NR	100	0.0	0.63
	2009	Berman, et al.	3	100	34.7 (18.5)	24-56				✓	✓	100	100	0.0	0.78
	2012	Parling, et al.	34	100	23.4 (4.4)	18 and over			✓	✓	?	NR	14.7	50.0	0.87
	2013	Sim, et al.	2	50	16 (2)	14-18		✓	✓			NR	100	100	0.59
	2015	Cooper & Kelland	253	97	27.1 (9.8)	18-65			✓	✓	✓	96.7	11.9	17.4	0.78
	2015	Davenport, et al.	119	100	25.4 (6.9)	18-46			✓	✓	✓	NR	37.0	63.0	0.82
	2016	Smith, et al.	129	94.6	15.8 (2.4)	10-22	✓	✓	✓	✓		89.1	12.4	87.6	0.64
	2016	Bachmann, et al.	153	100	24.6 (NR)	18-45			✓	✓	✓	NR	28.8	41.8	0.91
	2017	Gledhill, et al.	40; 21	100	18.2 (.37); 27.7 (7.5)	NR		?	✓	✓	?	NR	100	0	0.50
	2017	Harrison, et al.	1	100	16 (0)	16		✓				NR	100	0	0.61
	2017	Schorr, et al.	168	100%	25.7 (6.0) AAN	18-45			✓	✓	✓	NR	45.8%	41.7%	0.96
	2018	Olivo, et al.	60	100%	14.9 (1.6)	13-18		✓	✓			NR	36.7%	0.0%	0.77

Note. Abbreviations/Symbols: **AN**: anorexia nervosa; **AAN**: atypical AN; **ED**: eating disorder; **NR**: not reported; **PD**: purging disorder; **RED**: restrictive ED; **SD**: standard deviation; **?**: unclear; **†** denotes multiple waves or samples in single study

Table 1.2

*Quality Assessment of Included Articles*

Citation	a) Question/objective sufficiently described?	b) Study design evident and appropriate?	c) Method of subject/comparison group selection or source of information/ input variables described and appropriate?	d) Subjects and comparison group (if applicable) characteristics sufficiently described?	e) If interventional and random allocation was possible, was it reported?	f) If intervention and blinding of investigators was possible, was it reported?	g) If interventional and blinding of subjects was possible, was it reported?	h) Outcome and (if applicable) exposure measure(s) well defined & robust to measurement/ misclassification bias? Means of assessment reported?	i) Sample size appropriate?	j) Analytic methods described/ justified & appropriate?	k) Some estimate of variance is reported for the main results?	l) Controlled for confounding?	m) Results reported in sufficient detail?	n) Conclusions supported by the results?	Summary Score
Rockert (2007)	1	2	1	2	n/a	n/a	n/a	2	2	2	2	1	2	1	0.82
Zimmerman (2008)	2	2	1	2	n/a	n/a	n/a	1	1	2	0	2	2	2	0.77
Eddy (2008)	2	2	1	2	n/a	n/a	n/a	2	1	2	2	1	2	1	0.82
Wolter (2009)	1	2	1	1	n/a	n/a	n/a	1	1	n/a	n/a	n/a	2	1	0.63
Santonastaso (2009)	2	1	1	2	n/a	n/a	n/a	2	2	2	2	1	2	2	0.86
Berman (2009)	2	1	1	2	n/a	n/a	n/a	2	1	2	2	0	2	2	0.77
Ricca (2010)	2	1	2	1	n/a	n/a	n/a	2	1	2	2	2	1	2	0.82
Peebles (2010)	1	2	2	2	n/a	n/a	n/a	1	2	2	2	2	2	2	0.91
Thomas (2010)	2	2	2	2	n/a	n/a	n/a	2	1	2	n/a	n/a	2	2	0.94
Bayes 2011	1	1	1	2	n/a	n/a	n/a	1	1	1	n/a	n/a	1	2	0.61
Parling (2011)	1	2	2	1	n/a	n/a	n/a	2	1	2	2	2	2	2	0.86
Ekeroth (2013)	1	2	2	2	n/a	n/a	n/a	2	2	2	2	2	2	1	0.91
Stice (2013)	2	2	2	2	n/a	n/a	n/a	1	1	2	2	2	2	2	0.91
Conceicao (2013)	1	2	1	1	n/a	n/a	n/a	1	1	1	n/a	n/a	1	1	0.56
Sim (2013)	1	1	1	1	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1	2	0.58
Ornstein (2013)	2	2	2	2	n/a	n/a	n/a	1	1	2	2	2	1	2	0.86
Allen (2013)	2	2	2	1	n/a	n/a	n/a	1	1	2	2	2	2	2	0.86
Forman (2014)	1	1	2	2	n/a	n/a	n/a	1	2	2	2	2	1	2	0.82
Whitelaw (2014)	1	2	2	2	n/a	n/a	n/a	2	1	2	2	2	2	2	0.91
Wade (2014)	2	2	2	2	n/a	n/a	n/a	1	1	2	1	2	1	2	0.82
Cooper (2015)	2	1	1	2	n/a	n/a	n/a	1	1	2	2	1	2	2	0.77
Damiano (2015)	2	2	1	2	n/a	n/a	n/a	2	1	2	2	1	2	2	0.86
Davenport (2015)	2	2	1	1	n/a	n/a	n/a	2	1	2	2	2	2	2	0.82
Silen (2015)	1	2	1	2	n/a	n/a	n/a	1	1	2	2	1	1	1	0.68
Redgrave (2015)	1	1	2	1	0	0	0	1	2	2	2	1	1	2	0.54
Bachmann (2016)	1	2	2	2	n/a	n/a	n/a	1	2	2	2	2	2	2	0.91

Citation	a) Question/objective sufficiently described?	b) Study design evident and appropriate?	c) Method of subject/comparison group selection or source of information/ input variables described and appropriate?	d) Subjects and comparison group (if applicable) characteristics sufficiently described?	e) If interventional and random allocation was possible, was it reported?	f) If intervention and blinding of investigators was possible, was it reported?	g) If interventional and blinding of subjects was possible, was it reported?	h) Outcome and (if applicable) exposure measure(s) well defined & robust to measurement/misclassification bias? Means of assessment reported?	i) Sample size appropriate?	j) Analytic methods described/ justified & appropriate?	k) Some estimate of variance is reported for the main results?	l) Controlled for confounding?	m) Results reported in sufficient detail?	n) Conclusions supported by the results?	Summary Score
Hughes (2016)	1	1	2	2	0	0	n/a	1	1	2	2	1	2	1	0.62
Sawyer (2016)	1	1	2	2	n/a	n/a	n/a	2	1	2	2	2	2	2	0.86
Swenne (2016)	1	2	2	1	n/a	n/a	n/a	2	2	2	2	2	2	2	0.91
Smith (2016)	2	1	2	1	0	0	0	1	1	2	2	2	2	2	0.64
Bacopoulou (2017)	1	1	1	1	n/a	n/a	n/a	1	1	2	2	1	2	1	0.64
Swenne (2017)	1	1	2	2	n/a	0	n/a	2	2	2	2	1	2	2	0.79
Swenne & Ros (2017)	1	2	1	2	n/a	n/a	n/a	2	1	2	2	2	2	2	0.86
Forney (2017)	2	2	1	2	n/a	n/a	n/a	2	1	2	1	2	1	2	0.82
Gledhill (2017)	2	1	1	1	1	0	0	1	1	1	2	1	1	1	0.50
Harrison (2017)	2	1	1	1	n/a	n/a	n/a	n/a	2	1	n/a	n/a	1	2	0.61
Nagata (2017)	2	2	2	1	n/a	n/a	n/a	2	2	2	2	1	1	2	0.87
Kennedy (2017)	1	2	2	2	n/a	n/a	n/a	2	1	2	2	2	2	2	0.91
Peebles (2017)	2	2	2	2	0	0	0	2	1	2	2	2	2	2	0.75
Schorr (2017)	2	2	2	2	n/a	n/a	n/a	2	1	2	2	2	2	2	0.95
Hay (2017)	2	2	2	2	n/a	n/a	n/a	1	2	2	2	2	2	1	0.91
Olivo (2018)	2	1	2	1	n/a	n/a	n/a	2	1	2	2	1	2	1	0.77

Notes. Abbreviations: n/a: not applicable to study design. Quality assessment performed using Kmet, Lee, & Cook's (2004) Quality Assessment Scale.

Table 1.3

*Mean BMI, Weight History, and Weight Suppression Data*

Article	Mean BMI (SD)		Lifetime BMI (SD)				Weight History				% WL (SD)		Mo. % WL	
1st Author (Year)	AAN †	AN †	AAN Min BMI	AN Min BMI	AAN Max BMI	AN Max BMI	AAN % History OW/OB	AN % History OW/OB	AAN % Current OW/OB	AAN % History Under-Wt	AAN †	AN †	AAN (SD)	AN (SD)
<b>Zimmerman (2008)</b>	19.5 (0)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Stice (2013)</b>	21.9 (2.1)	16.8 (.8)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Allen (2013)</b>	20.6 (3.3)	15.6 (0)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Wade (2014)</b>	47.7 (5.8)%ile AAN; 55.3 (3.8)%ile RED	30.0 (6.0) %ile	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Forney (2017)</b>	F: 23.7 (3.5), 24.1 (4.0), 23.7 (2.9); M: 25.2 (3.1), 25.2 (3.9), 24.8 (3.6)	NR	NR	NR	NR	NR	F: 37.1 OW + 28.1 OB; M: 45.3 OW + 38.4 OB	NA	F: 23.9% OW + 4.0% OB, ; M: 40.7% OW +8.1% OB	NR	F: 12.0 (6.5), 16.0 (6.6), 21.5 (7.4); M: 12.4 (6.6), 18.1 (5.6), 20.4 (4.8)	NR	NR	NR
<b>Hay (2017)</b>	27.8 (6.3)	17.9 (.5)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Rockert (2007)</b>	24.0 (7.1) AAN; 23.1 (10.1) PD	16.3 (1.5) ANr; 16.8 (1.8) ANbp	18.7 (3.8); 18.4 (3.2) PD	15.1 (1.8) ANr; 15.3 (1.9) ANbp	25.6 (8.6); 26.4 (6.0) PD	21.7 (3.4) ANr; 22.7 (3.6) ANbp	NR	NR	NR	54 AAN; 47 PD	NR	NR	NR	NR
<b>Eddy (2008)</b>	114.1 (28.6) %IBW	77.3% (5.9)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Santonastaso (2009)</b>	18.1 (1.1)	15.6 (1.5)	17.8 (1.4)	15.0 (1.7)	23.3 (3.2)	21.1 (2.8)	NR	NR	NR	NR	5.5 (3.1) BMI	6.1 (2.7) BMI	NR	NR
<b>Ricca (2010)</b>	19.9 (2.0)	15.6 (1.7)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Peebles (2010)</b>	97.7 %mBMI	75.8 %mBMI	NR	NR	NR	NR	NR	NR	NR	NR	34	23	3.5/ mo.	2.4/ mo.
<b>Ornstein (2013)</b>	103.5 (15.3) %mBW	86.6 (6.3) %mBW	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Ekeroth (2013)</b>	22.7 (4.5) AAN; 21.9 (3.5) PD	16.1 (1.6) ANr; 16.8 (1.4) ANbp	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Conceicao (2013)</b>	25.5 (4.9)	15.9 (2.0)	NR	NR	51.8 (12.4)	44.8 (2.1)	100%	100%	42.80%	NR	49.8 (9.3)	64.2 (5.8)	NR	NR

Article	Mean BMI (SD)		Lifetime BMI (SD)				Weight History				% WL (SD)		Mo. % WL	
1st Author (Year)	AAN †	AN †	AAN Min BMI	AN Min BMI	AAN Max BMI	AN Max BMI	AAN % History OW/OB	AN % History OW/OB	AAN % Current OW/OB	AAN % History Under-Wt	AAN †	AN †	AAN (SD)	AN (SD)
Forman (2014)	72.7% AAN had mBMI>90%	13.7% AN had mBMI>90%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Whitelaw (2014)	93.0 (5.3) %mBMI	74.5 (7.1) %mBMI	NR	NR	83.0 IQR med BMI centile	64.5 IQR med BMI centile	17 OW + 29 OB	11 OW, 7 OB	NR	NR	13.2 (NR) kg	12.7 (NR) kg	6.1 (NR)	9.3 (NR)
Silen (2015)	21 (0)	NR	NR	NR	NR	NR	NR	NR	NR	NR	lost 13 kg	NR	NR	NR
Hughes (2016)	20.5 (2.4)	NA	NR	NA	NR	NA	64 OW/OB	NA	5%OW/OB	NR	21.7 (7.5)	NA	13.2 (8.7)	NA
Sawyer (2016)	21.4 (3.0)	16.0 (1.5)	NR	NR	27.7(5.5)	20.1 (3.2)	71	12	17	NR	17.6 (9.7) kg	11.0 (7.8) kg	13.3 (8.5)	10.2 (8.3)
Swenne (2016)	NR	NR	NR	NR	NR	NR	30.1 BMI SDS>1 + 9.2 BMI SDS>2	NR	NR	1.6% BMI SDS<-1	NR	NR	NR	NR
Bacopoulou (2017)	18.3 (NR)	15.1 (NR)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Swenne (2017)	-.56 (1.04) BMI SDS	NA	NA	NA	BMI SDS: .7 (1.0)	NA	NR	NR	NR	NR	6.3 (5.7) kg	NA	NR	NA
Nagata (2017)	101.4 (NR) %mBMI	78.9 (NR) %mBMI	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Kennedy (2017)	NR	NR	NR	NR	NR	NR	66.3	33.7	7.9	NR	NR	NR	NR	NR
Peebles (2017)	99.6 (6.3) %mBMI	78.6 (7.0) %mBMI	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Wolter (2009)	19.8	NA	19.8	NA	100kg	NA	NR	NA	NR	NR	38.8%	NA	4m	NA
Berman (2009)	18.8 (.26)	NA	NR	NA	NR	NA	NR	NA	NR	100%	NR	NA	NR	NA
Parling (2012)	18.8 (.4)	16.1 (1.2)	NA	NA	NA	NA	NR	NA	NR	NR	NA	NA	NA	NA
Sim (2013)	NR	NR	1: 16; 2: 18	‡	1: 33.6; 2: 32.0	‡	100 OW; 100 OB	‡	NR	‡	1: 39.5 kg; 2: 38 kg (45%)	‡	1: 24; 2: 36	‡
Cooper (2015)	20.2 (6.1)	15.8 (1.2)	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Davenport (2015)	21.0 (1.9)	16.0 (1.8)	16.5 (2.6)	14.0 (1.7)	25.7 (4.6)	22.9 (6.5)	NR	NR	NR	82	NR	NR	NR	NR

Article	Mean BMI (SD)		Lifetime BMI (SD)				Weight History				% WL (SD)		Mo. % WL	
1st Author (Year)	AAN †	AN †	AAN Min BMI	AN Min BMI	AAN Max BMI	AN Max BMI	AAN % History OW/OB	AN % History OW/OB	AAN % Current OW/OB	AAN % History Under-Wt	AAN †	AN †	AAN (SD)	AN (SD)
Bachmann (2016)	19.6 (1.0)	17.0 (1.1)	16.8 (2.0)	14.9 (1.8)	NR	NR	NR	NA	NR	80	NR	NR	NR	NR
Gledhill (2017)	19.5 (3.3)	NA	NR	NA	NR	NA	NR	NA	NR	NR	NR	NA	NR	NA
Harrison (2017)	20.8	NA	NR	NA	NR	NA	NR	NA	NR	NR	13.6 kg	NA	24	NA
Schorr (2017)	19.3 (.7)	17.2 (.7) DSM-IV; 17.5(.9) DSM-5	16.6 (1.7)	15.0 (1.6) DSM-IV; 15.5(1.7) DSM-5	23.2 (3.0)	22.3 (3.3) DSM-IV; 21.4(4.1) DSM-5	24	NR	NR	NR	NR	NR	NR	NR
Olivo (2018)	19.3 (2.0)	NA	NR	NA	22.1 (2.3)	NA	9.1 BMI > 25	NA	4.5%	NR	6.7 kg	NA	7.9	NA

Note. Abbreviations and Symbols: **AN**: anorexia nervosa; **AAN**: atypical AN; **ANr**: AN restrictive; **ANbp**: AN binge/purge; **BMI**: body mass index; **DSM**: Diagnostic and Statistical Manual; **F**: female; **IQR**: interquartile range; **kg**: kilograms; **M**: male; **Max**: maximum; **Min**: Minimum; **mo.**: months; **mBMI%**: median BMI percentile; **med**: median; **NA**: not applicable; **NR**: not reported; **OB**: obese BMI; **OW**: overweight BMI; **PD**: purging disorder; **RED**: restrictive eating disorder; **SD**: standard deviation; **SDS**: SD score, **sAN**: subthreshold AN; **tx**: treatment; **Under-Wt**: underweight; **WL**: weight loss; **%ile**: percentile; **%mBW**: percent median body weight; † = Multiple waves, studies, or samples separated by semi-colons; ‡ = this study reported on two cases with history of overweight that progressed to AAN with one appearing to progress to AN

Table 1.4

*Rates of Amenorrhea and Other Findings Regarding Menstruation*

1st Author (Year)	% AAN with Amenorrhea	% AN with Amenorrhea	Other Menstruation Findings
Zimmerman, 2008	0 (n=1)	100	AAN patient (1/1) did not have amenorrhea. All AN had amenorrhea by definition.
Wolter, 2009	100 (n=1)	NA	Patient had amenorrhea at normal weight.
Berman, 2009	see notes.	NA	1 patient had amenorrhea (menses returned after treatment); 1 patient on hormonal contraceptives; 1 patient post-menopausal.
Ricca, 2010	100	22.10	All AAN had amenorrhea by definition.
Sim, 2013	100 (n=1)	NA	Female patient (n=1) experienced amenorrhea.
Forman, 2014	59.2* irregular menses	82* irregular menses	Differences in menstruation rates reached statistical significance.
Whitelaw, 2014	100	100	All either premenarchal or amenorrhea for both groups.
Damiano, 2015	NR	NR	Used latent class analysis to identify a low-pathology (43.7% AAN) with 50% amenorrhea rate and high-pathology (97.5% AAN) cluster with 43.5% amenorrhea rate.
Bachmann, 2016	29.5*	57.8*	Differences in rates and lifetime duration of amenorrhea (AAN 20 lifetime months; AN 43 lifetime months) reached statistical significance. Lifetime duration of amenorrhea predicted vertebral strength.
Hughes, 2016	43, amenorrheic; 54, irregular menses	NA	With treatment, rates of amenorrhea and irregularity significantly improved to 19% and 32%, respectively.
Sawyer, 2016	32*	61*	Differences in menstruation rates reached statistical significance. Menarche earlier for AAN compared to AN.
Bacopoulou, 2017	6.1 lifetime mos.	8.5 lifetime mos.	Differences in lifetime duration of amenorrhea did not reach statistical significance.
Swenne, 2017	29	NA	For AAN sample: 9% premenarcheal; 29% secondary amenorrhea; 55% no amenorrhea; 7% hormonal contraception.
Swenne & Ros, 2017	31.3	NA	NR
Forney, 2017	4.5 (5% WL); 5.9 (10% WL); 0 (15% WL)	NA	Rates of amenorrhea not different between AAN sample and other DSM-5 ED diagnoses.
Harrison, 2017	0 (n=1)	NA	Patient did not experience amenorrhea; completed pregnancy.
Schorr, 2017	27.8*	70.3* DSM-IV AN; 18.2 DSM-5 AN	AAN differed from DSM-IV AN regarding amenorrhea rates; did not differ from DSM-5 AN. Lifetime months duration of amenorrhea differed statistically between all three groups: 14.9 AAN; 53.1 DSM-IV AN; 5.2 DSM-5 AN. History of amenorrhea did not differ at statistically significant rates: 83.1% AAN; 91.7% DSM-IV AN; 80.0% DSM-5 AN. Amenorrhea associated with lower bone mass density.
Olivo, 2018	42.9	NA	NR

Note. Abbreviations: **AN**: anorexia nervosa; **AAN**: atypical AN; **DSM**: Diagnostic and Statistical Manual; **NA**: not applicable; **NR**: not reported; **WL**: weight loss

\* Differences between AN and AAN reached statistical significance  $p < .05$

Table 1.5

*Rates of Bradycardia, Orthostatic Instability, Hypothermia, and Additional Medical Findings*

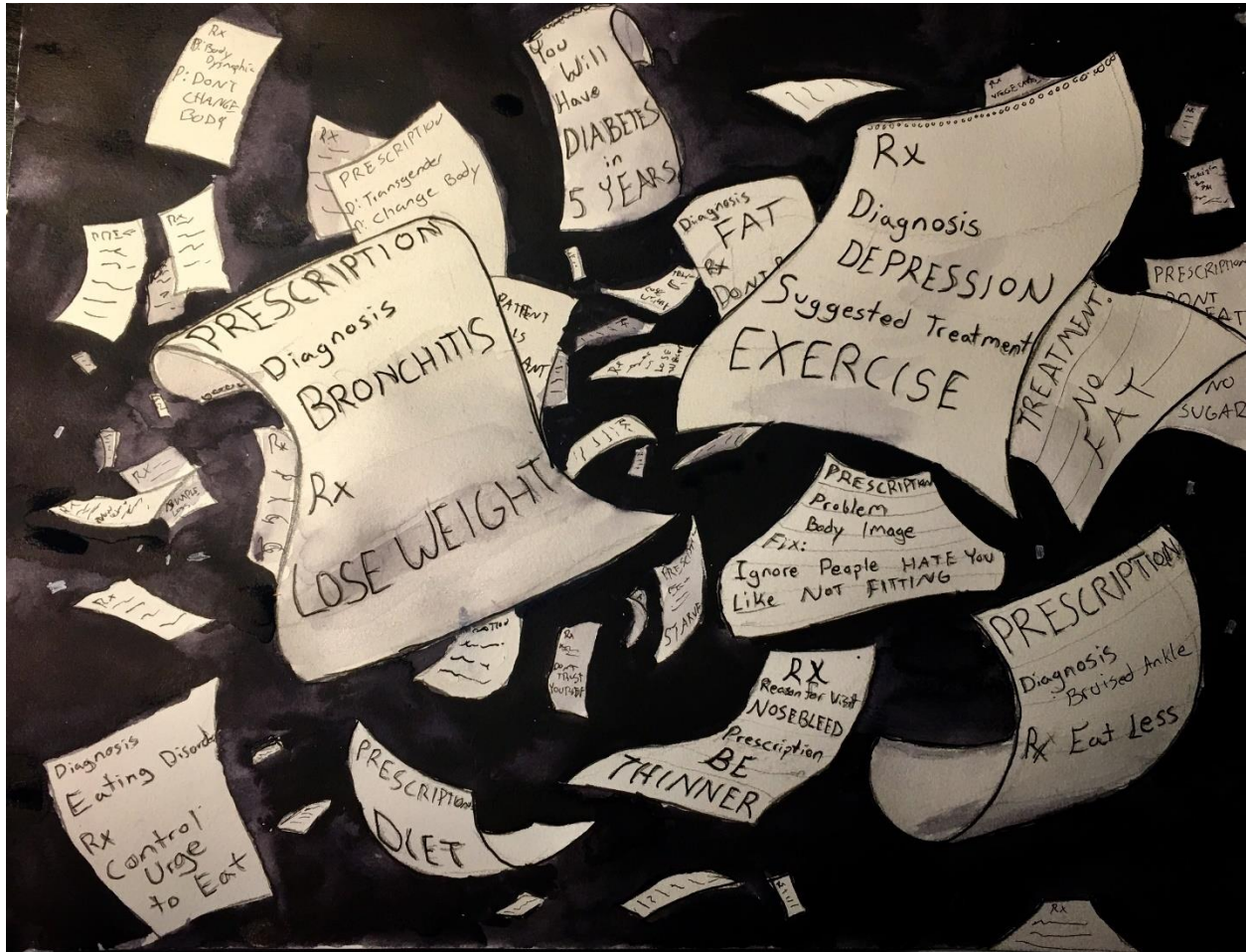
1st Author (Year)	Rate of Bradycardia		Rate of Orthostatic Instability		Rate of Hypothermia		Additional Medical Findings
	% AAN	% AN	% AAN	% AN	% AAN	% AN	
<b>Wolter, 2009</b>	NR	NR	NR	NR	NR	NR	Symptoms mentioned: amenorrhea, headaches, abdominal pain.
<b>Peebles, 2010</b>	43.5*	38.5*	57.1* by HR	32.8* by HR	"no difference"		No differences between AN and AAN in regard to orthostatic hypotension, hypothermia, hypokalemia, or serious hospital complications. AN higher rates of hypotension (16.4% v. 6.5%), lower phosphorus levels (3.7 v. 3.8), and longer QTc intervals (378 AAN vs. 388 AN).
<b>Bayes, 2011</b>	See additional findings		See additional findings		See additional findings		All boys with AAN had low heart rate, hypotension, and/or hypothermia, requiring hospitalization (inpatient chart review).
<b>Conceicao, 2013</b>	NR	NR	NR	NR	NR	NR	6 of 12 patients with EDs (58% AAN>18.5 BMI) had medical complications due to bariatric surgery. Comorbidities for the entire sample mentioned.
<b>Sim, 2013</b>	†	†	†	†	†	†	Medical symptoms mentioned: Case 1: concentration difficulty, intermittent postprandial chest pain, cold intolerance, fatigue, bloating, constipation, sinus bradycardia, dehydration. Case 2: amenorrhea, dizziness, orthostatic intolerance, cold intolerance, fatigue, back pain, stress fractures.
<b>Redgrave, 2015</b>	NR	NR	NR	NR	NR	NR	Mixed AN and AAN sample tolerated a refeeding protocol for rapid weight regain. No AAN (0) and 5 AN patients required transfer to a medical floor (not related to refeeding symptoms). No AAN (0) and no AN (0) patients died.
<b>Whitelaw, 2014</b>	47.1 lowest bpm	45.1 lowest bpm	NR	NR	34.8° C (mean)	35.9° C (mean)	No difference between AN and AAN in severity of acute medical complications, lowest pulse rate, severity of sinus bradycardia (35 bpm AN; 34 bpm AAN), lowest body temperature, or incidence of hypophosphatemia (41% AN; 38% AAN), hypomagnesemia (11% AN; 4% AAN), hypokalemia (5% AN; 0% AAN). AN statistically lower lying systolic BP (84 AN; 91 AAN).
<b>Sawyer, 2016</b>	24 < 50bpm	33<50bpm	43	38	10	13	Compared with AN, AAN, no difference in resting pulse rate (59.8 AAN; 59.3 AN), frequency of bradycardia, orthostatic changes, diastolic BP (59.6 AAN; 57.0 AN), hypothermia, or admission to hospital (41% AAN; 52% AN). Systolic BP (106.2 AAN; 99.1 AN) and temperature (36.8C AAN; 36.4C AN) were higher in AAN, and hypotension was less frequent in AAN (10% AAN; 23% AN).
<b>Swenne, 2016</b>	NR	NR	NR	NR	NR	NR	Medical results reported in premorbid BMI groups (not AN vs. AAN). Clinical and lab signs of starvation in higher weight girls with restrictive EDs despite near-normal weight.
<b>Smith, 2016</b>	NR	NR	NR	NR	NR	NR	All patients in this trial admitted for medical stabilization. Trial of "start high advance fast" caloric refeeding protocol for AN and AAN individuals. No AAN (or AN) patients with experienced full refeeding syndrome.
<b>Bachmann, 2016</b>	NR	NR	NR	NR	NR	NR	BMD and VS impaired in AN and AAN. BMD and VS was lowest in AN, highest in controls, intermediate in AAN. BMI, nadir lifetime BMI, illness duration, lifetime duration of amenorrhea predicted VS. Current amenorrhea, DHEA-S, and total testosterone predicted BMD.



1st Author (Year)	Rate of Bradycardia		Rate of Orthostatic Instability		Rate of Hypothermia		Additional Medical Findings
	% AAN	% AN	% AAN	% AN	% AAN	%AN	
Bacopoulou, 2017	NR	NR	NR	NR	NR	NR	No significant differences between AN and AAN kisspeptin levels, LH, FSH, PRL, FT4, T3, E2, or 17OHP. AN had lower TSH than AAN. Results often appeared in a stepwise fashion with AAN between AN and controls. In kisspeptin AAN tended towards elevated levels.
Swenne, 2017	NR	NR	NR	NR	NR	NR	Medical comorbidities recorded in article.
Swenne & Ros, 2017	NR	NR	NR	NR	NR	NR	53% (8/15) of ED patients with emergency admissions (progressive weight loss, refusal to eat, medical instability) had AAN.
Peebles, 2017	See additional findings		See additional findings		NR	NR	All patients required medical stabilization. Common reasons included: bradycardia, hypotension, orthostasis, significant malnutrition, acute food refusal, failure to thrive, syncope, electrolyte imbalance.
Harrison, 2017	NR	NR	NR	NR	NR	NR	Pregnant patient with AAN had healthy term infant. Patient's exam within normal limits. ED remission during pregnancy; relapse after pregnancy.
Schorr, 2017	NR	NR	NR	NR	NR	NR	BMD Z-scores for AAN were higher than AN, less than healthy controls. BMD Z score less than -1.0 present in 78% AN DSM-IV, 82% AN DSM-5, 69% AAN. BMD Z-score less than -2 present in 49% DSM-IV AN, 39%DSM-5 AN, 24% AAN. Past low weight and amenorrhea associated lower BMD. Loss of lean mass and loss of fat mass present in AN and AAN.
Olivo, 2018	NR	NR	NR	NR	NR	NR	No differences in gray matter found between recently diagnosed adolescents with AAN and healthy controls.

Note: Abbreviations and Symbols: **AN**: anorexia nervosa; **AAN**: atypical AN; **BMD**: bone mineral density; **BMI**: body mass index; **BP**: blood pressure; **bpm**: beats per minute; **C**: degrees Celsius; **DHEA-S**: dehydroepiandrosterone-sulfate; **DSM**: Diagnostic and Statistical Manual; **ED**: eating disorder; **E2**: estradiol; **FSH**: follicle-stimulating hormone; **FT4**: free thyroxine; **LH**: luteinizing hormone; **PRL**: prolactin; **TSH**: thyroid-stimulating hormone; **T3**: triiodothyronine; **VS**: vertebral strength; **17OHP**: 17-hydroxyprogesterone; † = this study reported on two cases with history of overweight that progressed to AAN with one appearing to progress to AN.

\* Indicated statistically p<.05 significant group difference found between AAN and AN.



Artwork by Mary, Participant 17

“So, thinking about... “first, do no harm” like shit. My first eating disorder was doctor-prescribed and mother-approved and then perpetuated. For 40 years. That's fucked up.”

-Carly, Participant 9

## CHAPTER TWO:

### INTRODUCTION TO THE WINTER STUDY

Primary data were collected for Papers Two and Three by creating the Women's Illness Narratives Through Eating Disorder and Remission (WINTER) Study. Data were collected over the course of one year from participants with a history or current diagnosis of atypical anorexia (AAN). This study was designed with several aims in mind (outlined below), to build a rich, mixed method, longitudinal database that could be used to answer a variety of research questions. This chapter serves as an introduction to the methods used in this parent study; Papers Two and Three will cover the specific methods utilized for each analysis conducted.

#### **A Brief Note on Scope**

The WINTER sample was chosen *purposively* (Emmel, 2013) to capture the breadth of AAN experiences across the BMI spectrum and in regard to other diversity factors (e.g., age, different sexual orientations, race, trans identities, etc.). Participants were required to have a *history* or current diagnosis of AAN. Not all participants met criteria for AAN diagnosis at baseline; rather, all participants *had* met criteria at some point in the past and could speak about their experiences with this illness retrospectively. This sampling design was chosen to capture narratives throughout the illness journey (in illness, recovering, in remission) to show how each participant developed, experienced, and potentially healed from AAN.

#### **Overview of WINTER Study Methods**

##### **Funding and Investigators**

This study was supported by two TL1 fellowships through the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number TL1

TR002318. Additionally, this study was supported through the Academy of Eating Disorders RSH fellowship, which funds dissertation research related to eating disorder (ED) prevention or weight stigma, and a Health at Every Size® Expansion fund grant through the Association for Size Diversity and Health. The author (EH) was the primary investigator (PI) on this study, supervised by Taryn Lindhorst (dissertation chair) and Janell Mensinger (committee member), with additional consultation from Megan Moore (committee member). Additionally, the author was assisted by multiple master's student research assistants (Elizabeth Dios, Sara Gorcos, Maria Cortez, Meredith Blumenthal, Natalie Franz, Noahloni Garcia, Priyanka Ghosh, Wesley Jones) and two doctoral student research assistants (Rebecca Hutcheson, Vern Harner). Six master's students used these data for class research projects (Elizabeth Dios, Sara Gorcos, Maria Cortez, Noahloni Garcia, Priyanka Ghosh, and Wesley Jones), and two master's students (Elizabeth Dios, Meredith Blumenthal) used these data for their masters theses, doing secondary data analysis. Student researchers represented the following fields: social work, health sciences, dietetics, and public health.

### **Study Design**

The WINTER study was a mixed-methods study of women and non-binary/trans assigned-female-at-birth (AFAB) persons with a history of AAN. Participants in the WINTER Study were enrolled for one year, completing quantitative surveys every two months. In depth, semi-structured interviews were conducted at baseline (assessing the development and progression of their illness), at 6-months (assessing their interactions with healthcare providers), and at 12-months (assessing their perspectives on remission and relapse processes). A diagram showing the study design is found in Figure 2.1.

*< Insert Figure 2.1 here >*

## **Study Aims**

The original aims of this study were to 1) examine how people who have experienced AAN conceptualized the course of their ED (e.g. development of illness, course of illness, treatment and remission), 2) identify turning points or pivotal moments in participants' experiences of their illness and remission, 3) examine patient narratives to identify characteristics of negative (unhelpful) and positive (helpful) interactions with healthcare providers, and 4) compare the various quantitative diagnostic measures (e.g. ED severity, ED-related functional impairment, comorbid depression and anxiety, quality of life, self-esteem, comorbid substance use, internalized weight stigma, intuitive eating, and broad conceptualizations of beauty) with participants' narrative descriptions of their current illness status to examine the utility of these measures.

This study was designed to build a database with mixed methods measures (quantitative measures, participant-produced art, qualitative interviews) to characterize the patient experience of living with, treating, and potentially recovering from AAN. This study was conceptualized to be both retrospective (in that participants were asked to share the story of their ED and how it developed), and prospective, in that their illness experiences and symptoms were measured throughout the year of the study. Participants were recruited intentionally across the illness continuum (pre-treatment, in treatment, post-treatment, remission) to better capture different aspects of the illness experience and how it changes over time.

## **Recruitment**

Participants were recruited through flyers posted at local ED treatment centers, provider referral, social media groups, snowball recruitment, and interested participants directly contacting the researcher. The researcher also reached out to community leaders in more marginalized groups (people of color, trans/nonbinary communities, higher weight communities) to post

recruitment flyers to increase representation of these groups. Several media outlets (*The Huffington Post*, the *Medium*, the *Seattle Times*, and *FoodPsych Podcast*) featured articles discussing the WINTER Study, which resulted in additional recruitment following these media releases.

One-hundred-and-eighteen ( $n = 118$ ) interested participants contacted the author. Of those, 56 screened as eligible; 39 of the 56 were enrolled, two decided not to participate, and the remaining 15 were put on a waiting list. Ten participants screened as ineligible due to having typical AN without history of AAN ( $n = 3$ ), having Avoidant and Restrictive Food Intake Disorder (ARFID) without AAN ( $n = 1$ ), being outside the United States ( $n = 4$ ), being currently hospitalized ( $n = 1$ ), and declining the screening questions ( $n = 1$ ). Forty-seven unscreened individuals were waitlisted due to time constraints, and five did not respond to the researcher. Eligible participants were prioritized through purposive sampling techniques (Emmel, 2013) to enroll those least represented in ED literature.

## **Sampling**

This sample utilized purposive sampling (including maximum variation, snowball, and criterion sampling) as is common in qualitative research (Emmel, 2013). Study participants were intentionally recruited to represent the diversity of the AAN experience (specifically across the BMI spectrum). This sample achieved diversity in age (age 18-74), sexual orientation (36% heterosexual), gender (13% trans/nonbinary at baseline<sup>5</sup>), socioeconomic status (44% low income as children), and weight (BMI range 21-61), in addition to race (to a lesser extent, as people of color made up 28% of the sample). This diversity is innovative as many previous samples of AAN have been relatively homogenous, particularly in terms of weight (Harrop, Mensinger,

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<sup>5</sup> Three participants came out as nonbinary during the course of the study, and one participant came out as a trans man. At study end, 23% of the sample identified as trans/nonbinary; all contacted the researcher to update their gender and pronouns for the study.

Moore, & Lindhorst, under review). Published research on AAN is largely limited to a narrow spectrum of the BMI (eg. BMI 18.5-25), and rarely goes above a BMI of 30 (See Paper 1). While epidemiological samples have included a more diverse representation of AAN, these studies were limited in their description of the AAN experience, and some also included weight caps, thus truncating the AAN experience in regard to weight presentation. Current AAN literature lacks diverse samples across the weight spectrum. This study represents a beginning step to increasing this needed representation.

### **IRB Approval**

All study procedures were approved by the University of Washington Institutional Review Board (IRB); revisions to IRB protocols were submitted as needed, and the study was renewed annually according to IRB protocols.

### **Screening, Eligibility, and Inclusion/Exclusion Criteria**

Potential participants were screened by the researcher by phone or in person using the clinician-guided diagnostic assessment tool, Eating Disorder Assessment for DSM-5 (Sysko et al., 2015) to assess for whether or not the person had experienced AAN. Following this screening, the researcher conducted a brief mental status examination, screening for acute suicidality and psychosis. The first author (EH), who is also a mental health evaluator and medical social worker, completed all screenings and clinical interviews. To be eligible, respondents had to be a cisgender woman, transgender woman, or nonbinary/trans individual assigned female at birth (AFAB), be 18 years of age or older, live in the US, speak English, and have met criteria for a restrictive, subthreshold ED at a BMI above 18.5. Due to current lack of consensus regarding definitions of “significant weight loss” for AAN, no minimum weight loss level was required for AAN diagnosis (Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017). Participants who experienced multiple lifetime ED diagnoses were included, due to the significant rates of diagnostic

crossover noted between ED diagnoses, and from subthreshold to threshold presentations (Schaumberg et al., 2019; Stice, Marti, & Rohde, 2013; Wolter, Schneider, Pfeiffer, & Lehmkuhl, 2009). Those in inpatient or residential treatment settings, those outside the United States, and those with acute suicidality or acute psychosis were ineligible.

*< Insert Table 2.1 here >*

### **Quantitative Measures**

Participants completed online surveys every two months that included multiple validated measures. A full list of study measures, when they occurred, length of the measure, and number of items can be found in Table 2.1. Quantitative measures included the following: EDE-Q (Fairburn, 2009), Patient Health Questionnaire-9 (PHQ-9; Kroenke & Spitzer, 2002), Generalized Anxiety Disorder-7 (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006), CIA 3.0 (Bohn et al., 2008), WBIS (Durso & Latner, 2008), World Health Organization Quality of Life Brief Measure (WHOQOL-BREF; The WHOQOL, 1998), Body Appreciation Scale (BAS; Avalos, Tylka, & Wood-Barcalow, 2005), Broad Conceptualizations of Beauty Scale (BCBS; Tylka & Iannantuono, 2016), Intuitive Eating Scale-2 (IES-2; Tylka & Kroon Van Diest, 2013), Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1979), Alcohol Use Disorders Identification Test (AUDIT; Saunders, Aasland, Babor, De la Fuente, & Grant, 1993), Drug Use Disorders Identification Test (DUDIT; Berman, Bergman, Palmstierna, & Schlyter, 2005), Stanford Trust In Physician Scale (STIPS; Thom, Ribisl, Stewart, & Luke, 1999), and the Consultation and Relational Empathy Measure (CARE; Mercer, Maxwell, Heaney, & Watt, 2004). In addition to self-reported height and weight (given on the EDE-Q), clinician-gathered height and weight (participant was not informed of the measurements) were also collected when meeting in person, with



the participants' consent. As only a subset of participants was local (and some participants declined to be weighed), clinician-gathered data was available for 44% ( $n = 17$ ) of participants.

### **Qualitative Data**

The qualitative portion of this dissertation takes an interpretivist approach focused on explaining behavior by “rendering it meaningful or intelligible” (Rosenberg, 2016, p. 25). An underlying assumption of the interpretive framework is that there is no objective, absolute truth. According to interpretivists, “what we might identify as universal or true or optimal in our beliefs, values, and institutions is really parochial, local, and merely convenient for some of us” (Rosenberg, 2016, p. 27). As such, interpretivist approaches view knowledge progress as further interpretations that help social scientists understand the actions of others and ourselves, such that we learn to “place our own society in perspective” (Rosenberg, 2016, p. 27). Finally, interpretive approaches also introduce deliberate engagement with the “moral dimension of social science” which may be absent from more naturalistic empirical approaches (Rosenberg, 2016, p. 27).

Participants completed three qualitative interviews, with each interview building on the previous interview. Drawing on theoretical ideas from Kleinman (1988), the first interview (See Appendix B for interview guide) addressed the patient's illness story: how they saw their illness starting or developing, how it changed over time, and their attempts to get help. The first interview revealed that most participants had lived with their EDs for many years (often decades) and their ED presentation (specific behaviors and cognitions) varied by time period.

Given this information, the second interview included a diagnostic history with a structured DSM-based interview to determine which ED diagnoses the participant met during their illness journey. Illness time periods were developed by the researcher based on data from the first interview, then verified with the participant at the beginning of the second interview. Time markers were developed to signal each distinct diagnostic time period in the participant's

memory, using a method of signaling (through key dates, key words, and anchor points) similar to techniques used in the Timeline Follow-Back Method, a strategy used to help people recall specific patterns of substance use and behavior over long periods of time (Sobell & Sobell, 1992). During the structured diagnostic interview, diagnoses (based on DSM-5 criteria) were assigned to each of the time periods, or the participant was noted to be in remission. For a sample participant timeline with anchor points and sample diagnostic timeline, please see Appendix C.

During the second interview, participants were asked about their interactions with healthcare providers and experiences in treatment, and how these experiences (positive and negative) affected their illness trajectory (see Appendix D for interview guide). Interview qualitative coding processes are described in Chapter Three. For a summary of the coding guide used for this interview, see Appendix E.

The third interview explored participants' attempts to get better, their experiences with remission (if that was something they had experienced), and lapses back into ED thinking and behavior (See Appendix F for interview guide). In addition to the interviews and art, several short-answer qualitative questions were asked via the online survey instead of during the interview, to reduce the length of interviews,

All interviews were semi-structured, audio recorded, and conducted in person or over Zoom. As part of the interview protocol, prior to the interview, participants were given an “art prompt” and asked to draw (or otherwise create) something in response to the prompt. Art prompts focused on the “heart of the interview” and served several purposes. First, the art prompts primed the participant to think of experiences or elements of their story related to the content of the interview. Many people were reflecting on years or decades of experiences, and it could be difficult to recall events in the moment. Thus, the art served a preparation purpose.

Second, the art served as an anchoring device during the interview, such that the participant could reference parts of the art while answering various questions. Also, the art provided a meaningful, information-dense way of communicating concepts that were sometimes difficult to describe with words. Fourth, using art methods tapped into more sub-conscious, or less-conscious elements of a person's story (e.g. a person saying, "I didn't realize it while making this, but x seems to really fit because of y"). Finally, the art provided a visual communication tool, to enhance dissemination of study findings and promote understanding of the patient experience through the use of visuals and metaphor. Most participants chose to complete the art prompts (74% completed art 1, 71% completed art 2, 63% completed art 3). Some declined participation in the art prompts, as all aspects of the study were at the participants' discretion. A sample of one participant's artwork for each of the three interviews can be found in Appendix G; sample artwork are also provided between chapters of this dissertation.

All qualitative interviews were audio-recorded and transcribed, and then validated by a research assistant, the primary investigator (EH) and the research participant. To validate the transcription, the researcher listened to the audio file, while reading the transcript, pausing to correct any words that were unclear or misheard. Transcription was completed using a modified verbatim format such that filler words (e.g. um, uhs, like) and false starts (I I I I went to the doctor → I went to the doctor) were omitted. During validation, nonverbal cues (e.g. noises, crying, laughing, sarcasm, joking, tearful, etc.) that provided additional information on emotion or context were added to the transcripts in [brackets]. Additionally, identifying words (names of people, cities, treatment centers, schools) were changed to preserve participants' anonymity. Participants were permitted to make any changes or omissions from their validated, deidentified transcripts as a final validation check.

## **Self-Reflection Processes**

Throughout this dissertation, the researcher integrated a consistent self-reflexivity practice to deepen engagement with the data, promote self-awareness, track emerging themes, explore the transference and countertransference that interviews evoked, make ongoing improvements to study procedures, and engage the iterative aspects of data analysis. The researcher engaged in regular consultation with their dissertation mentoring team. As a part of each interview, interview reflections were completed, summarizing emerging themes, similarities and differences between interviewees, and noting moments of transference, countertransference, identification, boredom, alarm, sadness, and annoyance. Periodically, research poems were produced, as a way of creatively synthesizing major themes (Piirto, 2009). A sample research poem, comprised of master's student reactions to a brief presentation on WINTER Study data (written entirely from quotes taken from a Zoom chat and rearranged into poetic form) is found in Appendix H, along with the participant's accompanying artwork that the students were discussing. These reflections offered greater insight into participant stories, contributed to the iterative process of coding development, and fostered resilience when hearing difficult stories.

## **Data Collection and Retention**

Data collection began in November 2017 with the last 12-month interview completed in May 2020. The secure web-based Research Electronic Data Capture (REDCap; Harris et al., 2009) system was used to collect and store participant data in a Health Insurance Portability and Accountability Act-compliant database. At the beginning of the study, paper measures were used for the first 13 participants (as the database was being built). Later, these paper measures were entered into the RedCap database by three Masters-level research assistants (ED, SG, MC). The PI conducted all interviews. Retention rates for each timepoint are as follows: baseline interview (100%,  $n = 39$ ), baseline survey (100%,  $n = 39$ ), 2-month survey (97.4%,  $n = 38$ ), 4-month

survey (97.4%,  $n = 38$ ), 6-month interview (97.4%,  $n = 38$ ), 6-month survey (97.4%,  $n = 38$ , an additional one participant completed half the survey measures), 8-month survey (97.4%,  $n = 38$ , an additional two participants completed half the survey measures), 10-month survey (97.4%,  $n = 38$ ), 12-month interview (97.4%,  $n = 38$ ), 12-month survey (97.4%,  $n = 38$ ).

### **Ethics Considerations and Confidentiality**

All research participants completed an informed consent process, which included five levels of consent: 1) consent for basic study procedures, 2) consent to be contacted for future study opportunities, 3) consent to have the audio retained by the researcher to be used in presentations and teaching, 4) consent to be contacted to review manuscript drafts prior to publication, and 5) consent to be contacted with test scores (e.g. PHQ-9, GAD-7 scores). Per IRB, a waiver of signed informed consent was in place for participants who were interviewed online; all others completed signed informed consent documents. A copy of the informed consent document is found in Appendix I. First author (EH) retained full access to all original data and was responsible for the integrity of the data and accuracy of the data analysis.

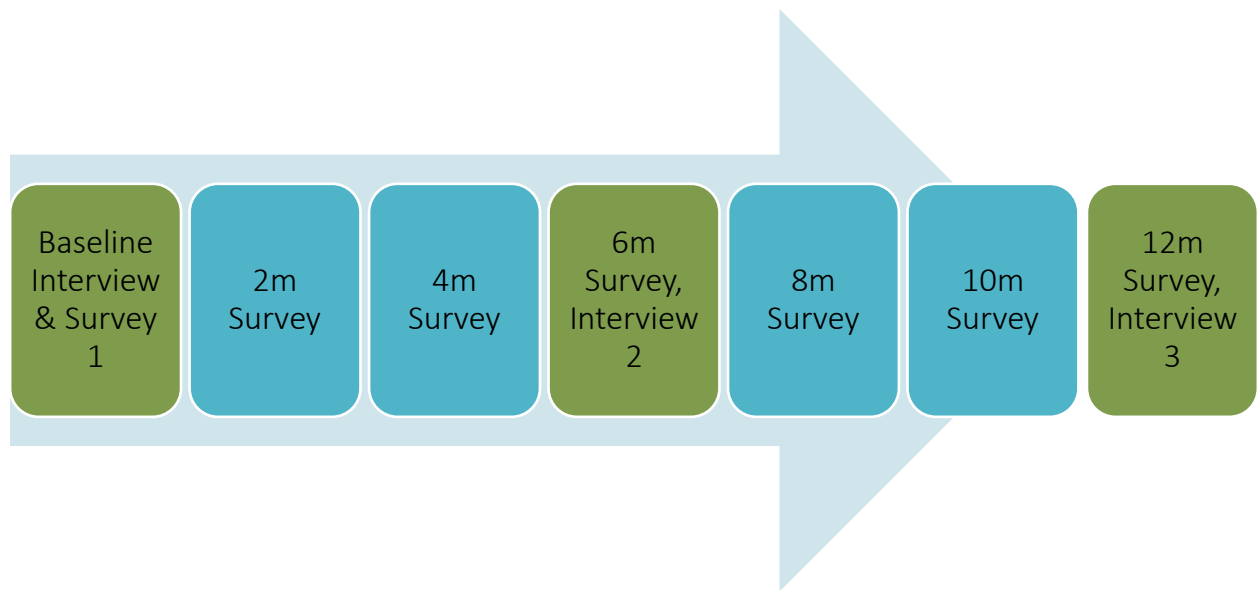
### **Conclusion**

This chapter served as an overview of the broad aims, study design, general procedures, and measures of the WINTER Study. Study-specific research questions and methods for qualitative analysis are found in the following chapter, and quantitative questions and analysis are described in Chapter Four.

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*Figure 2.1.* WINTER study design.

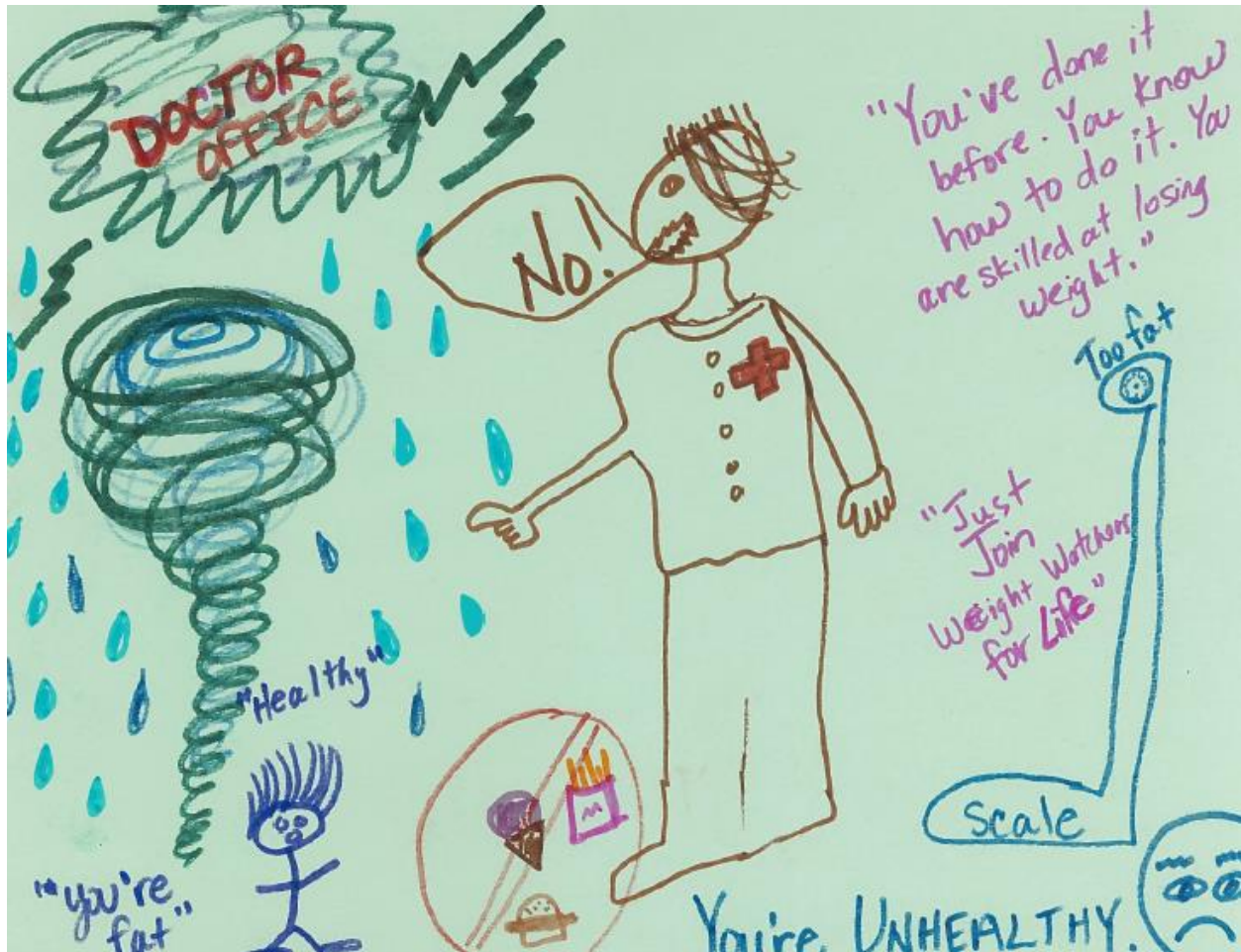


Table 2.1

*Timing, Setting, Length, and Number of Items of All Study Measures*

Measure	Brief Description	Timepoint Administered <sup>a</sup>	Setting <sup>b</sup>	Length (min)	# of Items
<b>EDA-5</b>	Eating Disorder Assessment for DSM-5	Screening	I, P	5-10	various
<b>MSE</b>	Mental Status Exam	Screening	I, P	2-5	various
<b>Weight history</b>	Weight history by self-report	BL, 12m	I, O	2	6
<b>BMI</b>	Body Mass Index: height and weight	BL, 6M, 12M	I, O	1	2
<b>EDE-Q 6.0</b>	Eating Disorders Examination Questionnaire 6.0	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	3-5	22
<b>PHQ-9</b>	Patient Health Questionnaire 9	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-2	9
<b>GAD-7</b>	Generalized Anxiety Disorder-7 item Scale	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-2	7
<b>CIA</b>	Clinical Impairment Assessment Questionnaire	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-3	16
<b>WHOQOL-BREF</b>	World Health Organization Quality of Life Brief	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	3-5	26
<b>BAS</b>	Body Appreciation Scale	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-2	13
<b>BCBS</b>	Broad Conceptualizations of Beauty Scale	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-2	9
<b>IES-2</b>	Intuitive Eating Scale 2	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	2-3	23
<b>RSES</b>	Rosenberg Self-Esteem Scale	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-2	10
<b>WBIS</b>	Weight Bias Internalization Scale	BL, 2M, 4M, 6M, 8M, 10M, 12M	O	1-3	11
<b>DUDIT</b>	Drug Use Disorders Identification Test	BL, 6M, 12M	O	1-2	11
<b>AUDIT</b>	Alcohol Use Disorders Identification Test	BL, 6M, 12M	O	1-2	10
<b>CARE</b>	Consultation and Relational Empathy Measure	6m	O	1-2	10
<b>STIPS</b>	Stanford Trust in Provider Scale	6m	O	1-2	11
<b>Interview 1</b>	Qualitative interview: Eating disorder development	BL	I, O	60-90	1
<b>Art 1</b>	Art preparation for qualitative interview	BL	HW	30	1
<b>Interview 2</b>	Qualitative interview: Interactions with providers	6M	I, O	60-90	1
<b>Diagnostic Interview</b>	Structured DSM-5-based checklist with symptoms	6m	I, O	60-120	172
<b>Art 2</b>	Art preparation for qualitative interview	6M	HW	30	1
<b>Interview 3</b>	Qualitative interview: Recovery turning points	12M	I, O	20-60	1
<b>Art 3</b>	Art preparation for qualitative interview	12M	HW	30	1
<b>Kleinman's Q's</b>	Kleinman's interview questions: short answer	12M	O	10	8
<b>Demographics</b>	Demographic question	Screening, BL, 12m	P, O	10, 1	20, 3

Note. <sup>a</sup> Timepoints; BL = baseline; M1 = Month 1, M2=Month 2, M3=Month 3, M4= Month 4, etc. <sup>b</sup> P = phone, O = online, I = in person, HW = homework



Artwork by Carly, Participant 9

“I have been before doctors my entire life, and no one diagnosed me with an eating disorder until I went into treatment and said, ‘I have an eating disorder and I need you to pay attention.’ ... Doctors... helped me find better ways to starve myself for 30 years... You have a child who is passing out, you have someone whose potassium drops so low they have to be hospitalized. ... no one ever suspected that I might have an eating disorder... I was a fat woman; it wasn't even a possibility that I might have anorexia.” –Riley, Participant 19

## CHAPTER THREE:

### “YOU DON’T LOOK ANOREXIC:” PATIENT-PERCEIVED EXPERIENCES OF WEIGHT STIGMA IN MEDICAL CARE FOR PATIENTS WITH ATYPICAL ANOREXIA

#### Abstract

Eating disorders (ED) and weight stigma pose significant challenges to healthcare providers. ED patients who are higher weight, like some with atypical anorexia (AAN) may face increased challenges as they encounter weight stigma in healthcare. The present study analyzed AAN patients’ lived experiences with weight stigma in healthcare, and patient perceived effects of this stigma. *Methods:* In-depth semi-structured, arts-based qualitative interviews were thematically coded for patient experiences of weight stigma in healthcare as they sought (and received) treatment for AAN. *Results:* Across the ED illness trajectory (risk development, pre-treatment, treatment, relapse prevention), patients reported that provider weight stigma contributed to initiation and persistence of ED behaviors, complicating recognition and recovery from the illness. Qualitative themes included “providers’ pathologizing patient weight,” which patients reported triggered ED behaviors and sometimes relapse, “provider minimization and denial” of patients’ EDs, which contributed to missed screening opportunities and delays in care, and “overt forms of weight discrimination” for higher weight patients, contributing to healthcare avoidance, particularly during aftercare from ED treatment. In sum, participants reported that experiences of weight stigma prolonged ED behavior engagement, delayed care, created suboptimal treatment environments, deterred help-seeking, and lowered healthcare utilization. *Discussion:* Unfortunately, many providers reinforced participants’ EDs rather than bolstered their recovery. Increasing provider training around EDs, screening for EDs across the weight spectrum, and targeting

health behavior promotion rather than universal weight loss, could enhance quality of care and improve healthcare engagement for patients with EDs, particularly those at higher weights.

**Key words:** Weight Stigma, Atypical Anorexia Nervosa, Eating Disorders, Anorexia Nervosa, Body Size



Artwork by Abby, Participant 8

## CHAPTER THREE:

### “YOU DON’T LOOK ANOREXIC:” PATIENT-PERCEIVED EXPERIENCES OF WEIGHT STIGMA IN MEDICAL CARE FOR PATIENTS WITH ATYPICAL ANOREXIA

Eating disorders (EDs) pose significant clinical challenges for healthcare providers in terms of diagnosis, treatment and relapse prevention. EDs are complex biopsychosocial conditions, wherein denial, minimization, and difficulty engaging in treatment contribute to illness persistence (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013; Couturier & Lock, 2006). Within EDs, atypical anorexia nervosa (AAN) is a serious psychiatric illness characterized by severe caloric restriction, an overvaluation of weight and shape, body image disturbance involving an intense fear of gaining weight, and despite significant weight loss, a body mass index (BMI) “within or above the normal range” (American Psychiatric Association, 2013)(p. 353).

Low weight anorexia (AN) is one of the deadliest of all mental disorders (Chesney, Goodwin, & Fazel, 2014). Individuals with AAN also experience life-threatening medical consequences (Sawyer, Whitelaw, Le Grange, Yeo, & Hughes, 2016), at commensurate rates to those with low-weight anorexia (AN; Peebles, Hardy, Wilson, & Lock, 2010). While ED prevalence rates are growing worldwide (Galmiche, Déchelotte, Lambert, & Tavoracci, 2019; Mitchison, Hay, Slewa-Younan, & Mond, 2014), the majority of frontline medical providers report feeling “unsure” how to diagnose and treat ED patients and endorse the desire for more training (Linville, Benton, O’Neil, & Sturm, 2010). Healthcare provider attitudes toward ED patients have been shown to reflect frustration, hopelessness, lack of competence, and worry, undoubtedly contributing toward provider unease with these challenging illnesses (Thompson-Brenner, Satir, Franko, & Herzog, 2012).

Weight stigma is a similarly challenging issue in healthcare and a pervasive phenomenon in much of the world (Charlesworth & Banaji, 2019; Puhl, Andreyeva, & Brownell, 2008).

Weight stigma refers to how higher weight (“fat”) people are systematically devalued. Research shows that fat people experience discrimination, fewer opportunities, and other forms of systemic abuse and mistreatment (e.g. microaggressions, marginalization, and violence) (Apos, Brien, Latner, Ebner, & Hunter, 2013; Pausé, 2014). While weight stigma manifests as discrimination in many spheres including employment, education, and social relationships (Puhl & Heuer, 2009; Rudolph, Wells, Weller, & Baltes, 2009), it is particularly problematic within the medical sphere, wherein healthcare providers have been found to have strong negative attitudes towards heavier patients, leading to negative stereotypes which influence provider judgments, perceptions, interpersonal behaviors, decision-making, and ultimately quality of care (Phelan et al., 2015). Physicians (including pediatricians) are more likely to believe their higher weight patients are unattractive, less intelligent, and less likely to respond to clinical recommendations; nurses reflect similar attitudes (Budd, Mariotti, Graff, & Falkenstein, 2011). Healthcare provider weight stigma has been hypothesized to lead to increased healthcare avoidance, mistrust of providers, and poorer engagement on the part of heavier patients (Phelan et al., 2015).

Within the fields of EDs and obesity, contentious debates persist regarding the long-term benefits of weight-centric health approaches. Obesity experts focus on obesity prevention efforts, medicalizing higher weight bodies (Blackburn, 2011), and strive to shift population health by focusing on diet and weight management recommendations (e.g. Falconer et al., 2014). Other experts question the long-term outcomes of weight-centric healthcare, noting that BMI is a poor predictor of cardiometabolic health in both normal and high BMI populations (Tomiya, Hunger, Nguyen-Cuu, & Wells, 2016). Fat-advocates further argue that weight-centric approaches actively reproduce health inequities and other adverse consequences such as unhealthy weight

control behaviors, weight-cycling, weight stigma (O'Hara & Taylor, 2018; Tylka et al., 2014). ED researchers are often divided on this issue with some ascribing to weight-centric approaches to care (e.g. Cooper, Calugi, & Dalle Grave, 2019), and others arguing the potential harms for ED-vulnerable individuals who often progress from dieting to EDs, particularly in pediatric populations (Neumark-Sztainer et al., 2006).

Provider weight stigma is particularly concerning within the field of EDs, because EDs involve a significant degree of *internalized* weight stigma, wherein patients have negative, shame-inducing self-evaluations, along with body image disturbances, and fear of fat. Thus, if healthcare providers mimic these disordered beliefs about the inherent pathology of larger bodies, they may unwittingly reinforce the disordered, fat-phobic beliefs that are a hallmark of EDs (Harrop, 2018). This type of healthcare messaging may be particularly impactful in pediatric settings during developmental periods when children form foundational beliefs about the acceptability of their growing bodies and during which they are at greater risk of developing EDs. When healthcare providers adopt weight-centric messaging (focusing on individual weight management goals) versus more inclusive health aims, some researchers have suggested that this may lead to unintentional harm (O'Hara & Taylor, 2018; Tylka et al., 2014). Further, longitudinal evidence has shown that dieting in childhood and adolescence is associated with increased likelihood of developing an ED and with elevated BMI (Neumark-Sztainer et al., 2006). These data suggest that alternative approaches (as opposed to traditional weight management) may be needed in pediatric settings to support health enhancement and prevent the development of EDs.

Little is known about how weight stigma may be manifested in the medical care of people with AAN. Because individuals with AAN present at higher weights compared to AN patients (by definition), AAN individuals are more likely to experience weight stigma—both in their daily lives and in healthcare. To wit, previous research has suggested that weight stigma

may complicate or elongate the disease trajectory for AAN (Sim, Lebow, & Billings 2013). One AAN case study examined factors related to weight stigma in ED treatment (Harrop, 2018); this researcher suggested that those with AAN may face compounded challenges in ED treatment, as they must confront both the challenges of the AN diagnosis (and all the problematic behaviors and cognitions therein), *and* the challenges of weight stigma as they seek to recover into bodies which may be pathologized by society and the medical community (Harrop, 2018). To date there are no studies which have examined AAN patients' lived experiences of weight stigma in healthcare environments. The present study sought to address this knowledge gap by exploring AAN patients' lived experiences with weight stigma in healthcare settings by answering the following questions:

- 3) How do patients with a history of AAN report experiencing weight stigma in healthcare settings?
- 4) What are the patient-perceived impacts of these experiences?

## **Methods**

### **Study Design**

The Women's Illness Narratives Through ED and Remission (WINTER) Study is a purposive, mixed-methods study of individuals with a history of AAN. Semi-structured interviews were conducted at baseline, 6-months, and 12-months in addition to the collection of survey data. Data for the current study were drawn from the 6-month interviews which focused on experiences with healthcare providers. Given the longitudinal nature of the parent study, participant stories were situated within a larger narrative of multiple interview engagements, providing greater depth, familiarity, and nuance. Six-month interviews typically took two hours, ranging from 90 minutes to four hours.



## **Sample and Recruitment**

Thirty-eight participants completed their 6-month interview, representing 97.5% of enrolled WINTER participants. Participants were recruited through flyers at ED treatment centers, provider referral, social media groups, snowball recruitment, and through interested potential participants directly contacting the researcher.

## **Screening, Eligibility, and Inclusion/Exclusion Criteria**

Potential participants were screened by phone or in person using the ED Assessment for DSM-5 (Sysko et al., 2015) to verify a history of AAN, in addition to completing a brief mental health status examination. The first author (EH), who is also a mental health evaluator and medical social worker, completed all screenings and clinical interviews. To be eligible, women and non-binary or trans assigned-female-at-birth (AFAB) persons had to be 18 years of age or older, live in the US, speak English, and have experienced AAN. Presentations of Other Specified Feeding or ED (OSFED) for which restriction was a primary symptom but individuals had not experienced the “significant weight loss” required for AAN categorization, were eligible for inclusion due to current lack of consensus regarding guidelines for clinically significant levels of weight loss for AAN (Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017). Those currently in inpatient or residential treatment settings, and those with acute suicidality or acute psychosis were ineligible.

Seventy-six percent of the sample identified as cisgender female, 18.4% as nonbinary AFAB individuals, one (2.6%) woman was assigned male at birth, and one male (2.6%) was AFAB.<sup>6</sup> Mean age was 35.6 years at baseline ( $SD=11.8$ , *range* 18-74). The sample was 73.7% non-Hispanic white, 15.8% Latinx, 7.9% Black or African American, 2.6%% Alaska Native,

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<sup>6</sup> At the baseline assessment, 10.5% of participants identified as nonbinary AFAB, 86% as cisgender AFAB, and 2.6% as trans female. Over the course of the study, 3 participants who initially reported cisgender female gender came out as nonbinary AFAB, and an additional came out as trans male. All requested their genders be updated in study materials. Genders in the Table 3.1 reflect these genders.

2.6% Middle Eastern, 2.6% Asian and Pacific Islander with 18.4% of the sample reporting more than one race. Thirty-four percent ( $n=13$ ) reported being heterosexual. Forty-two percent were on financial assistance as children. Mean BMI at baseline was 37.8 ( $SD=10.8$ , range 21.8-61.1) which is in the obese range according to current BMI standards. Three (7.9%) participants had BMIs between 18.5-24.9 (in the normal range of BMI), eight (21.1%) between 25.0-29.9 (in the overweight range of BMI), nine (23.7%) between 30.0-34.9 (in the Class 1 range of obesity), four (10.5%) between 35.0-39.9 (Class 2), and 14 (36.8%) had BMIs over 40 (Class 3).<sup>7</sup>

*<Insert Table 3.1 Here>*

## **Measures and Procedures**

Prior to the interview on provider experiences, participants completed a structured diagnostic interview with the researcher; this was used to establish time landmarks regarding ED symptoms during the coding and data analysis process. Participants completed an in-depth, semi-structured qualitative interview with the primary researcher, which addressed their healthcare experiences, attempts at seeking care for their ED, any ED treatment experiences, and patient perceived impacts of helpful and unhelpful healthcare provider interactions. In preparation for the interview, participants were given an art prompt at least two weeks in advance, in which they were asked to create an image depicting their “interactions with the medical, healthcare, and/or ED treatment systems.” They were asked to create a response to the prompt, “What has it been like to be an ED patient in your healthcare system?” Twenty-seven participants (71.1%) chose to complete the art prompt for the six-month interview.

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<sup>7</sup> The terms “overweight” and “obesity” are not the preferred words of fat communities to describe their body habitus. See (Meadows & Daníelsdóttir, 2016) for alternative language suggested by these communities.

## **Ethics Considerations and Confidentiality**

All study protocol and procedures were approved by the University of Washington Institutional Review Board and conformed to recognized standards set by the US Federal Policy for the Protection of Human Subjects. Study data were collected and managed using Research Electronic Data Capture (Harris et al., 2009), a secure, web-based application designed to support data collection for research studies.

## **Data Analysis**

Qualitative interviews were audio-recorded, transcribed, validated, and de-identified. During the interview, the interviewer took notes on the participant's appearance, affect, mannerisms, and emotional valence. Following the interview, the interviewer recorded reflections in a document, summarizing the main themes to aid in interpretation of the transcripts. Transcription utilized a modified verbatim format in which false starts and filler words were omitted. Following initial validation and de-identification, the first author and participants performed a second and third validation of all transcripts. In de-identification, all participant names were changed to the pseudonym of their choosing; those that did not provide a pseudonym were assigned one by the researcher. Of the 38 participants, two provided minor corrections to their transcripts.

To begin analysis, all transcripts were summarized with brief narrative hermeneutic summaries (Hollway, 2000) outlining the themes in each interview. Following this, the first author produced pen portraits for each participant (Sheard & Marsh, 2019). A pen portrait is a type of analytic tool used in longitudinal qualitative research to summarize participant data and create a holistic summary of each participant's story. In these pen portraits, data were summarized from the diagnostic interviews (occurring immediately prior to the qualitative interview), the interviewer notes on participant appearance and affect, the qualitative interview, and artwork produced in response to the prompt. Additionally, the first author created visual diagnostic and ED symptom timelines, showing the development and maintenance (or remission) of ED symptoms

and diagnoses across each participant's lifetime; these were based on the data collected in the clinical interview preceding the qualitative interview, and were used in combination with qualitative interview data to specify when in a participant's illness trajectory various events occurred. The first author also created thematic summaries for each participant, listing major recurring themes, in addition to creating a list of targeted quotes which summarized participant perspectives. A sample participant summary portrait can be found in Appendix J.

To begin the coding process, four coders (Harrop, Harner, Franz, & Hutcheson) divided half of the transcripts ( $n = 20$ ), read through participant interviews, and submitted a list of codes to be potentially incorporated into a coding guide. Over 200 codes were identified in this process; codes were condensed by grouping similar codes together and by creating higher level codes to summarize related codes. Codes not related to weight stigma were discarded. These inductive codes (arising from the data) were added to a list of a priori codes (arising from previous literature and theory) developed by EH during study conceptualization. Stigma codes were sorted into two large a priori categories, because weight stigma is experienced in *externalized* ways (where people experience weight stigma from others or society) and *internalized* ways (when people internalize stigma towards themselves). Other a priori codes included categories of *stigma impact*, *provider disciplines*, *ED behaviors*, *ED cognitions*, and *physical symptoms*. The final coding guide was developed and organized by EH, discussed between coders, and updated with four versions of revisions until consensus was reached. Code definitions and sample codes were also developed iteratively with all coders contributing, as new specifications for codes arose during the coding process.

To begin, experiences of weight stigma in healthcare were coded across four a priori codes based on illness trajectories: 1) ED risk and development when disordered eating behaviors emerged, prior to full ED engagement, 2) ED pre-treatment when participants experienced a

symptomatic ED prior to care, 3) during ED treatment, and 4) ED relapse prevention, the period post-treatment or during periods of partial or full remission. The first 20 transcripts were analyzed by Harrop, Harner, Franz, and Hutcheson using established coding conventions (Miles, Huberman, & Saldana, 2013) for thematic analysis. Coding and analysis were conducted via Dedoose Version 8.0.35, a web-based data management application permitting multiple coders to code data concurrently (SocioCultural Research Consultants, 2018). A second round of coding (of the first 20 transcripts) was conducted by authors Harner and Franz on other researchers' analysis to check for missing or wrongly attributed codes. Disagreement in coding decisions was addressed using discussion and consensus. An additional six codes were added following the second round of coding, and all transcripts were coded a third time by the first author, who then coded the remaining 19 transcripts, following the process outlined above.

Following coding completion, coders met to discuss emerging themes. Disconfirming cases were sought to deepen understanding of each theme (Emmel, 2013). Facilitated by Dedoose, matrices were developed tracking the weight stigma themes across illness periods. Primary quotes (approximately 10-30) were selected for each participant, based on the hermeneutic narratives developed in the summary pen portraits. Following this, themes were printed on paper, cut up, and organized by the researcher, who worked in collaboration with a community partner (who is a local fat activist living in a large body) to organize quotes into distinct, related "buckets." Discrepancies were addressed through discussion and consensus. Following this, the first author organized themes into hierarchically related categories for each illness period (with themes and evidence). Illustrative quotes for each type of stigma and time period were recorded to determine the most robust themes. Following this a large document with all quotes, organized into themes was reviewed by the first author, and emailed to participants, and the community partner for member-checking and feedback.

## **Rigor**

To increase qualitative rigor, this study utilized the following: audio recording, transcription with multiple validation (research assistant, interviewer, participant), multiple coders, hermeneutic summary and analysis approaches, iterative coding, and qualitative software to manage and cull data. Additionally, self-reflexivity practices including memo-ing, expert consultation, and group discussion were regularly utilized during study conceptualization, data collection, and analysis. Finally, this study utilized participant member checking. Twenty-nine (76%) participants elected to review manuscripts prior to publication. Of those, seven (18.4%) provided feedback which has been incorporated into the current manuscript.

## **Results**

Full demographic characteristics of each participant, including participant age, gender, racial and ethnic identity, sexual and relationship orientation, highest level of education, employment status, financial status as children, and current occupation, can be found in Table 2.1. Of note, despite not using a weight loss cutoff for study participation, all participants in this sample qualified for AAN diagnosis according to the EDA-5, and all participants lost at least 10% of their premorbid body weight during their experiences of AAN.

*<Insert Figure 3.1 Here>*

Participants reported experiencing weight stigma from healthcare providers throughout each stage of their ED illness. As young children, participants learned that fat bodies were unhealthy; they were instructed by family and healthcare providers to control their bodies through food and exercise. As their disordered eating developed and progressed to full EDs, participants tended to “fly under the radar” (Uki) due to their lack of emaciation. For participants who

eventually received treatment, they reported receiving ongoing messages to focus on weight loss, even while in care for a restrictive ED. Finally, participants who reached a place of full or partial remission, were often targeted for more overt forms of weight stigma from providers due to gaining weight while in recovery. A figure outlining all qualitative themes is found in Figure 3.1. For a full list of all themes with sample participant artwork (from the pre-interview prompt) representing these themes, see Appendix L.

<Insert Table 3.2 Here>

### **ED Risk and Development**

Table 2 summarizes themes during ED development (themes *italicized* below). Beginning in childhood, participants reported *pediatricians pathologized their weight and growing bodies*. Participants who were heavy as children received messages from providers that their weight was too high or posed an imminent health risk. Eli recalls going to the doctor with her mother for a sore throat and being lectured on BMI; seven-year-old Carly was told to lose weight because of frequent ear infections. As a young teen, during an urgent care visit to cauterize a nosebleed, Mary was told that she was “destined” for hypertension, heart disease, and diabetes. While some participants reported first hearing weight stigma messages from their providers (e.g. Daisy), others mentioned they first heard the message at home, and *compounding messages from the medical community*, solidified their beliefs that their bodies were unacceptable. Though Sonja’s parents told her that her weight was too high, it was not until her physician reinforced this message that the “real thoughts of restriction started to settle in.” Participants frequently reported being put on their first diet by parents following advice from *pediatricians recommending weight loss*. In response to medical recommendations, parents started diet programs, withheld

“forbidden foods” (e.g. Carly’s mom withheld her birthday cake), and modeled other ED behaviors (Bette’s grandmother taped inspirational quotes about thinness to the refrigerator).

Finally, participants reported a theme of *providers triggering* (or at minimum sanctioning) disordered eating, citing provider conversations as directly leading to the initiation of ED behaviors. When her pediatrician recommended weight loss, Carly stated, “that probably started my ED journey,” saying that her first ED was “doctor-prescribed and mother approved.” Similarly, after initiating fasting, Ari reported that her pediatrician commented that though her weight was declining, she was “still overweight.” Ari was so crushed by this feedback, that when she got home from that doctor’s appointment, she purged for the first time, starting her on an ED journey that continued into adulthood.

<Insert Table 3.3 Here>

### **Pre-Treatment for EDs**

Table 3 summarizes themes reported pre-treatment. When patients initiated ED behaviors (e.g. caloric restriction, fasting, eliminating foods and food groups, calorie counting, compensatory behaviors), *physicians frequently praised these behaviors* (or the resulting weight loss). Dover was congratulated for her “perfect weight and size alignment” after beginning restriction and compulsive running. As an adolescent, Lexi was praised for her obsessive consumption of fruits and vegetables (at the exclusion of other foods). Her male physician also simultaneously warned that her BMI was “high,” while reassuring her that the weight was “distributed” in an “attractive” and “reassuring” way. After losing over half her body weight as an adolescent, Mary’s physician encouraged her to lose “a little more” and congratulated her “achievement.” Candy recalls being complimented on her thin, muscular frame; Bette, Molly, Josephine, and Carly reported that



physicians expressed “polite congratulations” following significant weight decreases. Josephine concluded, “they’ve never gone into *how* I’m doing it, so it was just encouragement to keep doing [it].” These findings emphasize the extent to which children and adolescents internalized potentially offhand remarks from providers, which became reinforcement for the ED.

Though their bodies were shrinking, *doctors did not notice their EDs*, failing to recognize their changing bodies and behaviors as problematic. Providers did not discuss EDs or discuss how participants were losing weight. Lynn recalls how she was perceived as “healthy” because she “looked healthy” and was in a “healthy BMI range,” despite the fact she was eating under 1000 calories and running 3-8 hours daily. Marie and Mary described themselves as “invisible” to providers; Lexi’s provider told her she didn’t “look anorexic” when she reported her ED history and ongoing struggles with restriction and purging. Veronica expressed dismay that providers ignored her “clearly malnourished” form (with clavicles protruding and lanugo, a fine hair that covers the body when malnourished), dismissing it as “normal” athleticism: “it’s ‘runners’ body.’” Others reported a complete absence of conversation regarding EDs. Though Uki sought help for amenorrhea (which later resolved after ED treatment and nutritional rehabilitation), she was never asked about restriction or compulsive exercise; rather her amenorrhea was blamed on her fitness regimen, and it was recommended that she lose additional weight to restore menses. Similarly, Carrie-Anne reported that no healthcare provider discussed her ED, though “nurses sometimes ma[d]e comments on my weight.” This continued until present day, with Carrie-Anne never receiving care, and treating her ED by attending 12-step meetings. She suspected if providers had asked her about her eating patterns and weight loss as an adolescent, she may have been able to identify her ED before the age of 25.

Nearly every participant reported symptoms of malnutrition to providers (e.g. amenorrhea, lanugo, fainting, dizziness, pitting edema, hair loss, dry/bleeding skin, vomiting blood,

fatigue, weakness) with *missed opportunities for screening*. Even when patient reports were validated by clinician-gathered measures (e.g., low heart rate, elevated bilirubin, orthostatic changes, weight loss), little follow-up occurred. Amanda was briefly asked “Are you starving yourself?” after lab work showed elevated bilirubin; her provider did not press when she denied self-starvation, no follow-up was recommended, and she never returned for additional care. Bette was recommended to use “lotion” for their dry/bleeding skin. Riley had repeated episodes of fainting and electrolyte imbalance as a result of malnourishment requiring hospital admission, but was not screened for an ED.

When patients were more forthcoming about ED behaviors, *providers discounted or minimized the possibility they had an ED*. As a teen, Eli believed she had an ED and disclosed this to her physician, but her doctor insisted that she did not have an ED, was “okay,” and “could actually probably lose a little bit of weight.” She, like many participants, wondered how much shorter her ED illness may have been had she received treatment when she first sought care, as opposed to eight years later (or decades later in the case of Bette, Arati, Josephine, and Riley). After being diagnosed by her therapist with a restrictive ED, Tori’s physician told her she was “too overweight” and denied treatment referrals. Daisy, one of the study’s younger participants (25 years old), was told their size precluded them from having an ED; Gretchen’s pediatrician insisted her 16-pound weight loss in two weeks was “water weight.” Gaia’s physician told her hair loss was “normal” with fasting and not to be concerned. Interactions like this nurtured participants’ own denial and minimization.

The combined impact of these healthcare experiences led participants to conclude that their higher weight contributed to *delays of care*. Participants frequently wondered how their illness courses (and lives) would have been different with earlier intervention. Uki wondered, “What if anyone would have asked? What if I didn’t have to fight another decade? What could

my life be like now, had someone noticed, asked, or even just suggested my behaviors were problematic?”

<Insert Table 3.4 Here>

### **During Treatment for ED**

A summary of weight stigma during ED treatment is found in Table 4. Though many participants received ED treatment, providers often continued to *encourage ED behaviors*. While inpatient for AAN, Joanna’s healthcare provider recommended weight loss and restriction; Marie’s ED therapist gave her a diet book to follow; Abby’s provider recommended a gluten free diet. Cabaletta had multiple providers focus on weight loss instead of ED treatment, oscillating between recommending weight loss, then encouraging her to stop purging and restricting, then cycling back to recommend weight loss again. Marie’s inpatient dietitian said she could “lose another ten pounds” after she disclosed only eating 400 calories daily at admission. These suggestions spurred participants to question treatment and recovery.

Similarly, even during treatment, healthcare providers *minimized their EDs*, leading participants to feel as if their EDs were taken less seriously than their thinner peers. Providers told participants that they didn’t “look like they had an ED” (Lexi, Marie, Elizabeth, Daisy, Abby), leading participants to believe that if their bodies did not fit a thin, white, cis female image of an anorexia patient, their suffering was invisible. This was most pronounced for participants with multiply marginalized identities such as participants of color, trans/nonbinary, and participants who experienced poverty. Two patients (Abby and Carter) with known ED diagnoses were admitted to inpatient psychiatry units due to suicidal ideation and ED behaviors, and then prohibited from joining ED-specific psychoeducation groups. When both requested to join the ED

groups, they were told this would not be allowed, due to their higher weight status. Neither was provided with meal supports inpatient; Carter was permitted not to eat meals, and was not offered meal supplement, even as an adolescent.

Participants also reported *instances of misdiagnosis*. Layla was diagnosed with “compulsive overeating” in a period wherein they ate only bone broth and lost 22% of their weight; they attributed this misdiagnosis to their higher body weight. Carter, Abby, and Marie were diagnosed with bulimia when they did not binge. Participants reported providers assumed binge or purge behavior, while failing to screen for restriction. This resulted in *missed symptoms*, such as Ari’s orthostasis (reflecting her body’s inability to regulate its own blood pressure), Marie’s kidney injury, and Uki’s pitting abdominal edema and bradycardia (indicating cardiac and possible electrolyte imbalance), all conditions which indicated the need for immediate medical stabilization.

Participants also reported *weight stigma in higher levels of ED care*. Joanna recalls inpatient peers making fatphobic remarks, stigmatizing bodies like hers. Bette explained how damaging it was to hear peers disparage their bodies (which were thinner than hers), while showing pictures of themselves in bikinis in group therapy. Participants also reported receiving little nutritional guidance, limited nutritional rehabilitation, low discharge meal plans (e.g. 1500 calories daily), and “goal weights” permitting little weight restoration. When they did gain weight, providers often assumed they were bingeing (e.g. Ari, Riley) or “noncompliant.”

Finally, participants reported *issues of systemic weight stigma in healthcare*. Notably, no participant believed they received adequate treatment. Participants universally reported insurance coverage ending while participants still needed higher levels of care or being prohibited from higher levels of care in the first place. As a result, several participants had to “fight insurance” for coverage (e.g. Abby, Lexi, Joanna, Lynn, Marie, Michelle), and others accepted lower levels

of care or no care at all (e.g. Hope, Tori, Candy, Molly, Bette, Elizabeth, Grace, Beth, Carter, Gaia, Daisy, Charlie, Wendy, Jessie, Sisú, Carrie-Anne, Elizabeth, Grace).

<Insert Table 3.5 Here>

#### **Time Period 4: Post-Treatment or Relapse Prevention**

A summary of weight stigma post-treatment can be found in Table 5. Even after patients were treated for EDs, providers still *disbelieved or failed to acknowledge their EDs*. Uki's provider falsely assumed her ED was "obviously not happening right now" a mere six-months after she was discharged from residential care. Similarly, Elizabeth, who continued to struggle with intense cognitive ED symptoms, reported her ED was "not seen as real." She attributed this to her not "look[ing] emaciated" following weight restoration. Candy's cardiologist disputed her ED diagnosis, and suggested she was not "telling the truth" about her medical history; another provider prescribed her a 500-calorie daily diet. Lexi and Elizabeth reported providers said they did not "*look anorexic*" when they disclosed EDs.

Additionally, participants reported experiencing *weight- or weight loss-focused healthcare* following treatment; Bette summarized these experiences, explaining that the medical community had become the "voice of [their] ED," agreeing with their ED more than contradicting it. Though Arati explained her ED and desire to stay weight stable, her physician regularly told her to lose weight. Candy, Riley, Veronica, and Sisú (who each disclosed their EDs and requested providers not discuss weight loss) were repeatedly told to lose weight and labeled "non-compliant." Tori was recommended weight loss surgery (for a sinus infection); four others were also recommended weight loss surgery. For several participants, this weight-loss focused *after-care triggered increased ED cognitions or relapse*. Abby described that her doctor speaking as

an “authority” and telling her to lose weight “trigger[ed] my eating disorder.” Similarly, Veronica said that medical professionals believed her ED was preferable to “being fat.” She has questioned her ED recovery every step of the way. Providers exacerbated her fears about recovery rather than enhancing her motivation. Her restriction symptoms have continued to present day, and she has maintained a subthreshold diagnosis for years, despite experiencing some remission. Sisu identified receiving a restrictive diet from their physician as the “beginning of when my orthorexia really deepened.”

For patients who recovered into larger, fatter bodies, *these experiences of poor healthcare experiences* were pronounced. Tori explained that she did not think thinner, smaller providers knew “how to be kind” to larger bodies; Sisu mentioned how providers treated her body “harshly,” assuming she felt less pain. Multiple larger participants reported being treated less-than-humanely, and treated instead as an “unapproved body” (Cabaletta), a “size” (Dover), “not human” (Tori), a “number” (Uki, Grace), “fat” (Carly, Riley), or “the obesity epidemic” (Dover). Participants cited multiple assumptions providers verbally endorsed, including that they were “lazy” (Candy, Riley, Layla, Josephine), “uncaring” (Layla, Candy), non-compliant, “not trying” (Carly), “unhealthy” (Jen, Cabaletta, Riley, Arati), “diabetic” (Carly, Riley), and surviving on MacDonald’s (Carly). Additionally, participants noted *systemic issues of weight stigma in healthcare*, such as a lack of size-inclusive providers, lack of medical equipment for larger bodies, and health insurance policies disproportionately impacting larger bodies.

Finally, experiences of *overt discriminatory care* were striking, disproportionately impacting those with other marginalized identities. Candy, an African American woman, told of how a white male provider threatened to tie her to a car (to enforce exercise). Riley had a traumatizing surgical procedure (episiotomy) performed on her to which she did not consent, verbally, repeatedly. After breaking her foot hiking, Carly immediately presented for care. Providers

refused to x-ray her foot for six weeks disbelieving that a “fat woman” had been hiking, and refusing to perform an x-ray, which later revealed a bone break that had spread. Rather they suspected a chronic condition, diagnosing her with hypertension, plantar fasciitis, and obesity. Josephine reported that providers were “repulsed” by her body, fabricating vital signs to avoid touching her.

## **Discussion**

A hallmark of EDs is how challenging it is for patients to break through denial around their condition and recognize their need for help. In the case of these participants, this minimization and denial was perpetuated for years, and sometimes decades, often with the unknowing collusion of medical providers. It was difficult for participants to see their EDs as problematic when providers recommended similar behaviors (restriction, weight loss, exercise) and perceived their larger bodies as unhealthy and in need of “fixing.” For these AAN patients, their EDs were hidden due to their larger body sizes. As Mary summarized, her ED was “rendered invisible, because I was a previously fat person who had become the correct size.” This aligns with previous researchers who have asserted that in absence of more visible “overt indicators” of EDs, AAN is less readily identified and treated (Hartmann et al., 2014; Thomas et al., 2015).

Participant minimization of their own ED behaviors and symptom severity was mirrored by minimization from medical professionals—a theme which persisted from ED initiation through treatment and into relapse prevention. This was demonstrated in themes in which providers minimized symptoms, denied, disbelieved, or negated ED diagnoses, and failed to screen patients or provide referrals after identifying ED behaviors and symptoms. Participants frequently displayed hallmark symptoms of malnutrition (e.g. amenorrhea, weight loss, low heart rate, electrolyte imbalance, dizziness, fainting), yet reported that their symptoms were not recognized as

being caused by malnutrition. Some providers explained these symptoms by participants' high levels of activity and athleticism (for thinner participants), but more often symptoms were blamed on participants' higher weight. In fact, Uki was told *both*—that her heart rate was low due to her intense CrossFit regimen, and her menses would resume if she lost more weight. Given that so many participants presented with hallmark signs of starvation, emphasizing screening for EDs across the weight spectrum, particularly when such symptoms present (e.g. rapid weight loss, orthostasis, bradycardia, amenorrhea) could facilitate speedier diagnosis and access to appropriate treatment.

Additionally, when participants rapidly lost weight, providers congratulated their “achievements,” supporting previous findings that AAN patients may lose greater percentages of weight prior to receiving care (Peebles et al., 2010; Sawyer et al., 2016). Provider failure to assess for and recognize hallmark symptoms of malnutrition in patients not acutely or visibly underweight led to participants experiencing delays in care and missed opportunities for diagnosis and referral. Many participants believed that had they been thinner (with the same symptoms), their EDs would have been identified and treated earlier. This finding mirrors previous research that AAN patients may experience greater delays of care and longer durations of symptoms compared to low-weight AN (Hughes, Le Grange, Court, & Sawyer, 2017; Sawyer et al., 2016). Many participants wondered how their lives may have been different had they received intervention for their EDs earlier, when they first sought treatment or when providers first identified signs of starvation. In light of literature linking early intervention to better outcomes, improving the speed at which AAN patients are identified and treated is paramount (Fichter, Quadflieg, & Hedlund, 2006; Treasure & Russell, 2011).

Themes of providers pathologizing weight and provider praise of ED behaviors were found throughout participants' illness experiences. Participants described these experiences



beginning when they were children, often predating (and contributing to) initiation of ED behaviors. Hearing that their bodies were “unhealthy,” “destined for disease” and death, “didn’t fit the numbers,” and were “off the curve,” had a profound impact on their self-concepts and medical interactions moving forward. Participants came to view their bodies as “wrong” and “controllable,” while approaching healthcare visits with increasing guardedness, fear, and shame. Given that “acceptance of body and self” is a hallmark of ED recovery (Bachner-Melman, Lev-Ari, Zohar, & Lev, 2018, p. 2456), it is understandable how patients experienced such messaging as antagonistic toward recovery.

Participants reported ongoing interactions with providers that pathologized their bodies during and following ED treatment. Joanna was told to lose weight while she was inpatient being treated for AAN. Other participants reported providers who disbelieved their medical chart and past diagnoses or continued to recommend caloric restriction (e.g. Candy’s 500-calorie daily diet prescription) without inquiring first about the level to which participants were already restricting. For these AAN patients, these recommendations may have been doubly harmful; not only were recommendations for weight loss made without considering their full medical history, but providers also often recommended the very behaviors patients were attempting to stop (e.g. restriction, compulsive exercise, calorie counting, dieting) in ED recovery. Thus, recommendations often unwittingly reinforced participants’ EDs.

While it may be hoped that providers treating patients with a history of restrictive EDs might be particularly careful when discussing issues of weight and eating, this was not born out as participants reported multiple overt experiences of weight discrimination. Participants, particularly those with higher BMIs, reported more overt forms of discrimination, including physicians voicing assumptions that they were “lazy” or “noncompliant,” and others who appeared repulsed by them or avoided touching their bodies. These experiences are similar to findings in weight

stigma literature, wherein higher weight patients encounter more negative attitudes by medical professionals (Buxton & Snethen, 2013; Lee & Pause, 2016; Mulherin, Miller, Barlow, Die-drichs, & Thompson, 2013). Thus, AAN patients appear to not be immune to the weight stigma in medical care that is experienced by other patient groups.

Finally, it is also worth noting that participants also reported experiencing weight stigma *systemically* (e.g. insurance company policies, milieus in treatment centers) in addition to *inter-personally* (e.g. individual medical providers). Multiple participants explained how stepping down in the level of care (i.e., from inpatient to intensive outpatient programs) too early led to cyclic admissions, and they postulated their illness trajectories were lengthened due to chronic undertreatment. Such experiences demonstrate how systemic stigma also contributes to illness duration.

## **Implications**

The lived experiences of these patients highlight the need for greater provider education regarding EDs, particularly in screening for and identifying EDs across the weight spectrum. Many participants presented to primary care as children and adults with hallmark symptoms of malnutrition (the majority beginning in adolescence) but were not screened or referred for ED treatment. Specifically, participant symptoms of amenorrhea, low heart rate, rapid weight loss, and dizziness/fainting were frequently overlooked or dismissed due to high levels of exercise or higher premorbid weights. While AAN patients may not present with visible emaciation due to their higher weight status, screening for some symptoms (such as heart rate, amenorrhea, dizziness, orthostasis, and low temperature) in addition to restrictive and compensatory ED behaviors is efficient and inexpensive, and may facilitate illness identification and treatment.

Additionally, these data highlight the potentially detrimental effects of primary care interventions which center weight or rely on universal weight loss or weight management

recommendations as the primary intervention for patients higher on the weight spectrum. These data suggest that instead of recommending weight loss, health promoting, attuned, self-care behavioral recommendations need to be underscored, as outlined in the practices of a *Weight Inclusive Healthcare* model (Tylka et al, 2014). This approach involves providers inquiring about diagnoses and behaviors (past and present), screening for current levels of nutritional intake, and inquiring about current ED behaviors (e.g. fasting, purging, compulsive exercise, binge eating) and cognitions to ensure that recommendations for various health promoting behaviors (e.g., physical activity, fruit and vegetable intake) do not cause further harm.

In any clinical practice, examining one's own implicit biases is one of the more baffling professional challenges. Implicit bias, by its very nature, operates at levels below a person's recognition, and in the case of weight stigma, the persistence of its social acceptability complicates this process even further. Participants in this study, particularly those in the largest bodies, reported at best neutral experiences with providers, and at worst, experiences that were so traumatic that they came to believe that presenting for potentially harmful care was more dangerous than going without. Stigma bred mistrust, mistrust bred fear, and fear bred avoidance—disengaging from preventative care for years or decades. To do no harm and to promote health equity requires a critical self-examination of our own implicit biases. Even without words, Josephine could intuit her provider's disgust through his reluctance to touch her body. As providers, without actively challenging our own weight stigma, we run the risk of missing visible symptoms, failing to ask simple questions, disbelieving honest reports, pathologizing ED remission, recommending behaviors we are trying to prevent in other (lower weight) patients, and prescribing the diseases that we are trying to cure. We risk malpractice, create a culture distrust, and we propagate harm towards the very patients who entrust us with their health.

Finally, it is important to note that part of the deleterious impact of weight stigma in healthcare was due to participants' high esteem for providers, who were viewed as authority figures. Participants cared what providers said. As such, when provider messaging reinforced ED cognitions or behaviors, it was particularly damaging (as demonstrated by participant reports of provider interactions triggering ED initiation or relapse). These encounters represent a critical opportunity to help patients towards greater health. Rather than being the "voice of the ED," healthcare providers could play a pivotal role in reinforcing healthy patient behaviors and recovery journeys, which are, at best, fraught with difficulty. By reinforcing the difficult work these patients do in choosing to nourish and care for their bodies, despite significant psychiatric distress, health providers could offer a voice of sanity and affirmation—particularly for those whose bodies least align with societal beauty standards.

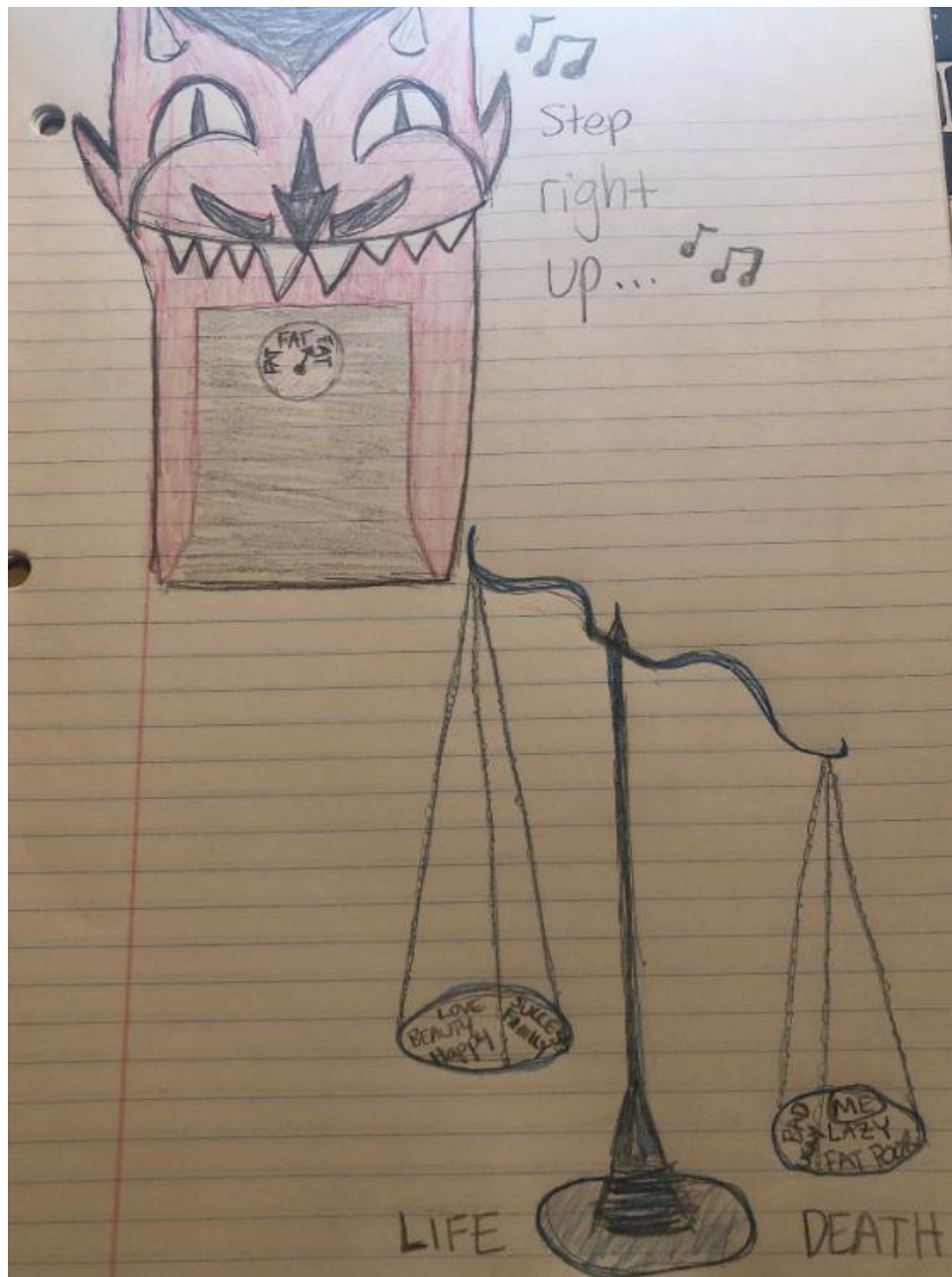
### **Limitations of the Current Study**

This study has several important limitations. First, though this sample achieved meaningful diversity in many ways, individual subgroups of participants (e.g. African American participants, participants assigned male at birth) remain limited, precluding robust subgroup analysis. Second, this study utilized a retrospective design for qualitative interviews, asking participants to reflect back on their life experiences of AAN; as such, many participants were recalling events that occurred decades prior, and their narratives reflected their current memories and perspectives on these life experiences. Third, though this study used a validated diagnostic measure and structured interview to verify participant diagnoses of AAN, some research has suggested these tools are less sensitive to OSFED subtypes compared to threshold disorders (Hartmann et al., 2014). Finally, this study utilized a sample of patients with a history of AAN and did not exclude participants who had also experienced other EDs within their lifetime. Thus, the findings of this study are not limited to, nor unique to, patients with AAN. Rather this study described the

experiences of patients with historical or current diagnoses of AAN, who experienced distressing symptoms of EDs, which may have taken various other diagnostic forms in their lifetimes. As such, many of the experiences reported by participants should not be considered unique to AAN, but rather should inform clinicians about the range of possible experiences with AAN and behaviorally similar disorders.

## **Conclusion**

To our knowledge, this is the first patient-centered study to explore experiences of weight stigma in medical settings for patients with AAN. Participants reported experiencing weight stigma from providers throughout their ED journeys extending from periods of risk development to relapse prevention. In particular, participants reported that weight loss focused pediatrician appointments contributed to ED behavior initiation, lack of ED screening prolonged behavior engagement, and weight loss focused visits in aftercare weakened recovery commitment (and in some cases triggered relapse). Thus, weight stigma resulted in delayed care, suboptimal treatment environments, deterred help-seeking, and lowered healthcare utilization, particularly during aftercare when bodies had weight-restored. Such findings suggest that addressing weight stigma in healthcare—as it manifests interpersonally, in provider behavior, and in larger systemic ways—has the potential to increase speed of referral, quality of care, and patient engagement for this important patient population.



Artwork by Gaia, Participant 30

“We can put you on HCG shots and like you just like do like a 500-calorie diet, but you won't be hungry, it's fine.” And I was like, “Whoa!,” like, “Whoa!!!” But she's been my best doctor. She knew all of my eating disorder history. And that hurt more because she knew, right?”

—Candy, Participant 20

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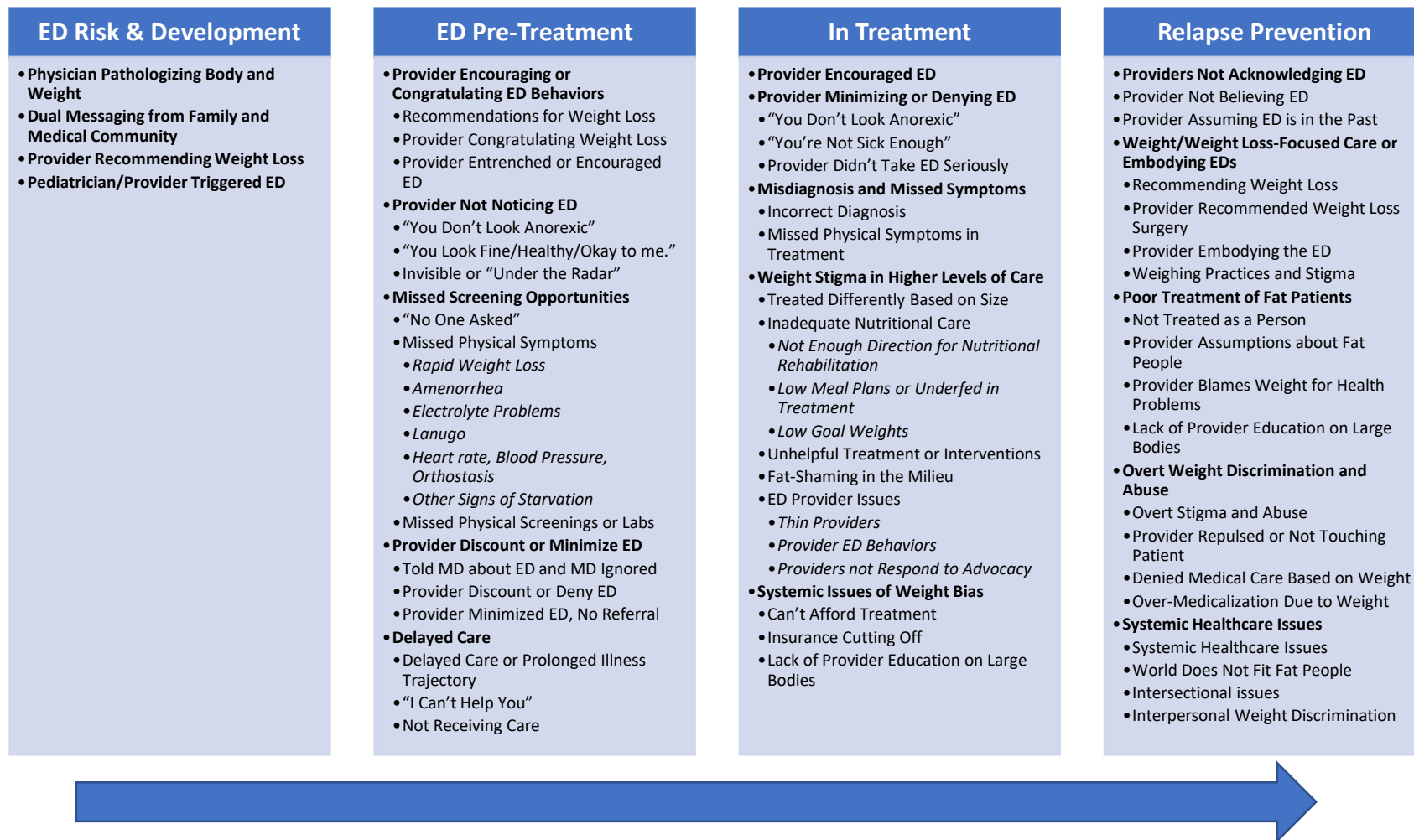


Figure 1. Themes identified across the illness trajectory.

Table 3.1

## Demographic Characteristics of Participants

<i>ID</i>	<i>Pseudo-nym</i>	<i>Age</i>	<i>Gender</i>	<i>Sex Assigned at Birth</i>	<i>Sexual Orientation</i>	<i>Relationship Orientation</i>	<i>Race</i>	<i>Ethnicity</i>	<i>Employment Status</i>	<i>Occupation</i>	<i>Highest Degree</i>	<i>Low income as child?</i>
1	Bette	38	Nonbinary/gender-queer	Female	Pansexual	Monogamous	Caucasian/white	Celtic	Full time	Social worker	Master's	Yes
2	Elizabeth	45	Female	Female	Lesbian	Monogamous	Caucasian/white	Non-Hispanic	Part time & student	Social worker	Master's	No
3	Amanda	33	Female	Female	Heterosexual	Monogamous	Caucasian/white	Caucasian	Full time	Research Scientist	Bachelor's	Yes
4	Gretchen	44	Female	Female	Bisexual	Polyamorous, but prefer monogamous relationships	Caucasian/white	Western Europe	Part time	Social worker, Exercise instructor, Grad student	Bachelor's	No
5	Joanna	30	Female	Female	Bisexual	Monogamous	Caucasian/white	Caucasian	Full time	Teacher	Bachelor's	No
6	Molly	47	Female	Female	Heterosexual	Monogamous	Caucasian/white	Gen-European	Part time	Theme reader	Bachelor's	No
7	Tori	32	Female	Female	Bisexual	Monogamous	Caucasian/white	Caucasian	Unemployed	Hairdresser	Some college	No
8	Abby	30	Female	Female	Asexual	Monogamous	Caucasian/white	Non-Hispanic	Full time	Counselor	Master's	Yes
9	Carly	45	Female	Female	Straight leaning	Open	Caucasian/white	Irish	Full time	Teacher	Master's	No
10	Dover	36	Female	Female	Bisexual	Currently monogamous	Caucasian/white	White, Finnish American	Full time	School psychologist	Master's	No
11	Uki	37	Female	Female	Heterosexual	Monogamous	Alaskan Native	Non-Hispanic	Full time	Public health	Post-Baccalaureate	Yes
12	Grace	22	Female	Female	Straight	Monogamous	Caucasian/white	White	Full time	Bank teller	Some college	Yes
13	Hope	30	Nonbinary/gender-queer	Female	Queer/ lesbian	Single	Biracial, White/ Hispanic (Latinx)	Mexican	Full time	Social services shelter worker, Grad student	Master's	Yes
14	Eli	23	Female	Female	Fluid	Monogamous	Latino	Latino	Full time	Youth case manager	Bachelor's	Yes
15	Lexi	29	Female	Female	Straight	Monogamous	Caucasian, Persian/ Middle Eastern	Persian (Iranian) and European	Part time & student	Administrative assistant, grad student	Bachelor's	No
16	Arati	74	Female	Female	None/ queer	Monogamous	Caucasian/white	Northern European mutt	Retired	Retired nurse	Bachelor's	No
17	Mary	26	Female	Male	Homoflexible	Monogamous	Caucasian/white	Polish, NW European	Full Time	Post-production film industry	Bachelor's	No

ID	Pseudo-nym	Age	Gender	Sex Assigned at Birth	Sexual Orientation	Relationship Orientation	Race	Ethnicity	Employment Status	Occupation	Highest Degree	Low income as child?
18	Josephine	66	Female	Female	Hetero to asexual	Monogamous	Caucasian/white	Northern European	Retired	Metalsmith	Master's	No
19	Riley	40	Female	Female	Bisexual	Polyamorous	Caucasian, Hispanic	Hispanic	Unemployed	Stay at home mom	Master's	No
20	Candy	28	Female	Female	Queer (as fuck)	Monogs	Black, biracial	Half Kenyan	Student, illness leave	Unemployed	Bachelor's	No
21	Cabaletta	24	Female	Female	Straight	Monogamous	Caucasian/white	Caucasian	Full Time	Technical customer service rep	Associate's	No
22	Rosalie	31	Female	Female	Straight	Monogamous	Caucasian/white	Irish-Italian American	Student	Grad student	Bachelor's	No
23	Layla	38	Nonbinary/gender-queer	Female	Bi queer	Monogamous-ish	Caucasian/white	Ashkenazi Jewish	Part time	Event planner	JD	No
24	Jen	47	Female	Female	Heterosexual	Monogamous	Caucasian/white	Caucasian American	Part time	Teacher	Masters	No
25	Chelsea	31	Female	Female	Straight	Monogamous	Caucasian/white	White	Full time	Engineering technician	Associate's	Yes
26	Lynn	28	Female	Female	Straight	Monogamous	Caucasian/white	Caucasian	Part time	Occupational therapist	Master's	No
27	Michelle	40	Female	Female	Lesbian	Married	Caucasian/white	White	Part time	Teacher, seasonal employee, therapist	Master's	No
28	Veronica	40	Female	Female	Heterosexual	Monogamous	Caucasian/white	White	Full time	Prior authorization representative	Bachelor's	Yes
29	Carter	18	Male	Female	Pansexual	Monogamous	African-American, Caucasian	African-American Caucasian	Part time	Delivery company	High school student	Yes
30	Gaia	38	Female	Female	Bisexual/pansexual	Monogamous	White, Asian, Pacific Islander	Italian, German, Scottish, Irish, Hungarian, Filipina, Indian	Unemployed & student	Grad student	Bachelor's	Yes
31	Daisy	25	Nonbinary/gender-queer	Female	Queer	Polyamorous	Caucasian/white	White	Part time	Grad student	Bachelor's	Yes
33	Ari	21	Female	Female	Unsure	Monogamous	Hispanic	Mexican	Part time	Hostess/cashier	Some college	Yes
34	Charlie	32	Nonbinary/gender-queer	Female	Queer	Primary-partnered open	Caucasian/white	White	Full time	Professor	PhD	Yes
35	Sonja	48	Female	Female	Heterosexual	Monogamous	Caucasian/white	Ashkenazi Jewish	Stay at home mom	SAHM	JD	No
36	Marie	51	Female	Female	Heterosexual	Monogamous	Caucasian/white	Anglo Saxon American	Part time	Speech language pathologist	Masters	No

<i>ID</i>	<b>Pseudo- nym</b>	<b>Age</b>	<b>Gender</b>	<b>Sex As- signed at Birth</b>	<b>Sexual Ori- entation</b>	<b>Relationship Orientation</b>	<b>Race</b>	<b>Ethnicity</b>	<b>Employ- ment Status</b>	<b>Occupation</b>	<b>Highest Degree</b>	<b>Low income as child?</b>
37	Jessie	25	Nonbinary/ gender- queer	Female	Bisexual/ queer	Polyamorous	Caucasian/white	Jewish	Part time & student	Student/home health aide	Some col- lege	No
38	Carrie- Ann	26	Female	Female	Gay	Monogamous	Black, Latina	Afrolatinx	Part time	Personal assistant	Bachelor's	Yes
39	Sisu	36	Nonbinary/ gender- queer	Female	Queer	Ethically non- monogamous	Caucasian/white	Italian, Ger- man, English	Full time	Group therapist, En- trepreneur	Bachelor's	Yes

Table 3.2

## Themes and Illustrative Quotes of Weight Stigma in ED Risk and Development Periods

Weight Stigma in ED Risk and Development Periods	
<b>Pediatrician Pathologizing Body and Weight</b>	
<b>Carly:</b>	99.9% of the things... medical professionals [said] are less than helpful. Like, "Ooh, you're not even on the growth chart?" ...But it wasn't until I think like the doctor said something that it was like a "problem we have to fix" ...because it's shameful.
<b>Gaia:</b>	My weight was like 99 <sup>th</sup> percentile plus, so he didn't quite tell me that I was fat, but really, really pointedly told me that that was a lot. And I was like, Oh, Okay, I guess I weight too much.
<b>Sonja:</b>	I was probably like 10, 11 years old, and he said, "You've gained 10 pounds this year. That's going to be a real big problem, gain ten pounds every year. You better watch how you're gaining weight." That was brutal for so many reasons.
<b>Compounding Messaging from Family and Medical Community</b>	
<b>Mary:</b>	So I was too fat for the regular doctor but not fat enough for the fat doctor... My mom and I resolved we'd just take care of it ourselves, which I think is the point at which we started trying our own brand of Weight Watchers and later Atkins.
<b>Joanna:</b>	Both of my parents were in medicine, and they are both very diet oriented and fat-phobic... I think my experience would have been a lot different if all the adults in my life besides medical practitioners had been able to look past my BMI and look at behaviors.
<b>Elizabeth:</b>	I guess the stuff around weight with my mom. But I think my mom initiated that. I don't think the doctor initiated.
<b>Pediatrician Recommending Weight Loss</b>	
<b>Joanna:</b>	My [MD] ...recommending Weight Watchers and warn[ed] me [to] get a handle on my weight now as a teenager... they were actually harmful.
<b>Chelsea:</b>	I first discussed diets with a healthcare provider when I was like 16 years old... He suggested Weight Watchers.
<b>Elizabeth:</b>	He [MD] recommended Children's Weight Watchers... when I was nine or 10.
<b>Provider Triggering Disordered Eating or ED</b>	
<b>Sonja:</b>	I was already getting messaging from my parents that my body was too big... [pediatrician] just reinforced whatever fears that I had that my body was wrong... that's when the real thoughts of restriction started to really settle in.
<b>Carly:</b>	So, thinking about... "First, do no harm" like shit. My first eating disorder was doctor-prescribed and mother-approved and then perpetuated for 40 years.
<b>Ari:</b>	[my pediatrician] be like, "Looks like your weight's going down" ...I was restricting. I remember she told me that I was... still overweight... I had been going through the fasting... that was the first time I went home and purged.

Table 3.3

## Themes and Illustrative Quotes of Weight Stigma Pre-Treatment for ED

Weight Stigma Pre-Treatment for ED
<b>Provider Encourage or Congratulate ED Behaviors</b>
<b>Mary:</b> 58% of my body weight gone... I was weak, cold all the time, lost most of my muscle mass... [Doctor] “you’ve lost some weight... Keep it up.” ... [I] was eating under 800 calories a day... But it was all rendered invisible because I was a previously fat person who had become the “correct” size. I was a success story
<b>Josephine:</b> “good, you’re losing weight.” They’ve never gone into how I’m doing it. Just encouragement to keep doing [it].
<b>Amanda:</b> I just got reamed out for 20 minutes by this [OBGYN]... I needed to lose weight that I shouldn’t be fat...I was terrified and mortified. Yeah, it just solidified my eating disorder.
<b>Providers Not Noticing or Seeing ED</b>
<b>Lynn:</b> [Doctors] just look at you, and if you look healthy, you’re good to go. But there can be a lot going on underneath even if you’re in a healthy weight range...
<b>Lexi:</b> I’ve had a doctor say, “Well, you don’t look anorexic. You don’t look underweight.”
<b>Daisy:</b> She still told me “I was too heavy to have an ED.” ...I’m tracking all my food, barely eating, exercising multiple hours a day, freezing all the time, standing up and getting dizzy, acid reflux, throwing up my food weekly, low heart rate, anemia, always bruised all over, my hair was falling out.
<b>Missed Screening Opportunities</b>
<b>Riley:</b> You have a child who is passing out, you have someone whose potassium drops so low they have to be hospitalized... no one ever suspected that I might have an ED... [but] I was fat.
<b>Arati:</b> I don’t remember they’re ever talking about [my ED] other than to say to put it in the context of some of my labs and to say you really need to exercise more. You really need to lose weight...
<b>Gaia:</b> I had told him that my hair was falling out... he said that was normal... we were talking about why my heart was racing. I hadn’t eaten for like 21 hours.
<b>Providers Discounting or Minimizing ED</b>
<b>Tori:</b> I went in and said, so I have an ED, and I feel like I’m sick all the time, and they said... “I don’t think you have an eating disorder—you’re too overweight. That’s not possible.”
<b>Eli:</b> I [told my doctor] that I thought I had an ED... he said that I was doing just fine... and I could actually probably lose a little bit of weight... I knew that I was sick... but I just wasn’t sick enough. I wasn’t physically emaciated or thin enough to be considered.
<b>Bette:</b> I started vomiting a considerable amount of blood... I called the doctor... and they said, “oh that’s fine. That’s just esophageal tearing.” That was really it for all our discussions.
<b>Delay of Care</b>
<b>Riley:</b> I have been before doctors my entire life, and no one diagnosed me with an ED until I went into treatment and said, “I have an ED and I need you to pay attention.”
<b>Sisu:</b> I think my body size is the reason why I was never diagnosed with an ED until this study... I think my body size has affected everything about my medical care and ED care.
<b>Layla:</b> She ultimately said “I don’t know how to treat your ED because people that I deal with are people that are really thin.



Table 3.4

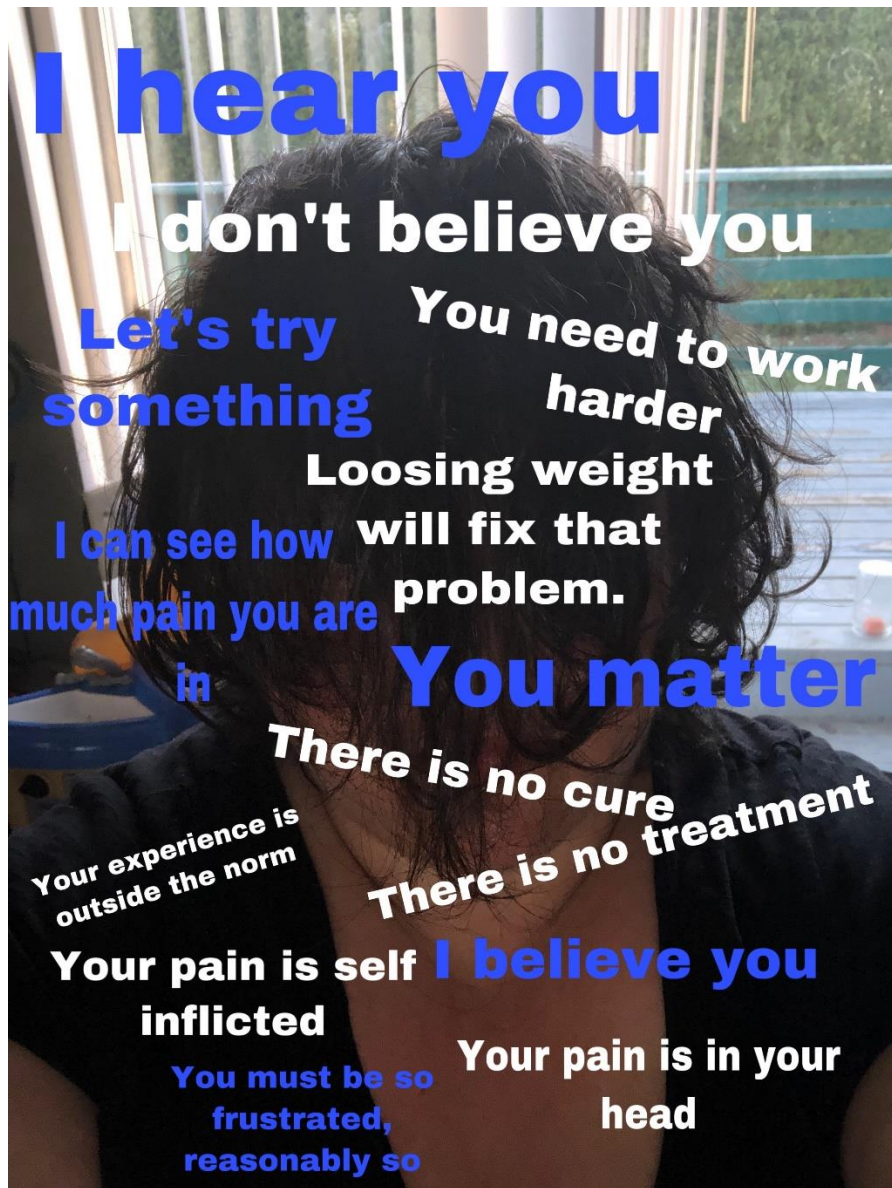
## Themes and Illustrative Quotes of Weight Stigma in ED Treatment

Weight Stigma in ED Treatment
<b>Provider Encouraged ED Behaviors</b>
<b>Marie:</b> She [provider] was really toxic for my eating disorder... she ended up giving me a diet book... because she thought that if I was more comfortable with what I was eating, that I would eat
<b>Cabaletta:</b> I go back, and he's [doctor] like, "you need to lose weight" and there's like this constant cycle of like losing weight versus not using an eating disorder.
<b>Joanna:</b> The interaction after I just said, "You know I am not sure how to hold your food restriction advice with the fact that I'm in recovery from anorexia. I don't know how to hold both those."
<b>Provider Minimize or Deny ED</b>
<b>Marie:</b> I said, "I have an eating disorder." And she looked at me. She said, "You don't look like you have an eating disorder."
<b>Grace:</b> When I started becoming eating disordered later, I don't think I was taken seriously.
<b>Carter:</b> [Providers] told me that I don't "meet the numbers" and I couldn't be a part of the [ED] group even though they said I had an eating disorder... they just said basically it wasn't bad enough for me to meet with that group.
<b>Misdiagnosis and Missed Symptoms</b>
<b>Layla:</b> I was diagnosed with compulsive overeating during one of my most restrictive points.
<b>Jessie:</b> Even when I was diagnosed with bulimia, okay... that wasn't really accurate, because I wasn't really bingeing, but they assumed, "this fat person must binge." ...the advice was "you shouldn't do that 'cause it won't help you lose weight."
<b>Jen:</b> [My body size] had everything to do with it. "I wasn't in any medical danger" or if I was, it wasn't looked for.
<b>Weight Stigma Experiences at Higher Levels of Care</b>
<b>Bette:</b> Then these skinny people showed pictures of themselves in bikinis to say... "how much my body is fat and disgusting." ...I brought it up in my team meeting... "Sitting around fat shaming... feels really destructive." ...the feedback wasn't heard.
<b>Marie:</b> It's my first day, my first hour of inpatient, and she's [RD] telling me "it's doable" that I continue to lose more weight. And I'm like, "okay, I am eating 400 calories a day." So much mistrust.
<b>Abby:</b> Being given a weight range and told I needed to be in that weight range was very unhelpful... I felt also like [my] food plan there was very restrictive... it was only 1500 calories.
<b>Systemic Issues of Weight Stigma in Healthcare</b>
<b>Bette:</b> Systemically it [ED treatment and medical system] just didn't seem it was designed to really properly assess people with bigger bodies.
<b>Lynn:</b> The eating disorder behavior started coming back, I was exercising significantly more... she wanted me to go back to residential... My insurance was trying to cut me to IOP.
<b>Michelle:</b> I wish [my insurance] hadn't sent me home. The conversation about suicide and the hospital, dis-closing [the abuse], having to move to an apartment by myself, and stepping down to IOP all happened in the same week. How can you hear all of that and still shove that client to a lower level of care?

Table 3.5

## Themes and Illustrative Quotes of Weight Stigma Post-Treatment (Relapse Prevention)

Weight Stigma Post-Treatment in Relapse Prevention
<b>Providers Not Acknowledging ED</b>
<b>Candy:</b> I was just like, “well I’ve been anorexic...” He said... “You weren’t anorexic. You have Binge Eating Disorder.”
<b>Elizabeth:</b> I don't look emaciated, [so] either it's not even been on people's radars or it's... something that's so in the past. It's not even on my problem list... It's been ignored... not seen as real.
<b>Uki:</b> I see this doc... “So, tell me about this eating disorder thing, obviously, it's not happening right now.” [I] was like, “No, I'm not currently using behaviors, but I've only been out of treatment for six months.” ...Just like, “I doubt your story and I just think that this thing in your medical record is completely useless.”
<b>Weight- and Weight-Loss Focused Healthcare</b>
<b>Candy:</b> I always told them, “I have an ED, like, prior history. I cannot diet...” And I would frequently--doctors be like, “Well you could diet.” ...Like only if you want to get better.
<b>Carly:</b> Doctors who discount eating disorders quite literally do harm by prescribing a diet even when there is a fucking eating disorder listed in my medical chart.
<b>Riley:</b> I have had continuously through my life had doctors tell me to lose weight... including the last almost three years while I've been in recovery... even telling them that I can't, like--intentional weight loss is not an option for me, it's like my tag line.
<b>Poor Treatment of Fat Recovering Patients</b>
<b>Tori:</b> When you're in a smaller body but you're trying to take care of someone in a bigger body and you can't understand what it is to be in a bigger body... they don't know how to take care of them and how to be kind to them...
<b>Dover:</b> [Doctors] are not going to view you as a patient, really. They're just going to view your size first, and they're going to make assumptions, and they're going to miss things.
<b>Caballetta:</b> I'm like a body, that's all they [providers] see is a body. And they don't approve of the body.
<b>Overt Discriminatory Medical Care</b>
<b>Candy:</b> [Cardiologist was] just like, “if you're not walking by the time it's six months of your treatment, then I'm gonna tie a rope around you and tie the other end to a car and make you walk.”
<b>Carly:</b> I've had quite literal disdain from providers based on the size of my body... because, I mean, when you walk in and have visible dislike of me... clearly, you're basing it on my appearance.
<b>Josephine:</b> Healthcare providers who have seen me have been repulsed by me, had a negative reaction to my size. I had one doctor that did not touch me to listen to my heart or anything.
<b>Systemic Issues in Healthcare</b>
<b>Rosalie:</b> I don't get health care anymore...my health insurance is shit... you only have a select amount of providers. [I don't want] a fat-shamer or someone who is going to promote weight loss on you. It's a nightmare.
<b>Candy:</b> You stop fitting in the world at about 300 pounds, right? So, the chair was uncomfortable... Doctor's offices were uncomfortable. The cot [at the doctor's] was uncomfortable.
<b>Grace:</b> We're [ED patients] struggling hard... because we're just pushed through the system. We're not actually helped.



Artwork by Layla, Participant 23

"I started vomiting a considerable amount of blood... And, so then I called the doctor...And they said... 'Oh that's fine. That's just esophageal tearing.' Then that was really it for all of our discussions. So, then I felt, I had thought that this was a big deal and I'm restricting and I'm purging and ...everybody's just telling me that I'm making a big deal out of nothing... All the times that I tried to communicate that I'm really tired, and my hair's falling out and my skin is just bleeding it's so dry... Providers would just answer back with... 'Are you putting on lotion?'"

--Bette, Participant 1

CHAPTER FOUR:

WEIGHTING FOR TREATMENT:

LINKING WEIGHT HISTORY, DISORDER SEVERITY, WEIGHT STIGMA,  
AND TREATMENT DELAY FOR PATIENTS WITH HISTORIES OF  
ATYPICAL ANOREXIA NERVOSA

**Abstract**

Atypical anorexia nervosa (AAN) is an eating disorder (ED) with presentations across the weight spectrum and life-threatening health consequences. Yet, AAN is largely understudied, particularly in diverse samples. While some studies suggest that AAN individuals may wait longer for care than other EDs, few studies have examined how weight relates to treatment delay and receipt. In this study, I examined 1) how AAN patients presented in regard to ED severity and functional impairment, weight stigma and suppression, and treatment receipt and delay, and 2) the association between weight-related variables, treatment delay, and highest level of care received. **Methods:** Structured interviews and self-report data were collected from a diverse sample of 39 individuals with histories of AAN. Descriptive statistics were used to assess ED severity, functional impairment, internalized weight stigma, weight suppression, and highest level of care received. Correlations and partial correlations were used to assess whether weight-related variables were associated with treatment delay and level of care. **Results:** Patients with AAN across the body mass index (BMI) spectrum presented with clinical levels of ED severity and impairment. The sample reported high levels of weight suppression and lengthy treatment delays. Internalized weight stigma and shape and weight concern were pronounced in this sample. In correlation analysis, higher lifetime BMI was associated with receiving lower levels of care. Controlling for patient age, higher lifetime minimum BMI was associated with longer treatment

delays. **Discussion:** Attaining a noticeable thinness may be a “key” to unlocking treatment, suggesting that provider expectations around weight may influence screening and referral. This suggests the need to: 1) address implicit weight stigma, 2) increase recognition of restrictive EDs in higher weight populations, and 3) increase screening for ED symptoms and behaviors across age and weight continuums.

**Key Words:** Atypical Anorexia Nervosa, Treatment Delay, Weight Suppression, Eating Disorder Severity

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### WEIGHTING FOR TREATMENT:

#### LINKING WEIGHT HISTORY, DISORDER SEVERITY, WEIGHT STIGMA, AND TREATMENT DELAY FOR PATIENTS WITH HISTORIES OF ATYPICAL ANOREXIA NERVOSA

Eating disorders (EDs) are complex biopsychosocial disorders that present with significant risks of mortality (Chesney, Goodwin, & Fazel, 2014) and high levels of role impairment (Hudson, Hiripi, Pope, & Kessler, 2007). Recent prevalence estimates of EDs suggest that global rates have nearly doubled in the past two decades (Galmiche, Déchelotte, Lambert, & Tavoracci, 2019), with concerning rises in prevalence for those with lower incomes, and those over the age of 45 (Mitchison, Hay, Slewa-Younan, & Mond, 2014). While women have historically experienced EDs at higher rates (American Psychiatric Association, 2013; APA), research has suggested that trans and gender non-conforming individuals may also experience EDs at disproportionate rates (Bell, Rieger, & Hirsch, 2019; Diemer, Grant, Munn-Chernoff, Patterson, & Duncan, 2015). Moreover, sexual minorities may also experience EDs more frequently (Bell et al., 2019; Diemer et al., 2015) and more severely (Mensing, Granche, Cox, & Henretty, 2020), compared to heterosexual peers. Higher body mass index (BMI) has also been linked with higher disordered eating severity in community samples (Rø, Reas, & Rosenvinge, 2012). While ED behaviors impact communities across race (Chao, Grilo, & Sinha, 2016), how ED rates differ between racial groups is debated (Rodgers, Berry, & Franko, 2018). Regardless, people of color may face inequities in seeking and accessing treatment (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001; Coffino, Udo, & Grilo, 2019).

Atypical anorexia nervosa (AAN) is a recently established category of ED. AAN is included under the Other Specified Feeding and Eating Disorders (OSFED) diagnosis, denoting

individuals who experience all of the diagnostic criteria for anorexia nervosa (AN), with the exception that their body weight is not below the traditional BMI cut off of 18.5 or their expected trajectory (APA, 2013). Recent studies have reported a nearly five-fold increase in AAN cases in treatment settings (Whitelaw, Gilbertson, Lee, & Sawyer, 2014). While research on AAN is still emerging, much of the work to date has focused on thin, young, white, female populations (Forman et al., 2014; Harrop, Mensinger, Moore, & Lindhorst, under review; Peebles et al., 2017; Wade & O'shea, 2015). While epidemiological samples have included greater diversity among adults with AAN (i.e. featuring individuals across the age and race spectrums, e.g. Hay et al., 2017), few studies have captured in-depth characterization of the AAN experience. Describing AAN in more diverse populations is crucial to understanding the breadth of the problem, and for understanding nuance within the broader population experiencing AAN. This research holds implications for tailoring screening, assessment, and treatment approaches to fit varied needs.

### **AAN Illness Trajectory and Treatment**

There is some debate in ED literature regarding the extent to which people with AAN experience similar illness trajectories as those with lower-weight AN. Some researchers suggest that AAN is less severe or is associated with more positive treatment outcomes (Silén et al., 2015). However, other studies have shown that individuals with AAN face many similar challenges to those with AN, experiencing medical complications and psychological distress often at commensurate rates as individuals with AN (Peebles, Hardy, Wilson, & Lock, 2010; Sawyer, Whitelaw, Le Grange, Yeo, & Hughes, 2016). AAN individuals may present with distinct challenges compared to their thinner peers, such as increased eating and body image concern (Sawyer et al., 2016), longer illness duration (Sawyer et al., 2016), greater weight suppression (Sawyer et al., 2016), and higher rates of bradycardia and hypotension (Peebles et al., 2010).

Additionally, higher rates of elevated BMI may also impact illness trajectory and treatment access (Kennedy et al., 2017).

Treatment delay and illness duration has been linked with less favorable physical and psychological outcomes for those experiencing AN (Fichter, Quadflieg, & Hedlund, 2006; Von Holle et al., 2008), leading some to suggest that early intervention may improve prognosis of this difficult to treat ED (Treasure & Russell, 2011). Unfortunately, early intervention in AN is not always the norm, with some studies suggesting illness durations of over six years prior to ED treatment (Fichter & Quadflieg, 1999). More recent adolescent studies have reported shorter illness durations of 3-12 months prior to treatment (Forman et al., 2014). Little is known about treatment delay among people with AAN. Studies from countries that utilize universal healthcare systems (with greater emphasis on ED screening and early intervention) have reported favorable outcomes when AAN is identified and treated early (Månsson, Parling, & Swenne, 2016). Understanding the extent to which patients with AAN experience treatment delay, and which factors are associated with longer treatment delay could aid in better understanding the challenges of diagnosing and treating AAN.

In addition to illness duration, weight suppression may be an important contributing factor to ED severity and a predictor of recovery outcomes (Bodell, Racine, & Wildes, 2016; Swenne, Parling, & Salonen Ros, 2017; Wildes & Marcus, 2012). In one study, Peebles and colleagues (2010) found that when comparing various subthreshold and threshold ED presentations, the AAN group who had lost at least 25% of their body weight (without being considered underweight) experienced the highest percentage of weight lost of any group and had higher rates of bradycardia and orthostasis than all other partial-AN Subgroups. As such, AAN patients were more likely than all other ED groups (except patients with AN) to meet hospital admission



criteria when weight measures were excluded. The authors noted that AAN individuals demonstrated this level of medical compromise, despite presenting at near “ideal” median body weights (97.7% median body weight), suggesting that weight suppression, in addition to presenting weight, should be considered when evaluating ED severity. Other research has suggested that AAN patients exhibit greater percentages of body weight lost compared to AN individuals (Sawyer et al., 2016), and that high body weight suppression may be coupled with lengthy treatment delay for AAN patients, particularly in the context of a prior history of higher weight (Conceição et al., 2013; Sim, Lebow, & Billings, 2013; Wolter, Schneider, Pfeiffer, & Lehmkuhl, 2009). Conversely, low weight suppression has been shown to predict more favorable outcomes in terms of ED behaviors and cognitions, emphasizing the importance of early identification and treatment for restrictive disorders (Swenne et al., 2017).

### **The Impact of Weight Stigma**

Weight stigma is an additional factor that could impact the experience of AAN. Weight stigma is a type of discrimination that results in the systematic devaluing and pathologizing of fatter bodies, resulting in disproportionate access to resources and opportunities for fatter people. Research suggests that a significant portion of AAN individuals have experienced an elevated BMI within their lifetime; one study found that two-thirds of AAN individuals had a history of overweight or obesity, and 7.9% of AAN individuals needing medical stabilization for malnutrition were currently overweight or obese by current BMI standards (Kennedy et al., 2017). Thus, weight stigma could differentially impact individuals with AAN, when compared to underweight AN patients. Researchers have postulated that weight stigma could result in higher weight individuals with restrictive EDs facing challenges related to getting care for their EDs, such as family members or healthcare workers who may not believe their symptoms, limited insurance coverage, and less access to care (Neumark-Sztainer, 2015). For example, to explore the potential

impact of weight on clinician's diagnostic patterns, one unique study randomly assigned clinicians to one of three nearly identical patient cases featuring AN behaviors (Veillette, Serrano, & Brochu, 2018). Each study condition was given a different description of the patient's body as either "underweight," "normal weight," or "overweight." Though all three cases had identical symptoms and behaviors of AN, clinicians assigned to the underweight case were more likely to assign an AN or AAN diagnosis than those assigned a "normal weight" or "overweight" case. Thus, the provider's perception of the patient's weight status may impact treatment delay even when patient's proactively and truthfully report ED symptoms.

Lastly, weight stigma is also concerning to the extent that it is *internalized*. Higher levels of internalized weight stigma have been linked with multiple adverse outcomes in ED populations (Durso et al., 2012), and have also been found to moderate the relationship between BMI and health related quality of life (Latner, Barile, Durso, & O'Brien, 2014). However, little is known about the experiences of AAN individuals with externalized and internalized weight stigma. For individuals with AAN, who by virtue of their diagnosis are already acutely attuned to overvaluation of weight or shape, further exacerbation of internalized weight stigma may be an important concern.

### **The Current Study**

In sum, while it is possible that AAN individuals experience treatment delay, the extent of that delay, and the degree to which AAN is considered a significant ED in need of treatment is debated. Further, factors associated with that treatment delay, and with the levels of care received, are unknown. In this study, I sought to address these gaps regarding the links between AAN severity and impairment, weight history, and treatment receipt and delay. I was guided by two primary aims. Aim 1 examined how features of AAN, including ED severity, functional impairment, and internalized weight stigma were characterized in a diverse sample of adults with

histories of AAN. Additionally, the presence of weight suppression and treatment delay, including the frequency of ED treatment and the highest level of care received were also examined. Aim tested the association between weight related variables and treatment delay, and between weight-related variables and highest level of care received. Within Aim 2, I hypothesized that higher lifetime maximum BMI, higher lifetime minimum BMI, and higher percentage of weight loss, would each be associated with longer treatment delay, and lower levels of care received.

## **Methods**

### **Data and Procedures**

Data for this study come from the baseline survey of the Women's Illness Narratives Through Eating Disorder and Remission (WINTER) Study. WINTER was a longitudinal, observational, mixed-methods study of women and nonbinary/trans assigned-female-at-birth (AFAB) persons who had a history (or current diagnosis) of AAN. Participants were recruited through multiple strategies including posting flyers at local ED treatment centers, provider referral, social media groups, snowball recruitment, and through direct contact from interested participants. To increase representation from underrepresented identities in AAN research, flyers were also posted, with permission, in community spaces frequented by communities of color, trans and nonbinary communities, and higher weight communities.

A total of 118 individuals were initially recruited; see Figure 4.1 for participant recruitment, screening, and enrollment flow diagram. To be eligible for participation in the study, respondents needed to speak English, be 18 years or older and female (including cis- or trans-women, and nonbinary/trans AFAB individuals) and residing in the United States. Respondents also needed to have met criteria for AAN at a BMI above 18.5 at some point in their lifetime. AAN diagnosis was assessed by the clinician-guided diagnostic assessment tool, Eating

Disorders Assessment for DSM-5 (EDA-5; Syscko et al., 2015).<sup>8</sup> There is a current lack of consensus regarding definitions of “significant weight loss” for AAN. Thus, to fully explore the broadest potential spectrum of possible AAN presentations, no strict weight loss minimum was required (Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017). Following the EDA-5 screening, the researcher (who is a clinical social worker and mental health evaluator) conducted a brief mental status examination. Those with acute suicidality or acute psychosis in the previous two weeks, and those currently admitted to inpatient or residential treatment settings were ineligible.

Data were collected from November 2017 to May 2020 using the Research Electronic Data Capture (REDCap; Harris, et al., 2009) only survey system. REDCap captures and stores data in a Health Insurance Portability and Accountability Act-compliant database. Participants completed baseline surveys to ascertain demographic background, weight and treatment history, current ED symptoms, severity, and ED-related impairment, internalized weight stigma, in addition to other measures. All study procedures were approved by the University of Washington Institutional Review Board (IRB).

*<Insert Figure 4.1 here>*

## **Sample**

The sample for the current analysis included 39 participants (see Table 4.1). Mean age of this sample was 35.41 years at baseline ( $SD = 11.68$ , range 18-74). Eighty-seven percent ( $n = 34$ )

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<sup>8</sup> The EDA-5 is designed to measure current ED diagnosis. A lifetime version (to detect past ED diagnoses) is currently under development. The researcher contacted the measure developers regarding best practice adaptations to use the EDA-5 for lifetime ED screening. The modifications needed to adapt the EDA-5 for this purpose were minimal; full communication with Dr. Deborah Glasofer specifying these modifications are available upon request.

of the sample were cis-gender and AFAB; 10.3% ( $n = 4$ ) were nonbinary<sup>9</sup>, and one woman was assigned male at birth. The sample was 71.8% ( $n = 28$ ) non-Hispanic white, 2.6% ( $n = 1$ ) Alaska Native, 7.7% Latinx ( $n = 3$ ), 17.9% ( $n = 7$ ) were multiracial. Full racial breakdown and demographic characteristics are shown in Table 4.1. Thirty-six percent ( $n = 14$ ) of the sample reported being heterosexual; additionally, 17.9% ( $n = 7$ ) reported being bi- or pansexual, 17.9% ( $n = 7$ ) queer, 12.8% ( $n = 5$ ) lesbian, 5.1% ( $n = 2$ ) asexual, with one participant each reporting being “straight-leaning” (2.6%), “fluid” (2.6%), “homoflexible” (2.6%), and “unsure” (2.6%). Regarding education, 7.7% ( $n = 3$ ) had a doctoral degree (PhD or JD), 33.3% ( $n = 13$ ) had completed a master’s degree, 41.0% ( $n = 16$ ) had completed a bachelor’s degree, 5.1% ( $n = 2$ ) had completed an associate’s, 10.2% ( $n = 4$ ) had completed some college, and one participant (2.6%) was working towards her GED. Regarding economic status in their families of origin, 43.6% ( $n = 17$ ) reported that their family received state assistance when they were children.

<Insert Table 4.1 here>

## Measures<sup>10</sup>

**ED Severity.** *ED severity was assessed using the EDE-Q (Fairburn, 2008), which shows strong diagnostic capabilities (Petty, Rosen, & Michaels, 2000), has demonstrated excellent reliability and validity (Berg, Peterson, Frazier, & Crow, 2012), and allows for comparisons with*

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<sup>9</sup> At the end of the year of data collection for this study, three additional AFAB participants reported their gender as nonbinary, and one additional AFAB participant reported their gender as male, resulting in the following gender breakdown: 76.9% cisgender AFAB, 20.5% nonbinary, 2.6% male AFAB, and 2.6% female assigned male at birth.

<sup>10</sup> A full data dictionary with notes on variable cleaning and validation can be found in Appendix L.

normed data in community samples (Mond, Hay, Rodgers, & Owen, 2006). Additionally, the EDE-Q has also been used to screen for EDs within community samples (Mond, Hay, Rodgers, Owen, & Beumont, 2004). The EDE-Q is a 32-item self-report questionnaire surveying the past 28 days, containing four subscales each ranging from 0 to 6 (0 = No days to 6 = Every day), indicating different areas of ED pathology (eating concern, eating restraint, shape concern, weight concern), and a global score, with higher scores indicating higher ED severity (Crowther & Luce, 1999; Fairburn, 2008; Mond et al., 2004). The EDE-Q was utilized in its entirety; in the current sample, the scale demonstrated excellent reliability ( $\alpha = 0.89$ ).

**ED-Related Functional Impairment.** ED-related functional impairment was assessed by the Clinical Impairment Assessment (CIA; Bohn et al., 2008), a 16-item self-report scale that measures to what degree a person's ED interferes with their daily life. The CIA includes 16 items on a Likert scale (0 = not at all to 3 = a lot) with higher scores indicating higher levels of secondary psychosocial impairment. CIA global scores (sums) range from 0 to 48, with 16 or higher predicting presence of an ED due to clinically significant functional impairment relating to eating and body distress (Bohn et al., 2008). The CIA has demonstrated norms within community and clinical ED settings, which can serve as useful comparisons for samples (Welch, Birgegård, Parling, & Ghaderi, 2011). The CIA was utilized in its entirety; in the current sample, the scale demonstrated excellent reliability ( $\alpha = 0.93$ ).

**Internalized Weight Stigma.** Internalized weight stigma was assessed using the Weight Bias Internalization Scale (WBIS; Durso & Latner, 2008) which has demonstrated psychometric properties and construct validity. This scale consists of 11 self-report items scored on a seven-point Likert scale (1 = Strongly disagree to 7 Strongly agree). Items were summed to create a single scale score ranging from one to seven, with higher scores indicating more severe

internalized weight stigma. WBIS was scored according to the conventions outlined by Hilbert and colleagues (2014; eliminating the first item for a total of ten items) to increase scale validity. Community normed data has also been provided for the WBIS measure (Hilbert et al., 2014). The WBIS was utilized in its entirety; in the current sample, the scale demonstrated excellent reliability ( $\alpha = 0.91$ ).

**BMI.** Three measures of BMI ( $\text{BMI} = (\text{weight in kg})/(\text{height in m}^2)$ ) were used in the current analysis to provide an absolute measure of BMI currently, in addition to BMIs which demonstrated the range of BMIs at which participants had presented during their lifetimes. Thus, current, lifetime minimum, and lifetime maximum were used. *Current BMI* was calculated based on self-reported current height and weight and was validated with clinician-collected data when possible. *Lifetime minimum BMI* was calculated using adult height and participant's lowest reported adult weight across their lifetime. *Lifetime maximum BMI* was calculated using adult height and highest weight. For participants whose highest weight was not their highest BMI due to height changes, the highest BMI replaced the BMI value based on the largest weight. Additionally, proportions of the sample reaching BMIs of 18.5, and 19 at any point in their ED illness were calculated to identify whether AN could have been diagnosed; similarly, proportions of the sample with histories of underweight BMIs were reported. This approach aligned with the Centers for Disease Control and Prevention (CDC) guidelines for determining high and low BMI thresholds based on age and gender (CDC, 2020).

**Weight Suppression.** Two measures of weight suppression were used in the current analysis to provide measures of BMI variability across time. *Lifetime BMI suppression* was calculated by taking the difference between the lifetime maximum BMI and the lifetime minimum BMI, and it was expressed in BMI units. *Percent largest weight loss* was calculated as the

percentage of premorbid body weight lost, using two questions: “What is the largest amount of weight (in pounds) you have lost in your lifetime and when did this occur?” and “What is the second largest amount of weight (in pounds) you have lost in your lifetime and when did this occur?” If a participant lost a larger amount of weight at one point in their life, but this larger amount represented a smaller percent of their premorbid body weight, the largest *body weight percentage* of weight loss was entered. This variable was expressed as a percentage of largest amount of weight lost, divided by premorbid body weight (prior to loss). Operational definitions for weight suppression are inconsistent within the field (Gorrell, Reilly, Schaumberg, Anderson, & Donahue, 2018). Expressing weight suppression in BMI units (as done by Witt et al., 2014) and as percentage of premorbid weight lost was chosen to account for differences in height and habitus, and to permit greater comparison between individuals (as opposed to absolute weights that do not take into account height).

**Treatment Delay.** *Treatment delay* was assessed by taking the difference in years for responses to the following questions: “At what age did you first think you might have a problem with an ED?” and, “At what age did you first get specialized ED treatment?” ED treatment was defined as therapy, medical care, or dietitian therapy that was specifically addressing their ED (e.g. therapy for depression that did not address the ED did not qualify). Participants who saw a provider for three or fewer sessions were considered “untreated.” This cutoff was used to distinguish participants who had successfully engaged in some amount of meaningful treatment versus those who had been unsuccessful in securing care (e.g. seeing a provider for an intake appointment, and then not attending any subsequent treatment did not qualify as treatment). Community resources such as Overeaters Anonymous, Eating Disorders Anonymous, reading self-help



books, attending body positivity retreats, or other forms of self- or peer-directed supports did not qualify as treatment.

**Treatment Receipt.** Participants were asked if they had received outpatient care for an ED which included seeing a mental health provider, dietician, or outpatient medical professional (e.g. psychiatrist, physician) to treat an ED, and if they had ever attended an intensive outpatient program (IOP), partial hospitalization program (PHP), or inpatient (IP) or residential care for an ED. *Highest level of care received* was coded as: 0 = no care, 1 = outpatient treatment, 2 = IOP, 3 = PHP, and 4 = IP or residential. Additionally, proportions of the sample receiving each level of care were also recorded.

### **Data Analysis**

The analysis proceeded in two steps according to study aims. First, descriptive statistics (e.g. frequencies, means) were used to characterize AAN experiences among participants in the sample (Aim 1). Next, correlations were calculated to assess the relationships between weight related variables, treatment delay, and highest level of care (Aim 2). Partial correlations were also calculated, controlling for the confounding effect of age on treatment delay. Significance level was set at  $p < .05$ .

*<Insert Table 4.1 here>*

### **Results**

*<Insert Table 4.2 here>*

### **Aim 1: ED Severity, ED-Related Functional Impairment, and Internalized Weight Stigma**

EDE-Q, CIA, and WBIS scores for participants are reported in in Table 4.2. Of the four subscales of the EDE-Q, shape ( $M = 4.03$ ,  $SD = 1.61$ ) and weight concern ( $M = 4.05$ ,  $SD = 1.36$ ) were particularly elevated for this sample. Mean scores on the CIA ( $M = 20.92$ ,  $SD = 10.83$ ) indicated current functional impairment due to ED symptoms. Sixty-four percent ( $n = 25$ ) scored a 16 or higher, indicating a likelihood of current ED diagnosis. Mean score on the WBIS was  $M = 5.11$ ,  $SD = 1.39$ .

Weight history and treatment delay data are reported in Table 4.3. Participants presented across the BMI spectrum, with BMIs at baseline ranging from 21.8 to 61.1 ( $M = 37.90$ ,  $SD = 10.7$ ). Five participants (12.8%) experienced lifetime BMIs under 18.5, and an additional five participants (12.8%) experienced lifetime BMIs under 19.0. Two participants (5.1%) were considered underweight at those BMIs according to gender and age standards outlined by the CDC, as the majority of these low BMIs occurred during adolescence wherein lower BMIs were within expected ranges for their gender and age. Lifetime minimum adult BMIs ranged from 18.1 to 41.7 ( $mean = 24.46$ ,  $SD = 5.65$ ); maximum BMIs ranged from 23.0 to 65.7 ( $M = 42.03$ ,  $SD = 11.33$ ), with 89.7% ( $n = 35$ ) of the sample having experienced a BMI considered obese by current BMI standards ( $BMI \geq 30$ ). Lifetime BMI suppression ranged from 4.2 to 47.0 BMI points ( $M = 19.39$ ,  $SD = 10.89$ ). Largest single episodes of weight loss ranged from 11.8% to 50.2% ( $M = 28.41$ ,  $SD = 10.02$ ) of participants' premorbid weight.

*<Insert Table 4.3 here>*

Approximately one quarter of participants had never received treatment prior to the study (28%,  $n = 11$ ). Seventy-seven ( $n = 30$ ) percent of the sample had received outpatient ED

treatment from a therapist, dietician, or medical provider; of those, two-thirds ( $n = 20$ ) had also received group therapy for their ED in a provider-facilitated group. Forty-one percent ( $n = 16$ ) of participants had received IOP treatment, and 33% ( $n = 13$ ) had attended PHP programs. IP and residential levels of care had been attended by 31% ( $n = 12$ ) participants. Sixty-two percent ( $n = 24$ ) of individuals reported receiving ED treatment from a provider who practiced Health at Every Size® approaches to treatment. Additionally, multiple untreated individuals reported utilizing informal treatment supports such as 12-step groups, podcasts, and self-help groups.

Treatment delay ranged from 0 to 48 years, with some participants receiving treatment as soon as they realized they had an ED, and others waiting decades for treatment ( $M = 11.70$ ,  $SD = 11.31$ ). Of note, as part of the study, all participants were given lists of treatment providers, and two previously untreated individuals initiated treatment following study enrollment.

*<Insert Table 4.4 Here>*

## **Aim 2: Correlations between Weight-Related Variables, Treatment Delay, and Level of Care**

Correlations between weight-related variables, treatment delay, and level of care can be found in Table 4.4. Lifetime minimum BMI was associated with treatment delay ( $r = .392$ ,  $p = .039$ ), such that lower minimum BMI was associated with lower treatment delay; this association remained significant in partial correlations after controlling for age ( $r = .445$ ,  $p = .020$ ). Largest percent weight loss was marginally correlated with treatment delay ( $r = -.357$ ,  $p = .068$ ), such that greater levels of premorbid body weight lost were associated with lower treatment delay, when controlling for age. Finally, highest level of care was inversely associated with lifetime

maximum BMI, such that higher BMIs experienced in a lifetime were associated with receiving lower levels of care ( $r = -.348, p = .030$ ).

## **Discussion**

The purpose of this study was to describe the psychosocial impact of AAN and examine the association between weight-related variables, treatment delay, and levels of care among a diverse sample of adults with AAN histories. Despite presenting at a wide range of BMIs, this sample experienced ED symptom severity and impairment scores that indicated they were experiencing a significant, psychosocially impairing illness. Participants also reported lengthy treatment delays which were associated with lifetime minimum BMI, with thinness associated with receiving care more quickly, and fatness associated with receiving lower levels of care.

### **AAN Sample Presented with Impairing EDs**

Previous AAN samples have demonstrated high clinical levels of ED severity and impairment within lower weight samples of AAN patients (Damiano, Reece, Reid, Atkins, & Patton, 2015; Ekeröth, Clinton, Norring, & Birgegård, 2013; Sawyer et al., 2016). This study sample demonstrated similarly significant symptoms, despite a more widespread BMI range. EDE-Q, CIA, and WBIS scores showed that for this sample, ED symptom severity scores were generally commensurate with other clinical samples of ED patients (Durso, et al., 2012; Mond et al., 2006; Welch et al., 2011). Participants scores on the EDE-Q, CIA, and WBIS exceeded all community norms (Hilbert, et al., 2014; Mond et al., 2006; Pearl & Puhl, 2014; Welch) for all measures. EDE-Q scores revealed that the WINTER sample's global score ( $M = 2.92, SD = 1.29$ ) approximated that of clinical ED samples ( $M = 3.09, SD = .83$ ), meeting or exceeding every subscale (Eating Concern, Shape Concern, Weight Concern) except for Eating Restraint (Welch et al., 2011). Lower scores on the restraint subscale are likely explained by the sampling strategy in

which participants were recruited throughout their illness journey (36% were in partial or full remission). Still, CIA scores similarly reflected clinical levels of functional impairment because of their ED symptoms, with the sample mean above the score that best predicts the presence of an ED. These data provide further validation that individuals with a history of AAN, may present at a wide spectrum of BMIs, and experience formidable, impairing EDs, while waiting years for care (or remaining untreated).

### **Importance of Weight and Shape Concerns: The Link to Weight Stigma**

A second notable finding was the particularly high scores in regard to shape concern, weight concern, and internalized weight stigma, which are similar findings by Sawyer and colleagues who found that individuals with AAN showed increased distress regarding body image compared to thinner peers with typical AN (Sawyer et al., 2016). Internalized weight stigma scores were nearly twice community norms and exceeded those of a higher-weight BED sample (Hilbert et al., 2014; Pearl & Puhl, 2014). High levels of internalized weight stigma are understandable in the context of a mental disorder that is characterized by overvaluation of weight and shape and intense fear of fatness, particularly as many were also higher weight individuals. This finding suggests that the weight stigma likely experienced by many higher weight individuals with AAN may exacerbate underlying ED pathologies associated with overvaluation of weight and shape and fear of fatness. Thus, addressing internalized weight stigma in conceptual models for AAN, and as treatment targets, may be crucial to improving quality of life for AAN individuals.

### **Weight, Treatment Delay, and Level of Care: Thinness as a De Facto “Key” to Treatment**

Data from this study further validate previous AAN research which has suggested that AAN individuals may wait longer for care (Sawyer et al., 2016). Mean treatment delay in the sample showed that many waited over a decade for care—a significant barrier to early

intervention practices, which are associated with better disease outcomes for EDs (Fichter et al., 2006; Von Holle et al., 2008). By contrast, studies of combined diagnostic groups of EDs reported treatment delays of five to six years (Rosenvinge & Klusmeier, 2000), suggesting that AAN patients may be waiting longer for care. Regarding treatment experiences, it is noteworthy that 28% of the sample had not received any treatment for their ED prior to the start of the study. Both Cooper and Kelland (2015) and Forman and colleagues (2014) found similar findings, wherein AAN individuals were less likely than lower-weight ED peers to receive higher levels of care, or treatment in general. Further, the finding that higher lifetime BMI was associated with lower levels of care further bolsters this earlier work.

Treatment delay may explain the high levels of weight suppression found within this sample, as the mean BMI suppression experienced by this sample was 19.4 BMI points (ranging from 4.2 to 47.0), a concerning finding in light of the association of weight suppression with poorer disease outcomes for individuals with EDs (Swenne et al., 2017). Similarly, the largest single weight loss in this sample ranged from 20 to 150 pounds, approximating 11.8% to 50.2% of their premorbid body weight. Previous case reports of higher weight individuals have reported patients with AAN losing similarly large percentages of weight, with symptoms of weight loss (and other physical indicators of restrictive EDs) often overlooked by or praised by medical professionals or loved ones (Sim, 2013; Conceição et al., 2013; Peebles et al., 2010). Finally, while this study did not require a minimum level of weight loss for study inclusion (in an effort towards greater clarity on the multiple thresholds of weight loss proposed by various researchers), all individuals in this study presented with weight loss that was at least 11.8% of their premorbid weight. This is in line with previous researchers who found significant functional ED-related

impairment occurring at 5%, 10%, and 15% levels of weight loss for individuals with AAN (Forney et al., 2017).

Interestingly, while maximum lifetime BMI was not associated with treatment delay, lifetime *minimum* BMI was. This suggests that for this higher weight AAN sample, a patient's fatness may matter less than a patient's thinness in regard to successfully initiating treatment for an ED. Thus, it is possible that regardless of how large a patient presents, past a certain point, that person may be less likely to be screened for an ED; however, if a patient presents with a certain degree of thinness, even if not markedly underweight by BMI standards, they may be at an increased likelihood of being screened for an ED and referred for care. A possible explanation for this finding is that systemic forms of weight stigma may be influencing treatment referral for AAN populations, such that those who are thinner may be more likely to get care, and moreover, get care earlier in the course of their illness.

Finally, while maximum BMI was not associated with treatment delay, higher maximum BMI was associated with receiving lower levels of care. A possible explanation for this finding is that in addition to influencing provider screening behaviors, systemic forms of weight stigma may also be influencing the type of treatment providers deem appropriate, whether due to norms of the field or out of concern for the patient feeling out of place (or disruption to the treatment milieu).

### **Research and Clinical Implications**

People with fat bodies are not readily recognized as having EDs. These findings suggest several important next steps to further understand and treat this important patient population. First, the high levels of treatment delay experienced by this group, and the large proportions of weight that many patients lost prior to treatment suggest that some individuals with AAN (particularly adults with AAN), may be experiencing long waits and protracted periods of illness prior

to treatment. Many people in this study reported that their ED had progressed for decades, beginning in adolescence or young adulthood, and building for years prior to intervention. Such lengthy engagement with ED behaviors and symptoms may have a high cost—not just medically and psychologically, but also on quality of life. Understanding why individuals in this sample experienced such long periods of treatment delay could help identify various points of intervention to ensure more speedy ED identification and referral for treatment.

Second, regarding the weight history findings, taken collectively, these weight data suggest that restrictive EDs occur across the BMI spectrum, with individuals presenting with a wide range of weight suppression, highlighting the importance of screening for EDs whenever an individual presents with rapid weight loss, regardless of their premorbid BMI.

Third, for this sample, both minimum lifetime adult BMI and (marginally) largest percent weight loss were associated with treatment delay, suggesting that thinness in addition to periods of rapid weight loss (when it is a large percent of a person's premorbid weight) may serve as overt indicators of treatment need. Emphasis on the importance of minimum BMI (at the exclusion of maximum lifetime BMI), suggests that there may be some threshold of “weight appearance” beyond which healthcare providers may not be screening for restrictive EDs or believing patients when symptoms or behaviors of malnutrition are reported. This implicit “degree of thinness” may operate as the primary indicator of treatment need among healthcare professionals and third-party payors. Previous research has suggested that AAN may be more difficult to detect in community populations as it presents with fewer “overt indicators” of disordered eating, such as the presence of bingeing or purging behaviors or a very low body weight (Thomas et al., 2015). Thus, developing ED screening protocols that are sensitive to the restrictive behaviors, symptoms, and presentations experienced by AAN individuals and inclusive across a wide range of



weights is indicated; adapting an existing screening tool such as the SCOFF questionnaire (Morgan, Reid, & Lacey, 1999) to be more weight-inclusive could accomplish this goal. Additionally, developing interventions to assist healthcare providers in more speedily identifying these disorders, particularly in higher weight populations wherein weight loss recommendations may be the norm, may also reduce treatment delay and improve patient outcomes.

Fourth, regarding potential treatment interventions for AAN groups similar to this sample, internalized weight stigma may be an underrecognized element for consideration. Of all measures examined in this study, the sample showed particularly high levels of internalized weight stigma (scoring between the 95<sup>th</sup> -99<sup>th</sup> percentile), with shape and weight concern lasting at high levels even during times when these participants were doing better in terms of ED behaviors and impairment. In the context of other higher weight individuals, internalized weight stigma has been shown to moderate treatment outcomes of interventions aimed at decreasing disordered eating behaviors and increasing physical activity (Mensinger, Calogero, & Tylka, 2016; Mensinger & Meadows, 2017). Thus, given the high levels of internalized weight stigma experienced by AAN individuals in this sample, it is likely that interventions aimed at decreasing AAN symptomatology may need to address internalized weight stigma in order to maximize treatment outcomes. It is also worth noting that interventions aimed at reducing internalized weight stigma may also need to address the factors of structural weight stigma, or other forms of weight-based discrimination that AAN individuals may experience, given that some individuals with AAN at times present at higher weights.

Finally, maximum BMI being negatively associated with level of care suggests that heavier patients may receive lower levels of care despite demonstrating high levels of pathology and weight suppression. For example, the participant experiencing the highest level of weight loss in

a given period of AAN (losing 50.2% of her body weight) received only outpatient treatment for her ED (and not until the age of 42), despite three separate significant restriction periods of AAN which resulted in a weight loss of at least 100 pounds, beginning in her early 20s. This highlights two important issues. First, when higher weight patients present with weight loss that is presumed to be health-enhancing, it is important to screen regularly for cognitive and behavioral symptoms of EDs such as preoccupation with weight and shape, obsessive and compulsive behaviors around body and food, eating- and body- related distress, compensatory behaviors, and unhealthy weight control practices, as these individuals' EDs may be less likely to be detected. Second, treatment recommendations based solely on absolute weight or BMI, without the context of a patient's weight history and levels of weight suppression, may result in undertreatment of potentially dangerous EDs.

## **Limitations**

While innovations regarding sample diversity were achieved, results should be interpreted considering several limitations. First, a purposive sampling strategy was leveraged to maximize sample diversity. As such, this sample was small, and not representative, and findings should be interpreted accordingly. Additionally, due to recruiting from treatment centers with greater proportions of AAN patients, over half (62%) of participants had experienced Health at Every Size® treatment approaches, which are less typical of the ED field as a whole and may have impacted participant perceptions. Second, in this study, I utilized retrospective, self-report measures for participants' ED and weight history. While the historical presence of AAN was validated using the EDA-5, this method still relies on a participant's memory of previous ED behaviors, and a single clinician (the first author) performed the EDA-5 screenings to verify current or past diagnosis of AAN. An effort was made to increase validity of these diagnoses by using a validated diagnostic measure and using the corroborating measures of the EDE-Q and CIA.

Regarding self-report measures, an attempt was made to validate in-person participants' self-reports of weight and height with clinician collected measures when possible; however, this was not possible for long-distance participants. Similarly, by allowing any lifetime experience of AAN, the sample included participants who were in various states of recovery and not necessarily in the height of their disorder. Because the sampling strategy precluded measures at a single stage of the illness process (such as recently diagnosed, beginning treatment, or in recovery), scores on the EDE-Q, CIA, and WBIS may be skewed toward more positive reporting than was actually the case at the height of their ED.

## **Conclusion**

In this study, I examined ED severity and impairment, internalized weight stigma, weight-related variables, and treatment experiences in a diverse sample of patients with AAN histories. Results demonstrated that individuals with a history of AAN presented with clinical levels of ED severity and ED-related functional impairment, with particularly elevated levels of shape and weight concern. Internalized weight stigma scores reflected the top 1-5% of the population, indicating that addressing internalized weight stigma within this population may be pivotal to alleviating eating- and body- related distress. Participants presented across the weight continuum, experienced variation in weight loss, and reported substantial treatment delays or being untreated. Minimum BMI was associated with treatment delay, suggesting that attaining a certain level of thinness and weight loss may be necessary before treatment can be accessed. Together, these findings point to the need for providers to screen for ED symptoms and behaviors across the weight continuum, noting not only patients with lower weights, but also those experiencing weight loss, particularly in the context of high levels of internalized weight stigma. Ensuring patients with AAN receive treatment that is relevant to their needs regardless of

presentation weight will be critical to reducing health risks and promoting wellbeing among this population.



Artwork by Jessie, Participant 37

“Whoa 192 pounds! What?” She was like, ‘You don’t look it in the face,’ She’s like, ‘Where you gonna be in ten years? Where you gonna be in 20 years...?’ And it was... mortifying, horrible, and then, I just sit there with my fucking vag out for her... All that did was reinforced my belief that I needed to lose weight that I shouldn’t be fat. Being fat is bad. I was terrified and mortified.... Yeah, it just solidified my eating disorder.” --Amanda, Participant 3

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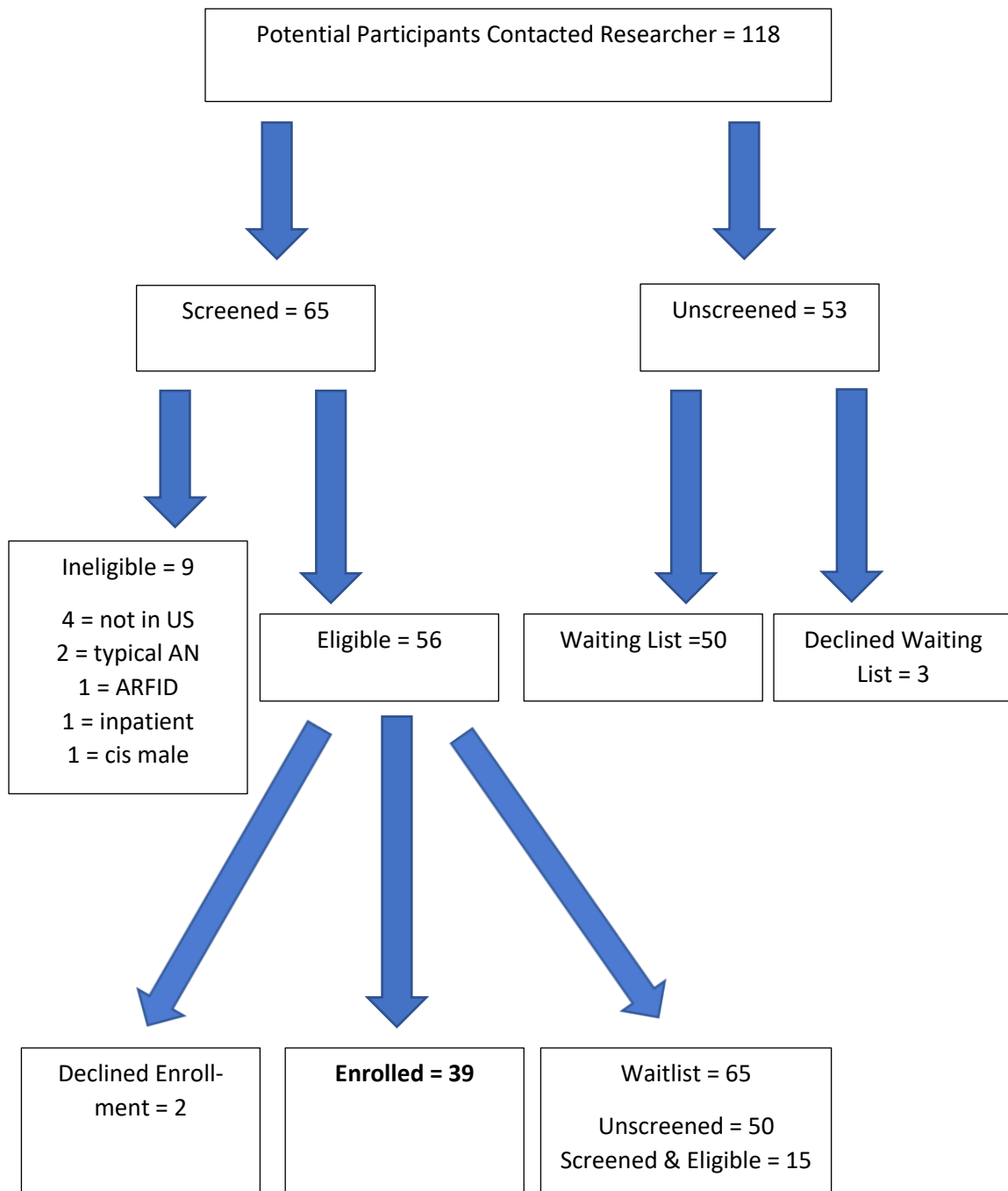


Figure 4.1. Recruitment, screening, and enrollment flow enrollment diagram.

Table 4.1

*Demographic Characteristics of Sample*

Characteristic	N	%
<b>Gender</b>	Cisgender Female <sup>a</sup>	34
	Nonbinary AFAB	4
	Trans Female	1
<b>Race</b>	Non-Hispanic White	28
	Latinx	6
	African American	3
	Middle Eastern	1
	Asian/Pacific Islander	1
	Alaska Native	1
	Multiracial	7
<b>Sexual Orientation</b>	Heterosexual	14
	Bisexual/Pansexual	7
	Queer	7
	Lesbian	5
	Asexual	2
	Straight-Leaning	1
	Fluid	1
	Homoflexible	1
	Unsure	1
<b>Highest Education</b>	Doctoral	3
	Master's	13
	Bachelor's	16
	Associate's	2
	Some College	4
	Working toward GED	1
<b>Lifetime BMI Maximum</b>	18.5 - 24.9	1
	25.0 - 29.9	3
	30.0 - 34.9	12
	35.0 - 39.9	5
	BMI > 40.0	20
<b>Lifetime BMI Minimum</b>	Underweight by Age	2
	Under 18.5	5
	Under 19	10
<b>On Financial Assistance</b>	As Child	17

<sup>a</sup> Data given here are gender at baseline. After baseline, three additional participants identified as nonbinary and one identified as male, creating the following gender breakdown: cisgender female, 76.9% ( $n = 30$ ), nonbinary AFAB, 17.9% ( $n = 7$ ), trans male, 2.6% ( $n = 1$ ), and trans female, 2.6% ( $n = 1$ ).

Table 4.2

*EDE-Q, CIA, and WBIS Scores of WINTER Study Sample, Community Norms, and Clinical ED Samples*

<b>Measure</b>	<b>WINTER Sample Mean (SD)</b>	<b>Community Norms Mean (SD)</b>	<b>ED Clinical Sample Mean (SD)</b>
<b>EDE-Q Restraint Subscale<sup>a</sup></b>	1.57 (1.70)	1.27 (1.43)	2.65 (1.48)
<b>EDE-Q Eating Con- cern Subscale<sup>a</sup></b>	2.02 (1.47)	0.69 (1.04)	2.02 (.95)
<b>EDE-Q Shape Con- cern Subscale<sup>a</sup></b>	4.03 (1.61)	2.10 (1.67)	4.01 (.98)
<b>EDE-Q Weight Con- cern Subscale<sup>a</sup></b>	4.05 (1.36)	1.64 (1.48)	3.68 (1.08)
<b>EDE-Q Global Score<sup>a</sup></b>	2.92 (1.29)	1.42 (1.24)	3.09 (.83)
<b>CIA Global Score<sup>a</sup></b>	20.92 (10.83)	8.25 (9.25)	30.22 (10.21)
<b>WBIS Global Score<sup>b</sup></b>	5.11 (1.39)	2.90 (1.20)	4.62 (1.22)

<sup>a</sup> Welch, et al., 2011

<sup>b</sup> Community norms from Hilbert, et al., 2014; Clinical data from Pearl, et al., 2014

Table 4.3

*Weight-Related Variables and Treatment Delay*

	N	Minimum	Maximum	Mean	Standard Deviation
<b>Age in Years</b>	39	18	74	35.41	11.68
<b>Current BMI</b>	39	21.8	61.1	37.90	10.70
<b>Lifetime Maximum BMI</b>	39	23	65.7	42.03	11.33
<b>Lifetime Minimum BMI</b>	39	18.1	41.7	24.46	5.65
<b>Lifetime BMI Suppression</b>	39	4.2	47.0	19.39	10.89
<b>Lifetime Largest Weight Loss in Pounds</b>	39	20	150	64.05	32.99
<b>Percent Largest Weight Loss</b>	39	11.8	50.2	28.41	10.02
<b>Age First Thought had ED</b>	39	5	44	18.74	9
<b>Age First Received ED Treatment</b>	28 <sup>a</sup>	15	72	30.79	13.77
<b>Treatment Delay</b>	28 <sup>a</sup>	0	48	11.61	11.72

<sup>a</sup> 11 participants had not received treatment at baseline

Table 4.4

*Correlations between Weight-Related Variables, Treatment Delay, and Level of Care*

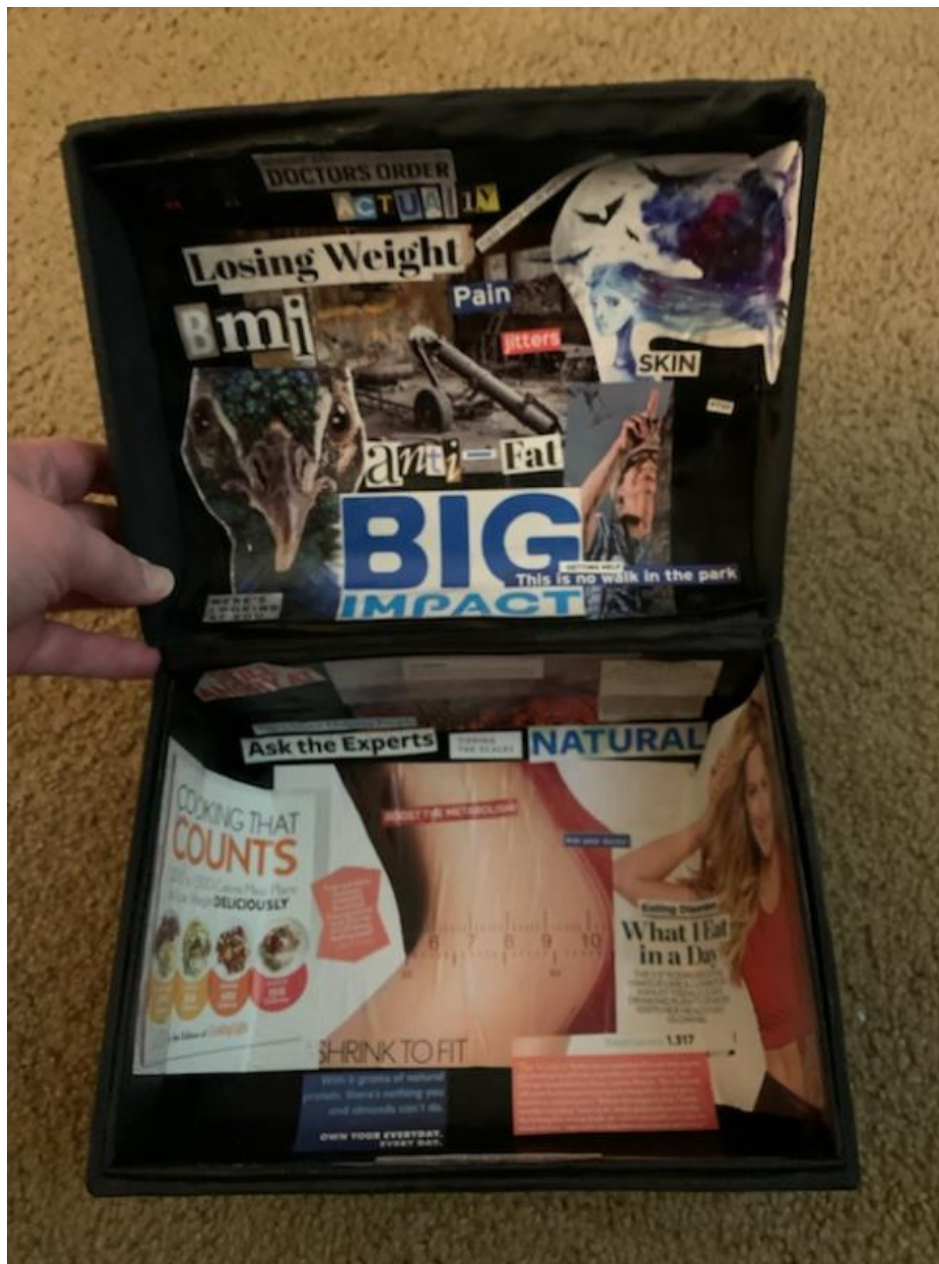
Control Variables		Lifetime Maxi- mum BMI	Lifetime Mini- mum BMI	Largest Weight Loss Percent	Treatment De- lay in Years	Age in Years
a No con- trol varia- bles	Lifetime Mini- mum BMI	.476**	--			
		.002	.			
	Largest Weight	.187	-.328*	--		
	Loss Percent	.254	.041	.		
	Treatment De- lay	.216	.392*	-.244	--	
		.269	.039	.210	.	
	Age in Years	.237	.043	.089	.560**	--
		.147	.797	.590	.002	.
Control for Age	Highest Level of Care	-.348*	-.254	-.254	-.300	-.105
		.030	.119	.119	.121	.525
	Lifetime Mini- mum BMI	.480**	--			
		.002	.			
	Largest Weight	.172	-.334*	--		
	Loss Percent	.303	.041	.		
	Treatment De- lay	.104	.445*	-.357 †	--	
		.605	.020	.068	.	

a. Cells contain zero-order (Pearson, Spearman, respectively) correlations.

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

†. Correlation marginally significant at the .10 level (2-tailed).



Artwork by Sisu, Participant 39

“Because I was in a larger body... it [eating disorder] was facilitated and like promoted, and I was told to restrict and do all these things for disordered eating behaviors... then when that kind of took off... it was just like... ‘You were obese, and now you're not, so thank god. You're not going to die now.’” –Daisy, Participant 31



## CHAPTER 5:

### CONCLUSION

In this dissertation, I sought to better characterize the experiences of patients with atypical anorexia (AAN) by using a weight stigma lens. Building on current research, I began by conducting a systematic review of AAN literature that examined the weight history and medical consequences of people with AAN. Following this, I analyzed primary mixed method data collected from individuals with a history of AAN in the Women's Illness Narratives Through Eating Disorder and Remission (WINTER) Study. The following is a brief synopsis of the findings.

#### Summary of Findings

##### Main Findings of Paper One

In Paper One, I reviewed published literature from 2007-2018 on the weight history and medical consequences of AAN, and compared these to the experiences of lower weight individuals with anorexia nervosa (AN). In all, 42 eligible studies were identified and coded. Aside from presenting at higher weights compared to AN individuals, AAN samples were also more likely than AN samples to have a history of elevated body mass indices (BMIs). Interestingly, a large portion of AAN individuals also had histories of *underweight* BMIs, suggesting that some may have previously qualified for AN diagnosis. Additionally, in all but one study (a bariatric surgery sample) measuring percent weight loss, samples with AAN tended to lose at least as much of their premorbid body weight (or in some cases more) prior to treatment, compared with AN samples. Studies reporting on nutritional rehabilitation and weight regain tended to report little to no weight restoration for AAN samples, alluding to potential inequities in nutritional rehabilitation treatment.

Regarding medical consequences of AAN, the results were more mixed. Overall, individuals with AAN tended to present with medical consequences of their eating disorders (EDs) in roughly comparable ways to patients with AN. However, there were some notable differences. Menstrual irregularity and amenorrhea were common experiences for AAN samples, though AN rates always exceeded those of AAN samples. This finding was mirrored in studies on bone density, which found that AAN individuals tended to present with impaired bone mineral density compared to normal controls, yet overall presented as less impaired compared to AN samples; amenorrhea often mediated these findings. Rates of life-threatening medical consequences, such as bradycardia, orthostatic hypotension, hypothermia, and electrolyte imbalance tended not to differ between AN and AAN groups; however, some studies found small variations, with AAN groups sometimes faring better, and sometimes faring worse than AN groups. For example, AAN patients fared worse regarding rates of bradycardia and orthostasis, but better regarding rates of hypotension and length of QTc intervals.

### **Main Findings of Paper Two**

In Paper Two, I utilized in depth qualitative data to explore how experiences of weight discrimination impacted patients while they engaged in healthcare. This qualitative analysis found that participants with AAN reported experiencing weight stigma throughout their illness trajectories. Beginning in childhood, participants received messages from healthcare providers that their bodies were “wrong,” untrustworthy, and needed to be “controlled” through diet and exercise. Participants internalized these messages, deepened restrictive and compensatory behaviors, and began to experience fully symptomatic EDs. Participants reported being congratulated on weight loss, treated as “success stories” when meeting with providers. They described these experiences as “flying under the radar” with “invisible EDs” that providers failed to detect, though their EDs were beginning to take a toll on their psychological wellbeing and physical

health. This lack of screening was worrisome as most participants reported hallmark symptoms of malnutrition (e.g. low heart rate, amenorrhea, lanugo, fainting, orthostasis, electrolyte imbalance) that went unaddressed and untreated. Providers also minimized or discounted symptoms, saying that they “weren’t sick enough” or had not lost enough weight for it to become “problematic.” This made it harder for participants to see their EDs as problematic, strengthening the denial beliefs typical of EDs and culminating delay of care and increased disengagement from healthcare.

For those who did receive ED treatment, many continued to report discriminatory experiences—both in outpatient ED settings and at higher levels of care. Participants reported that providers continued to recommend weight loss, and many were assigned incorrect ED diagnoses (such as bulimia or binge eating disorder). Participants reported that providers continued to minimize their ED, telling participants that they didn’t “look anorexic” or they didn’t “look like they had an ED.” In higher levels of care, participants reported instances of discriminatory treatment that included: low meal plans, low goal weights, being prohibited from joining ED groups, and therapeutic activities that were not geared towards a range of bodies (e.g. body image shopping outings to a juniors department). Participants experienced systemic weight stigma when their insurance was cut off prior to them feeling ready to step down in level of care. These experiences contributed to participants feeling out of place at treatment; they reported doubting recovery, question the nutritional information and behaviors they were learning in treatment, and believing that true “recovery” required being thin.

For participants who experienced partial or full remission of symptoms, weight stigma often increased (likely due to their growing, more nourished bodies). Participants universally reported weight- and weight loss-focused healthcare experiences, with providers regularly recommending weight loss and restriction, while ignoring persistent ED behaviors and cognitions.

Larger participants reported instances of blatant mistreatment, stereotyping, and overt, abusive behavior from providers. Participants believed that their physicians likely preferred them thinner with an ED, compared to fatter and in remission. Participants remarked that providers often became the “voice of their ED” rather than bolstering their recovery. These experiences led participants to fear or avoid healthcare at the expense of destabilizing of their recovery.

### **Main Findings of Paper Three**

Paper Three explored the connection between weight-related variables, level of care received, and treatment delay. Additionally, this paper characterized the WINTER study sample in terms of current ED severity, current functional impairment related to the ED, levels of internalized weight stigma, weight history, weight suppression, treatment delay, and ED treatment history.

Regarding weight findings, participants presented across the BMI spectrum (BMIs ranging from 21 to 61). A few participants had experienced an underweight BMI in their lifetimes (5%), and nearly all (89.7%) had experienced an elevated BMI in the overweight or obese ranges of current BMI standards. Lifetime BMI suppression averaged 19.4 BMI points, with average percentage of body weight lost being 28.4% ( $SD = 10.0$ ) of their premorbid weight, with a large range (10.0 to 50.2%). Largest weight loss percentages and weight suppression measures show significant evidence of weight cycling. While this sample was intentionally recruited to capture patients with a range of experiences with AAN, both previous and remitted diagnoses, as well as current diagnoses, this sample still reported elevated ED severity, particularly in regard to shape, weight, and eating concern. Mean clinical impairment scores were also elevated, with the sample mean above the suggested diagnostic cutoff, demonstrating functional ED-related impairment commensurate with other ED samples. Importantly, this sample experienced internalized weight stigma at particularly high rates, nearly double the rates of the general public, similarly reflecting

their concern with weight and shape. At baseline, 28% of the sample had never received treatment for their ED; average treatment delay in years from the time that participants first thought they had an ED to the time they received ED-specific care was 11.6 ( $SD = 11.7$ ).

Regarding the connection between weight and treatment delay, after controlling for age, higher minimum BMI was associated with longer treatment delays. Largest percent weight loss was marginally associated with treatment delay (approaching significance), suggesting that the larger the percentage of body weight lost, and the lower the weight they sink to, the faster they receive care. Additionally, higher maximum BMI was associated with receiving lower levels of care in treatment. Thus, while fatness may impact the level of care participants receive, it may be that it is how *thin* a person becomes in their ED (their minimum lifetime BMI) that is more deterministic of the length of treatment delay they experience. Thus, a person's thinness, more so than a person's fatness, appears to be a driver in how efficiently people are treated for EDs. Beyond a certain point of perceived "fatness," it may not matter how much fatter a person gets—they may be perceived as "too fat to have an ED." However, it appears that the thinner a person gets, the more likely they are to be screened and referred for care for an ED.

### **Synthesis and Summary of Arguments**

In this dissertation, I examined the healthcare and treatment experiences of individuals with AAN by reviewing prior literature on the topic, while also collecting primary data to include more diverse voices than typically appear in ED literature. Through the WINTER Study, I identified a diverse sample of people who experienced AAN, representing a range of different social identities. I recruited AAN patients who presented across the age and weight spectrums, while incorporating other aspects of diversity, including race, gender-identity, and sexual orientation. I examined their experiences with AAN through a lens of weight stigma theory.

### **AAN is a Significant Illness**

The first conclusion from this work is that AAN is a significant and concerning ED. People with AAN experience dangerous consequences of their ED illness in terms of weight suppression and medical instability, despite their higher weight status. BMIs. These AAN patients are heavier and at times considered overweight by current BMI standards, and thus more likely to face weight stigma in society, in addition to medical complications due to starvation.

### **Higher Weight Masks Recognition of ED Behaviors and Cognitions**

Second, this higher weight status appears to function as a mask for the ED, rendering it less visible to providers. Despite participants reporting sentinel symptoms of starvation, including bradycardia, amenorrhea, electrolyte imbalance, lanugo, hair loss, and orthostasis, providers frequently either failed to screen for these symptoms, formed alternative explanations for these symptoms, or showed a lack of concern. Serious symptoms like amenorrhea and bradycardia were interpreted in contradictory ways, as when some providers attributed them to patient's higher weights or to intense fitness regimens.

### **Treatment Delay Prolonged Suffering**

Third, failure to recognize these significant symptoms led to treatment delay and years (and sometimes decades) of living with an impairing illness (treatment delay  $M = 11.6$  years,  $SD = 11.7$ ). Understanding what factors contribute to this long delay in care is critical to promoting efficient screening intervention. The correlation analysis revealed that length of treatment delay was associated with minimum lifetime BMI, such that patients reached lower BMIs received care fastest. This finding supports the argument that for patients with AAN, some part of treatment delay may be due to assumptions about higher weight status and hence, weight stigma, with heavier individuals taking longer to receive care. Multiple participants expressed regret over the

time lost to their ED, with many losing critical years (or decades) of their adolescence, young adulthood, and middle ages. Provider lack of recognition of the dangerous nature of AAN (and its medical consequences) and apparent lack of awareness that higher weight individuals *could* suffer with a restrictive ED not only prolonged treatment delay, but it also actively contributed to patients second guessing their hard-won recovery. All these data suggest that while higher weight status functions to mask the ED, thinness may be a visual key towards expediting treatment. Training providers to recognize these dangerous disorders in higher weight populations earlier in the illness trajectory (before so much weight loss occurs) is necessary if we are to reduce treatment delay and compounding harm.

### **Iatrogenic Messages from Healthcare Providers**

Fourth, not only did providers fail to recognize many participants EDs, but they also continued to recommend weight loss, at times even when participants were actively engaged in ED-specific care. One patient was told upon admission to inpatient care that she could “reasonably lose another 10 pounds” (Marie), despite her 400-calorie daily intake; during a specialty provider consult while inpatient, another patient (Joanna) was instructed to lose weight and “watch her sugar”—iatrogenic messages for any ED patient, particularly when engaged in weight restoration. For Joanna, this recommendation was an invitation back into her ED (which was obsessed with counting and tracking her daily intake), and it affirmed the voice of her ED which had been telling her that her dietitian was feeding her too much and causing excessive weight gain. She reported questioning her ED treatment program after this experience, feeling destabilized in her recovery, and her food and weight fears increased.

### **Weight Stigma is Real and Problematic: Diverging Experiences in AAN and AN**

Fifth, the lived experiences of weight stigma for patients with AAN contributed to multiple negative outcomes for patients, from their perspectives. In Paper Two, I demonstrated how

weight stigma manifested throughout participants' illness journeys, contributing to ED behavior initiation, entrenchment of cognitive ED symptoms, missed opportunities for screening and intervention, and ultimately, prolonged periods of untreated (or undertreated) illness. Participants believed that weight stigma caused them to receive poorer treatment (in both general healthcare and ED-specific care), undertreatment (through less insurance coverage), and led many to disengage from healthcare in order to avoid potentially stigmatizing experiences. Given the emerging, serious medical consequences AAN, delivering efficient, high quality care must be a priority for this population. Addressing weight stigma—both in interpersonal interactions between patients and providers and in the healthcare system at large is necessary if we are to improve the timeliness and quality of care.

## **Implications and Future Directions**

### **Social Justice Implications**

These findings highlight how weight stigma may be impacting patients with AAN differently than patients with AN, by virtue of their larger bodies. Though both AN and AAN patients are more likely to be attuned to issues of weight stigma and body image due to the cognitive symptoms of AN which include overvaluation of weight and shape, some AAN patients experience these cognitive symptoms while embodying bodies which are also systematically devalued by society due to their weight. Study Three showed that this sample presented with levels of internalized weight stigma twice as severe as the general population. Coping with internalized weight stigma has important implications for treatment and sustaining remission, as internalized weight stigma moderates and mediates health outcomes for disordered eating populations (Mensing, Calogero, & Tylka, 2016; Mensinger, Tylka, & Calamari, 2018). As AAN patients engage in nutritional rehabilitation, and their bodies restore weight that was lost in their EDs,



many may restore to weights considered “problematic” or “pathological” by medical providers, family members, and society. As such, this puts them at increased risk for more severe experiences of weight stigma. Given this, it could be argued that helping AAN patients cope with this stigma is a necessary part of relapse prevention if remission efforts are to be sustained. Furthermore, this type of resiliency intervention may also benefit remitting AN patients at lower weights, who though currently lower weight, are likely to experience weight shifts over time, as would be expected in response to ageing and the lifecourse (e.g. pregnancy, post-partum, menopause, disability, activity changes, hormonal or medication changes).

As social work clinicians, it is our charge not only to bolster natural resilience to oppression, but to *change oppressive systems*. Rather than simply asking, “how do we help our higher weight patients cope?” a more ethical question is, “how do we challenge, dismantle, and eradicate the systems that make living in fat bodies difficult?” As providers, we play a pivotal role in the social construction of care for our patients. Dismantling oppression in any form is not fast, and it is not done alone. Participants reported that the impacts of weight stigma on their illness experiences were far reaching; they permeated their experience of healthcare from childhood to present day, and consequences of that stigma endured. For many, their attempts to seek healthcare were so damaging that they concluded healthcare disengagement was the path of least harm and most good. As providers, if we desire to not only do less harm, but to also help our patients *heal*, our clinical work must involve both disengagement from these oppressions, and active resistance to them.

### **Implications for DSM Nosology: Shifting to an AN-Spectrum Disorder**

First, it is important to consider how current DSM-5 nosology may inadvertently contribute to some of the challenges facing AAN diagnosis and treatment. Currently, the distinction between AN and AAN, and between PD and AAN with purging is unclear. In my analysis of Paper

One, there were far more similarities in medical consequences of AAN and AN than differences. Differences in life-threatening complications rarely reached statistical significance between the two disorders, yet the levels for both were clinically significant and troubling. Other research has demonstrated that weight alone is a poor indicator of AN severity (Garber et al., 2019; Machado, Grilo, & Crosby, 2017; Peebles, Hardy, Wilson, & Lock, 2010), and this appears equally true for AAN. Similarly, in a recent Delphi study of experts' priorities for AAN, identifying the BMI cutoff distinguishing AN from AAN was the lowest priority item of the entire survey, reflecting a belief among experts that a focus on BMI will not significantly improve diagnosis, treatment, and relapse prevention for these patients (Strand et al., 2020).

Given that AAN individuals present with all symptoms of AN except a body weight considered "less than minimally normal or expected" (APA, 2013, p. 338), and that weight is not the only (or best) indicator of AN severity (Peebles et al., 2010), shifting our nosology is indicated. The similarities in symptoms and consequences of these disorders suggest moving away from two distinct diagnostic categories demarked by an unknown BMI cutoff and shifting towards conceptualizing these illnesses as existing on an AN spectrum, wherein weight may be one of several possible severity indicators. Other potential severity indicators suggested by this research include intensity of exercise, frequency of purging behaviors, duration of amenorrhea, extent of weight suppression, co-occurring trauma, degree of body dissatisfaction and dysmorphia, and illness duration or persistence.

Conceptualizing AN as a spectrum disorder, similar to the DSM-5 nosology of substance use, has important implications for AAN prevention and treatment. First, if we conceptualize AAN as beginning with diet changes in the absence of ED cognitions and behaviors, we can imagine this spectrum continuing towards disordered eating (with increasing cognitive and behavioral symptoms of ED), and into the realm of threshold EDs (such as AN or AAN). With a

spectrum approach, once a patient initiated behaviors on this spectrum (e.g. dieting, weight loss, activity changes), this would indicate an increased level of risk, similar to the risk entered when substance use is initiated. Within this framework, the much-debated distinction between “normative dieting” and “disordered eating” is unnecessary; both serve as an indicator of awareness for the physician and a prompt for regular screening.

Following a prevention science framework, once initiation of potentially problematic behaviors begins, regular screening for increasing consequences is indicated. Thus, if a child began dieting or a weight loss was observed (regardless of premorbid weight), this would trigger healthcare providers to begin routine ED screening to evaluate the possibility of progression toward more disordered behaviors or cognitions. Just as annual check-ups focus on trends in blood pressure or blood sugar levels, annual evidence-based assessments of ED risk behaviors could be instituted. If an individual progressed towards more symptomatic behaviors (e.g. increasing food fears, extreme dietary restriction, more compulsive exercise, rapid weight loss), this would prompt a more intensive response. In this way, dieting and weight loss would serve as one of the primary flags for providers to begin screening for ED behaviors (at any age, with particular vigilance around lifecourse transitions that often pre-date ED risk periods, such as puberty, college transitions, parenting and pregnancy, menopause, and older age). This could result in providers having to rely less on what they *see*, so there is less risk missing the unseen behaviors and cognitions. Perhaps this type of model would speed recognition of emerging problematic behaviors and cognitions for all patients, especially benefiting individuals who may be missed by standard screening practices.

Regarding further prevention efforts for EDs and early intervention for those beginning to struggle with EDs, Paper Two highlights how many common practices in pediatric primary care (e.g. weighing children at every appointment, recommendations for weight loss, lack of

screening for ED symptoms and behaviors, particularly in higher weight children) may unwittingly contribute to the development of ED behaviors in higher weight children. Many participants reported that weight-related conversations with healthcare providers, sometimes involving their parents, were the trigger for initiating ED behaviors. Participants reported internalizing a sense of shame about their bodies from these conversations, which communicated that their bodies were wrong and flawed, and needed to be controlled. Similarly, for those who were already engaged in dieting or ED behaviors, these conversations represented missed opportunities for providers to offer a valuable alternative, health-based perspective, to the messages young patients were receiving from society. Here, Mary discusses one crucial pediatric appointment, and the impact it had on her going forward:

I was... learning that I must monitor everything that passed my lips. I was an 11-year-old child - being told that my body was wrong. That it was too big, too much, and that it should be smaller. In context with the world, an exact confirmation of everything it told me every day. In the context, without any further explanation, functionally [it was] a verification that the images and messages in the media and external world were right. In the context of how children interpret the world I was being told there were good bodies and bad bodies and that mine, and therefore I, was bad. I looked to the medical community to set me straight on reality, and in that moment, it failed, and failed horrifically... I'd spend the next 15 years of my life doing everything possible to lose weight and being constantly reminded of my failure. (Mary)

### **Clinical Implications for Pediatric Care**

Shifting from weight-focused care (which mimics aspects of the ED) toward more weight-inclusive practices may benefit a wide range of patients with known and unknown EDs (Tracy et al., 2014). To aim towards prevention of disordered eating in pediatric samples, I suggest the following recommendations for pediatric primary care based on the findings of these studies: 1) conduct weight measurement in a fashion so that patients do not learn (and then focus on) their measurements, 2) if discussion of a patient's weight is medically indicated, have this discussion with the parent (and not the child), 3) screen the patient for ED behaviors (restriction, purging, compulsive exercise, binge behaviors, food insecurity) prior to making recommendations for alterations in patient diet, 4) encourage patients to intuitively connect with their bodies

(recognizing hunger and fullness, connecting with bodily and emotional sensations), 5) be aware of divergences from patient growth charts and provide follow-up (e.g. neutrally inquire about drops or increases in patient growth curves), 6) screen for EDs when patients present with weight loss (as opposed to congratulating weight loss), regardless of premorbid weight, 7) reserve compliments and congratulations for wholistic wellbeing practices and qualities within a patient's control (engagement in a hobby, dedication to dental hygiene, pursuing social connections with peers, completing a challenging athletic event) rather than weight. Often weight loss was one of the first physical symptoms participants reported experiencing—and one of the first to be noticed by a provider, yet sadly this symptom rarely resulted in ED screening and referral.

### **Clinical Implications for Adolescent and Adult Care**

In older years (adolescence and adulthood), it is noteworthy that participants in this study presented with ED behaviors across a range of BMIs and continued to present with problematic ED behaviors and cognitions well into adulthood and older adulthood, highlighting the need to screen for the full range of disordered eating behaviors at all weights and ages. Many participants reported only being screened for *some* disordered behaviors (e.g. higher weight patients being asked about bingeing, or perhaps, purging), allowing other behaviors (e.g. restriction, fasting, compulsive exercise, diet pill use) to persist unbeknownst to healthcare providers (or at times, with their encouragement). Based on these studies, I suggest the following recommendations for healthcare providers in adolescence and adulthood: 1) weigh all patients only when medically necessary (undue focus on weight may increase obsessiveness and trigger ED behaviors or relapse) and at the end of appointments if possible, 2) if weighing is required, default to weighing the patient backwards to reduce anxiety about weighing in patients where an ED history is unknown, 3) screen the patient for ED behaviors (e.g. restriction, purging, compulsive exercise, binge behaviors, food insecurity) prior to making recommendations for alterations in diet, 4)

encourage patients to intuitively connect with their bodies (practicing mindful embodiment, engaging in joyful activities and movements, knowing when their body wants to stop exercise), 5) screen for EDs when patients present with weight loss (as opposed to automatically congratulating weight loss), regardless of premorbid weight, and 6) investigate physical symptoms that are correlated with malnutrition (e.g. menstrual irregularity, amenorrhea, bradycardia, dizziness, orthostasis, low body temperature, anemia) even if patient presents at normal or higher weights or is highly athletic.

### **Future Directions for Research**

This dissertation represents one step in the process of understanding the breadth of AAN experiences, and how they are impacted by weight stigma. It is clear from the sheer duration of EDs reported by participants that longer follow-up is needed to understand how AAN develops, persists, potentially morphs into other EDs, and remits. Thus, prospective longitudinal methods will allow for more in depth understanding of how AAN develops over time. Secondly, while Paper Two provides an in-depth examination of patient perspectives on their healthcare experiences, understanding healthcare providers' perspectives could provide valuable insight into how to best tailor interventions aimed at provider behaviors and implicit bias. Similarly, surveying “master clinicians” identified by patients as particularly skilled in assessing or treating these challenging conditions may be a useful endeavor, as many patients pointed out the positive impact of one skilled clinician on their illness trajectory. Next, it is also clear that developing a short assessment tool that could be used to screen for EDs in primary care settings, across a range of ages and BMIs may also speed the identification and referral for AAN; alternatively, adapting an existing tool such as the SCOFF questionnaire to be weight-inclusive could accomplish similar goals. Finally, given the frequency with which AAN individuals report experiencing societal weight stigma (interpersonally, in healthcare, and systemically in society), and given the

severity of internalized weight stigma exhibited by this sample, developing ED interventions that address these internalized processes may buffer AAN patients against the ongoing harm perpetuated by weight stigma, while equipping them to better sustain ED remission. This suggestion is a distinct diversion from the recent Delphi study (Strand et al., 2020), which reported weight stigma to be the second lowest priority for experts. In my analysis of factors impacting patient engagement with help-seeking and healthcare, weight stigma and internalized weight stigma emerged as crucial considerations, particularly when approaching AAN from an anti-oppressive lens.

## **Two Final Remarks**

Two final considerations are worth noting. First, participants frequently reported being impacted deeply by study participation. For multiple participants (particularly those who had not had ED treatment) the study represented the first time they had spoken of their ED. For others, it was the first time they spoke of their ED and were heard and believed. Over and over participants mentioned the personal impact of telling their story and being heard. After years of feeling “invisible” and “flying under the radar” within the healthcare system, they had a fundamentally different experience. The invisible became visible; the pain, the medical system’s continual trauma on their bodies, became validated and real. They did not have to question their own reality, and for some, that led to deeper insights about their own experiences, with participants frequently following up with emails of revelations that occurred to them as they reflected on their interview experiences. Hope, who began therapy for the first time shortly after their baseline appointment, summed up their experience saying”

I remember it being so hard to tell my story and articulate my experiences, because so much of it I was saying for the first time... This was a powerful experience for me. It was the first time I felt truly validated in my experiences as someone with an ED and encouraged to seek help.

Second, the stories told in this dissertation represent those who survived their EDs (thus far) and those who were able to see through the minimization and denial of their EDs to reach out regarding possible study participation. Given the severe medical consequences faced by individuals with AN and AAN alike, these participants are the lucky ones—the ones who survived. It is sobering to recognize that there are many other stories that presently go untold when individuals with AAN pass away, whether due to causes directly attributable to their EDs (e.g. heart failure, electrolyte imbalance, malnutrition), or those attributable to systemic weight stigma (e.g. missed medical diagnoses, undiagnosed refeeding syndrome, protective healthcare disengagement). Thus, while reading the stories of survivors in this dissertation, we must also keep in mind the stories that are not told yet, as these will help to paint a fuller picture of the experience of AAN.

## **Conclusion**

In summary, people with AAN experience clinically significant, impairing, life-threatening EDs, as reflected in the quantitative measures, qualitative interviews, and systematic review. Previous research on other EDs shows that early intervention that leads to shorter illness duration is predictive of better long-term outcomes (Vall & Wade, 2015). The hope of early intervention is currently elusive as many participants waited more than a decade for care. This treatment delay allows significant suffering to continue unabated and potentially risks the preventable loss of life. The stakes are high for people caught in the web of AAN.

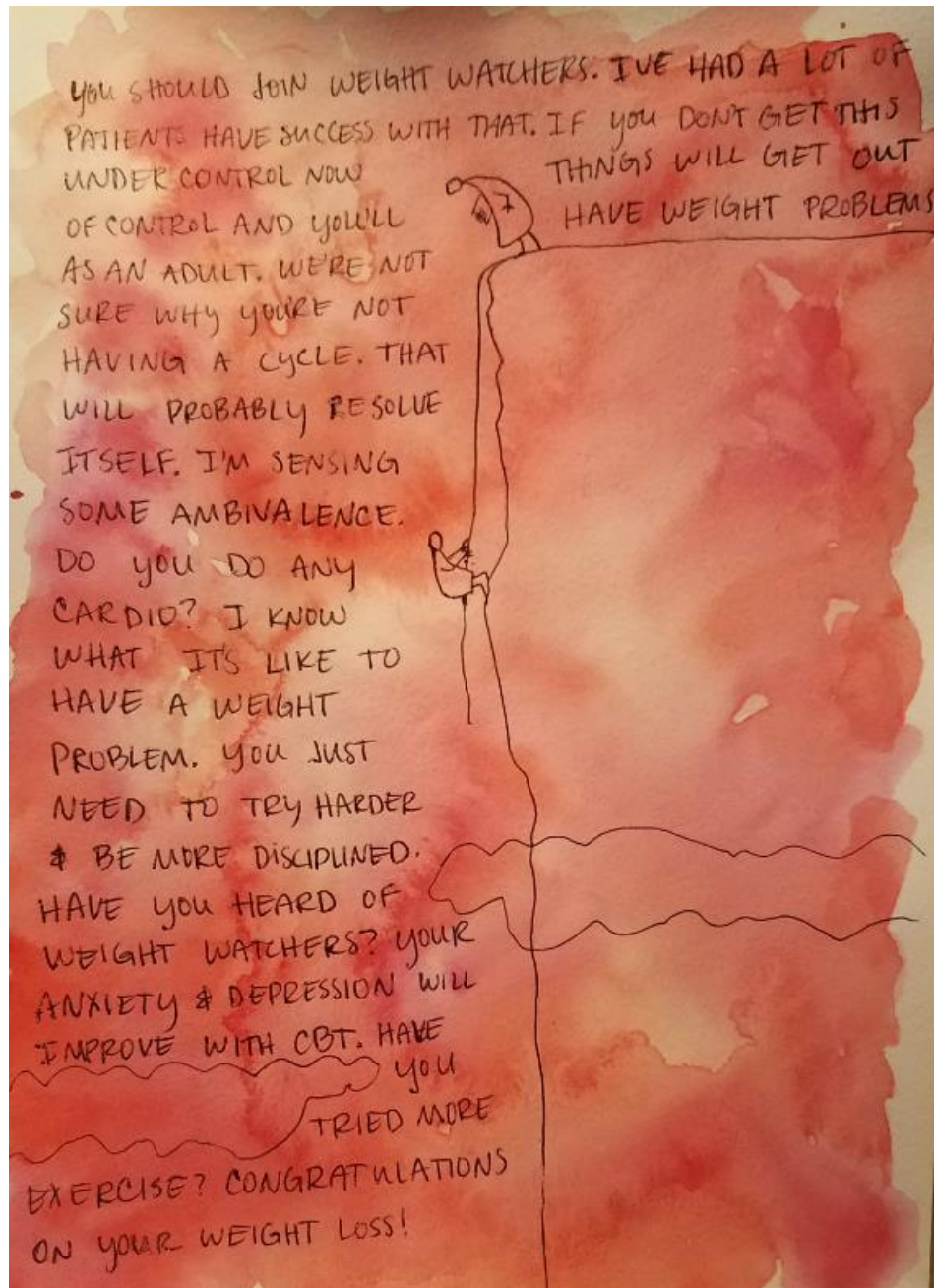
Despite our desire to provide humane, compassionate care to all patients, healthcare providers can become “the voice of the ED” by engaging in normative weight-centric healthcare practices (e.g. weight loss recommendations, frequent weighing). As providers, our charge requires us to not only do no harm, but to also do some good. Our patients will always struggle to accept bodies that we reject. They will distrust us if we disbelieve them. They will not feel



supported if we react with disgust. To unmask the ED hidden by weight stigma, we must first unmask our own bias, so that we may become a force for healing rather than harm.

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Artwork by Joanna, Participant 5

“Treat me as a person, not as fat. . . My weight is not even the most exciting thing about me. It’s not the most important part of my heath. . . I know I’m fat, trust me, I see it in the mirror every day. I hear from helpful individuals from the grocery store. I hear from my coworkers. I know I’m fat. My family tells me I’m fat. I get it. Let’s focus on something else now.”

—Carly, Participant 9

## Appendix A

### *Checklist for Authors of Review Articles*

Section/Topic	Item	Completed
<b>TITLE</b>		
<b>Title</b>	Identify the report as a systematic review, meta-analysis, or both.	✓ p.31
<b>INTRODUCTION</b>		
<b>Rationale</b>	Describe the rationale for the review in the context of what is already known	✓ pp. 33-37
<b>Objectives</b>	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	✓ p. 36-37
<b>METHODS</b>		
<b>Eligibility Criteria</b>	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	✓ pp. 37-38
<b>Information Sources</b>	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	✓ p. 38
<b>Search</b>	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	✓ p. 39
<b>Study selection</b>	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	✓ p. 40
<b>Data Collection Process</b>	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	✓ p. 40
<b>Data Items</b>	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	✓ p. 40
<b>Risk of Bias in Individual Studies</b>	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	✓ p. 41
<b>Summary Measures</b>	State the principal summary measures (e.g., risk ratio, difference in means).	✓ p. 40
<b>Synthesis of Results</b>	Describe the methods of handling data and combining results of studies, if done.	✓ p. 40
<b>Risk of Bias Across Studies</b>	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies)	✓ p. 41
<b>Study Selection</b>	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram	✓ PRISMA diagram, 42
<b>Study Characteristics</b>	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	✓ p. 43, table 1.1
<b>Risk of Bias within Studies</b>	Present data on risk of bias of each study.	✓ p. 43, table 1.2
<b>Risk of Bias within Individual Studies</b>	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	✓ p. 12, table 1.3, 1.4, 1.5
<b>Synthesis of Results</b>	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	✓ table 1.3, 1.4, 1.5, pp. 44-51

Section/Topic	Item	Completed
<b>RESULTS</b>		
<b>Risk of Bias Across Studies</b>	Present results of any assessment of risk of bias across studies.	✓ p. 43
<b>DISCUSSION</b>		
<b>Summary of Evidence</b>	Summarize the main findings including the strength of evidence for each main outcome.	✓ pp. 51-56
<b>Limitations</b>	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	✓ pp. 56-57
<b>Conclusions</b>	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	✓ pp. 61-62

**Note.** This checklist was adapted from the PRISMA 2009 Checklist (see Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Journal of Clinical Epidemiology*. DOI: [10.1016/j.jclinepi.2009.06.005](https://doi.org/10.1016/j.jclinepi.2009.06.005)).

## Appendix B

### Baseline Interview Guide

#### **Art Prompt 1:**

Thank you for your willingness to take part in this research interview. During the interview, we will be talking about your experiences with disordered eating behaviors, treatment, relapse, and remission. Prior to the interview, please take some time to sketch out (sketch, draw, collage, paint, whatever you want!) a picture of your illness story with your eating disorder. Consider any turning points or poignant moments that come to mind in the development of your illness.

*Feel free to use any materials that you wish. You do not need to be artistic or have the picture look any particular way. Take as much time as you want—there is no time minimum or maximum. Please bring your picture to the interview.*

#### **Interview 1: Illness story**

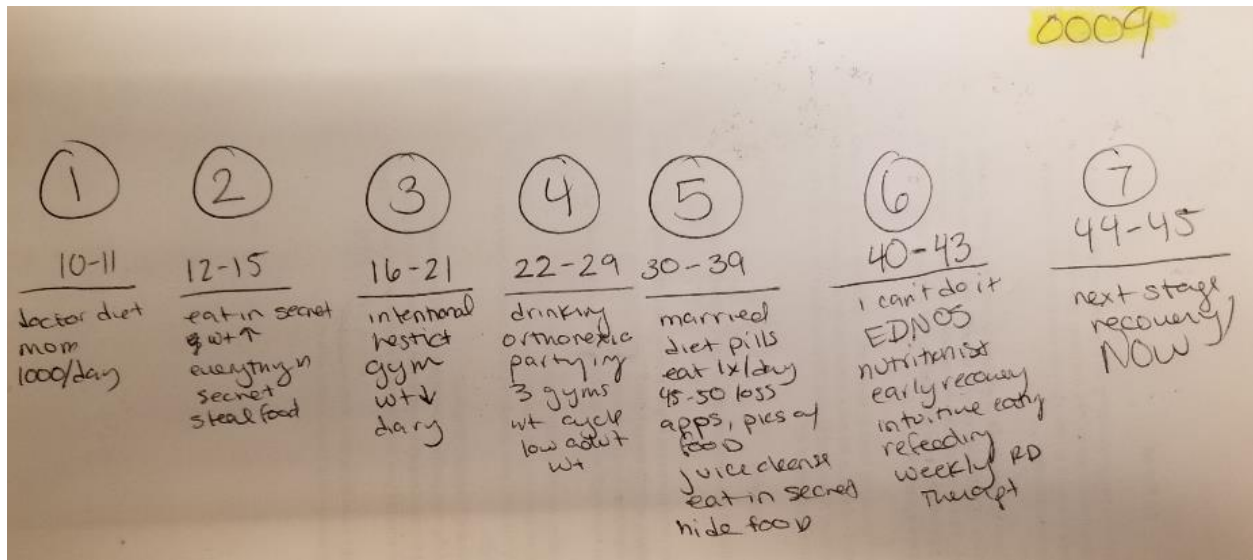
1. Please tell me the story of how your eating disorder developed and changed over the years.
  - a. If prompts are needed: Tell me about how you first noticed your body/eating/exercise was distressing you.
2. Tell me what “having an eating disorder” means to you. What do you see as problematic or most distressing about your eating disorder?
  - a. If needed: From your perspective, what was disordered about your eating, exercise, or relationship with your body?
  - b. If needed: How does this differ from what your providers or family have said about your eating disorder?
3. How have other people responded to your disordered eating behaviors over the years? What specific conversations come to mind?
4. Tell me about the events that led up to you receiving treatment?
5. How do you think your body size affected your illness journey with your ED? (if needed: how might your experience have been different in a thinner body?)
  - a. If needed: How has your body size affected your understanding of what was happening to you?
  - b. If needed: Other people’s beliefs?
6. Describe where you are in your disease or remission process today?
7. Looking forward to the next year, what do you expect in your eating disorder journey?
8. Tell me about your picture.
  - a. Probe for anything not heard during interview.

#### **General prompts:**

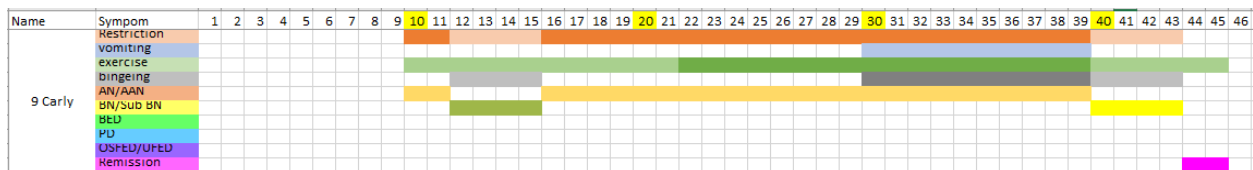
So, tell me how you came to interpret X this way?

## Appendix C

### Sample Participant Timeline, Participant 9, Carly



### Symptom and Diagnostic Timeline



### Legend for Colored Symptom and Diagnostic Timeline

Symptom or Diagnosis	Low Intensity	Medium Intensity	High Intensity
Restriction	any restriction endorsed	not marked	consumed under 1200 calories daily
Vomiting	any vomiting or laxative use	vomiting + laxative	purging behavior once weekly or more
Exercise	any regular exercise	with guilt	regular exercise with guilt and compulsion
Bingeing	any bingeing	not marked	bingeing occurs once per week or more
Anorexia (AN/AAN)	Atypical Anorexia (AAN)		Anorexia Nervosa (AN)
Bulimia (BN/SubBN)	Subthreshold Bulimia Nervosa (SubBN)		Bulimia Nervosa (BN)
Binge Eating (SubBED/BED)	Subthreshold Binge Eating Disorder (SubBED)		Binge Eating Disorder (BED)
Purging Disorder (PD)	Purging Disorder (PD)		
Other Specified Feeding or Eating Disorder (OSFED)	Other Specified Feeding or Eating Disorder (OSFED)		
Remission (Partial or Full)	Partial Remission		Full Remission

## Appendix D

### 6-Month Interview Guide (Interactions with Providers)

#### **Art Prompt:**

Thank you for your continued participation in this research study. During the interview, we will be talking about your experiences with medical providers, including doctors, nurses, physician assistants, therapists, psychologists, psychiatrists, and nutritionists/dieticians. Please take some time this week to reflect on your interactions with healthcare providers and your experiences with any eating disorder treatment (if you've had ED treatment). Prior to the interview, please take some time to sketch out or otherwise create (sketch, draw, collage, paint, sand, whatever you want!) a picture of your interactions with the medical, healthcare, and/or eating disorder treatment systems. You can pick one interaction that seems important to you or summarize multiple experiences. Essentially, I am wondering, "what has it been like to be an eating disorder patient in your healthcare system?"

#### **Interview:**

I'd like to hear about your experiences with healthcare providers, including doctors, nurses, therapists, psychologists, psychiatrists, and nutritionists.

1. How is the study going?
2. Please describe a couple of your most positive or helpful experiences with healthcare providers:
  - i. in regard to eating, weight, or body image issues?
  - ii. What impact did this experience have on your journey?
3. Please describe a couple of your most negative or unhelpful experiences with healthcare providers.
  - i. Prompt: in regard to eating, weight, or body image issues?
  - ii. What impact did this experience have on your journey?
4. How have medical professionals discussed your disordered eating behaviors? Any specific conversations that come to mind?
  - i. Prompt: Restriction? Purging? Exercise? Bingeing?
5. Please tell me about a couple of the most positive experiences you had in ED treatment.
6. Please tell me about a couple of the most negative experiences you had in ED treatment.
7. How do you think your body size affected your experiences of medical care or eating disorder treatment?
8. How might health professionals be more supportive of your recovery?
  - i. Of the recovery of other women with larger bodies with EDs?
9. How have the visible identities of providers (race, gender, body size, etc.) impacted your experiences of healthcare or ED treatment?
10. Tell me about your picture.



## Appendix E

### Coding Guide

#### **WINTER CODING GUIDE 1: Identifying Stigma and Time Periods**

##### **INSTRUCTIONS**

- For all quotes about STIGMA (internal, external), code time period
- Code for the categories of Weight stigma—EXTERNAL sources and INTERNALIZED weight stigma
- Flag any instances of positive provider interactions; flag any provider disciplines mentioned
- Code any references to ED behaviors, ED cognitions, and any physical symptoms

##### **A. Time Periods**

- a. **ED Development**
- b. **ED Pre-treatment**
- c. **During Treatment**
- d. **After Treatment**
- e. **Unknown Time Period**

##### **B. Weight Stigma/Discrimination-External**

- a. **Unhelpful things providers say**
- b. **Unhelpful things providers Do**
- c. **Things providers DON'T DO or MISS or DON'T ASK**
- d. **Lack of provider ED training**
- e. **Structural Weight Stigma in healthcare**
- f. **Stigma in treatment milieu**
- g. **Weight Stigma in broader society**
- h. **Weight Stigma with family, friends, partners:**
- i. **Providers not Listening**
- j. **OTHER**
- k. **Provider identity and stigma**

##### **C. Patient Internalized Stigma**

- a. **Body Dissatisfaction**
- b. **Minimization/Denial**
- c. **Low Advocacy or Voice**
- d. **Avoidance of Stigma/Anticipatory**
- e. **Participants own weight bias**
- f. **OTHER**

##### **D. Intersectional forms of discrimination with weight stigma**

- a. **Interpersonal intersectional stigma**
- b. **Structural intersectional stigma**

##### **E. Impacts**

- a. **IMPACTS on patient health behaviors**

- b. IMPACTS on patient's health care engagement
      - c. IMPACTS on patient's illness journey
      - d. IMPACTS on patient feelings and beliefs
      - e. OTHER
- F. Positive Health Provider Interactions
- G. Provider Disciplines
  - a. Medical doctors
  - b. RNs, CAN
  - c. Therapist
  - d. Psychiatrist
  - e. Dietician
  - f. Other profession/discipline
  - g. Informal supports (online, peer)
  - h. Treatment or healthcare providers in general
- H. ED Behaviors
- I. ED Cognitions
- J. ANY PHYSICAL symptoms/problems:

## Appendix F

### 12-Month Interview Guide: Attempts to Get Better, Recovery, and Relapse Processes

#### Art Prompt:

Thank you for your continued participation in this research study. During the interview, we will be talking about your experiences with recovery/remission, and what it's been like to get better.

Prior to the interview, please take some time to sketch out or otherwise create a picture of your recovery or remission process from your eating disorder, or what it has been like to try to “get better.” What does “getting better” really look like from your perspective? Where are you at? Or, where do you hope to go?

#### 12-month Interview:

11. Recovery/remission/healing/getting better means different things to different people. Please tell me in your own words what recovery/remission (from EDs) means to you? What words do you prefer to use to describe this and why? (**then use their words** [Remission: \_\_\_\_\_])
  - i. Do you see an endpoint in this journey? Why or why not?
  - ii. If so, what does it look like?
12. Where are you at in this process today? (Tell me the story of your recovery and how it started, and what has happened as you have tried to recover)
13. Think of a metaphor or simile to describe process of getting better. What has your experience of [remission: \_\_\_\_] been like? [\_\_\_\_\_] is like \_\_\_\_\_. [\_\_\_\_\_] is like a \_\_\_\_\_. [\_\_\_\_\_] is a \_\_\_\_\_.
14. What have healthcare professionals told you to expect as you try to get better from your eating disorder? How has this aligned with your experience?
15. How has your attitude toward [remission: \_\_\_\_\_] changed during your journey? Why? Is there a specific story that comes to mind?
16. Where do you have left to go as you get better from your ED? What changes are you hoping for? (in the near future? Years down the road?)
17. Have you ever had an experience of looking as if you were getting better/recovering/recovered when feeling like you were not?
18. Over the course of this study, what kind of treatment have you had for your ED
  - i. If new tx experiences since 6 month, inquire about helpful/unhelpful experiences.
19. Have you had any involvement with advocacy movements? If so, how has this advocacy affected your journey?

#### PROCEED TO PATH 1 or PATH 2

**Path 1: Some experiences with remission/recovery/[\_\_\_\_\_]**

For the remainder of this interview, we will be talking about periods when your ED has gotten better. Specifically in looking at your illness timeline, I'm thinking of these time periods: \_\_\_\_.

**PROMPT:** When you think about your own journey, am I missing any periods of getting better? Would you think of this any differently? [**Could shift to path 2 if needed**]

- a. From your perspective, looking back in your story, what has been your most significant period of getting better? When did it start? Is there a specific memory that comes to mind?
  - i. Why do you think it started then?
  - ii. [If multiple periods of recovery] What makes this period “most significant” compared to your other experiences?
- b. Sometimes change happens without us realizing it. Tell me a story of a time when you realized that your eating disorder had changed for the better—or that things were improving. What happened? How did you know this?
- c. How has your body changed as you have gotten better? How have you experienced this?
  - i. How has your *relationship* with your body changed as you have tried to get better?
  - ii. Tell me about a time when you realized that your relationship with your body was shifting.
- i. If needed: For the better? For the worse?
  - iii. How do you think your body size has affected your [remission: \_\_\_\_\_] journey?
- d. How have you changed as a person throughout your [remission: \_\_\_\_\_] journey?
- e. When you are getting better, how does your daily life look different? What does it look like? How do you maintain it? ED behaviors? Family/friends? Education and career? Free time?
- f. Tell me a story about one of the setbacks you have experienced as you have tried to get better.
  - i. What language do you like to use for these setbacks? Others? Preferred language:
  - ii. [If specific prompt for relapse is needed]: Have you ever returned to your eating disorder after a period of [remission: \_\_\_\_\_]? Preferred language: [relapse: \_\_\_\_\_]. Tell me a story about one of the [relapse: \_\_\_\_\_] you experienced.
- g. Describe some of the key learnings or mental shifts or changes in thinking that have occurred as you have experienced your eating disorder getting better.
- h. Tell me about your picture.
- i. You've been in this study for the past year, and this is our final meeting. Looking back, how (if at all) has being in this study impacted your journey or perspective?
- j. I wanted to acknowledge that interviews are not neutral. We are both people with bodies, and histories of our own. How has it been with me, with this body, sometimes eating with you (or not)? What impact has that had on you?

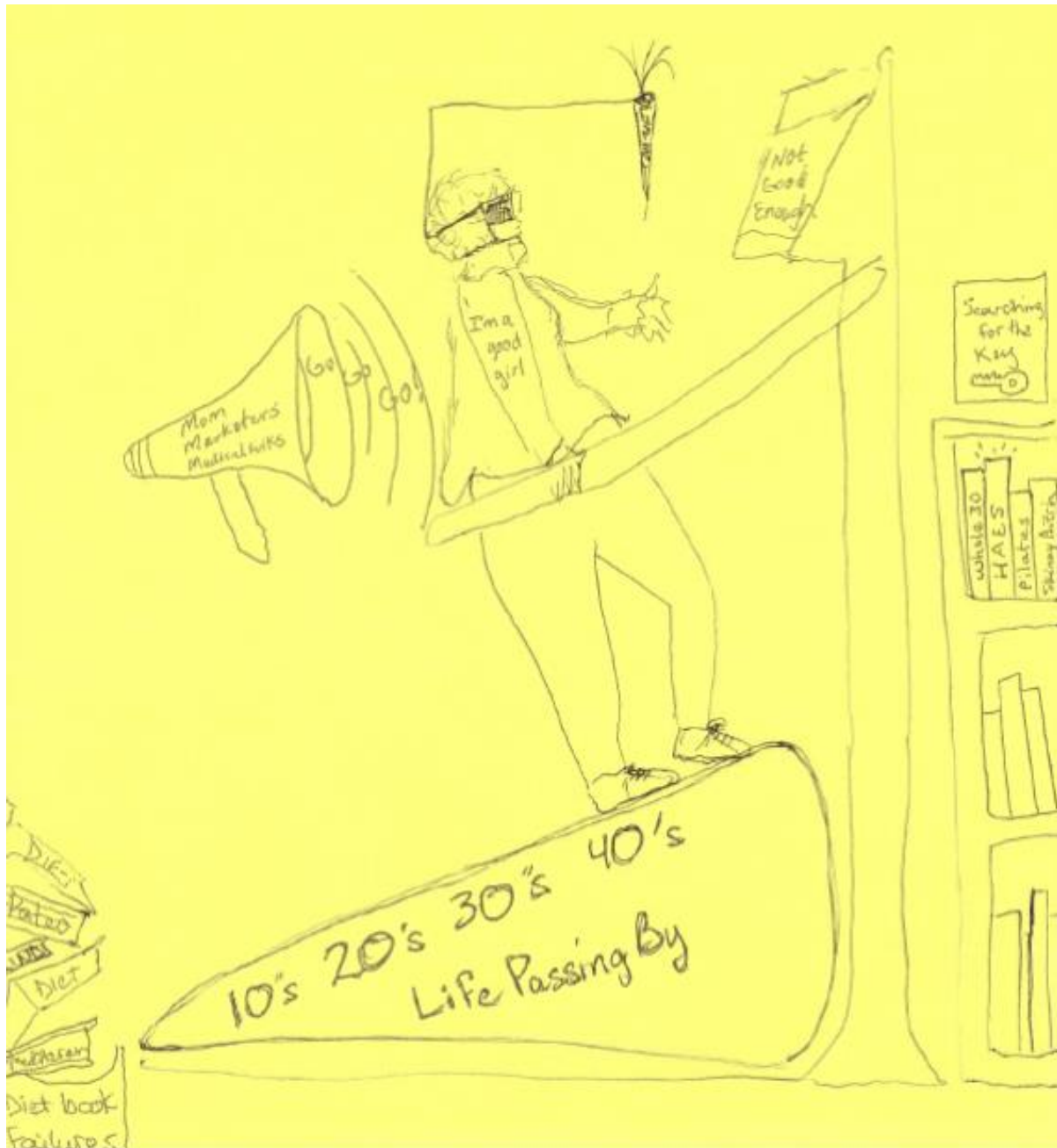
**Path 2: No experiences with remission/recovery/[\_\_\_\_\_]**

- a. When you think about the possibility of getting better from your eating disorder, what comes up for you? What hopes and fears do you have?
- b. Have you ever had a time, even a brief temporary time, when your ED shifted for the better—or things improved? If so, what happened? How did you know this?
- c. Tell me a story about one of the setbacks you have experienced in your eating disorder journey.
  - i. What language do you like to use for these setbacks? \_\_\_\_\_
- d. Tell me about a time when you realized that your relationship with your body was shifting. What happened? (If needed: For the better? For the worse?)
- e. How has your body size has affected your expectations about getting better?
- f. If your ED were to get better, how do you anticipate this affecting your life?
  - a. Your body? Your relationship to your body?
  - b. You as a person?
  - c. Your daily life? How you spend your time? Your social life? Education, career?
- g. Tell me about your picture.
- h. You've been in this study for the past year, and this is our final meeting. Looking back, how (if at all) has being in this study impacted your journey or perspective?
- i. I wanted to acknowledge that interviews are not neutral. We are both people with bodies, and histories of our own. How has it been with me, with this body, sometimes eating with you (or not)? What impact has that had on you?

## Appendix G

### Sample Participant Artwork by Participant 6, Molly

*Art 1 Prompt:* During the interview, we will be talking about your experiences with disordered eating behaviors, treatment, relapse, and remission. Prior to the interview, please take some time to sketch out (sketch, draw, collage, paint, whatever you want!) a picture of your illness story with your eating disorder. Consider any turning points or poignant moments that come to mind in the development of your illness.



*Art 2 Prompt:* Prior to the interview, please take some time to sketch out or otherwise create (sketch, draw, collage, paint, sand, whatever you want!) a picture of your interactions with the medical, healthcare, and/or eating disorder treatment systems. You can pick one interaction that seems important to you, or summarize multiple experiences. Essentially, I am wondering, “what has it been like to be an eating disorder patient in your healthcare system?”



*Art 3 Prompt:* Prior to the interview, please take some time to sketch out or otherwise create a picture of your recovery or remission process from your eating disorder, or what it has been like to try to “get better.” What does “getting better” really look like from your perspective? Where are you at? Or, where do you hope to go?



## Appendix H

“thank you for acknowledging”

### *Art and Data from Participant 1, Bette*

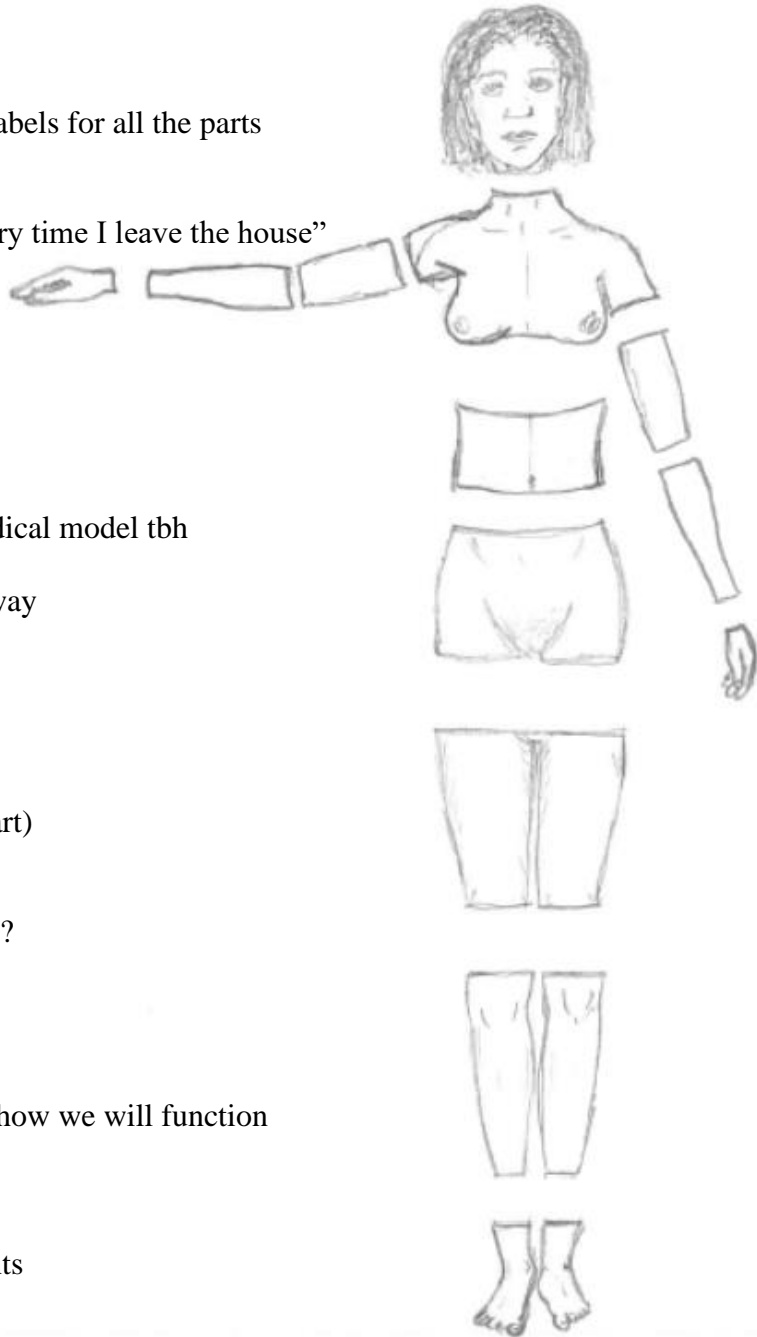
*Research poem featuring exact verbiage from the Zoom Chat in the unit on Qualitative Analysis*

*Written by our SOCW 506 Class & Arranged by your instructor*

How do you even code this  
Brokenness  
Disconnection  
Like in a medical textbook with labels for all the parts  
Relationship with body  
It's so violent  
And also normal. “It happens every time I leave the house”  
“I broke my body”  
It's really graphic  
“feeling overweight”  
Shame  
Feels really heavy.

That body is really small.  
That looks like the American medical model tbh  
(our DSM... is crap)  
the body used to respond in one way  
and now it responds in another.  
Comparing her body to theirs  
Almost as if they are on display?  
Maybe.  
Like when you look at your body  
(analyzing or scrutinizing each part)  
in little pieces,  
and pick each piece apart?  
Why are they positioned that way?

Internalized oppression.  
(There is so much there).  
Society has a huge hold on  
how we feel about ourselves and how we will function  
We live in a society that tells us  
to disconnect from our body,  
die  
and just ignore the needs and wants  
that our body presents to us.  
The body is the enemy





Transcendence ("respond better" to not eating)  
can only come from self-destruction  
sounds like icky language.

This also has the added layer that they are trans  
(They use "she" and "they" pronouns)  
Bette's trans identity also really plays into feeling dismembered  
(Princess Bride quote Bette noted)  
And in pieces,  
because their body does not fit the ideal trans androgynous body.

Were you doing anything to support them?  
The power of listening to a story and believing them  
Was there an intervention?  
The first time they told their story and were believed  
How do you care for yourself when swimming in all this pain?

("call and response" and "self-care")  
Themes of disconnection and then connection  
Heavy stuff but really impactful  
This is intense content,  
Hard to read and see  
Eye-opening  
Heartbreaking  
Thank you, Bette, for sharing.  
Feeling warm, feeling energy

In reality, it is not just Bette  
It is what they experience  
and others experience  
so its opening my mind  
A better language is just:  
thank you for acknowledging.

## Appendix I

### Informed Consent Document

# UNIVERSITY OF WASHINGTON CONSENT FORM EATING DISORDER AND REMISSION STUDY

**Principal Investigator:**

Erin Harrop, MSW  
Doctoral Student  
University of Washington  
School of Social Work  
206-708-5637  
erind2@uw.edu

**Faculty Advisors**

Taryn Lindhorst, PhD, LCSW  
University of Washington  
School of Social Work  
tarynlin@uw.edu  
Janell Mensinger, PhD  
Danae Dotollo, PhD  
Megan Moore, PhD

**Research Assistants:**

Elizabeth Dios, BA  
Maria Cortes, BA  
Sara Gorcos, BA  
Meredith Blumenthal, BA  
Vern Harner, MSW  
Janell Mensinger, PhD  
Rebecca Hutcheson, MSW  
Wesley Jones, BA  
Natalie Franz, BA  
Priyanka Ghosh  
Noahloni Garcia

**24-hour emergency telephone number: Erin Harrop, MSW, at 206-708-5637**

### RESEARCHER'S STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

### PURPOSE OF THE STUDY

Eating disorders come in all shapes and sizes. For this research study, we are interested in getting a better picture of the diversity of experiences with restrictive eating disorders. We are particularly interested in the experiences of women-identified persons who have experienced the following: significant caloric restriction with at least one of the following: 1) no weight loss or a limited amount of weight loss, 2) doctors who encouraged weight loss despite disordered eating behaviors, 3) body weight above the "cut off" for anorexia nervosa, 4) experienced symptoms of malnutrition without visible emaciation, or 5) having a diagnosis of "atypical anorexia." The purpose of this study is to better understand how women experience these disorders, how the disorders progress, and how remission occurs.

## STUDY PROCEDURES

This is a longitudinal research study, which means that we intend to assess study participants at multiple time points over the course of one year. This study involves three individual interviews (with an internet survey component), and four additional internet surveys. The three individual interviews will each occur six months apart, and the internet surveys will occur at each individual interview, with additional online surveys every two months. A timeline for the study schedule is shown in the table below:

<b>Timing of Appointment</b>	<b>Place of Appointment</b>	<b>Type of Appointment</b>	<b>Length of Appointment</b>
Baseline	In-Person or Online Interview	Consent, Interview and online survey	2-3 hours
2-month	Online	Online survey	30-60 min
4-month	Online	Online survey	30-60 min
6-month	In-Person or Online Interview	Interview and online survey	2 hours
8-month	Online	Online survey	30-60 min
10-month	Online	Online survey	30-60 min
12-month	In-Person or Online Interview	Interview and online survey	2 hours

Each individual interview will last approximately 1-2 hours. Interviews will be conducted in person if possible, though online platforms can be used if you are out of the area. During the interviews, I will ask you questions about the development of your eating disorder, your experiences with treatment and health providers, and your experiences with recovery, remission, and/or relapses. We will talk about disordered eating behaviors (dieting, food/fluid restriction, bingeing, laxative abuse, chewing/spitting, purging, excessive exercise, food/calorie obsession). We will also talk about your journey with your body, body image, weight, and self-acceptance (or lack thereof). Examples of questions that may be asked include: 1) Tell me about an experience with a health provider that did not go well, 2) How do you think your body size affected your experiences of medical care or eating disorder treatment? and 3) Recovery/remission means different things to different people; please tell me in your own words what recovery/remission means to you.

The interviews will be audio recorded and then transcribed (typed out). You will have the opportunity to review (and correct if desired) each of your interview transcripts. You will also have the option of requesting a copy of your interview transcripts for your own personal use. You can refuse to answer any questions. You can also withdraw from the study at any time.

Prior to each interview, you will receive an internet survey to complete, which takes 30-60 minutes, and includes measures of things such as depression, anxiety, eating habits, body image and attitudes, drug and alcohol use habits, and physical symptoms. Sample questions include: 1)

Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless? 2) On how many of the last 28 days have you been deliberately trying to limit the amount of food you eat to influence your shape or weight? 3) Over the last 2 weeks, how often have you been bothered by feeling nervous, anxious, or on edge? This survey will also ask you to self-identify your race, ethnicity, age, sex assigned at birth, gender, and sexual orientation, in addition to other demographic variables. You may refuse to answer any question.

When you receive the internet survey, you will also receive a prompt that asks you to draw (or otherwise create) something. No drawing or artistic experience is required, and there is no minimum amount of time that you must spend on this. You will be asked to bring this drawing to your in-person interview. During the in-person interviews, we will discuss your drawing and what it means to you. You will have the option of keeping your artwork; if you elect to keep your artwork, a Xerox copy or picture will be taken for study analysis.

Talking about weight can be triggering and uncomfortable, especially for eating disorder patients. For this reason, you will also be asked to sign a Release of Information so that the study may obtain the following information from your eating disorder treatment provider: 1) eating disorder diagnosis, and 2) weight history. No other information will be collected from medical records. As part of the baseline interview, we will ask you questions about your weight history (e.g. history of weight loss or gain, highest and lowest weights). We ask these questions because weight cycling and weight changes can be indicative of eating disorder symptoms and severity. You may refuse to answer any question. Additionally, as part of the baseline, 6-month, and 12-month in-person surveys, we will also take a height and weight measurement. We collect this information for group demographic purposes only. These measurements will be “blinded;” and study staff will not reveal these measurements to you. If you wish to know your height or weight measurements, please speak with your medical provider or eating disorder treatment professional at your next appointment.

### **RISKS, STRESS, OR DISCOMFORT**

There are no physical health risks to participating in this study. However, I will ask you questions that include sharing personal information. This could bring up feelings of discomfort, such as embarrassment or anxiety. If you would like to seek support services after the interview, you may contact the 24/7 crisis hotline at (800) 273-8255. The study Principal Investigator can also be reached at the number listed at the top of this consent form.

When interviews are transcribed, personal information such as names and places will be removed from the document. In interview transcripts, you will have the option of choosing a pseudonym, or if you prefer, the researcher will assign you a pseudonym. This pseudonym will be used in publications instead of your real name, to help ensure confidentiality. All of your data will be confidential and identified by the use of a study identification number (e.g. Participant 00012). You will also have the option of choosing to have your audio recording destroyed after the transcription process, or to have the recording retained in the researcher’s password-protected archive for future use in presentations.

## **ALTERNATIVES TO TAKING PART IN THIS STUDY**

Participation in this study is completely voluntary; you have the alternative not to participate or to end your participation at any time if you wish.

## **BENEFITS OF THE STUDY**

Individual participants may not experience any direct benefits from participating in this study. However, the process of telling one's story, reflecting on one's experience, and creating artistic representations may have a therapeutic impact or be enjoyable to participants. This study will also add to knowledge base of eating disorders and how people recover from eating disorders.

## **CONFIDENTIALITY OF RESEARCH INFORMATION**

All of the information you provide will be confidential. All interview transcripts will have names and places removed from the transcript so as to make the transcripts less identifiable. In research publications, pseudonyms (chosen either by you or the researcher), will be used when quoting from your transcript. However, audio recordings may still be identifiable by a participant's voice. For each individual interview, you will have the choice of whether or not the audio recording is destroyed after transcription, and whether or not you would like to receive a copy of the audio.

There are some limits to this confidentiality. If we learn that you intend to harm yourself or others, we must report that to the authorities, per Washington State law. Also, if any instances of child abuse or neglect or elder abuse are reported, these will also be reported, per standard mandated reporting laws. Additionally, government or university staff sometimes review studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk of harm.

## **RETURN OF INDIVIDUAL DATA AND RESULTS**

Each participant will be asked to review their interview transcripts and will have the opportunity to make any changes or corrections at that time. You may also request a copy of the audio-recording and/or transcript for your own personal use. If you choose to receive a copy of your audio recording, it is requested that you request permission from the researcher before sharing it in a public setting. Prior to any results being published, participants will also have the option of reviewing preliminary manuscripts to provide the researchers with feedback regarding their interpretations of the data. Participants who wish to participate in this way should indicate this on the informed consent signature page.

During the course of this study, you will take several tests which evaluate various mental health symptoms including anxiety, depression, suicidality, drug and/or alcohol abuse, and eating disorders. If your scores on any of these tests indicate that you may be experiencing distressing mental health symptoms (such as depression or anxiety), a researcher will follow up with you. You will receive a mailed letter and a follow-up phone call to inform you of any elevated scores, so that you can discuss these potential issues with your healthcare provider and mental health team. It is also possible to elect to not to be informed of any elevated test scores, if you would prefer. If you would prefer not to be informed of any elevated scores, please indicate this choice at the appropriate section of this informed consent document. Most people with eating disorders also have other mental health conditions, so it is expected that participants in this study will have elevated

scores on multiple tests. It is recommended that you follow up with a healthcare provider to receive more information and/or possible treatment.

### OTHER INFORMATION

You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled.

Participants will receive compensation for their participation in the form of Gift Cards. For in-person research interviews, participants will receive compensation at the conclusion of the interview. For online surveys, the participant will receive a mailed gift-card within two-weeks of completing the online survey. The schedule of compensation is outlined in the table below:

Timing of Appointment	Place of Appointment	Type of Appointment	Length of Appointment	Gift Card Amount
Baseline	In-Person or Online	Consent, Interview and online survey	2-3 hours	\$25
2-month	Online	Online survey	30-60 min	\$10
4-month	Online	Online survey	30-60 min	\$10
6-month	In-Person or Online	Interview and online survey	2 hours	\$25
8-month	Online	Online survey	30-60 min	\$10
10-month	Online	Online survey	30-60 min	\$10
12-month	In-Person or Online	Interview and online survey	2 hours	\$25

### RESEARCH-RELATED INJURY

It is important that you promptly tell the researchers if you believe that you have been harmed because of taking part in this study. You can tell the researcher in person or call her at the number(s) listed at the top of this form. This number is monitored 24 hours a day. Additionally, if you have questions, complaints or concerns about this study, you can contact Erin Harrop at 206-708-5637 or [erind2@uw.edu](mailto:erind2@uw.edu) or her faculty advisor, Taryn Lindhorst, at [tarynlin@uw.edu](mailto:tarynlin@uw.edu).

The UW does not normally provide compensation for harm except through its discretionary program for medical injury. However, the law may allow you to seek other compensation if the harm is the fault of the researchers. You do not waive any right to seek payment by signing this consent form.

### STATEMENT OF CONSENT

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Printed name of study staff obtaining consent

Signature

Date

### Consent Quiz

1. My participation in this study is completely voluntary, and I can choose to end my participation at any time.  
TRUE FALSE
2. This is a one-time study, and I will not be contacted by study staff following my participation in this interview.  
TRUE FALSE
3. As a participant in this study, I will be asked some sensitive questions about my eating habits, weight, body image, and mental health.  
TRUE FALSE
4. I have the right to refuse to answer any question asked of me in this study.  
TRUE FALSE
5. I will have measurements of my height and weight taken in this study, and I will be shown these measurements to measure my anxiety response.  
TRUE FALSE
6. I will receive copies of my interview transcripts and have the option of correcting them if I find a mistake, or wish to change my response.  
TRUE FALSE
7. If I have any elevated scores on screening measures (e.g. anxiety, depression, alcohol abuse), I can choose to be informed of this by mail and a phone call so that I can follow up with my healthcare provider.  
TRUE FALSE
8. Study staff will contact me twice a month to update contact information and answer any question about the study.  
TRUE FALSE

### **Participant's Statement**

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I have been harmed by participating in this study, I can contact one of the researchers listed on the first page of this consent form. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940. I give permission to the researchers to use my medical records as described in this consent form. I will receive a copy of this consent form.

---

Printed name of Participant	Signature of Participant	Date
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### **Permission to be Contacted for Future Studies**

If you agree that research staff may contact you for future study opportunities, please sign below. This permission may be revoked at any time.

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Printed name of Participant	Signature of Participant	Date
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### **Permission for Audio Recordings of Interviews to be Retained by Researcher**

If you agree that research staff may retain the audio-recordings of your interviews for use in future presentations, please sign below. This permission may be revoked at any time.

---

Printed name of Participant	Signature of Participant	Date
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### **Permission to be Contacted to Review Manuscripts Prior to Publication**

If you agree that research staff may contact you to review research manuscripts and provide feedback to the research team about these manuscripts prior to publication, please sign below. This permission may be revoked at any time.

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Printed name of Participant	Signature of Participant	Date
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### **Permission to Opt Out of Results-Reporting for Mental Health Symptom Tests**

Most people with eating disorders also have other mental health conditions (such as depression or anxiety). During the course of this study, you will take several tests which evaluate various mental health symptoms including: anxiety, depression, suicidality, drug and/or alcohol abuse, and eating disorders. Please initial your preference for whether or not you would like a researcher to follow up with you regarding your scores on any of these tests:

\_\_\_\_\_ Yes, I would like to be informed of elevated test results.

\_\_\_\_\_ No, I would NOT like to be informed of any elevated test results.

If you elect to be informed of elevated test results, you will receive a letter in the mail and a phone call from the Principal Investigator informing you of the result, and encouraging you to speak with your treatment team regarding additional information and possible treatment. This permission may be revoked at any time.

---

Printed name of Participant

Signature of Participant

Date

Copies to:     Researcher

                  Subject

## Appendix J

### Sample Pen Portrait

#### Medical Provider Interview Pen Portrait 34: Charlie (They/them)

Diagnostic and Symptom Timeline Produced by Researcher with 6-Month Interview Data:

Name	Symptom	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33
34 Charlie	Restriction																																	
	vomiting																																	
	exercise																																	
	bingeing																																	
	AN/AAN																																	
	BN/Sub BN																																	
	BED																																	
	PU																																	
	OSFED/UFED																																	
	Remission																																	

Participant Artwork in Response to 6-Month Interview Art Prompt:



#### Highest LOC: Outpatient

**Demographics:** nonbinary AFAB genderqueer, 32 years old, white, queer, primary partnered and open, professor, PhD, on financial aid as child

**Key Quote:** She would then ask, she would ask a lot of questions that indicated to me that she was thinking that I really consuming more than that, but telling her that I was consuming less than that, which more fed into the well maybe I'm counting them wrong

Patient 34 is an androgynous person AFAB with a short men's style haircut. They are wearing large clear glasses that remind me of glasses from the 60s. They have bushy eyebrows, short hair, clear skin, blueish appearing eyes, straight white small teeth, and a gender queer presentation. They are wearing a baggy V-necked t-shirt. They started their appointment on the phone after getting out of their therapist, and then transitioned to Zoom in their office at a college as a professor. Their office has plants around it, and a container of miracle grow. There is also a

framed piece of art with three drawings, one of a heart, one of lungs, and one of a skull. There is a stack of folders on the desk and several bottles of water.

Their diagnostic interview went smoothly despite the vast number of questions. They have kept multiple spreadsheets of their caloric intake, exercise, weight (with pictures at various weights) and so the data seems to flow readily as they have spent a lot of time thinking about these things. Their best quote ever during the interview summarizing their personality and experience: “Now I use my spreadsheeting abilities for good. But I honed those skills on weight loss.”

Their dog is also in the office and occasionally grunting, or whining; they report that the dog has a meet up club where students and staff volunteer to take the dog out on jaunts around campus. Several folks come by during the interview.

In general most of their medical experiences have been negative, and they tell me about a recent experience of going to the doctor for a severe flu, and being told instead to lose weight, and maybe that would cure the muscle weakness, joint pain, lack of energy, and fever. They have drawn this interaction in comic book style for their art for today.

Regarding negative experiences, they reported that the first time they had attempted to get ED treatment, they went to an “ED specialist” therapist who repeatedly tried to convince them that they really were eating more than they said they were and repeatedly doubted their level of reported restriction, resulting in patient increasing their “margin of error” in their spreadsheets to account for potential underestimation, which then resulted in even higher levels of restriction. They summarized their experiences with medical people saying they have had lots of negative experiences (providers insisting they be on birth control despite not having male partners; not telling them about other options, speaking to them as if they are stupid) and some neutral interactions, but no real positive or helpful ones—with the exception of one story (potentially classified as “neutral”) during which provider listened about not wanting to take birth control, and presented multiple other options.

Regarding positive experiences, they focused on their current therapist who has been very affirming in terms of their eating disorder, listened and believed them, and actually provided AN diagnosis, which they grudgingly eventually changed to AAN after some time. They reported that their therapist pushes back on patient, and sometimes does so in a joking or sarcastic way (occasionally swearing) and challenges the ED thoughts and behaviors. Their therapist is also good at being kind in the midst of hearing the illogical thoughts and helping patient sort through them. They also spoke of how challenging it was for their ED to adjust to having a much smaller partner, and how triggering it could be to compare their body sizes and food consumed.

They also mention that after getting one good provider who took their ED seriously, that set into motion a whole new way of them interacting with the healthcare system, where they started setting better boundaries with providers and insisting on getting good care (or not returning). The one provider who acknowledged their disorder broke through their denial, and that helped them start a new journey.

Regarding providers, they mentioned looking for providers of size or queer appearing, or providers who are just “different” and so might understand oppression from other lenses.

#### **Notable Themes:**

- **Seeking out queer or other marginalized provider bodies**
- **Liking it when providers push patient or challenge ED, tough on them**
- **Providers not believing levels of restriction**
- **Patient minimizing restriction**
- **Provider disbelief increasing patient distrust of self**

#### **Notable Quotes:**

34: one of my most formidable doctors experience... is realizing that I could actually have a doctor that I both trusted and was going to treat me like an intelligent and capable human that was able to make my own decisions.

34: I said “you have to be okay with the fact that I am fat and will still be fat. And, also you need to take the fact that I have these challenges with food and eating in restriction seriously.” And, she just looked at me and went “yeah okay, that is my job.”

34: I finally went back to the doctor, I went to the dentist, I've got a psychiatrist, I routinely went to my PCP... like normal routine healthcare... I feel comfortable enough to actually start doing the work in my own head and not feeling like I needed to be guarded around even the people who are supposed to be helping me, but I also... set my own boundaries around what I need

34: I felt weird to even want to be treated because I couldn't possibly have a problem because no one thought I had a problem.

34: She would ask a lot of questions that indicated to me that she was thinking that I really consuming more than that, but telling her that I was consuming less than that, which more fed into the “well maybe I'm counting them wrong?”

34: I just spent a lot of time not getting any treatment

34: I could have potentially been diagnosed really early on... I had like really deeply entrenched behaviors, and thoughts and coping mechanisms, and I could have lived a less stressful life.

34: she was asking me what I wanted my ideal body to look like... I told her “a brain in a jar”

34: [It's] the intersectionality of all of my identities. I also actively look for queer folk, or folk who are at least knowledgeable... because it's difficult to explain to somebody... that gender is a construct and sex isn't binary why I don't want to be on a birth control pill right now.

34: She also has forbidden me from saying “meat sack,” “flesh vessel,” “corpse carrier.” I have a long list of names that I have called my body... I now must choose something different...

## Legend for Colored Symptom and Diagnostic Timelines:

Symptom or Diagnosis	Low Intensity	Medium Intensity	High Intensity
Restriction		not marked	
Vomiting			
Exercise			
Bingeing		not marked	
Anorexia (AN/AAN)	Atypical Anorexia (AAN)		Anorexia Nervosa (AN)
Bulimia (BN/SubB)N	Subthreshold Bulimia Nervosa (SubBN)		Bulimia Nervosa (BN)
Binge Eating (SubBED/BED)	Subthreshold Binge Eating Disorder (SubBED)		Binge Eating Disorder (BED)
Purging Disorder (PD)	Purging Disorder (PD)		
Other Specified Feeding or Eating Disorder (OSFED)	Other Specified Feeding or Eating Disorder (OSFED)		
Remission (Partial or Full)	Partial Remission		Full Remission

### Themes (T) with Evidence (E) and Representative Artwork

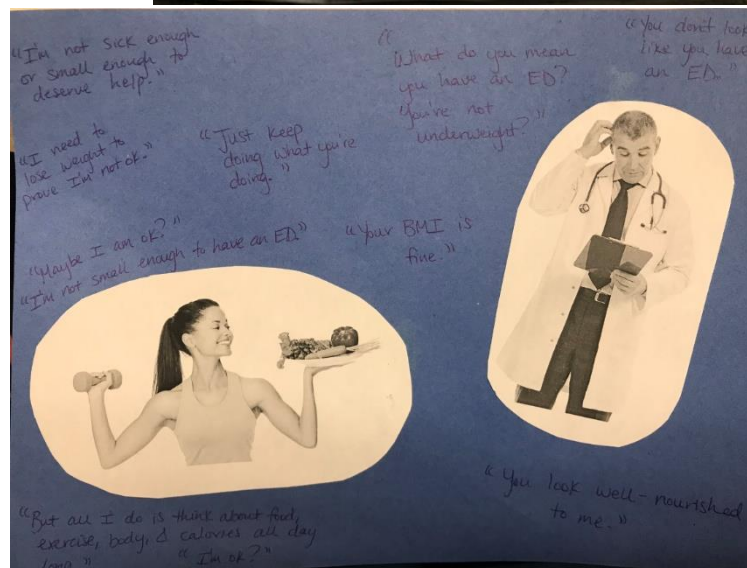
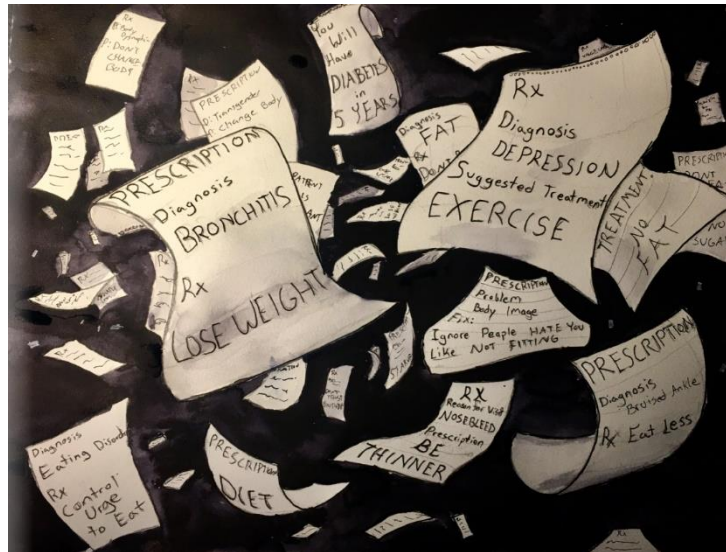
### Illness Time Period: ED Develop- ment

## T1: Physician Pathologizing Body and Weight

## T2: Compounding Messaging from Family and Medical Community

### T3: Recommending Weight Loss

#### T4: Pediatrician/MD Triggered ED



## Illness Time Period: ED Pre-Treatment (T: Themes, E: Evidence)

### **T1: Provider Encouraging or Congratulating ED Behaviors**

- E1: Recommendations for Weight Loss
- E2: Provider Congratulating Weight Loss
- E3: Provider Entrenched or Encouraged ED

### **T2: Provider Not Noticing ED**

- E1: "You Don't Look Anorexic"
- E2: "You Look Fine/Healthy/Okay to me."
- E3: Invisible or "Under the Radar"

### **T3: Missed Screening Opportunities**

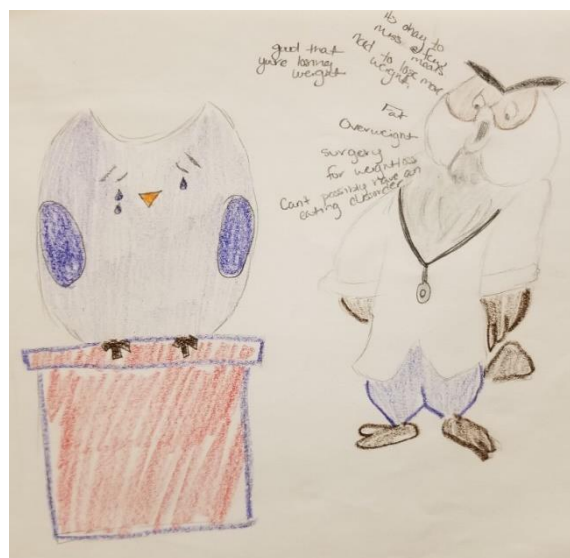
- E1: "No One Asked"
- E2: Missed Physical Symptoms  
*Rapid Weight Loss, Amenorrhea, Electrolyte Problems, Lanugo, Heart rate, Blood Pressure, Orthostasis, Other Signs of Starvation*
- E3: Missed Physical Screenings or Labs

### **T4: Provider Discount or Minimize ED**

- E1: Told MD about ED and MD Ignored
- E2: Provider Discount or Deny ED
- E3: Provider Minimized ED, No Referral

### **T5: Delayed Care**

- E1: Delayed Care or Prolonged Illness Trajectory
- E2: "I Can't Help You"
- E3: Not Receiving Care





## Illness Time Period: In Treatment (T: Themes, E: Evidence)

### **T1: Provider Encouraged ED**

### **T2: Provider Minimizing or Denying ED**

E1: "You Don't Look Anorexic"

E2: "You're Not Sick Enough"

E3: Provider Didn't Take ED Seriously

### **T3: Misdiagnosis and Missed Symptoms**

E1: Incorrect Diagnosis

E2: Missed Physical Symptoms in Treatment

### **T4: Weight Stigma in Higher Levels of Care**

E1: Treated Differently Based on Size

E2: Inadequate Nutritional Care

*Not Enough Direction for Nutritional Rehabilitation, Low Meal Plans or Underfed in Treatment, Low Goal Weights*

E3: Unhelpful Treatment or Interventions

E4: Fat-Shaming in the Milieu

E5: ED Provider Issues

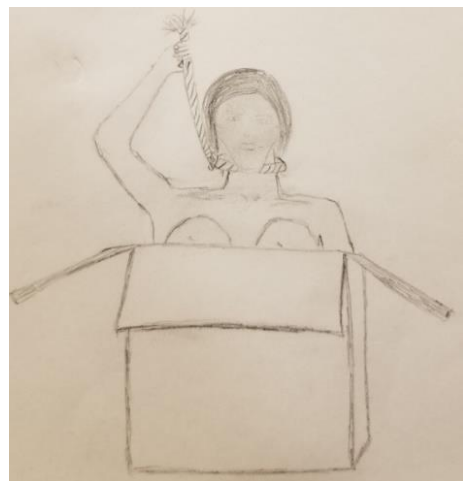
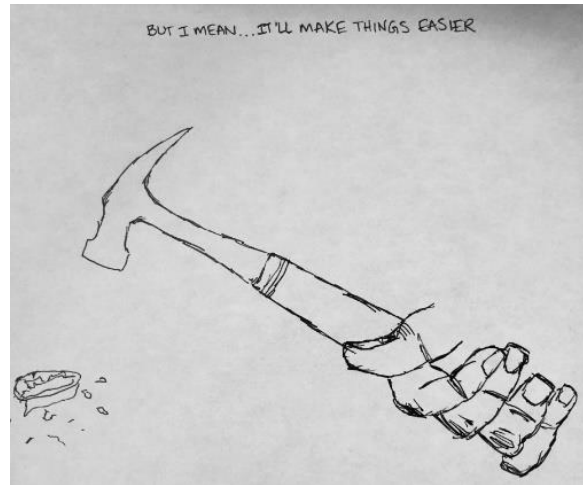
*Thin Providers, Provider ED Behaviors, Providers not Respond to Advocacy*

### **T5: Systemic Issues of Weight Bias**

E1: Can't Afford Treatment

E2: Insurance Cutting Off

E3: Lack of Provider Education on Large Bodies





## Illness Time Period: Relapse Prevention (T: Themes, E: Evidence)

### **T1: Providers Not Acknowledging ED**

E1: Provider Not Believing ED

E2: Provider Assuming ED is in the Past

### **T2: Weight/Weight Loss-Focused Care or Embodying EDs**

E1: Recommending Weight Loss

E2: Provider Recommended Weight Loss Surgery

E3: Provider Embodying the ED

E4: Weighing Practices and Stigma

### **T3: Poor Treatment of Fat Patients**

E1: Not Treated as a Person

E2: Provider Assumptions about Fat People

E3: Provider Blames Weight for Health Problems

E4: Lack of Provider Education on Large Bodies

### **T4: Overt Weight Discrimination and Abuse**

E1: Overt Stigma and Abuse

E2: Provider Repulsed or Not Touching Patient

E3: Denied Medical Care Based on Weight

E4: Over-Medicalization Due to Weight

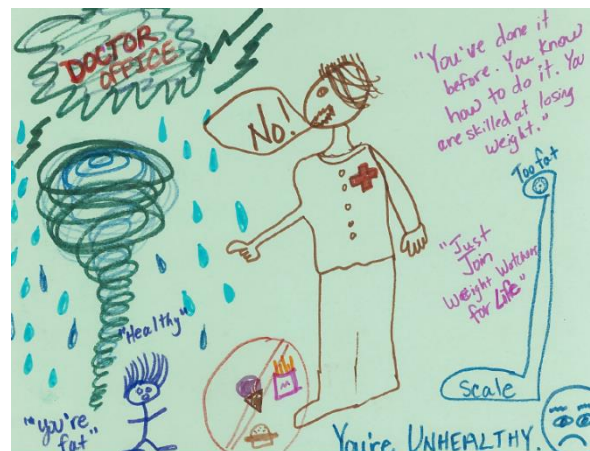
### **T5: Systemic Healthcare Issues**

E1: Systemic Healthcare Issues

E2: World Does Not Fit Fat People

E3: Intersectional issues

E4: Interpersonal Weight Discrimination



Appendix L  
Data Dictionary and Data Cleaning/Validation

\*Main variables used in analysis demarked with an asterisk

**ID:** Study ID

**DemPseudonym:** Either participant chose (if desired) or researcher chose (if desired): *“Desired pseudonym for study materials.”*

**\*DemAgeBL:** BL age measure

**DemGender:** Gender at 12m, as some genders changed during study; *“Please identify (in whatever words you choose) your gender here.”* Additionally, this data was combined with questions “Gender” and “Sex assigned at birth” from baseline. **Anything not "male or female" was coded as trans/nonbinary (e.g. nonbinary, female leaning)**

**\*DemGenderCode:** coded 1 for cis female, 2 for nonbinary assigned female at birth, coded 3 for trans female

**\*DemGenderCode01:** coded 1=cis female, 2=nonbinary assigned female at birth or trans female

**DemSexAABCode:** sex assigned at birth code; coded 1 for female, 2 for male

**DemSexAAB:** from BL survey; *sex assigned at birth*

**\*DemRace:** *Race* at BL measure and screening measure

**\*DemRaceWhiteOnly:** coded 1 = only non-Hispanic white; coded 0 for other race and ethnicity

**DemEthnicity:** *ethnicity* at BL

**\*DemSexOrient:** Sexual orientation at 12m as some changed during study; *“Please identify (in whatever words you choose) your sexual orientation here.”*

**\*DemHetero:** coded from DemSexOrient; 1 for heterosexual, 0 for anything else

**DemRelOrient:** relationship orientation at 12m as this was only time point asked; *“Please identify (in whatever words you choose) your relationship orientation (e.g. monogamous, poly-amorous, etc.) here.”*

**DemEmployStatus:** Baseline *“Employment status (full time, part time, unemployed, on leave)”*

**DemOccup:** Baseline occupation; *“Current occupation”*

**DemHighEdu:** baseline highest education; *“highest education received”*

**DemFinAidChild:** Baseline financial assistance as child; *“Growing up, was your household eligible for any governmental assistance (WIC, Medicaid, SSI, free/reduced lunches, etc.)?”*; operationalized this to a binary 0,1 variable

**DemFinAidType:** [currently not included] BL *“If your family was eligible for assistance growing up, what kind of assistance did you receive?”*

**WtHeightBL:** height at baseline; clinician recorded for all participants where this was possible; self-report on EDE-Q for out of area or patients who refused height and weight.

**WtWeightBL:** weight at baseline; clinician recorded for all participants where this was possible; self report on EDE-Q for out of area or patients who refused height and weight.

**\*WtBMIBL:** BMI at baseline; BMI at baseline; was calculated via online CDC BMI calculator entering participant height and weight as describe above.

**WtHeightLifeMaxBMI:** Height at lifetime max BMI: For this variable, I looked across highest reported BMI, including the BL question for highest weight/height (*What is your highest past adult height in inches?*), and all study EDE reports or clinician measures of height across the study. If a weight was higher, but BMI was lower (height changes), went with the height at the *highest BMI*. If it was unclear what the height was during that weight period, referred to diagnostic checklist for self-report of height during that time period. All heights in inches.

**WtWeightLifeMaxBMI:** Weight at lifetime max BMI: for this variable, I looked across highest reported BMI, including the BL question for highest weight (*What is your highest past adult (non-pregnant) weight in pounds?*), and all study EDE reports or clinician measures of weight across study. If a weight was higher, but BMI was lower (height changes), went with the weight at the *highest BMI*. If unclear, referred to diagnostic checklist for self-report of weight. All weights in pounds. Validated against BL question on qualitative descriptions of weight shifts.

**\*WtLifeMaxBMI:** Lifetime max BMI; for this variable, I looked across highest reported BMI, including the BL question for highest weight, and all study EDE reports or clinician measures of weight and height. If a weight was higher, but BMI was lower (height changes), went with the *highest BMI*. For one participant (31), lifetime max BMI was at age 17; all others over 18.

**WtAgeLifeMaxBMI:** Age of lifetime max BMI: if max occurred during study, recorded study time point, so that age can be calculated later. All ages in years, unless study time point is identified in which case the following abbreviations were used: BL: baseline, 2m: 2 month, 4m: 4 month, 6m: 6 month, 8m: 8 month, 10m: 10 month, 12m: 12 month.

**WtWeightLifeMinBMI:** Weight at lifetime minimum BMI: *What was the lowest weight in pounds that you reached in your eating disorder?* Checked this against diagnostic interview and second question: What is the lowest weight in pounds that you have reached as an adult? In case low weight was not low BMI due to height changes. Entered the weight at the lowest BMI reached in ED, including adolescent. Also validated against BL question on qualitative descriptions of weight shifts.

**WtAgeLifeMinBMI:** Age at lifetime minimum BMI: *How old were you (in years) when you reached this weight?* Corrected age if low BMI was different from low weight.

**WtHeightLifeMinBMI:** Height at lifetime minimum BMI: entered using diagnostic interview as this was not asked in weight history questionnaire. Entered in inches.

**\*WtLifeMinBMI:** Lifetime minimum BMI: Checked this against diagnostic interview and all time points of EDE. Checked other weights in case low weight entered in low weight question was not lowest BMI due to height changes. Entered the weight at the lowest BMI reached in ED. Included lowest BMI if in adolescent years.

**WtWtLifeMinBMIAdult:** Weight at lowest lifetime adult BMI: *What is the lowest weight in pounds that you have reached as an adult?* Checked against diagnostic interview and all EDEs. Checked other weights in case low weight entered in low weight question was not lowest BMI due to height changes. Entered the weight at the lowest BMI reached in ED over age 18.

**WtHtLifeMinBMIAdult:** Height at lowest lifetime adult BMI: entered using diagnostic interview as this was not asked in weight questionnaire. Entered in inches.

**\*WtLifeMinBMIAdult:** Lifetime Minimum adult BMI: Checked this against diagnostic interview and all time points of EDE. Checked other weights in case low weight entered in low weight question was not lowest BMI due to height changes. Entered the weight at the lowest BMI reached in ED while over age 18.

**WtAgeLifeMinBMIAdult:** Age at lowest lifetime adult BMI: *How old were you in years when you reached this weight?*

**\*WtLifeBMI185:** Lifetime BMI<18.5: coded 0, 1. Coded 1 if participant ever had a lifetime BMI equal to 18.5 or less, including adolescent.

**\*WtLifeBMI19:** Lifetime BMI<19: coded 0,1. Coded 1 if participant had ever had a lifetime BMI equal to 19 or less. Included if adolescent or adult.

**WtLifeMinBMIAdoPerc: Percentile:** Notes variable for me to keep notes for percentiles of adolescents with low weight, according to CDC calculator.

**\*WtLifeUnderWt: Lifetime underweight:** Coded 0,1. Coded 1 if BMI was ever equal to 18.5 or less while an adult *or if percentile considered underweight* as a teen. E.g. Participants did not receive a 1 code if BMI was less than 18.5 as an adolescent, but this BMI percentile was not considered underweight for their age.

**\*WtLifeBMISupp:** Lifetime BMI suppression: lifetime maximum BMI – Lifetime minimum BMI (including ado)

**\*WtLifeBMISuppAdult:** Lifetime BMI suppression adult: lifetime maximum BMI – Lifetime minimum adult BMI (including ado)

**WtIdealWt12m:** Ideal weight: taken from 12m survey (only asked then): “In an ideal world, what is your desired body weight (in pounds)?”

**\*WtLifeLgWtLoss: Lifetime largest weight loss:** “*What is the largest amount of weight (in pounds) you have lost in your lifetime?*” If people entered a range (e.g. 60-70 lbs.), took the average of the two numbers (e.g. 65). Variable from the 12mfu. Validated against BL question requesting participants to report any major weight shifts. Also compared first large weight loss with second large weight loss to make sure largest weight was largest percentage of weight lost. If needed validated against participant transcripts and diagnostic interview.

**WtWtPriorLgLoss:** weight prior to the largest weight loss; calculated by taking largest lifetime loss plus weight after largest loss

**\*WtLgstWtLossPercent:** calculated by taking lifetime largest weight loss divided by WtPriorLgLoss, multiplied by 100 to get percentage

**AgeLgWtLoss:** “*How old were you (in years) when this weight loss occurred?*”

**WtWtAfterLgLoss:** weight after largest weight loss: 12mfu; “*After this weight loss, how much did you weigh in pounds (e.g. what was your low weight after this weight loss)?*” If range was presented, validated it against age and weight from minimum weight (in case this was lifetime minimum weight). If it was a different age reported, took the average of the range (e.g. 115-120 became 117.5) Validated against BL question requesting participants to report any major weight

shifts. Also compared first large weight loss with second large weight loss to make sure largest weight was *largest percentage* of weight lost. Consulted with participants if data were unclear or conflicting

**WtMonthsLgWtLoss:** This variable got murky and I don't know how useful it will be. If range of months was entered (e.g. 3-4 months), took the mean of the two numbers (e.g. 3.5). I don't know what to do for participants where I ended up entering ages (22-24yo). Mostly planning on leaving this variable alone for the time being. For some "*How many months did it take you to lose this amount of weight?*"

**\*TxAgeThotHadED:** Age thought had ED; baseline measure: "At what age did you first think that you might have a problem with an eating disorder?" If answers were words instead of numbers, this was collaborated with their BL and 6m interviews to identify age. If two ages were given (e.g. 18-19), the younger of the two ages was chosen. If a participant provided a very young age (eg. Age 5 or 6), I did a validity check with the qualitative interview. This was validated with 6-month interview: "At what age did you think you had an eating disorder? (If prompt is needed) or think that what you were doing to try to control your weight was unhealthy?" If these ages were close, went with baseline. If these answers were not close, examined BL interview and 6-month interview to see if patient identified age in transcript of when they thought they had a problem. If additional clarification was needed, emailed participants for clarification; if still unclear, went with baseline as that was the original most straight forward question.

**\*TxAgeEDTx:** Age of ED treatment: Baseline question: "At what age did you first get specialized eating disorder treatment?" If patient received treatment after starting the study, entered the age they got treatment following the study. Compared ages from baseline to 6m diagnostic interview question: "At what age did you get eating disorder specific treatment?" If there was a discrepancy between the ages, went through BL, 6-m, and 12-m interviews to get clarification on treatment. If it was still unclear, contacted participant if able. If participant reported only several sessions without any ongoing treatment for an ED, this was not counted as "any treatment". Things that did NOT count as treatment: LESS THAN 4 SESSIONS, 12-step groups, peer led support groups, podcasts, online support, therapy for other mental health concerns with brief mentions of EDs but not ED specific treatment, RD appointments that were not with ED specialist providers or that did not target ED behaviors, regular medical care that did not directly address eating disorder, Be Nourished retreats. Things that did count as treatment: outpatient therapy for ED, outpatient nutrition appointments for an ED, IOP, PHP, inpatient, residential, outpatient ED support group led by a provider.

**TxTxAnySessAtBL:** At BL, any treatment prior to study. I made the variable based on treatment variable from baseline, coded as 0,1 with ANY ED treatment (regardless of number of sessions) counting as 1. This did not include those who acquired treatment in the course of the study. Coded 0,1 with 1 representing those who had any treatment prior to BL.

**\*TxTxAtBL:** At BL, any treatment prior to study BEYOND several sessions. I made this variable based on variable coded from baseline. This did not include those who acquired treatment in the course of the study and did not include those who only had a few sessions with an ED provider, but no ongoing treatment. Coded 0,1 with 1 representing those who had treatment prior to BL that went beyond several sessions.

**TxFIRSTEDTxStudy:** Acquired first time ED specific treatment in the course of the study. I made this variable based on treatment variables mentioned above. Coded 1, 0 with 1 representing those who had ED treatment for the first time in the course of the study.

**\*TxTxDelay: Treatment delay:** age got treatment-age thought had an ED; or “never”. 11 people had never had treatment at start of study; including all participants with treatment (including 2 who got tx during study). range of 0 to 42 years treatment delay, mean 11.7, SD 11.12.

**\*TxTxDelayBL: Treatment delay:** age got treatment-age thought had an eating disorder; or “never”. 11 people had never had treatment at start of study. Including only participants with treatment at baseline, range of 0 to 42 years treatment delay.

**\*TxEDOP: ED OP:** Coded 0,1 based on 6m interview treatment received data. 1= patient received eating disorder specific outpatient therapy or nutritional therapy with therapist or dietitian. 77% had received OP; 72% at start of study (two got OP during study for the first time)

**\*TxEDOPGroup: ED Group:** Coded 0,1 based on 6m interview treatment received data. Coded 1 if patient attended an eating disorder support group that was facilitated by a professional. 51% had received Group OP treatment.

**\*TxEDIOP:** Coded 0,1 based on 6m interview treatment received data. Coded 1 if patient attended intensive outpatient program. 41% had received IOP treatment.

**\*TxEDPHP:** Coded 0,1 based on 6m interview treatment received data. Coded 1 if patient attended partial hospitalization program. 33% had received PHP treatment.

**\*TxEDIPRes:** Coded 0,1 based on 6m interview treatment received data. Coded 1 if patient attended an inpatient hospital program for an eating disorder or if attended residential for an eating disorder. Did not code 1 if patient attended general psychiatric inpatient unit without emphasis on eating disorder (e.g. if inpatient psych was for suicidal ideation, psychosis, or other concerns). 31% had received IP/Res treatment.

**TxHAESTx:** Coded 0,1 based on 6m interview treatment received data. Code 1 if patient had ever received HAES-based treatment. Did not code 1 if HAES “treatment” was through a Be Nourished retreat, or if HAES familiarity was through podcasts, personal reading, etc. 62% had received HAES treatment.

**TxHAESBeNour:** HAES ONLY Be Nourished: Coded this if the only HAES “treatment” an individual received was through Be Nourished retreats, as this was not considered treatment, but these individuals would be well-familiar with HAES.

An additional 8% had not received HAES treatment but had attended a Be Nourished Retreat.

**\*TxHighestLOC:** Highest level of care received: coded as the following: 0 = no treatment or less than 4 sessions, 1 = outpatient or outpatient group therapy, 2 = IOP, 3 = PHP, 4 = IP/Res.

Including those who started treatment during study (as treatment) 9/39 had no treatment, 13/39 highest LOC was OP, 3/39 highest LOC was IOP, 2/39 highest LOC was PHP, and 12/39 highest LOC was IP/res.

**\*TxHighestLOCBL:** Highest level of care Received prior to BL: coded based on the following: 0 = no treatment or less than 4 sessions, 1 = outpatient or outpatient group therapy, 2 = IOP, 3 = PHP, 4 = IP/Res. Coded this variable so that the two participants who got treatment during the course of the study would be reflected as untreated at start of study.

At the start of the study 11/39 had no treatment, 11/39 highest LOC was OP, 3/39 highest LOC was IOP, 2/39 highest LOC was PHP, and 12/39 highest LOC was IP/res.

**\*EDEQRestBL:** EDEQ subscale for Eating Restraint of EDEQ at baseline: summed EDEQ items 1, 2, 3, 4, 5 and took the average. Mean 1.57; SD 1.70.

**\*EDEQEatConcBL:** EDEQ subscale for Eating Concern of EDEQ at baseline: summed EDEQ items 7, 9, 19, 20, 21 and took the average. Mean 2.02; SD 1.47.

**\*EDEQShapeBL:** EDEQ subscale for Shape Concern of EDEQ at baseline: summed EDEQ items 6, 8, 10, 11, 23, 26, 27, 28 and took the average. Mean 4.02; SD 1.61.

**\*EDEQWeightBL:** EDEQ subscale for Weight Concern of EDEQ at baseline: summed EDEQ items 8, 12, 22, 24, 25 and took the average. Mean 4.05; SD 1.36.

**\*EDEQGlobalBL:** EDEQ Global Score at baseline interview, summed 4 EDEQ subscales and took the average. Mean 2.92; SD 1.29.

**\*CIAGlobalBL:** Global CIA score at BL calculated by taking sum of items (all scored 0,1,2,3) and adding them with higher scores indicating more impairment, and scores over 16 generally most predictive of ED status. Mean 20.92; SD 10.83

**\*CIABL160ver:** Coded 0,1 based on CIA global BL score; if participant scored 16 or higher, received 1 as code. If scored under 16, received 0 code. 64% CIA over clinical cut off of 16.

**\*WBISGlobalBL:** Global score of WBIS; taken by eliminating first item (per Hilbert & Colleagues), reverse score item 9, and take the average of all items. Mean 5.11; SD 1.39.

**\*TIPSGlobalMD:** all items scored 1,2,3,4,5 with 6 indicating refusal. Items 1, 5, 7, 11 reverse scored. To calculate total score, transform to 0-100 scale by taking sum of times, and multiplying by 1.818. Then scores represent a score from 0 to 100 with lower scores representing lower satisfaction. Mean 63.99; SD 18.09.

**EDEQRest6m:** EDEQ subscale for Eating Restraint of EDEQ at 6-month interview: summed EDEQ items 1, 2, 3, 4, 5 and took the average.

**EDEQEatConc6m:** EDEQ subscale for Eating Concern of EDEQ at 6-month interview: summed EDEQ items 7, 9, 19, 20, 21 and took the average.

**EDEQShape6m:** EDEQ subscale for Shape Concern of EDEQ at 6-month interview: summed EDEQ items 6,8,10,11, 23, 26, 27, 28 and took the average.

**EDEQWeight6m:** EDEQ subscale for Weight Concern of EDEQ at 6-month interview: summed EDEQ items 8, 12, 22, 24, 25 and took the average.

**EDEQGlobal6m:** EDEQ Global Score at 6-month interview, summed 4 EDEQ subscales and took the average.

**WtLifeLgWtLossAAN:** Lifetime largest weight loss during AAN: calculated this based on the 12m question: *“What is the largest amount of weight (in pounds) you have lost in your lifetime?”* Also examined the question about the second largest amount on the 12mfu. If neither large period of weight loss was during a period of AAN, calculated by looking at diagnostic timelines and baseline question asking about weight shifts (and validated against BL interview and BL question regarding weight shifts).



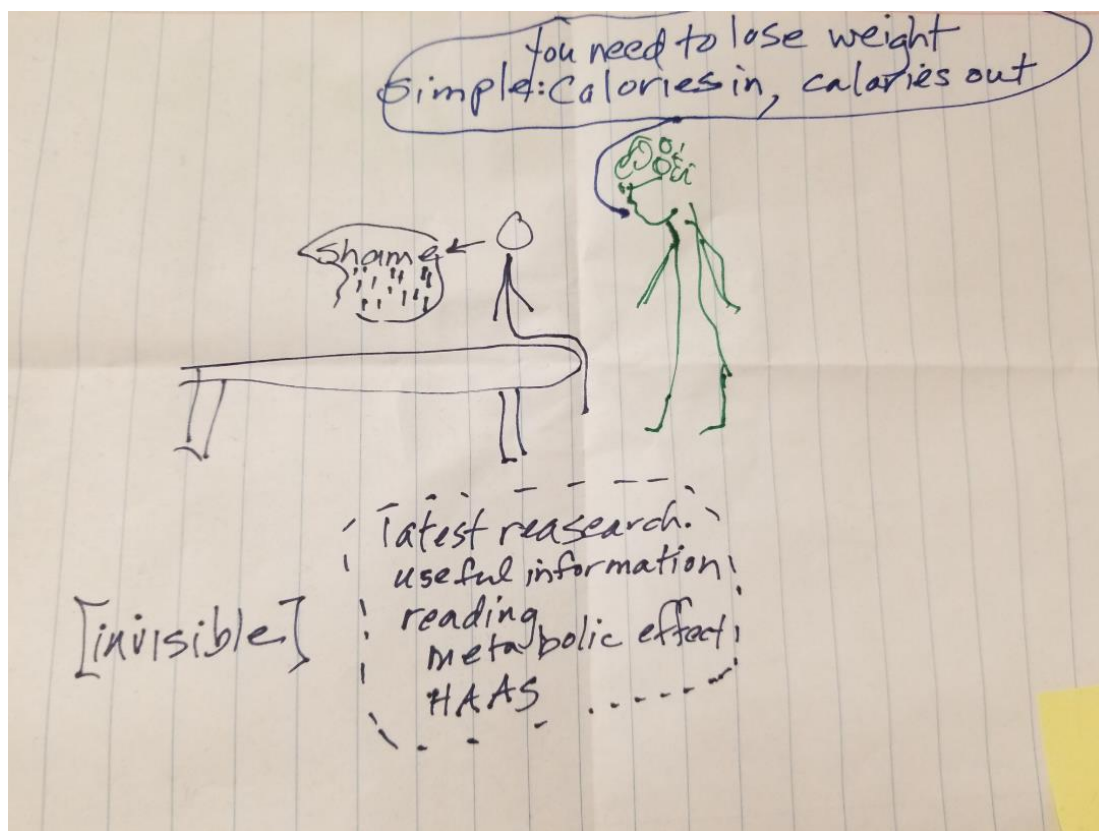
**WtWtPriorLgLossAAN:** weight prior to the largest weight loss during period of AAN; calculated by taking largest lifetime loss plus weight after largest loss.

**WtLgstWtLossPercentAAN:** calculated by taking lifetime largest weight loss (during AAN) divided by WtPriorLgLossAAN, multiplied by 100 to get percentage.

**AgeLgWtLossAAN:** “How old were you (in years) when this weight loss occurred?” or, took from baseline question on weight shifts. Or took from diagnostic interview.

**WtWtAfterLgLossAAN:** weight after largest weight loss during period of AAN: 12mfu; “After this weight loss, how much did you weigh in pounds (e.g. what was your low weight after this weight loss)?” If range was presented, validated it against age and weight from minimum weight (in case this was lifetime minimum weight). If it was a different age reported, took the average of the range (eg. 115-120 became 117.5) Validated against BL question requesting participants to report any major weight shifts. Also compared first large weight loss with second large weight loss to make sure largest weight was *largest percentage* of weight lost. Consulted with participants if data were unclear or conflicting.

**WtMonthsLgWtLossAAN:** Months took for large weight loss to occur during AAN: This variable got murky and I don’t know how useful it will be. If range of months was entered (e.g. 3-4 months), took the mean of the two numbers (eg. 3.5). Don’t know what to do for participants where I ended up entering ages (22-24yo). Mostly planning on leaving this variable alone for the time being. For some “How many months did it take you to lose this amount of weight?”



Artwork by Arati, Participant 16



## GLOSSARY

**17-Hydroxyprogesterone (17OHP):** 17OHP is a hormone produced by the adrenal glands leading to the production of cortisol. Endocrine functioning is often impacted in EDs, including 17OHP.

**A Priori:** A type of qualitative code developed prior to data coding, usually based on a theory or hypothesis, or preconceived idea about the data. A priori codes are contrasted with *inductive* codes, which arise from the data (rather than being generated prior to coding).

**Acute Medical Complications of Eating Disorders:** Acute medical complications of EDs are those that are considered life-threatening and generally include such things as: electrolyte imbalance, bradycardia, prolonged QTc interval, orthostasis, and Refeeding Syndrome.

**Adherence:** Adherence refers to how well patients follow directions prescribed by healthcare providers. Often adherence is used in a pejorative sense wherein patients “struggle with adherence.” This language is often used from a provider’s perspective as the extent to which patients “listen and obey.” This language is similar to provider language around compliance and noncompliance.

**Aftercare:** Aftercare refers to treatment of a reduced intensity for an ED following a higher intensity of treatment. For instance, if an individual experiences severe symptoms and attends a higher level of care (inpatient, partial hospitalization, or intensive outpatient), and later steps down to outpatient care, seeing a therapist and dietician once per week, this outpatient care would be referred to as “aftercare”

**Alcohol Use Disorders Identification Test (AUDIT):** A scale developed by Saunders, Aasland, Babor, de la Fuente, and Grant (1993), designed to screen for and detect alcohol use disorders of varying degrees of severity across a lifetime. For women an AUDIT score of 6 or more is highly indicative of a likely alcohol use disorder at some point during the lifetime.

**Amenorrhea, Amenorrheic:** The loss of one’s menstrual cycle. If a young person with a uterus has not started menstruation by age 16, this is considered primary amenorrhea. Loss of menstruation following initiation of menstruation is considered secondary amenorrhea. Individuals with EDs often experience amenorrhea, particularly if they restrict intake. Amenorrhea has been linked with multiple long-term consequences for EDs, including BMD loss. In addition to measuring amenorrhea, studies measuring menstruation effects of EDs often measure menstrual irregularity, which may indicate less severe disruption of reproductive hormones. Menstruation can also be altered by hormonal administration, such as oral contraceptive pills, in which case the effect of the ED cannot be assessed. It should be noted that people with testicles experience similar suppression of reproductive hormones, which can manifest as symptoms such as lack of libido, often indicating disruptions in hormones in growing severity (though not as severe as amenorrhea).

**American Psychological Association (APA):** The governing body of psychologists who determine criteria for various psychological disorders, collective author of the DSMs.

**Anorexia Nervosa (AN):** An eating disorder diagnosis assigned to individuals who: A) restrict energy intake leading to significantly low body weight, that is “less than minimally normal” or “less than that minimally expected,” B) have intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain, and C) experience 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 persistent lack of recognition of the seriousness of the current low body weight" (APA, 2013, pp. 338-339).

**Anorexia Nervosa, Binge/Purge Subtype (ANbp).** A DSM subtype of AN wherein individuals either engage in bingeing and purging (in addition to restriction) or engage in purging in the absence of binges (sometimes denoted AN-P).

**Anorexia Nervosa, Restrictive Subtype (ANr):** A DSM subtype of AN wherein individuals do not engage in bingeing or purging; sometimes encompassing individuals who engage in restriction and compulsive exercise.

**Anorexic Behaviors:** AN behaviors encapsulate behaviors typically ascribed to individuals with AN, including: caloric restriction, calorie counting, body checking, body measuring, repeated weighing body or food, food rituals, compulsive movement, compulsive exercise, eliminating foods from ones diet, and fasting.

**Anorexic Cognitions:** AN cognitions encapsulate cognitions typically ascribed to individuals with AN, including: fearing food or calories, fearing fat, body image distortions, inflexible thinking, black and white thinking, thoughts of self-blame, obsessive thoughts about food, weight, and body, negative thinking directed towards the self, thoughts of self-harm and suicide, and a "harsh voice of the ED" that tells them to engage in ED behaviors and derides them when they fail.

**Arrhythmias:** Potentially dangerous irregular heart rhythms. In the context of EDs, arrhythmias can occur for a variety of reasons including atrophy of the heart muscle from starvation, electrolyte imbalance, dehydration, prolonged QTc interval, and autonomic instability.

**Art Prompt:** In the WINTER Study, participants were given brief art prompts two weeks prior to each interview as a way of priming them for the interview and creating visual data for analysis alongside the interview data.

**Assigned Female At Birth (AFAB):** Refers to the gender assigned to individuals at birth, usually based on external genitalia.

**Atypical Anorexia Nervosa (AAN):** A category of OSFED in the DSM-5, defined as: "All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual's weight is within or above the normal range" (APA, 2013, p. 353).

**Atypical Eating Disorders:** Atypical EDs are EDs which do not neatly fit into a given category of the DSM, also called residual EDs, or those which fit into the OSFED or EDNOS categories. AAN is considered an atypical ED, because individuals with AAN almost meet criteria for AN, but they are "atypical" for AN in that their weight is not considered low enough. The word "atypical" has been criticized by ED advocates as appearing to minimize or dismiss the significance of these common, dangerous EDs.

**Avoidant or Restrictive Food Intake Disorder (ARFID).** An ED characterized by avoidance and restriction of food, not primarily influenced by body image disturbance, characterized instead by lack of interest in food, avoidance due to sensory characteristics, and concern about aversive consequences of eating.

**Bariatric Sample:** At times in ED literature, this refers to samples of individuals who have all had bariatric surgery. At other times in ED literature, this refers to samples of individuals who would be eligible for bariatric surgery, but have not yet had surgery; in some cases, “bariatric” replaces the word “obese” referring to individuals with BMIs over 30.

**Beats Per Minute (bpm):** A count of the number of heartbeats that occur in one minute. Pulse rate and heart rate are reported in bpm. Orthostatic heart rate changes are expressed in the “bpm difference” between supine (lying down) and standing heart rate.

**Binge Eating Disorder (BED):** An ED characterized by binge eating in the absence of compensatory behaviors. Binge eating must occur at least once per week for three months, and to qualify as a binge, the eating episode must 1) occur within a distinct period of time, 2) involve an amount of food “definitely larger than what most people would eat in a similar period of time,” 3) involve a sense of “lack of control over eating,” and 4) be associated with marked distress (APA, 2013, p. 350).

**Blood Pressure (BP):** A measure of how hard the heart must work to pump blood throughout the body. Blood pressure is reported as two measures (systolic pressure/diastolic pressure). Systolic pressure refers to the amount of pressure in the arteries when the heart contracts; diastolic refers to the amount of pressure in the arteries when the heart muscle relaxes between heart beats. EDs can be associated with blood pressures that are too high (hypertension), too low (hypotension), or not regulated consistently in homeostasis (orthostatic blood pressure change).

**Body Appreciation Scale (BAS):** A scale developed by Avalos, Tylka, and Wood-Barcalow (2005) to reflect a person’s degree of positive body image (as opposed to negative body image).

**Body Checking:** Body checking encapsulates a variety of repetitive rituals in which individuals with EDs often engage, such as frequently weighing, measuring, pinching, mirror-checking, or examining oneself.

**Body Distortion:** Body distortion is a phenomenon in which a person’s perception of their own body size and/or shape is grossly inaccurate.

**Body Image Disturbance:** When people relate “unhealthily” or “negatively” or “inaccurately” towards their bodies, they are said to have body image disturbance.

**Body Image:** Body image refers to the way people perceive and relate to their bodies. Often this is emphasized in a more physical or visible sense, though others have argued that body image includes other types of relationship encapsulating things such as relationship with body, sexuality, and body trust and intuition.

**Body Liberation:** A concept referring to a type of liberatory embodiment that goes beyond “body positivity” or thinking well of one’s body, and encapsulates a liberatory stance that strives for ownership over one’s body, autonomy, cultivation of intuition, and embracing one’s identities, and accepting (however conflictedly) all parts of oneself. Body liberation often applies to concepts of embodiment beyond the visible or physical into more experiential, political, and spiritual realms.

**Body Mass Index (BMI):** Also called the “Quetelet Index.” A mathematical index of weight relative to height developed by a mathematician, Lambert Adolphe Jacques Quetelet, in the 1800s to describe the distribution of body weights across a given population (Strings, 2019). Later this index was taken up by a life insurance company in the Metropolitan Life Tables (early 1900s) to

assess level of insurance risk by presuming BMIs further from the mean imparted higher risk. While Quetlet was interested in how heterogeneity in populations contributed to naturally occurring normal distributions (in a mathematical sense), his work was later taken up by scientists primarily interested in “nature’s ideals” in the interest of eugenics for individual persons (Eknoyan, 2008). Currently, BMI is used to classify individual’s weights as “underweight,” (under BMI 18.5) “normal,” (BMI 18.5-24.9) “overweight,” (BMI 25.0-29.9) or “obese” (BMI 30.0 and higher).

**Body Mass Index Cutoff (BMI Cutoff):** BMI cutoff refers to a numerical value of BMI below or above which meets some criteria. For instance, the BMI cutoff for obesity is 30. The BMI cutoff for anorexia in the DSM-IV was 17.5. Currently in the DSM-5, there is no diagnostic cutoff for AN, however, a guideline of 18.5 is proposed in the DSM-5, and this is often operationalized as a “rule” rather than a “guideline.”

**Body Mass Index Percentile (BMI Percentile):** See %ile.

**Body Mass Index Spectrum (BMI Spectrum):** BMI, like many physical characteristics (e.g. height), falls along a bell-shaped curve distribution in the population, such that most people fall in the middle of the BMI distribution, and fewer people fall near the tails of the distribution. This distribution is also referred to as the BMI spectrum.

**Body Shame:** Body shame refers to shame that is internalized about the wrongness, unacceptability, disgustingness, or moral depravity of one’s body. The aspect of shame implies that this is a witnessed phenomenon wherein an individual’s body is not only esteemed by the self to be unacceptable, but also viewed that way by someone outside the self (others, society).

**Bone Density Loss:** A long term consequence of EDs that can occur due to suppression of reproductive hormones and/or nutritional deficiencies. Levels of bone loss are described as normal, low for age/osteopenia, or osteoporosis. The risk of fracture is increased in any restrictive eating disorder and increased further if there is bone density loss. Nutritional rehabilitation halts bone loss, and if achieved early in development, may reverse bone loss.

**Bone Mineral Density (BMD):** A measure of the density of a person’s bones, which may become impaired in EDs. Low BMD creates an increased risk of fracture, and increased risk of osteoporosis later in life. There are multiple methods of measuring BMD, including an x-ray test called a DEXA.

**Bradycardia:** A condition in which the heart beats more slowly than normal, which can lead to sudden death. Heartbeats below 60 beats per minute are considered bradycardic. Often bradycardia is part of admission criteria for medically admitting someone with an ED.

**Broad Conceptualizations of Beauty Scale (BCBS):** A scale developed by Tylka and Iannantuono (2016) to assess a positive aspect of body image, wherein individuals conceive of a broad variety of body types to have attractive qualities.

**Bulimia Nervosa (BN):** An ED characterized by recurrent episodes of bingeing and purging that occurs at least once a week for at least three months. Additionally, individuals experience overvaluation of weight and shape. Compensatory behaviors may include self-induced vomiting, laxative or diuretic misuse, medication misuse, fasting, or excessive exercise (APA, 2013).

**Calorie Counting:** A process people with EDs often engage in which involves obsessively counting the calories in food items, in an attempt to measure and restrict food that is consumed.

This type of behavior also manifests in counting grams of types of foods, counting macros (macronutrients), counting points (as in Weight Watcher's points) or counting exchanges (as in meal plans). This same type of cognitive pattern is also reflected in obsessively measuring or weighing food and keeping detailed records of consumption and compensation.

**Clinical Impairment Assessment (CIA).** A measure developed by Bohn and colleagues (2008) to measure the degree of impairment individuals experience in relation to their EDs. This measure is designed to be administered directly after the EDE-Q.

**Code:** A code refers to an individual portion of qualitative data that is assigned a label or bucket or category, so that like codes can be grouped together to develop themes.

**Cognitive Symptoms:** Cognitive symptoms of EDs refer to the distinctive cognitive patterns and content of individuals with EDs which often involve the following: obsessional thinking about food, weight, and body, calorie or macro counting, planning for how to reduce intake or increase compensation, either/or thinking, inflexible thinking, perfectionistic thinking, and a distinct, harsh ED voice that derides patients.

**Compensatory Behaviors:** Compensatory behaviors may include self-induced vomiting, laxative or diuretic misuse, medication misuse, fasting, or excessive exercise (APA, 2013).

**Compulsive Behaviors:** Individuals with EDs often engage in compulsive, repetitive behaviors that often seem to blend compensatory behaviors with cognitive symptoms. For instance, individuals might move restlessly, compulsively in attempts to burn more energy, they may check or count calories or foods with repeated measurement or counting, they may engage in compulsive body checking or food rituals.

**Consecutive Admissions:** Studies utilizing consecutive admissions samples attempt to get a less biased sample by examining all patients that admit to a given ED facility within a certain time period.

**Consecutive Referrals:** Studies utilizing consecutive referral samples attempt to get a less biased sample by examining all patients that are referred to a given ED facility within a certain time period. By looking at referrals (as opposed to admission) researchers hope their sample will be less biased by factors affecting a patient's ability to admit to treatment (e.g. ability to pay for treatment).

**Consultation and Relational Empathy Measure (CARE):** A measure developed by Mercer, Maxwell, Heaney, and Watt (2004) to measure how well patient's experience empathy from their healthcare providers.

**Cumulative Index of Nursing and Allied Health Literature (CINAHL):** A database of nursing literature.

**Dangerous Weight Loss Behaviors:** In ED literature, this usually refers to such things as purging, diuretics, laxatives, diet pills, and other pharmacological medications used for weight loss. In general, it references more "extreme" behaviors. Others have argued that bariatric surgery, fasting, and compulsive exercise should also be categorized in this way.

**Dehydroepiandrosterone-Sulfate (DHEA-S):** This hormone is associated with both testosterone and estrogen production. Endocrine functioning is often impacted in EDs, including DHEA-S.

**De-Identified, De-identification:** De-identified data is data that is not considered personally identifiable. De-identification is a systematic process in data cleaning in which participant identifiers (names, addresses, birthdays, names of close others, etc.) are removed and replaced with pseudonyms, to ensure that research participants' anonymity is protected in publications.

**Diagnostic and Statistical Manual (DSM):** A publication by the APA outlining mental health disorders and their criteria.

**Diagnostic and Statistical Manual Edition 5 (DSM-5):** The fifth edition of the DSM.

**Diagnostic and Statistical Manual Edition IV (DSM-IV):** The fourth edition of the DSM. Two major differences between DSM-IV AN and DSM-5 AN is that the amenorrhea requirement for AN was removed, and a specific BMI cutoff for AN was also removed.

**Diastolic:** See blood pressure.

**Diet Culture:** Diet culture refers to modern-day phenomenon in which dieting has been normalized, and thin bodies are generally privileged, while fatter bodies are more oppressed. Diet culture refers to the cultural normalization of dieting practices which are culture-wide in many circles, wherein foods, bodies, and exercise have moral value such that thin, active, or healthy bodies and foods are valued more than fat, inactive, or unhealthy bodies. Typically diet culture is also linked to fitness culture, white supremacy, and capitalism, as it is linked to white-influenced beauty ideals and multiple business efforts aimed at selling diet products.

**Dieting:** A process wherein individuals change their food intake in some intentional way. Usually dieting refers to efforts that are specifically aimed at goals of weight loss and body size reduction through reduction in caloric intake or modification of the types of foods one consumes. Often within dieting, foods are labeled as “good” and “bad” or “healthy” or “unhealthy.”

**Disordered Eating:** Disordered eating is a phenomenon that describes a pathological disturbance in eating behaviors in which individuals experience distress due to food, weight, shape, or exercise, and then alter their feeding and eating patterns as a way of coping with this distress. Usually disordered eating is considered one of the first steps on a continuum leading towards greater eating-related impairment and disturbance that can culminate in an ED.

**Diuretic:** A substance (sometimes a medication, other times naturally occurring in foods) that increases urine output. This can impact a person's weight and fluid and electrolyte balances. Diuretics are sometimes abused by people with EDs in attempts to manipulate their weight.

**Double Hermeneutic:** In qualitative research, the single hermeneutic refers to a person telling a story, which involves one level of interpretation (the teller's interpretation). The double hermeneutic refers to the second level of interpretation in which the researcher interprets what is told them (which has already been interpreted by the teller).

**Drug Use Disorders Identification Test (DUDIT):** A measure developed by Berman, Bergman, Palmstierna, and Schlyter (2005). Based on its precursor, the AUDIT, this measure is designed to screen for problematic drug use that may indicate a disorder. A score above 25 indicates likely substance use dependence; a score of 2 or more for women indicates likelihood of problematic substance use.

**Eating Disorder (ED):** A disturbance in eating that impairs functioning; different types of EDs are categorized in the DSM.

**Eating Disorder Behaviors (ED Behaviors):** ED behaviors refer generally to a range of strange, often compulsive behaviors that individuals with EDs engage in repetitively. These include compulsive exercise, time-consuming food rituals, mental obsession with food, obsessive calorie counting, secretive eating, eliminating “fear foods” from a diet, caloric restriction, body checking behaviors, bingeing, purging, or taking medications or substances to influence weight or shape.

**Eating Disorder Cognitions (ED Cognitions):** As opposed to things that ED patients do (e.g. ED behaviors), ED cognitions refer to things that people with EDs think. ED thoughts and cognitions often revolve around obsessive thoughts about food, calories, body shape, body weight, exercise, or other compensatory behaviors. Cognitions may also involve inflexible thinking, perfectionism, or thoughts of self-blame, or self-derision.

**Eating Disorder Not Otherwise Specified (EDNOS):** This is the category of the DSM-IV in which all residual cases of EDs, which failed to meet full criteria for an ED, were assigned. This is a heterogeneous category that could refer to folks with AN symptoms who still menstruated or whose weight was above the diagnostic cutoff of a BMI < 17.5, or individuals who did not experience bingeing and purging at the frequency and duration required for a bulimia diagnosis.

**Eating Disorder Risk, Eating Disorder Development (ED Risk, ED Development):** This refers to a time period of vulnerability when a person is at risk of, or in the process of developing an ED. Some developmental periods are considered especially risky for ED development, such as pre-pubertal and adolescent periods. During ED risk periods, people have an increased risk of starting to experience disordered behaviors. In this dissertation, I use risk period to refer to periods in a person’s life prior to ED behaviors becoming full threshold EDs.

**Eating Disorder Severity (ED Severity):** This refers to the severity of an ED which is often measured in different ways, including amount of weight loss, the BMI to which a person falls, and degrees of physical and functional impairment.

**Eating Disorder-Related Impairment (ED-Related Impairment):** ED-related impairment refers to the degree that a person’s ED impacts their daily living and creates functional impairment for their roles and functioning. For instance, if a person experiences poor health, misses school, has their employment performance impacted, or deterioration in relationships or hobby engagement, each of these are evidences of ways that their life is functionally impaired by the ED.

**Eating Disorders Assessment for DSM-5 (EDA-5):** A clinician-led structured interview measure developed by Sysko and colleagues (2015) to screen for EDs.

**Eating Disorders Examination Questionnaire Version 6.0 (EDE-Q):** A self-administered questionnaire developed by Fairburn (2009) to assess for presence of an ED. This measure produces five scores ranging from 0 to 6 with higher scores indicating greater severity: Eating Concern subscale, Eating Restraint subscale, Weight Concern subscale, Shape Concern subscale, and a Global EDE-Q score.

**Electrolyte Imbalance:** Electrolytes are the blood salts that support healthy cellular functioning. Typically, the body maintains an intricate balance of these salts through homeostasis. When nutritional stores are depleted or when there is dehydration, purging, water loading or compulsive exercise, the balance of these salts can be disrupted. Electrolyte imbalance can lead to life threatening arrhythmias or swelling of the brain.

**Emaciation:** Emaciation refers to the pronounced loss of fat and muscle tissue that can occur in situations of starvation and other severe medical illnesses. As not all bodies become emaciated in response to starvation, the amount of muscle mass or fat should not be used to estimate the nutritional status or health of a body.

**Embodied:** In EDs, this often refers to a process or experience of meaningfully, intuitively, kindly inhabiting one's body in a way that is emotionally and physically attuned to one's body and experiences.

**Energy Restriction:** Energy restriction refers to deliberate attempts to restrict food and caloric intake. At times those engaged in energy restriction strive for a "negative energy balance" in which they seek to metabolize (e.g. burn) more energy than they take in, which can sometimes lead to weight loss.

**Episiotomy:** Episiotomy describes the surgical cutting of the birth canal opening to allow more space for an infant to emerge during a difficult labor. The historical practice of routine episiotomy is no longer generally accepted as beneficial due to the pain and functional problems it can cause.

**Estradiol (E2):** A hormone and type of estrogen. Endocrine functioning is often impacted in EDs, including E2.

**Fasting:** Fasting refers to going for prolonged periods of time without food. Different guidelines are used to define fasting. In the EDE-Q, fasting is measured by going eight or more waking hours without food. Fasting is also considered a compensatory behavior when done in conjunction with binge behaviors.

**Fat Identity:** Fat activists argue that fat is a visible part of a person's identity (e.g. a characteristic), similar to other types of identity (e.g. race, gender, sexual orientation, etc.). In contrast to many other types of identity (e.g. queer communities), many fat folks avoid group identification with other fat people and may avoid acknowledging their fat identity. Some researchers have posited that fat folks may also go through a process of "coming out" with their fat identity, and this is generally thought of as a time when people not only acknowledge their fat identity to others, but also to themselves (Saguy & Ward, 2011).

**Fat Phobia:** Systematic devaluation, fear, and hate of fat folks due to their higher weight status. Fat phobic beliefs associate fatness with immorality, laziness, stupidity, lack of self-control, and gluttony.

**Fat:** Fat is a word describing those with larger body habitus that has traditionally (in modern-day Western culture) become associated with negative associations (e.g. fat phobia). However, fat activists have begun to reclaim the word fat, in an attempt to redefine it as a neutral body descriptor.

**Fat-Liberation:** A social movement dedicated to attaining equity, meaningful involvement, representation, and rights for fat people.

**Fear Foods:** Foods that are particularly feared by a person with an ED. Often these are foods that are nutrient- and energy-dense or are associated with enjoyment, craving, or shame.

**Follicle-Stimulating Hormone (FSH):** A hormone that stimulates development in the ovaries and testes and is also related to egg release during ovulation. FSH is hormone released by the pituitary gland to stimulate the development of the ovaries and testes, and the release of estrogen



and testosterone by those organs. Typically, in situations of low estrogen or testosterone, the pituitary increases FSH release to rebalance the system. FSH also rises as part of the triggering of ovulation. In EDs, the hypothalamic-pituitary axis (or HPA) can be suppressed, causing low testosterone and lack of ovulation

**Food Rituals:** Food rituals are compulsive behaviors that people with EDs unconsciously and consciously engage in, often as a coping mechanism during eating times. Food rituals may include such things as cutting food into small pieces, eating food in a particular order, or chewing food a certain number of times.

**Free Thyroxine (FT4):** A test that evaluates the amount of circulating thyroid hormone. Endocrine functioning is often impacted in EDs, including FT4.

**Gender Minorities:** Generally used to refer to folks with less represented genders, such as non-binary and trans individuals. However, in ED literature, this often refers to men as well, as men are less represented than women in ED literature.

**Generalized Anxiety Disorder-7 (GAD-7):** A short measure developed by Spitzer, Kroenke, Williams, and Löwe (2006). A score of 10 or greater indicates a likely generalized anxiety disorder diagnosis.

**Health at Every Size® (HAES®):** A weight-inclusive approach to health that does not rely on BMI as a primary indicator of health. This name was coined by Lindo Bacon (2010) and copyrighted by the Association for Size Diversity and Health and is based on five principles of well-being: 1) weight inclusivity, 2) health enhancement, 3) respectful care, 4) eating for wellbeing, and 5) life-enhancing movement.

**Healthcare Avoidance:** A term used to describe how some patients choose to (or perhaps are forced to) disengage from care. Often this is described by patients as a reaction to stigmatizing or harmful experiences in healthcare.

**Healthcare Providers Behaviors:** Healthcare provider behaviors references the behaviors that providers engage in in relation to their patients, such as assessment, diagnosis, screening, treatment, prevention, outreach, conversation, etc.

**Healthcare Providers:** A general, encompassing term used to describe people within the healthcare industry, ranging from medical professionals (e.g. general practitioners, nurses, physicians, specialists, surgeons, psychiatrists, chiropractors, physical therapists), dietitians, mental health professionals (e.g. therapists, social workers, substance use counselors, treatment center staff).

**Hermeneutic:** Hermeneutic refers to a process of understanding interpretations of phenomena; this term is often used in regard to a specific text (e.g. Bible) and is also used in some qualitative approaches to analysis. Hermeneutic analyses require looking at different levels of interpretation, and how concepts are interpreted by speakers, and reinterpreted by hearers, or how concepts are understood as whole—parts—whole (the hermeneutic circle).

**Heterogeneity:** The quality of encompassing diversity.

**Higher Weight Individuals:** A more neutral term used to describe fat individuals.

**Hypokalemia:** Hypokalemia refers to low blood potassium levels. Severe hypokalemia can lead to fatal arrhythmias. In EDs, hypokalemia can occur from overuse of laxatives, diuretics, vomiting, dehydration, and refeeding syndrome.

**Hypotension:** Low blood pressure for age and situation. In EDs, this often occurs in the context of malnutrition or dehydration and can be life-threatening. Orthostatic hypotension refers to blood pressure that drops on standing.

**Hypothermia:** Low body temperature (below 95 degrees Fahrenheit or 35 degrees Celsius). In EDs, this can occur in the context of severe malnutrition and can be life-threatening.

**Ideal Body Mass Index (Ideal BMI):** See “normal BMI.”

**Illness Narrative:** Kleinman’s (1988) concept of illness narratives is central to my thinking in this dissertation. An illness narrative is a patient’s description how they experience their illness and how their illness impacts them. Kleinman argues that understanding a patient’s illness narrative and patient explanatory model (patient’s understanding of the functioning, causes, and projected outcomes of their illness) is critical to successful treatment. Kleinman drew a distinction between the patient’s *illness* (which refers to the *lived experience and perception* of symptoms and disability from the patient’s perspective) and *disease*, which is the practitioner’s interpretation of the *illness* (as they have been trained to see and understand the patient’s problems).

**Illness Trajectory:** A patient’s illness trajectory refers to the course that an illness takes, from the developmental stages of an illness beginning, on to the illness becoming more significant and persisting, or remitting. Within this dissertation, I conceptualized illness trajectories as having four types of stages that individuals may enter, or re-enter successively during an illness experience: 1) a risk and development phase, 2) an illness phase prior to treatment, 3) for some, an experience with treatment, and 4) for some, an experience with partial or full remission.

**Inpatient Care:** One of the highest levels of care available to people with EDs for treatment, involving 24-7 monitoring, usually requiring medical stabilization, and often focused on goals of reducing or interrupting ED behaviors, reaching medical stability, and beginning nutritional rehabilitation.

**Institutional Review Board (IRB):** A governing body associated with various institutions that oversees the ethics of research conducted in association with that institution.

**Intensive Outpatient Program (IOP):** Intensive outpatient programs are the lowest level of “higher levels of care” in which individuals attend an ED treatment program for 3-7 days per week for a set number of hours each day (usually between 3 and 5 hours). Often participants have meals and/or snacks together with their treatment providers and engage in psychoeducation and other therapy groups.

**Internalized Weight Stigma:** Internalized weight stigma (also internalized weight bias) refers to how individuals internalize societal or familial or community negative beliefs about higher weight individuals and direct these beliefs and stigmas inwards towards themselves. This often manifests as believing one’s own body to be wrong, immoral, disgusting, or unhealthy, or believing negative things about the self due to one’s higher weight status.

**Interpretive Framework:** In interpretive frameworks, there is no objective, absolute truth. Rather, each person experiences a different reality and truth, and truths can be learned by exploring

the perspectives of others. The most accurate picture of reality is thought to be represented by capturing as many concurrent perspectives of a given truth or experience as possible.

**Interquartile Range (IQR):** A statistical measure of variability which, in the ED field, is often applied to measures of weight and BMI. To calculate IQR, datasets are divided into four rank-ordered equal quartiles. Being in the lowest quartile would indicate an individual scored in the bottom 25% of participants, and scoring in the highest quartile would indicate the opposite.

**Intersectional, Intersectionality:** Crenshaw's concept that individuals who experience multiple forms of oppression experience them differentially based on the combination of their oppressed and privileged identities. For Crenshaw, this meant that black women experienced sexism differently than white women, as an example. Similarly, in the case of weight stigma, fat oppression is often experienced differently by people of different races, genders, and social classes.

**Intuitive Eating Scale (IES):** A measure designed by Tylka and Kroon (2013) to measure to what extent individuals rely on internal cues of hunger and fullness to regulate eating patterns. This study utilized the IES-2 version of the scale.

**Lanugo:** A fine hair that grows on some bodies under situations of malnourishment. It is hypothesized that lanugo functions to warm the body when the layer of fat under the skin is lost. This hair is also sometimes present on newborn babies and is shed shortly after birth. In EDs, lanugo growth is a marker of severe malnutrition.

**Lesbian, Gay, Bisexual, Trans, and Queer (LGBTQ) Communities:** This acronym often has additional letters (to include other groups: Intersex, Asexual, Two Spirit, and others). In this dissertation, I use LGBTQ for simplicity's sake, to encapsulate all queer gender and sexual orientations.

**Lifetime BMI Suppression:** Lifetime BMI suppression is a measure of a person's BMI variability during a lifetime. This measure is calculated different ways in the literature. In this study, lifetime BMI suppression was measured by the difference between a person's highest BMI that they had reached and their lowest adult BMI they had reached; it was also measured by the highest percentage of premorbid weight lost in one specific instance of weight loss.

**Lower-Weight Individuals:** Lower-weight individuals (also "thin-bodied") is a term used in this dissertation to describe thinner individuals, who usually benefit from weight stigma.

**Luteinizing Hormone (LH):** A hormone released by the pituitary (along with FSH) that regulates the release of estrogen and testosterone by the ovaries and testes. In EDs, hypothalamic and pituitary function can be suppressed (HPA suppression) resulting in low testosterone or irregular or absent ovulation.

**Malnutrition:** The state of having inadequate amounts of essential nutrients in the diet. Malnutrition can be from inadequate total calories, protein, fat, carbohydrates or specific vitamins and minerals. Malnutrition can lead to muscle, fat, and bone loss, as well as vitamin and mineral deficiencies and electrolyte imbalances. With prolonged malnutrition, the body's attempts to restore homeostasis and conserve energy can cause dangerous changes such as decreased appetite, decreased thirst, mental slowing, decreased immune function, lower heart rate, low body temperature, and reduced reproductive function.

**Marginalized Populations:** Marginalized populations are those that are systematically disadvantaged by the -isms (e.g. racism, sexism, classism, sizeism, homophobia, transphobia, ableism, ageism, colorism, etc.).

**Matrix Comparison Method:** A way of conducting literature reviews wherein studies are compared using matrices, with each row representing a different study, and each column representing a different variable for comparison. Described by Garrard (2014).

**Maximum Body Mass Index (Max BMI):** Maximum BMI refers to the highest BMI that a person has reached in their lifetime. This is a measure of BMI variability for a person.

**Median Body Mass Index (mBMI):** This measure of BMI is used mostly in growth trajectories of children and adolescents as a measure for how close a person's BMI is to the median BMI reported for their age and gender.

**Median Body Mass Index Percentile (mBMI%):** This measure of BMI is used mostly in growth trajectories of children and adolescents as a measure for what percentile of the median BMI they are for their age and gender. For example, a person with a 50<sup>th</sup> mBMI% would be exactly halfway to the median of a distribution, with 25% of children below their percentile, and 75% above; alternatively, a person at 97<sup>th</sup> mBMI% would have a body weight almost exactly at the median of the BMI distribution. Often refeeding body weights are set for certain mBMI%, such as aiming for the 50<sup>th</sup> mBMI% (e.g. the 25<sup>th</sup> percentile, often applied universally).

**Medicalization:** A process by which individuals and their bodies are viewed as medical objects rather than whole embodied people. With fat populations, this often means viewing a fat body as inherently diseased or pathological (e.g. viewing a size—obesity—as a disease). This can result in “overmedicalization,” in which people receive unnecessary treatments, screenings, or procedures. Critical obesity scholars argue that overmedicalization is not inherently harmless, and has iatrogenic effects, such that previously healthy persons may become less healthy due to medicalization.

**Member-Checking:** A process used mainly in qualitative and community-based research approaches wherein researchers report research results back to the community from which the data came, so that community members can give feedback on the researchers' interpretations or results presentations.

**Minimum Body Mass Index (Min BMI):** Minimum BMI refers to the lowest BMI that a person has reached. In the ED field, this is usually referencing a weight loss that has been the result of disordered eating behaviors. Minimum BMI is often used to calculate weight suppression, to evaluate whether or not a person has experienced “significant weight loss,” or to evaluate whether or not a person would qualify for typical anorexia as defined by the DSM-IV or International Classification of Diseases (APA, 2013, p. 338).

**Mirror-Checking:** An ED behavior in which individuals compulsively check different parts of their bodies in mirrors. Often this is fueled by body dysmorphia, when a person's perception of their body does not match the lived reality of other people, and so people engage in repetitive checking behaviors in attempts to verify their reality. Alternatively, these behaviors may be motivated by attempts to measure or track how much their body has changed shape or weight.

**Modified Verbatim:** A type of transcription format in which certain speech idiosyncrasies deemed “not meaningful” are omitted in favor of more readable transcripts. For instance, removing false starts or filler words like “uh,” “um,” or “like.”

**Mortality Rates:** Mortality rate is a measure of how many people die from a given condition. This is usually used to describe population impacts of a given disease.

**Multiply-Marginalized:** As with other forms of oppression, those embodying multiple marginalized identities face compounded challenges (Craig, 2006; Crenshaw, 1991) and experiences those forms of oppression in different ways, necessarily impacted by their other identities.

**Narrative Inquiry:** Narrative inquiry is a type of qualitative approach often used in more longitudinal qualitative research that is concerned with the narrative arch of stories and interviews. This is an interpretive approach that gathers research through storytelling, and often presents research in a more narrative form.

**Naturalistic Empirical Approaches:** Naturalistic empirical approaches to science emerge from more positivist and post-positivist paradigms. These approaches are usually less concerned with interpretation, and more concerned with discovering knowledge and working towards discovering more absolute, encompassing truths.

**Nonbinary:** Gender identities that fall within (or outside) the spectrum of masculine and feminine, without adhering rigidly to either. Nonbinary individuals may identify as genderqueer, gender nonconforming, trans, agender, gender fluid, and other genders.

**Noncompliant:** “Noncompliant” is typically used as an adjective to describe patients who do not follow directions prescribed by healthcare providers. This often regards attendance at medical appointments, taking medication as prescribed, or adhering to certain health behavior regimens for activity or diet. Language of “noncompliance” may be used by providers more often when describing members of more marginalized groups, with providers more likely to view certain groups as noncompliant, even when presenting with similar behaviors as other more privileged groups (e.g. racial groups, size groups, class groups, etc.).

**Normal Body Mass Index (Normal BMI):** Also called “ideal BMI.” A category of BMI currently defined by the Center for Disease Control and Prevention to be between a BMI of 18.5 and below 25.0. As with all categories of BMI, specific cutoffs for “normal” BMIs are subject to change at any point, as determined by a committee at the National Institute of Health.

**Nosology:** Nosology pertains to how we understand, classify, categorize, lump and separate diagnoses and what those diagnoses (and the differences between them) mean.

**Nutritional Rehabilitation:** Nutritional rehabilitation (also called “refeeding”) is the gradual process of replenishing nutritional stores following a period of malnutrition or starvation. This process may involve uncomfortable physical changes (bloating, swelling, nausea, bowel changes, night sweats, weight gain.) as food and nutrients are incorporated into a body acclimated to starvation. Following rapid or profound weight loss, or severe malnutrition, the process of nutritional rehabilitation can cause alterations in blood sugar, electrolytes, and organ functions. Patients experiencing nutritional rehabilitation are at risk for a potentially life-threatening condition called “refeeding syndrome,” which requires close medical monitoring.

**Obese:** Obese BMI. Obese is currently defined by the Center for Disease Control and Prevention to be a BMI above 30. There are also three classes of obesity which include Class 1 (BMI between 30.0 and below 35.0), Class 2 (BMI between 35.0 and below 40.0), and Class 3 (BMI above 40.0). Fat activists generally object to these classifications, believing that they pathologize and medicalize natural human body diversity, in a way that differentially impacts women, people of color, and folks in poverty, as obesity differentially impacts these groups.

**Orthostasis, Orthostatic Instability or Intolerance, Orthostatic Hypotension, Orthostatic Heart Rate Changes:** A condition in which the body is less able to maintain blood pressure and pulse in a state of homeostasis. This can result in orthostatic hypotension, a sudden decrease in blood pressure or rise in heart rate when changing posture. This can also result in dizziness or fainting. Orthostasis can occur in individuals with EDs and can indicate the need for medical stabilization.

**Other Specified Feeding and Eating Disorder (OSFED):** Other Specified Feeding and Eating Disorders. A category of EDs in the DSM-5 that replaced the EDNOS category of the DSM-IV. This category has several specified types, including atypical anorexia, purging disorder, bulimia nervosa of low frequency or duration, binge eating disorder of low frequency or duration. This category of ED is considered to encapsulate residual EDs that are not captured in the main diagnostic categories.

**Outpatient Care (OP):** One of the lowest levels of treatment available to individuals with EDs, such as seeing a dietitian or therapist once per week.

**Overuse Injuries:** Overuse injuries are caused by frequent repeated motion. In the context of EDs, overuse injuries such as shin splints, tendonitis, or stress fractures, are sometimes observed in individuals who engage compulsive exercise.

**Overvaluation:** Overvaluation is a term used to describe when something becomes pathologically out of balance in a person's life. In the context of EDs, we often see "overvaluation of weight and shape" discussed as part of the criteria for an ED. In this case, a person's weight or shape is overvalued to the point that their weight is a key defining part of their identity, playing a major role in their sense of self-worth.

**Overweight (OW):** Overweight BMI. Overweight BMI is currently defined by the Center for Disease Control and Prevention to be a BMI between 25 and under 30. Fat activists generally object to these classifications, believing that they pathologize and medicalize natural human body diversity, in a way that differentially impacts women, people of color, and folks in poverty, as obesity differentially impacts these groups.

**Partial Hospitalization Program (PHP):** One of the higher levels of care that people with EDs can attend. Partial hospitalization programs involve attending an ED treatment program all day, usually having all meals and snacks on site, with the support of treatment staff. Time between meals is spent in psychoeducation groups and individual therapy. This level of treatment is often used for individuals who are medically stable, but who require high levels of supervision to prevent engagement in ED behaviors.

**Partial Remission:** In EDs, partial remission is a term used in the DSM to describe individuals who previously met criteria for an ED, but now no longer meet all criteria while still experiencing some symptoms. For example, an individual who previously had AN, but currently no longer restricts intake to the point of significant weight loss and underweight, but still experiences overvaluation of weight and shape, may be said to be in "partial remission."

**Partial Syndrome:** Partial syndrome refers to individuals who meet part of the diagnosis for an ED but fail to meet all criteria. These individuals are sometimes called "subthreshold." Usually if using this term, one specifies which criteria is not met.

**Patient Explanatory Models:** Kleinman's (1988) theory of patient explanatory models posits that a clinician must understand how a patient understands their own illness experience in order to best treat their disease. See Illness Narratives.

**Patient Health Questionnaire – 9 (PHQ-9):** A measure developed by Kroenke and Spitzer (2009) to assess for depression. A score of 10 or greater indicates probable depression.

**Patient-Centered Research Methods:** Patient-Centered Research Methods are methods which emphasize the importance of individual patients' perspectives and experiences, beyond aggregate data aimed at the "average patient." I included the following specific elements of patient-centered approaches in this dissertation: patient interviews, patient stakeholders giving input into the design of the interview guides, participant validation of the final transcripts, member-checking study results, and participant feedback on quantitative measures.

**Percent Median Body Weight (%mBW):** In addition to percentiles, in ED literature, weights for children and adolescents are often measured by percent of median body weight. For instance, if someone was 100%mBMI, they would have a BMI that was the median of the BMI spectrum for their respective age and gender. Those above 100% would have BMIs above the median, and those below 100% would have BMIs below the median. Often goal weights in EDs are set uniformly (such as 25%mBMI, or 50%mBMI), which can be problematic if individuals enter treatment significantly above or below (or historically above or below) these standard recommendations.

**Percentile (%ile):** Often in ED literature, percentiles are used in calculating "healthy" or "unhealthy" weights for children. Generally, healthy weights for children are considered any percentile between 5%ile and 85%ile. With weights below 5%ile considered underweight, weights above 85%ile considered overweight, and weights above 95%ile considered obese.

**Phenomenological:** Phenomenological qualitative analysis is concerned with understanding the meaning of experiences as experienced by research participants. For instance, "what does having an ED mean to you?" or "what does recovery mean to you?" are primarily phenomenological questions.

**Pitting Edema (e.g. pitting abdominal edema):** Pitting edema is a type of edema that becomes so severe it leaves a "pit" or impression in the skin when you push on it. This type of edema can be indicative of more dangerous medical consequences of EDs, particularly kidney, liver, and/or cardiac failure, as the body struggles to maintain normal fluid balances.

**Power Differential:** Power differential refers to symbolic and real differences in power between people or groups of people. In research, this often refers to the power differential observed between the researcher and those about whom the research is conducted. Intentionally taking actions to reduce the power differential can be part of liberatory methods.

**Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA):** This is a list of required components of a systematic review in order for that review to be completed according to "PRISMA Standards" (Moher, Liberati, Tetzlaff, & Altman, 2009). This is one of the gold standards of systematic reviews for health sciences.

**Premorbid Body Weight:** Premorbid body weight refers to a person's body weight prior to a weight loss. For example, if a person started at 200 pounds and lost 50 pounds, you would say that they lost 25% of their premorbid body weight.

**Prevalence:** Prevalence is a measure for how many individuals within a given population experience a disease or condition. It is typically used to describe populations rather than individuals.

**Prodromal:** Prodromal refers to a presentation of an illness or disease that is a precursor to a more significant illness. For instance, for some individuals, AAN can be said to be a prodrome of AN, if they experience AAN for a while, and eventually lose so much weight that they are considered AN. Similarly, subthreshold disordered eating can be said to be a prodrome of an ED.

**Prolactin (PRL):** Prolactin is a hormone made in the pituitary glands and related to reproductive function and milk production. Endocrine functioning is often impacted in EDs, including PRL.

**PsycInfo:** APA database. A database of psychology literature.

**PubMed:** A database of biomedical literature MEDLINE, life science journals and online books from the National Library of Medicine.

**Purging Disorder (PD):** A category of OSFED wherein individuals engage in purging behaviors (self-induced vomiting, laxative misuse, diuretic misuse, or other medication misuse) in the absence of binges.

**Purging:** In EDs, purging refers to behaviors by which individuals expel food from the body in efforts to reduce weight or weight gain. Typical purging behaviors include self-induced vomiting, compulsive exercise, fasting, or laxative abuse.

**Q-T corrected interval (QTc):** The QT interval represents the time between the Q and T points of each heartbeat on the electrical tracing called the electrocardiogram (ECG). This measurement is “corrected” for the actual heart rate, giving a standardized measure called the QTc. The QT interval of a heartbeat can become prolonged (prolonged QT interval) in individuals with EDs, especially in those with a genetic predisposition or who take QT prolonging medications. This medical complication can result in arrhythmias that cause fainting or can lead to sudden death.

**Quality Assessment Scale (QAS):** A scale developed by Kmet, Lee, and Cook (2004) to assess empirical article quality for articles that utilize diverse methodologies. Articles are scored on 14 different items, and total scores are averaged and scaled such that scores are between 0 and 1, with higher scores indicating higher article quality.

**Quality of Care:** A measure of how effective, timely, and compassionately care is delivered to a patient. This measure has to do with how a patient experiences healthcare.

**Quality of Life:** A measure of how much a person lives a meaningful, fulfilling, healthy, resourced, supported life. This type of broad measure encapsulates many aspects of life satisfaction, usually drawing from physical, emotional, social, economic, and political realms.

**Recovered, in recovery (“classified as recovered”):** Patients with EDs frequently refer to being “in recovery” noting that they perceive recovery from their EDs to be an ongoing journey without a specified end point. Others refer to being “recovered” indicating that they believe they have reached a state of sustained remission. Recovery definitions often differ in ED literature, with some researchers focusing on medical markers (medical stabilization, resolving amenorrhea, weight regain) and others focusing on psychological symptoms (EDE-Q measures), whereas patients often focus in on experiences of quality of life or body image. Understanding how recovery is defined and in what context is critical to understanding recovery literature.



**Refeeding Protocols:** To reduce the risk of refeeding syndrome, clinicians follow refeeding protocols when beginning nutritional rehabilitation with patients who have experienced severe malnutrition. These protocols adjust nutrient balance and quantity in response to monitoring of electrolyte balance and organ function.

**Refeeding Syndrome:** Refeeding syndrome refers to life threatening fluid and electrolyte shifts that can develop when a person begins to eat following severe restriction. Heart and kidney failure can develop. These shifts occur because of the hormonal and metabolic compensations of the starving body as it begins to process food again. The possibility of refeeding syndrome is lowered when nutritional rehabilitation is supervised by ED treatment specialists following refeeding protocols (see above).

**Reflexivity:** Reflexivity is an ongoing practice and attitude in which a researcher examines their positionality in regard to their research, and reflects on how that positionality and perspective impacts the work they are doing, the data they are collecting, the way they are interpreting that data, etc. Reflexivity is an important practice in critical feminist approaches to research to ensure that the researcher is carefully examining the role of self in the research process. Reflexivity is pursued in the belief that unexamined bias is more dangerous than bias that is examined, considered, and explained.

**Remission (ED):** Remission refers to when a person who has previously met criteria for an ED no longer meets any criteria for an ED. If a person meets some criteria, but not all, they are referred to as “in partial remission.”

**Research Electronic Data Capture (RedCap):** A secure electronic database to capture primary data (Harris, et al., 2009) that is compliant with current health privacy laws.

**Residual Eating Disorders:** Residual EDs are those which do not meet criteria for full threshold disorders but still cause distress and impairment for an individual. They are often categorized in a residual “everything else” category such as EDNOS or OSFED.

**Restriction:** An ED behavior in which an individual restricts energy intake, types of foods, or other ways of decreasing, limiting, or controlling intake.

**Restrictive Eating Disorder (RED):** A category of ED in which individuals engage in energy restriction (e.g. limiting food or caloric intake). This term is used to broadly refer to EDs such as anorexia nervosa, atypical anorexia nervosa, bulimia nervosa, and other related EDs. This often refers to individuals whose EDs cause a negative energy balance, such that their bodies are metabolizing more energy than they are intaking. Some ED advocates have suggested that all EDs may involve restriction, as individuals with binge eating often also have restrictive behaviors that occur in the context of their EDs.

**Rosenberg Self-Esteem Scale (RES):** A measure developed by Rosenberg (1979) to measure positive and negative feelings about the self.

**Secretive Eating:** A disordered eating behavior in which a person eats in secret, sometimes described as “furtive eating.” Often this is due to feelings of guilt or shame associated with eating.

**Sentinel Symptom:** Sentinel symptoms are the “red flag” symptoms which should announce to a clinician the presence of a certain disease or disorder. For instance, the red pox of chicken pox are a sentinel symptom. In EDs, symptoms like amenorrhea, weight loss, or fainting are often common symptoms used to identify EDs, which may otherwise slip by a provider’s notice.

**Simple Hermeneutic:** In qualitative research, the single hermeneutic refers to a person telling a story, which involves one level of interpretation (the teller's interpretation).

**Social Esteem:** Social esteem refers to how one is esteemed or evaluated by others, either positively or negatively. This term is in contrast to self-esteem, which refers to how one is esteemed or evaluated by one's own self.

**Social Identity Threat Theory:** Social Identity Threat Theory involves the study of threats to the social self, meaning threats to how a person is socially experienced or perceived by others. According to social identity threat theorists (Major, Eliezer, & Rieck, 2012; Major & O'Brien, 2005), threats to the social self involve situations in which there is a potential for the loss of social esteem, status, or acceptance (Dickerson et al., 2004).

**Social Self:** In Social Identity Threat Theory, the social self is that aspect of a person that reflects a person's social value, status, esteem, and worth as perceived *by others* in society.

**Stanford Trust in Provider Scale (STIPS):** A measure developed by Thom, Ribisl, Stewart, and Luke (1999) to assess the degrees to which patients trust their primary care providers.

**Stigma:** Stigma manifests in many forms, resulting in some identities or attributes being systematically devalued or disadvantaged within societies.

**Stories:** Within narrative inquiry approaches to qualitative data, stories (Stone-Mediatore, 2003) are composed of "narrated experiences," which involve some level of interpretation as they are told by the author (also referred to as the simple hermeneutic, or the person interpreting their own experience). Within interview data, I conceptualized these stories as being co-created by the interviewer and interviewee, involving both the single and double hermeneutic.

**Subclinical:** Subclinical (in regard to EDs) refers to an ED that does not reach a threshold of clinical impairment. For instance, a person may experience an overvaluation of weight and shape, but experience these feelings in a more "normative" way, which fails to significantly impede the person's life.

**Subthreshold Anorexia Nervosa (sAN):** A term used to describe individuals who meet most criteria for anorexia nervosa, but fail to meet at least one criterion. In the DSM-IV, this frequently referred to people who still had menstrual cycles or whose BMI had not fallen below 17.5.

**Subthreshold Eating Disorder (Subthreshold ED):** A subthreshold ED is one that fails to meet criteria for a full threshold disorder, such as bulimia nervosa in which the binge and purge frequency is not at least once per week for at least three months. For example, if an individual were to binge and purge on a monthly basis, this individual would be considered to have a subthreshold form of bulimia.

**Systemic:** Systemic refers to how a phenomenon permeates a system in a more universal way, such that all parts of the system are impacted. In reference to discrimination and stigma, systemic refers to all parts of a social or geographical or organizational system being impacted by a type of discrimination. Systemic oppression, discrimination, or stigma involves whole groups being devalued in a similar fashion such that members of that oppressed group, experience discrimination, fewer opportunities, and other forms of abuse and mistreatment in a predictable way across the group (e.g. microaggressions, marginalization, and violence) in a given society.

**Systolic:** See blood pressure.

**Target Weight (also, Goal Weight):** In EDs, a target weight represents the weight to which healthcare providers attempt to restore a person's weight. Usually this is seen as a goal for weight gain in malnourished individuals. It is calculated in numerous highly debated ways and may take into account such things as absolute BMI or percentiles, previous growth curves, or weight suppression. In higher weight bodies, target weights are sometimes established in an effort to decrease an individual's current or premorbid weight (as in the case of bariatric surgery, or low goal weights in AAN), as opposed to increasing their weight, as is more common practice for treatment of AN or bulimia.

**Theme:** Themes are types of higher-level data interpretations that tie together multiple units (codes) of qualitative data, telling a greater truth than any one piece of data individually.

**Thin:** Thin is a descriptive word for body size, often used within the ED field to describe those in lower-weight bodies. It is considered a more neutral, encompassing term, compared to other more laden terms, such as "skinny." It specifically refers more to a person's bodily presentation visually rather than a specific interpretation of their BMI. For instance, a person in a "normal BMI" or even "overweight BMI" may still be described as "thin" if their body mass is dense enough and distributed in such a way such that people perceive them to be thin.

**Threshold Eating Disorder (Threshold ED):** An ED which meets criteria for a threshold disorder as defined by the DSM (e.g. anorexia nervosa, bulimia nervosa, ARFID, binge eating disorder).

**Thyroid-Stimulating Hormone (TSH):** A hormone produced by the pituitary gland that stimulates the thyroid. Endocrine functioning is often impacted in EDs, including TSH.

**Title Search:** A process in literature reviews during which article titles are read and determined to be pertinent to the review topic, potentially pertinent to the review topic, or obviously unrelated to the review topic. This screening requires a less intensive read of the article. Articles with ambiguous titles require abstract or full-text reviews to determine article eligibility.

**Transcription:** A process by which orally and visually communicated language is recorded into written words. Transcription may also attempt to capture other forms of meaning (affect, sarcasm, gestures, inferred meaning, emotional valence) depending on the type and manner of transcription. Usually things which are not directly stated in words are recorded in [square brackets].

**Transdiagnostic Approach:** Transdiagnostic approaches refers to ways of approaching multiple diagnoses concurrently by looking for collective similarities and differences in experiences, across diagnoses. For instance, within chronic illnesses, one might look transdiagnostically at struggles that mutually impact people with asthma, diabetes, and kidney disease. In EDs, this refers to thinking about similarities across multiple diagnoses (e.g. anorexia, bulimia, and binge eating disorder, such as how all typically involve some degree of food restriction and body dissatisfaction). Benefits of transdiagnostic approaches includes being able to treat multiple disorders with a single intervention and needing less specific diagnostic criteria to initiate treatment.

**Treatment Delay:** Treatment delay refers to the time that a person experiences an illness without intervention. Typically, illnesses persist or worsen without treatment; alternatively, some may spontaneously remit. Treatment delay is operationalized in diverse ways. Some look at the length of time one meets criteria for a disorder prior to intervention (which requires determining illness onset); others examine the duration from a person believing they have an illness until treatment (which involves a person's lived perception of need and possible denial), and others

evaluate duration from the time a person begins help-seeking until treatment (which requires defining help-seeking). In this study, I operationalized treatment delay in a patient-centered approach, such that I examined the amount of time between when individuals first thought they may have an ED and the first time they received ED-specific care.

**Treatment Engagement:** Treatment engagement refers to experiences when a person participates in or attends treatment. Examples include attending therapy, attending nutrition services, attending primary care, practicing a therapy skill, or taking a prescribed medication.

**Triiodothyronine (T3):** A hormone produced in the thyroid that contributes to regulation of heart rate, temperature, and metabolism. Endocrine functioning is often impacted in EDs, including T3.

**Underweight (Under-wt):** Underweight BMI is currently defined by the Center for Disease Control and Prevention to be a BMI under 18.5. In the context of growing and developing bodies (e.g. children and adolescents), experts usually define underweight according to percentiles and growth curves rather than by absolute BMIs; underweight BMIs tend to increase as adolescents age. For example, a BMI of 17 would be considered underweight for a 20-year-old, but “normal weight” for a 15-year-old due to judging underweight status by percentiles rather than an absolute BMI; as adolescents age, pubertal changes contribute to higher BMIs becoming more common as adolescents gain height, muscle, and fat mass.

**Undue Influence of Weight or Shape:** In ED illnesses, patients experience disturbance in the relative importance of their own body weight and/or shape, becoming hyper-focused on these elements of themselves. Importance or influence of body weight and shape is considered pathological when it becomes a major way that a person evaluates their own sense of value or self. Much like definitions of pornography, this is often conceptualized as a “you know it when you see it” type of phenomenon.

**Uniform Weight Cutoff (or Uniform BMI Cutoff):** This refers to a diagnosis or characteristic that is defined universally across diverse individuals at the same weight or BMI. For instance, “overweight” is uniformly defined to begin at a BMI of 25.0, regardless of individual factors for that individual (such as body composition or cardiometabolic health factors).

**Validation:** Validation is a process of verifying a transcript to ensure that the meaning of a written transcript accurately captures what was spoken and conveyed nonverbally in an interview. Validation processes typically involve strategies such as listening to interviews while reading a transcript or having interview participants review their transcript to check for instances of misunderstanding or transcription errors.

**Vertebral Strength (VS):** Vertebral strength refers to the strength of vertebral bones that can be adversely affected by EDs. Correlations have been found between both higher BMI and lower BMI and reduced vertebral strength.

**Weight Bias Internalization Scale (WBIS):** A measure created by Durso and Latner (2008) to measure the extent to which individuals internalize negative societal messages about fatness.

**Weight Cycling:** A process in which a person loses and then regains weight, such that their weight experiences instability. Weight-cycling has been found to be associated with cardiac disease (Rasla et al., 2016), insulin resistance (Oh et al., 2019), and overall mortality (Cologne et al., 2019; Zou et al., 2019). Weight-cycling is often a confounding, unmeasured factor in studies examining associations between BMI and mortality (Diaz, Mainous, & Everett, 2005).

**Weight Loss Percentage (WL%):** Weight loss percentage is calculated by taking the amount of weight lost and dividing it by a person's premorbid weight. This measure is often used as one way to measure weight suppression.

**Weight Restoration:** Weight restoration refers to a process in ED remission during which a person restores weight that was lost in their disorder. The amount of weight gain required for "remission" varies between different theoretical and operational definitions of remission. Evidence suggests that the risk of relapse is lower when full weight restoration has occurred.

**Weight Stigma:** Within weight stigma, higher weight ("fat") bodies are systematically devalued, experiencing discrimination, fewer opportunities, and other forms of systemic abuse and mistreatment (e.g. microaggressions, marginalization, and violence) compared to thin bodies. Weight stigma happens in internalized and externalized ways. Weight stigma carries consequences for fat bodies across multiple realms, with higher weight individuals paid lower wages, having less access to education, paying higher premiums for healthcare, and facing more weight-based bullying compared to thinner people (Puhl & Heuer, 2009).

**Weight Suppression:** Weight suppression is a measure of the degree to which a person experiences weight loss. Operational definitions for weight suppression are inconsistent within the field (Gorrell, Reilly, Schaumberg, Anderson, & Donahue, 2018). In this dissertation, I operationalized weight suppression as the difference between a person's lifetime maximum weight and lifetime minimum adult weight; I also measured weight suppression by examining the largest weight loss percentage.

**Weight-Centric:** A term used to describe an approach to healthcare in which weight and BMI are centered as main wellness goals and outcomes. Typically, weight centric approaches are the default healthcare approach in the United States. This approach is contrasted with weight inclusive approaches, which focus on other health indicators (activity level, blood pressure, blood sugar levels), rather than using BMI as a proxy for health (Tylka, et al., 2014).

**Weight-Inclusive:** A term used to describe an alternate paradigm in healthcare in which weight and BMI is defocused as a priority or goal outcome, and other more directly modifiable health behaviors (activity level, sleep, rest, , social supports) are empathized instead (Tylka, et al., 2014). This paradigm is contrasted with weight-centric approaches.

**World Health Organization Quality of Life Brief Measure (WHOQOL):** A measure created by The WHOQOL Group (1998) to measure quality of life across global settings and in multiple areas of a person's life.

These are not all. They are the ones that stick out that I remember on short notice.

I know there are more, & I know my mother has those stories.

"I don't think it's asthma, just too much fat on her heart." Age 14-14 2<sup>nd</sup>

"160 pounds in 2 weeks is probably just water weight." Age 16 160<sup>th</sup> → up 34<sup>th</sup> from starvation 1 yr prior, but felt most happy @ that 160<sup>th</sup>.

I also know that I still avoid doctor appointments if I can.

"You just need to lose weight. There's nothing wrong." After seeking help for a rapid 25<sup>th</sup> weight gain 4 mos postpartum & was on the lowest diet. (fat free)

"Well, if you lose more weight than you already have, that pain will probably go away." 4/0 numbness in my leg where there is a lump of adipose tissue → I had just lost 50<sup>th</sup> & never had that problem. (It hasn't gone away.)

Somehow I feel unsafe going, due to not weight trauma that I can't recall.

ME to every practitioner I have had since 2000

"I AM A FAT PERSON AND HAVE BEEN CONSIDERED THAT SINCE I WAS 5, NO MATTER HOW LOW THE SCALE GOT, CHECK EVERY COMPLAINT 1<sup>st</sup> BEFORE YOU TELL ME TO CHANGE MY WEIGHT."

I also know that the practitioners I currently have help me work through my own body shame & treat me for what I'm there for.

Artwork by Gretchen, Participant 4

## Glossary References

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Artwork by Tori, Participant 7

“This was a powerful experience for me. It was the first time I felt truly validated in my experiences as someone with an ED and courage to seek help. That I wrote this... while eating lunch feels like a testament to the impact of my participation in this study had on me.”

—Hope, Participant 13



Artwork by Eli, Participant 14

“So, the very first time I felt like I’ve ever been heard and understood and believed by a health care professional was seeing my nutritional therapist and my regular therapist too... and it’s the first time I’ve ever like had my anxiety and food thoughts calmed down and realized that it’s disordered.” –Carly, Participant 9

University of Washington School of Social Work  
4101 15<sup>th</sup> Ave. NE  
Seattle, WA 98105-6299

erind2@uw.edu  
erin.harrop@du.edu  
erinharrop@gmail.com

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**EDUCATION**

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PhD	<b>University of Washington</b> Qualitative Research Concentration completed 2018 <i>Dissertation:</i> "Maybe I really am too fat to have an eating disorder:" A mixed methods study of weight stigma and healthcare experiences in a diverse sample of patients with atypical anorexia	August 2020
MSW	<b>University of Washington</b> Mental Health Concentration Certified Prevention Professional Certificate completed in 2014 <i>Master's Thesis:</i> Follow-up difficulty and retention: Evaluating potential attrition bias in a longitudinal substance abuse treatment study	June 2014
BS	<b>University of Washington</b> Psychology	June 2010

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**HONORS, AWARDS, GRANTS, & FELLOWSHIPS**

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**RESEARCH GRANTS & FELLOWSHIPS**

<b>Academy of Eating Disorders RSH Scholarship: \$5,000</b> Dissertation support for those with career related to the prevention or treatment of eating disorders, or the amelioration of weight bias. Role: PI	08/2019
<b>NIH TL1 Translational Research Training Program Fellowship: \$41,344</b> National Center For Advancing Translational Sciences Award Number TL1 TR002318. Tuition support, research expenses, and living expenses for project: "Examining patient perceptions of patient-provider interactions: A mixed-methods study of women's experiences in treatment for Atypical Anorexia." Role: PI.	03/2018-02/2019
<b>Association for Size Diversity and Health Research Grant: \$1,500</b> Funded through Health at Every Size® (HAES®) Expansion Fund to support research supporting HAES® education, community HAES® advocacy, and tomorrow's leaders and advocates. Role: PI.	12/2018

<b>NIH TL1 Translational Research Training Program Fellowship: \$35,032</b> National Center For Advancing Translational Sciences Award Number TL1 TR002318. Tuition support, research expenses, and living expenses for project: "Examining patient conceptualizations of eating disorder and remission processes: A mixed-methods study of women's experiences with Atypical Anorexia." Role: PI.	06/2017-02/2018
<b>UW Leadership in Adolescent Health Fellowship: \$6,000</b> Fellowship by Health Resources & Services Administration and Maternal Child Health Bureau for interdisciplinary training in adolescent health.	09/2013-06/2014
<b>Mary Gates Scholar, Mary Gates Research Grant: \$2,000</b> Awarded for work in Dr. Mizumori's lab on the project: "Hippocampal and Ventral Tegmental Area Interactions and Spatial Learning." Role: PI	09/2009-02/2010

## TEACHING AWARDS

<b>Students' Choice Teaching Award (MSW), Nomination</b> Competitive award for MSW instructors, nominated by students.	2020
<b>Excellence in Teaching Award, Finalist</b> University-wide competitive award for instructors, nominated by students.	2018
<b>Students' Choice Teaching Award (MSW), Nomination</b> Competitive award for MSW instructors, nominated by students.	2018
<b>Outstanding Teaching Evaluations Spring 2017</b> Memorandum recognizing instructors with highest student evaluations.	2017
<b>Excellence in Teaching Award, Nomination</b> University-wide competitive award for instructors, nominated by students.	2017

## OTHER GRANTS, AWARDS, AND HONORS

<b>Group for the Advancement of Doctoral Education in Social Work Award for Student Leadership and Service, Honorable Mention</b> One honorable mention is awarded by GADE for a doctoral student demonstrating significant leadership in service to their School, University, or professional or academic associations.	2020
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<b>Distinguished Publication Award</b> Competitive award from the Association for Women in Psychology, honoring the special issue of Women & Therapy (“Making Space for Every Body”) in which my publication was featured (Harrop, 2018)	2020
<b>Group for the Advancement of Doctoral Education in Social Work Award for Student Leadership and Service, Nomination</b> Competitive, nominated by the University of Washington School of Social Work	2020
<b>Institute of Translational Health Sciences Travel Award</b> Competitive, full funding to attend national conference.	2019
<b>UW Graduate and Professional Student Senate Travel Grant</b> Travel grant to attend conferences. \$300	2019
<b>National Ass’n for the Advancement of Fat Acceptance Travel Award</b> Competitive, funding to attend national conference. \$289	2019
<b>UW Graduate and Professional Student Senate Travel Grant</b> Travel grant to attend conferences. \$300	2018
<b>UW Graduate and Professional Student Senate Travel Grant</b> Travel grant to attend conferences. \$300	2017
<b>Patient Centered Outcomes Research Institute Trainee Scholarship</b> Travel grant to attend training and annual PCORI conference.	2017
<b>UW Kath Wilham Doctoral Student Advanced Training Grant</b> Competitive funds for travel to international presentations. \$1,000	2017
<b>UW Graduate and Professional Student Senate Travel Grant</b> Travel grant to attend conferences. \$300	2015
<b>UW Graduate School Fund for Excellence and Innovation Fellowship</b> Competitive funds: full tuition paid plus living expenses stipend. \$9,334	2014
<b>University of Washington Leadership Education in Adolescent Health</b> Competitive Funds: Travel grant to attend LEAH National Conference.	2014
<b>UW Master of Social Work Tuition Fellowship</b> Competitive funds: Elizabeth Ann Roberts Endowed Fellowship. \$4,866 Competitive funds by: School of SW Students First Endowment. \$4,866	2012-2014

Quarterly Dean's List

2003, 2009

Pitzer College Presidential Scholarship

2002-3, 2004

## PUBLICATIONS & PRESENTATIONS

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### PEER-REVIEWED PUBLICATIONS

- Webster, K. L. W., Shields, M. C., **Harrop, E. N.**, Silverman, R., Love, A., & Lau, B. (Accepted). LGBTQ healthcare equality barriers and advancements. *Journal of Medical Systems*.
- Harrop, E.** (2018). Typical-atypical interactions: One patient's experience of weight-bias in an inpatient eating disorder treatment setting. *Women & Therapy*.  
DOI 10.1080/02703149.2018.1524068
- Harrop, E. N.** & Catalano, R. F. (2016). Evidence-based prevention for adolescent substance use. *Child and Adolescent Psychiatric Clinics of North America*, 25(3), 387-410. doi: 10.1016/j.chc.2016.1003.1001
- Grow, J. C., Collins, S. E., **Harrop, E. N.**, & Marlatt, G. A. (2015). Enactment of home practice following mindfulness-based relapse prevention and its association with substance-use outcomes. *Addictive Behaviors*, 40, 16-20. doi: 10.1016/j.addbeh.2014.07.030
- Bowen, S. Witkiewitz, K., Clifasefi, S. L., Grow, J., Chawla, N., Hsu, S. H., Douglas, H., **Harrop, E. N.**, Collins, S. E., Lustyk, M. K., & Larimer, M. E. (2014). Relative efficacy of mindfulness-based relapse prevention, standard relapse prevention and treatment as usual for substance use disorders. *Journal of the American Medical Association—Psychiatry*, 71(5), 547-556. doi: 10.1001/jamapsychiatry.2013.4546
- Witkiewitz, K., Bowen, S., **Harrop, E. N.**, Douglas, H., Enkema, M., & Hendrickson, C. (2014). Mindfulness-based treatment to prevent addictive behavior relapse: Theoretical models and hypothesized mechanisms of change. *Substance Use and Misuse*, 49(5), 513-524. doi: 10.3109/10826084.2014.891845
- Harrop, E. N.** & Marlatt, G. A. (2010). The comorbidity of substance use disorders and eating disorders in women: Prevalence, etiology, and treatment. *Addictive Behaviors*, 35(5), 392-8. doi: 10.1016/j.addbeh.2009.12.016

### BOOK CHAPTERS

- Norman, S., **Harrop, E. N.**, Chabot, A., Lansing, A., Myers, U., Rodgers, C., et al. (2019). Development of sexual relationships. In Brown, S. & Zucker, R. A. (eds.) *The Oxford handbook of adolescent substance abuse*. New York, New York: Oxford University Press. doi: 10.1093/oxfordhb/9780199735662.001.0001
- Catalano, R. F., Speaker, E. C., Skinner, M. L., Bailey, J. A., Hong, G., Haggerty, K. P., Guttmanova, K., & **Harrop, E. N.** (2018). Risk and protective factors for adolescent marijuana use. In K. C. Winters' and K. A. Sabet's (Eds) *Contemporary health issues on marijuana* (pp. 219-235). New York, New York: Oxford University Press.



- Walker, L., & **Harrop, E. N.** (2016). Chapter 63: Adolescent and young adult substance use and abuse. In L. Neinstein, D. K., Katzman, T. Callahan, C. Gordon, A. Joffe, & V. Rickert's (Eds.), *Neinstein's adolescent and young adult health: A practical guide (6<sup>th</sup> edition)* (pp.1-12). New York, New York: Lippincott Williams & Wilkins. ISBN: 9781451190083
- Bowen, S., Enkema, M., Roos, K., Douglas, H., **Harrop, E. N.**, & Kholodkov, T., & Witkiewitz, K. (2016). Chapter 8: Addictive disorders. In M. A. West's (Ed.), *The psychology of meditation: Research and practice* (pp. 177-191). Oxford, UK: Oxford University Press. ISBN: 9780191002779
- Harrop, E. N.**, Urquhart, G. B., Enkema, M. C., & Clifasefi, S. L. (2013). Twin studies and the heritability of substance use disorder. In P. M. Millers' (Ed.), *Biological research on addiction* (pp. 475-487). Elsevier. doi: 10.1016/B978-0-12-398335-0.00047-9

## UNDER REVIEW

- Harrop, E. N.**, Mensinger, J., Moore, M., & Lindhorst, T. Restrictive eating disorders in higher weight persons: A systematic review of atypical anorexia literature. Manuscript completed. *International Journal of Eating Disorders*.

## WORKS IN PROGRESS

- Harrop, E. N.**, Hutcheson, R., Harner, V., & Franz, N. "You don't look anorexic": Enacted and internalized experiences of weight stigma in medical care for patients with Atypical Anorexia. Manuscript completed; to be submitted to *Social Science and Medicine*.
- Dios, E., **Harrop, E. N.**, & Dotolo, D. "Doctor-prescribed and mother-encouraged": Interpersonal interactions and body image concerns in higher weight clients with eating disorders. Manuscript completed; preparing for submission. To be submitted to the *Journal of Social Work Education and Practice*.
- Harris, H., Lee, J., & **Harrop, E.** "This is the path you go on.": A qualitative study of Mormon religiosity and female member educational attainment. Manuscript completed; preparing for submission. To be submitted to the *Journal of Social Work Education*.
- Harrop, E. N.** & LaMarre, A. The "face" and "place" of eating disorder recovery: A critical discourse analysis of eating disorder treatment center promotional materials. First draft completed. To be submitted to *International Journal of Eating Disorders*.
- Harrop, E. N.**, Kuklinski, M., Walker, L., & Catalano, R. F. "We've made it this far. What could go wrong now?" A qualitative analysis of adolescents', parents', and providers' perceptions of risk for chronically ill teens. To be submitted to *Journal of Adolescent Health*.
- Harrop, E. N.**, Henretty, J., LaMarre, A., & Atkins, J. Weight Matters: Examining issues of weight bias in eating disorder research methodologies and treatment contexts. Draft in preparation.
- Harrop, E. N.**, Walker, L., Kuklinski, M., & Catalano, R. F. Meds, myths and marijuana: Adolescents with chronic illnesses talk medication management. Analysis completed; manuscript first draft in preparation.



## OTHER PUBLICATIONS

- Harrop, E. N.** (2019 March). Recovering abundantly in a one-size-fits-all world. Blog co-sponsored by the Association for Size Diversity and Health and the National Eating Disorder Association:  
<https://healthateverysizeblog.org/2019/03/07/the-haes-files-recovering-abundantly-in-a-one-size-fits-all-world/>  
<https://www.nationaleatingdisorders.org/blog/recovering-abundantly-one-size-fits-all-world>
- Harrop, E. N.** (2019). 27 weeks, 761 grams, and 104 days: On redefining “progress” and accepting loss. In E. Coplan’s, *Grief Dialogues: Stories on Love and Loss*.
- Harrop, E. N.** (2018 July). Getting my feet wet: Journeying from HAES® to social justice. Blog sponsored by the Association for Size Diversity and Health:  
<https://healthateverysizeblog.org/2018/07/>
- Harrop, E. N.** (2017). Creative and meditative processes: Reflections on leaving things untitled and unsigned. In, Modaro, L., Keyes, J., Liepman, W., & **Harrop, E. N.’s** (Eds.), *Reflective Meditation: A Creative Path for Mindful Practice*. Online eJournal.
- Harrop, E. N.** (2016). Featured Artist: A different language. *Cascadia Subduction Zone*, 6(1), 20-22.
- Harrop, E. N.** (2014). *Follow-up difficulty and retention: Evaluating potential attrition bias in a longitudinal substance abuse treatment study* (Master’s Thesis, University of Washington).
- Harrop, E. N.** (2013). Illustrations: Cover “Image reflected”, interior “Wasteland”, interior “Woman reading.” In J. Vanderhooft’s (Ed.), *The WisCon Chronicles, (Vol. 7): Shattering ableist narratives*. Seattle, WA: Aqueduct Press. ISBN: 978-1-61976-042-4
- Duncan, Erin.** (2004). “Propositions.” *In the Fray*. December 2004. Online magazine.

## MEDIA

- Sole-Smith, V. (5 August 2019). Who’s considered thin enough for eating disorder treatment? *Medium*. (Interview with **E. N. Harrop** featured in this article). Accessible at:  
<https://elemental.medium.com/whos-considered-thin-enough-for-eating-disorder-treatment-4be7f98e4d98>
- Dennett, C. (20 February 2019). Anorexia knows no body type—and thinking otherwise can be a barrier to treatment. *The Seattle Times*. (Research by **E. N. Harrop** featured in this article). Accessible at: <https://www.seattletimes.com/life/wellness/anorexia-knows-no-body-type-and-thinking-otherwise-can-be-a-barrier-to-treatment/>
- Hobbes, M. (19 September 2018). Everything you know about obesity is wrong. *The Huffington Post*. (Research by **E. N. Harrop** featured in this article). Accessible at: <https://high-line.huffingtonpost.com/articles/en/everything-you-know-about-obesity-is-wrong/>
- Feldman, J. (25 September 2018). ‘Someone has to speak up for us’: What it’s like to change the picture of obesity with your photo. *The Huffington Post*. (Featured interview with **E. N. Harrop**). Accessible at: [https://www.huffingtonpost.com/entry/obesity-article-photos-huffpost\\_us\\_5ba9011fe4b0181540df3a22?of0](https://www.huffingtonpost.com/entry/obesity-article-photos-huffpost_us_5ba9011fe4b0181540df3a22?of0)
- Harrison, C. (17 December 2018). The truth about high-weight anorexia with **Erin Harrop**. (Featured interview). *Podcast: Food Psych #178*. Accessible at: <https://christyharri-son.com/foodpsych/6/the-truth-about-atypical-anorexia-with-erin-harrop>

- Harrop, E. N.,** Umhau, C., & Church, J. (18 Jan 2018). The Appetite Episode #07: **Erin Harrop**, MSW, BS on weight stigma, fatness, and an intersectional lens into eating disorders. Interview with Julie Church, and Carter Umhau. An Opal: Food+Body Wisdom Podcast. Accessible at: <http://www.opalfoodandbody.com/podcast/appetite-interview-erin-harrop/>
- Aina, M. (23 Feb 2017). What does a healthy body look like? Featured interview with **E. N. Harrop** in the University of Washington's publication, *The Daily*. Accessible at: [http://www.dailyuw.com/wellness/article\\_8d4e7b2c-f977-11e6-8db7-ebd7071e458b.html](http://www.dailyuw.com/wellness/article_8d4e7b2c-f977-11e6-8db7-ebd7071e458b.html)
- Jenkins, S. (2 Feb 2017). Sizeism and Weightism Advocacy Group leads body stigmatization workshop. Featured interview with **E. N. Harrop** in the University of Washington's publication, *The Daily*. Accessible at: [http://www.dailyuw.com/news/article\\_715dd340-e900-11e6-bc4e-2b4f83ddfd31.html](http://www.dailyuw.com/news/article_715dd340-e900-11e6-bc4e-2b4f83ddfd31.html).
- Senkler, R. (2012). American culture 101: Eating disorders on college campuses. Featured interview with **E. N. Harrop** in *International Student Voice Magazine*. Accessible at: <http://www.isvmag.com/2012/08/americanculture101eatingdisorders/>
- Norimine, H. A clearer image. Featured interview with **E. N. Harrop** in the University of Washington's publication, *The Daily*. Accessible at: [http://www.dailyuw.com/features/article\\_f63a817b-da1c-5d0a-a8b4-f5255e924e12.html](http://www.dailyuw.com/features/article_f63a817b-da1c-5d0a-a8b4-f5255e924e12.html)

## POSTERS & PRESENTATIONS

- Kenny, T. E., LaMarre, A., Hower, H., **Harrop, E. N.,** & Bachner-Melman, R. (2020). *Taking a different perspective on recovery*. Workshop presentation for the International Conference of Eating Disorders. June 2020 (held virtually).
- Harrop, E. N.,** Harner, V., & Bishop, A. (2020, accepted). *Research methods 101: Integrating a social justice lens into foundation research courses*. Workshop presentation for Council on Social Work Education Annual Program Meeting. October 2020, Denver, CO.
- Harrop, E. N.** (2019). Patient perceptions of healthcare interactions among higher-weight women with eating disorders. Oral presentation for Council on Social Work Education Annual Program Meeting. October 24-27, 2019, Denver, CO.
- Harrop, E. N.** & Mensinger, J. M. (2019). *Restrictive eating disorders in higher-weight persons: A systematic review of Atypical Anorexia literature*. Poster presented at Eating Disorders Research Society Annual Conference. September 6-8, 2019, Chicago, IL.
- Harrop, E. N.** (2019). *Restricted from (health) care: Experiences of weight stigma in medical care*. Oral presentation at National Association for the Advancement of Fat Acceptance Conference. June 14-16, 2019, Las Vegas, NV.
- Harrop, E. N.** (2019). *Anorexia Nervosa in larger bodies*. Oral presentation at Multi-Service Eating Disorder Association. April 12-13, 2019, Boston, MA.
- Harrop, E. N.** (2019). *Patient perceptions of healthcare provider interactions among higher-weight women with eating disorders: Opportunities for earlier screening, improved referral, and increased clinician rapport*. Poster presented at Translational Sciences 2019. March 5-8, Washington, D. C.

- Harrop, E. N.** (2019). *Patient perceptions of healthcare provider interactions among higher-weight women with eating disorders: Opportunities for earlier screening, improved referral, and increased clinician rapport*. Poster presented at the ITHS (Institute of Translational Health Science) Translational Science Expo in Seattle, WA.
- Harrop, E. N. & Kinavey, H.** (2019). *Confronting weight bias and treating eating disorders in higher-weight patients*. 1 hour continuing education conference for EDPro Symposium, national continuing education for eating disorder specialists.
- Harrop, E. N., Aby, M., Willey-Sthapit, C., Lindhorst, T.** (2019). *Leveraging the reflexive self in research: Reflections on cultivating a self-reflexive practice*. Roundtable presented at the 23rd Annual Conference of the Society for Social Work and Research, January 16-20, 2019 in San Francisco, CA.
- Mensinger, J., Tylka, T., Calogero, R., & **Harrop, E. N.** (2019). *Internalized weight stigma and intuitive eating explain lower eating disturbances among higher BMI clients in healthy living program*. Paper presented at the International Conference of Eating Disorders in New York, NY, 2019.
- Ellis-Ordway, N., **Harrop, E. N.**, Clark, D., Collins, L., & Dios, E. (2018). *Weight stigma and social justice 101*. Presentation at the 2018 Association for Size Diversity and Health conference in Portland, OR.
- Flores, A., **Harrop, E. N.**, Largess, C., Millner, R. (2018). *Plenary: All bodies affected; Not all bodies accepted: Inequality of eating disorder treatment for higher-weight populations and solutions toward accessibility*. Plenary at the 2018 Association for Size Diversity and Health Conference in Portland, OR.
- Harrop, E. N.** (2018). *Recruiting participants for a longitudinal mixed-methods study of Atypical Anorexia: Baseline characteristics, demographics, and eating disorder severity*. Poster presented at the Association for Size Diversity and Health Conference in Portland, OR.
- Dios, E., & **Harrop, E. N.** (2018). *Disordered eating and mental health: Psychological comorbidity study in higher weight women with restrictive eating disorders*. Poster presented at the 2018 Association for Size Diversity and Health Conference in Portland, OR.
- Harrop, E. N.** (2018). *Recruiting participants for a longitudinal mixed-methods study of Atypical Anorexia: Baseline characteristics, demographics, and eating disorder severity*. Poster presented at the ITHS (Institute of Translational Health Science) Translational Science Expo in Seattle, WA.
- Harrop, E. N.**, Clark, D. M., & Church, J. (2018). *Fat Allyship 101: How to Advocate for Body Justice in Whatever Bod You've Got*. Workshop presented at the 2018 Association for Size Diversity and Health Conference in Portland, OR.
- Harrop, E. N.**, Church, J., Kinavey, H., LaMarre, A., Mensinger, J., Underhill-Turner, C. (2018). *"But what if my patient gets fat?": Research and clinical implications of weight stigma in treating higher-weight patients with eating disorders*. Workshop presentation at the Academy of Eating Disorders Conference, April 19-21, 2018 in Chicago, IL.
- Millner, R., **Harrop, E. N.**, Cool, C., Flores, A., & Kirkpatrick, M. (2018). *Exploring recovery through a Health at Every Size and fat acceptance lens: What we can learn from recovered professionals who identify as HAES-oriented and fat positive*. Workshop presentation at the Academy of Eating Disorders Conference, April 19-21, 2018 in Chicago, IL.

- Harrop, E. N. & LaMarre, A. (2018).** *Painting pretty pictures of recovery: A critical discourse analysis of eating disorder treatment center promotional materials.* Oral presentation, publication #10, at the 2018 Annual Meeting of the Society for Adolescent Health and Medicine in Seattle, WA.
- Harrop, E. N., Walker, L., Kuklinski, M., & Catalano, R. F. (2018).** *"We've made it this far. What could go wrong now?" Adolescents', parents' and providers' perceptions of substance use risk factors for chronically ill teens.* Poster presentation, publication #268, at the 2018 Annual Meeting of the Society for Adolescent Health and Medicine in Seattle, WA.
- Willey-Sthapit, C., **Harrop, E. N.,** Ercin, H., & Lindhorst, T. (2018). *Beyond coding: Alternative hermeneutics for qualitative data analysis.* Workshop presented at the 22nd Annual Conference of the Society for Social Work and Research, January 10-14, 2018 in Washington, DC.
- Harrop, E. N. & LaMarre, A. (2017).** *The "face" and "place" of eating disorder recovery: A critical discourse analysis of eating disorder treatment center promotional materials.* Oral presentation at the Academy of Eating Disorders Conference, June 8-10, 2017 in Prague, Czech Republic.
- Harrop, E. N.,** Henretty, J., LaMarre, A., & Atkins, J. (2017). *Weight matters: Examining issues of weight bias in eating disorder research methodologies and treatment contexts.* Oral presentation at the International Weight Stigma Conference June 6-7, 2017 in Prague, Czech Republic.
- Harrop, E. N. (2016).** *Walking with SWAG (Sizeism Weightism Advocacy Group): Examining the challenges and successes facing a student-led sizeism advocacy group.* Oral presentation workshop presented at the International Weight Stigma Conference April 29-30, 2016 in Vancouver, BC.
- Harrop, E. N.,** Walker, L., Catalano, R. F., & Haggerty, K. (2014). *Meds, myths and marijuana: Adolescents with chronic illnesses talk medication management.* Poster presented at Society for Adolescent Health and Medicine in March 2015 in Los Angeles, CA.
- Harrop, E. N.,** Walker, L., Catalano, R. F., & Haggerty, K. (2014). *Meds, myths and marijuana: Adolescents with chronic illnesses talk medication management.* Poster presented at Clinical Pediatrics, Family, and Emergency Medicine Conference. September 2014, Vancouver, B. C.
- Bowen, S. & **Harrop, E. N. (Co-Chairs).** (2012). *Meditation and mindfulness-based interventions in diverse populations and settings: Questioning assumptions and adapting practices.* Association for Behavioral and Cognitive Therapies (ABCT) Conference. Speakers: Brewer, J., Brown, K. W., Mistler, L. A., Reese, H., Schuman-Oliver, Z. D., & Sibinga, E. M.
- Douglas, H. A. C., Shilling, B., **Harrop, E. N.,** Bowen, S., Chawla, N., Marlatt, G. A., & Lustyk, M. K. (2011). *Cardiovascular responses to a laboratory stressor in substance abusers after treatment with Mindfulness-Based Relapse Prevention.* Poster presented at annual convention of the Association for Behavioral and Cognitive Therapies, Toronto.

## OTHER PRESENTATIONS & TRAININGS

- Harrop, E. N. (2019).** *Healing for all: Weight stigma in eating disorder treatment.* 1 hour invited presentation for graduate students at Bastyr University.
- Harrop, E. N. (2019).** *Body "isms": Engaging intersectionality around race, culture, gender, class, age, and size.* 1 hour invited presentation for graduate students at Bastyr University.

- Harrop, E. N. (2018).** *Enhancing ethical and evidence-based medicine across the weight spectrum: Critically examining weight stigma in clinical practice.* Invited lecture at Seattle Children's Diversity "Lunch and Learn," May 11, 2018.
- Harrop, E. N., & Conner, E. (2017).** *Health at Every Size 101: Weight-neutral approaches to wellbeing in the health sciences.* As part of the SWAG: Sizeism, Weightism Advocacy Group 2017 workshop series. Presented at UW School of Social Work, May 2017.
- Church, J. & Harrop, E. N. (2017).** *Navigating the complexity of weight and health.* Invited presentation for University of Washington, The Whole U. February 2017 in Seattle, WA.
- Harrop, E. N. & Collins, L. (2017).** *The journey from body shame to body acceptance.* As part of the SWAG: Sizeism, Weightism Advocacy Group 2017 workshop series. Presented at UW School of Social Work, March 2017.
- Harrop, E. N. & Collins, L. (2017).** *Body-Isms: The intersection of size- and weight-based stigmas and other identities.* As part of the SWAG: Sizeism, Weightism Advocacy Group 2017 workshop series. Presented at UW School of Social Work, February 2017.
- Harrop, E. N. (2016).** *Body-isms: Positioning size- and weight-based stigma at the intersection of gender, race, ethnicity, class, age, and ability-status.* Oral presentation workshop presented at the University of Washington's Office of Minority Affairs and Diversity's First-Year Retreat on October 1-2, 2016 in Auburn, WA.
- Harrop, E. N. (2016).** *Engaging size- and weight-based stigma in healthcare: The practitioner/client relationship.* 1 hour continuing education presentation, presented to dietitians at Seattle Children's Hospital in May 2016.
- Harrop, E. N. (2015).** *Body "isms": Engaging intersectionality around race, culture, gender, class, age, and size.* 1.5 Hour continuing education presentation, presented to Seattle Children's Hospital social workers in August 2015.
- Harrop, E. N. (2013).** *Retention strategies in chemically dependent populations: Exploring client reengagement.* Poster presented at University of Washington Master of Social Work Research Presentation.
- Kreiter, A., Harrop, E. N., & Askin, D. (Panelist). (2013).** *Intersections: Connecting body diversity & LGBTQ.* Hosted by: Social Outreach Seattle with Gender Justice League, UW Sizeism/Weightism Advocacy Group, Seattle Gay News, The Seattle Lesbian, Gay City Health Project, kapchur.us photography Studio Current, and Ayuthaya Thai.

## RESEARCH INTERESTS & EXPERIENCE

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### Research Interests

Medical social work, eating disorders, substance use, weight stigma, prevention science, adolescent health, health communication, intersectionality, mixed methods, longitudinal qualitative.

### Research Experience

<b>TL1 TR002318: WINTER: Women's Illness Narratives through Eating Disorder and Remission</b>	2017-present
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Dissertation: longitudinal (12-month) mixed-methods study of eating disorder patients utilizing 3 qualitative interviews and 7 quantitative surveys.  
 Role: PI, Committee: Drs. Taryn Lindhorst, Janell Mensinger, Megan Moore 2017-present

**Systematic Review of Atypical Anorexia Literature**  
 PRISMA systematic review for qualifying exam.  
 Role: PI, Committee: Drs. Taryn Lindhorst, Janell Mensinger, Megan Moore, Richard Catalano 2016-present

**Discourse Analysis of Eating Disorder Recovery Centers**  
 Critical discourse analysis of eating disorder treatment center promotional materials and websites.  
 Co-PI: Erin N. Harrop, MSW, Co-PI: Andrea LaMarre, PhD 2016

**NIDA 5RO1-DA015183-13 Community Youth Development Study**  
 Social Development Research Group, University of Washington  
 Content analysis of 4000 open-ended responses of young adults, coding for themes of substance use, substance use problems, and recovery.  
 Role: Data Analyst, PI: Sabrina Oesterle, PhD 2014-2017

**Framing of News Media Coverage on Suicide, 1991-2012**  
 Forefront Suicide Prevention, UW Royalty Research Fund Grant  
 Content analysis of 400 articles about suicide, analyzing the journalistic frames employed and use of prevention principles in media reporting.  
 Role: Research Assistant, Co-PIs: Drs. Jennifer Stuber, Randol Beam 2013-2016

**Adapting Guiding Good Choices for Chronically Ill Adolescents**  
 Children's Hospital, Social Development Research Group  
 Focus group study with chronically ill adolescents, their parents, and medical providers regarding program adaptation; thematic analysis.  
 Role: PI, Mentors: Richard Catalano, PhD; Leslie Walker, M.D. 2013-2014

**Potential Attrition Bias: Follow-Up Difficulty and Retention**  
 Master's thesis evaluating potential attrition bias in a longitudinal substance use intervention study.  
 Role: PI, Committee: Drs. Betsy Wells, Richard Catalano, Sarah Bowen 2010-2014

**R01 DA025764-01A1 Mindfulness-Based Relapse Prevention: Efficacy and Mechanisms**  
 Randomized controlled trial comparing the efficacy of three interventions for substance use and their associated mechanisms.  
 Role: Research Assistant, PI: Sarah Bowen, PhD 2011-2012



**NCT01402492 (CTN 48) Cocaine Use Reduction with Buprenorphine**

Randomized clinical trial testing the use of buprenorphine and vivitrol for the treatment of opioid use disorders.

Role: Research Assistant, Co-PI: Andrew Saxon, MD

2010-2011

**Evaluating Protocol Adherence in Alcohol Skills Training Program**

Qualitative coding for fidelity analysis for an empirically based intervention for alcohol abuse prevention.

Role: Research Assistant, PI: Diane Logan, PhD

2009-2010

**Mizumori Lab: Dopaminergic Circuitry and Spatial Memory**

Neuroscience study of how hippocampal and ventral tegmental area interactions impact spatial learning in rats.

Role: Research Assistant, PI: Adria Martig, PhD

2008-2009

**Insulin Regulation and Alzheimer's Disease**

Veterans Affairs Medical Center, Memory Wellness Program

Role: Research Assistant, PI: Suzanne Craft, PhD

## TEACHING INTERESTS & EXPERIENCE

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**Teaching Interests**

Critical pedagogy, mindfulness, research methods integrating social justice, fat studies.

**Teaching Experience****PRACTICE COURSES****Micro/Meso Social Work Practice 2: Families/Groups, Sole Instructor (MSW)**

Winter 2020

Skills for practice with families, small groups and service delivery systems to promote self-determination, functioning, and quality of life.

**Micro/Meso Social Work Practice 1: Individuals, Sole Instructor (MSW)**

Autumn 2019

Foundation skills: person-centered practice, engagement, relationship building, interviewing, assessment, and intervention planning.

**Advanced Social Work Practice in Health Settings, Teaching Practicum (MSW)**

Autumn 2017

Strengths-based practice in healthcare settings from biopsychosocial, multi-cultural, family systems, contextual, and lifespan perspectives.

<b>Community Service Learning, Teaching Assistant (BASW)</b>	Spring 2015
Apply social work theory to practice through the completion of community-based projects in social work-type agencies.	Winter 2015

## METHODS COURSES

<b>Social Welfare Research and Evaluation, Sole Instructor (MSW)</b>	Spring 2020
Emphasizes critical appraisal of literature, strategies for conducting practice-relevant research, including data collection and analysis.	Spring 2019
	Spring 2017

<b>Social Welfare Research and Evaluation, Course Tutor (MSW)</b>	Winter 2019
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<b>Foundations of Social Welfare Research, Sole Instructor (MSW)</b>	Winter 2017
Overview of research process/methods in social work, with focus on development of useful research questions about social work practice.	

<b>Quantitative Techniques in Sociology, Course Tutor (PhD)</b>	Spring 2016
Applied regression analysis with emphasis on interactive computer graphics techniques, interpretation. Application to sociological problems.	

<b>Applied Social Statistics, Course Tutor (PhD)</b>	Winter 2016
Analysis with imperfect data, probability in statistical inference, analysis of variance; contingency tables, nonparametric procedures; regression.	

<b>Intro to Probability and Statistics for Psychology, Teaching Assistant</b>	Winter 2010
Probability theory and scientific inference: conditional probability, binomial distributions, sampling distributions, confidence intervals.	

## POLICY COURSES

<b>Poverty and Inequality, Course Tutor and Grader (MSW)</b>	Winter 2016
Examines causes of poverty, role of policy, and dimensions of economic stratification (e.g. race, ethnicity, class, gender, disability, age, etc.).	Winter 2014
	Autumn 2013

<b>Social Welfare &amp; Practice with Communities &amp; Organizations, Teaching Assistant (BASW)</b>	Spring 2014
Generalist perspective of macro systems in a diverse society, including implications of system resources, & strategies for meeting human needs.	

## INTERPROFESSIONAL & MISCELLANEOUS COURSES

<b>Interprofessional Education, Weight Bias, Co-Instructor</b>	2019-2020
Class for 150 interprofessional health science students in weight bias.	



### **Interprofessional Education, Co-Instructor**

Year-long class for health science students to learn interprofessional communication and cooperation in the healthcare field.

Spring 2020

Autumn 2013

Winter 2014

Spring 2014

Summer 2004

### **Introductory Composition, Teaching Assistant**

Development of writing skills: sentence strategies and paragraph structures. Expository, critical, and persuasive essay techniques.

## **STUDENT MENTORSHIP**

1. **Haylee Harris**, Master's Thesis Committee Member. Thesis: *A Phenomenological study of the effects of religiosity and faith transition on the educational attitudes of Mormon women.* 2018-2020
2. **Elizabeth Dios**, Master's Thesis Committee Member. Thesis: *'Doctor-prescribed and mother-encouraged.': Interpersonal interactions and body image concerns in higher weight clients with eating disorders.* 2017-2019
3. **Meredith Bluementhal**, Master's Thesis Committee Member. Thesis: *Patient perspectives on nutrition professionals' attitudes and phenotypes during treatment for Atypical Anorexia.* 2018-2020
4. **Noahloni Garcia**, Research Mentor. Project: *Ways healthcare system affects participants with a history of atypical anorexia, and intersecting identities of their gender identity and sexual orientation.* 2019-2020
5. **Priyanka Ghosh**, Research Mentor. Project: *The intersections of race and weight bias in a diverse sample of patients with a history of atypical anorexia.* 2019-2020
6. **Natalie Franz**, Research Mentor. Project: *"You don't look anorexic": Enacted and internalized weight stigma in medical care for patients with Atypical Anorexia.* 2016-2018
7. **Maria Cortes**, Research Mentor. Project: *Demographic and weight characteristics of higher-weight women with restrictive eating disorders.* 2018
8. **Sara Gorcos**, Research Mentor. Project: *Psychosocial impairment in higher weight adult women with restrictive eating disorders.* 2018
9. **Lauren Collins**, Research Mentor. Project: *Do no harm: Exploring weight stigma in the clinical context.* 2014-2016
10. **Melody Saysana**, Senior Project Mentor. Project: *Be healthy, not hungry: An introduction to nutrition and eating disorders.* 2013-2014

## **GUEST LECTURES**

- Qualitative Study Design and Implementation** (1.5 hour). Class: PhD 2019  
Advanced Qualitative Methods with Taryn Lindhorst
- Self-Reflexivity in the Research Process** (1.5 hour). Class: Multi-Cohort 2018  
Doctoral Seminar with Paula Nurius, PhD

<b>From Theory to Model-Building</b> (1.5 hour). Research and Theory with Katarina Guttmanova, PhD	2018
<b>Qualitative Data Analysis</b> (3 hours, three times). Class: Research Methods II with Fernando Clara, MSW & Asia Bishop, PhD	2018
<b>Medical Social Work Career Paths and Clinical Work</b> (2 hours). Class: Intro to Social Work with Miriam Valdovinos, PhD	2015
<b>Meditation and mindfulness for the social work practitioner.</b> (1 hour). Class: Human Behavior/Social Environment, Tracy Brazg, PhD	2014
<b>Paths to Recovery from Substance Abuse</b> (1 hour). Class: Chemical dependency with Seema Clifasefi, PhD	2011
<b>Partnering with 12-step programs</b> (1 hour) Class: Chemical dependency with Seema Clifasefi, PhD	2011
<b>An introduction to 12-step programs</b> (1 hour). Class: Addictive behaviors with G. Alan Marlatt, PhD	2009

## ADDITIONAL PROFESSIONAL EXPERIENCE

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### CLINICAL EXPERIENCE

<b>Seattle Children's Hospital, Social Worker I</b> Perform biopsychosocial & mental health evaluations, grief support, resource coordination, crisis intervention, safety planning, and assess risk for child abuse and interpersonal violence. Supervisors: Deborah Doane, Gretchen Bower, Reina Dastur LICSWs	2014-present
<b>Seattle Children's Hospital Adolescent Medicine Clinic, Clinical Intern</b> Perform biopsychosocial assessments, resource coordination, crisis intervention. Conduct focus groups with adolescents and caregivers. Lead substance use prevention programming. Supervisors: Erik Schlocker, LICSW; Richard Catalano, PhD	2013-2014
<b>Fairfax Hospital, Clinical Intern</b> Perform biopsychosocial assessments, facilitate crisis intervention, lead psychoeducational groups with adolescents and adults in a locked psychiatric care facility. Supervisor: Latisha Rogers, LICSW	2012-2013
<b>Wits' End Church, Women's Sexual Abuse Support Group Leader</b> Facilitate 14-week course for adult survivors of child sexual abuse. Supervisors: Andrew Ide, M.A. and Carrie Barnes, M.A.	2009-2010

**Mount San Antonio Gardens Nursing Care Center, Clinical Intern** 2004-2005  
Facilitate support group for nursing care facility residents, engage in life-enhancing activities one-on-one with clients.  
Supervisor: Richard Tsujimoto, PhD

**ROOTS Young Adult Shelter, Intern** 2003-2004  
Supervise guests at a young adult shelter for homeless youth. Perform crisis management. Engage youth in activities.  
Supervisors: Laura Pritchard; Elissa Knight; Stephanie Saline

## OTHER PROFESSIONAL EMPLOYMENT

**Department of Defense Peer Review Medical Research Program, Reviewer** 2019-present  
Grant reviewer for grant applications for eating disorders research within the Department of Defense.

**Recovery Centers of King County: Research Assistant** 2010-2012  
Research coordinator on R01 grant testing the relative efficacy of three substance use interventions. Research assistant on a NIDA pharmacological trial.

## LICENSES & CERTIFICATIONS

**Social Worker Associate Independent Clinical License** 2014-present  
Washington State Department of Health #SC 60489854  
Currently hours have been approved for licensure, awaiting exam.

**Certified Prevention Professional** 2015-2019  
Washington State Department of Health #15-CPP-103. License representing 2,000 hours alcohol, tobacco and other drug (ATOD) prevention related experience. 120 hours supervised experience in prevention. 150 contact hours of prevention specific education/training.

## PROFESSIONAL AFFILIATIONS AND SERVICE

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### Service

### SERVICE TO SCHOOL AND UNIVERSITY

UW Graduate and Professional Student Library Advisory Committee	2019-2020
UW School of Social Work PhD Social Justice Committee Member	2017-2020
UW School of Social Work Curriculum Committee Member	2017-2018
UW Health Sciences Hogness Symposium Committee Member	2018-2019
UW School of Social Work Faculty Recruitment Committee Member	2016-2017
UW School of Social Work Awards Committee Member	2016-2017
UW School of Social Work PhD Program Committee Member	2016

## SERVICE TO PROFESSION

<i>Department of Defense Peer Review Medical Research Program</i> , Grant Reviewer.	2019-present
<i>Social Science and Medicine</i> , Ad-hoc Manuscript Reviewer.	2019
<i>Women &amp; Therapy</i> , Ad-hoc Manuscript Reviewer.	2017
<i>Psychology of Violence</i> , Ad-hoc Manuscript Co-Reviewer. (with T. Lindhorst)	2017
<i>Journal of Psychoactive Drugs</i> , Ad-hoc Manuscript Reviewer.	2016-2017
<i>Journal of Addiction Medicine and Therapy</i> , Ad-hoc Manuscript Reviewer .	2016
<i>Health Education Journal</i> , Ad-hoc Manuscript Reviewer.	2016
<i>Open Medicine Journal</i> , Ad-hoc Manuscript Reviewer.	2014
<i>Journal of Substance Abuse Treatment</i> , Ad-hoc Co-Reviewer. (with S. Bowen)	2011
<i>Psychology of Addictive Behaviors</i> , Ad-hoc Co-Reviewer. (with S. Bowen)	2011
<i>Journal of Dual Diagnosis</i> , Ad-hoc Manuscript Co-Reviewer. (with S. Bowen)	2011

## SERVICE TO COMMUNITY

National Eating Disorders Association Conference Planning Committee	2019-present
Association for Size Diversity and Health: Blog Coordinator	2018-2020
Academy of Eating Disorders: Weight Stigma and Social Justice SIG Co-Chair	2018-2022
Association for Size Diversity and Health Board Member: Secretary	2017-2018
Association for Size Diversity and Health: Conference Planning Committee	2017-present
Academy of Eating Disorders Workgroup for Addressing Size Discrimination	2017-2018
Association for Size Diversity and Health: Inclusivity Committee Member	2016-present
UW Sizeism and Weightism Advocacy Group (SWAG): President	2012-present
Department of Corrections King County Jail Volunteer Group Facilitator	2007-present
International School High School Mentor	2013-2014

## Membership in Professional Associations

International Association of Eating Disorder Professionals	2018-present
National Association for the Advancement of Fat Acceptance	2018-present
Society for Social Work and Research	2017-present
Academy for Eating Disorders	2016-present
Association for Size and Health Diversity	2015-present
Society for Adolescent Health and Medicine	2013-2018
National Association of Social Workers	2013-present
Seattle Implementation Research Conference	2011-present
American Psychological Association .	2008-present
National Eating Disorders Association	2007-present

## REFERENCES

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**Taryn Lindhorst, Professor**

Behar Professor in Integrative Oncology and  
Palliative Care Social Work  
UW School of Social Work  
4101 15th Avenue NE  
Seattle, WA 98105-6299  
tarynlin@u.washington.edu

**Megan Moore, Associate Professor**

Sidney Miller Endowed Associate Professor  
in Direct Practice  
UW School of Social Work  
4101 15th Avenue NE  
Seattle, WA 98105-6299  
mm99@u.washington.edu

**Richard F. Catalano, Jr., Professor**

UW School of Social Work  
4101 15th Avenue NE  
Seattle, WA 98105-6299  
rico@uw.edu

**Janell Mensinger, Research Professor**

Director of Biostatistics Service Center  
Drexel University  
3215 Market Street, 5th floor  
Philadelphia, PA 19104  
Janell.mensinger@villanova.edu