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Considerations in Evidence-Based Treatment of Adolescents With Atypical Anorexia Nervosa

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Title: Considerations in evidence-based treatment of adolescents with atypical anorexia nervosa

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**Bio:** Dr. Rachel Kramer is a clinical psychologist and Assistant Professor in the Department of Psychiatry and Behavioral Sciences at the University of California, San Francisco. Dr. Kramer has specialized training in eating disorders treatment, specifically (Family Based Treatment (FBT)) with adolescents. Her research examines factors that impact families during eating disorder treatment with a specific interest in atypical anorexia nervosa and understanding eating disorder pathology across the weight spectrum.

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2

Abstract

There is emerging evidence suggesting atypical anorexia nervosa (AAN), an eating disorder

(ED) introduced in the DSM-5 is as serious an ED as anorexia nervosa (AN) in terms of medical

risk and ED pathology. Medical hospitalizations among individuals with AAN have significantly

increased over the years and individuals with AAN are noted to have longer illness durations and

greater weight loss prior to receiving care than individuals with AN. Additionally, AAN is noted

to be two to three times more common than AN in community samples of adolescents. Given

AAN is a newer diagnosis, research knowledge and evidence-based treatment guidelines are

emerging, yet pivotal. Thus, this article discusses specific considerations during assessment and

treatment using Family Based Treatment (FBT) among adolescents diagnosed with AAN and

clinical and ethical concerns involved while providing effective care and mitigating any weight

bias or stigma related to historical and current weight status.

Keywords: Atypical Anorexia Nervosa, Eating Disorders, Adolescence, Family Based

Treatment, Weight Bias

# Clinical Case: Josephine

Josephine is a 16-year-old cisgender female who was admitted to a local pediatric medical hospital after fainting at school. There, she was triaged and met with an interdisciplinary eating disorder (ED) team of physicians, a dietitian, and a psychologist. Josephine's medical work-up indicated that she had bradycardia (with a heartrate in the 50s), was dehydrated and orthostatic, and was medically admitted given her symptoms. Over the first evening she was admitted (of a seven-day inpatient stay), her heart rate nadir during sleep was 35 beats per minute (BMP), with a minimal heartrate of 45 BPM being considered safe for outpatient treatment.

A review of Josephine's historic growth curve indicates that she tracked above the 85<sup>th</sup> BMI percentile (based on age-and-sex matched norms) throughout childhood and right before her ED development, weighed 150 lb (at 5 feet, 5 inches) with a BMI percentile of 86. This placed her in the "overweight" category per guidelines from the Center for Disease Control (CDC; Kuczmarski, 2000). When she presented to her PCP, having lost 30 lb, she was now a BMI percentile of 41.7 with a loss of 20% of her body weight in six months. See Figure 1.

During her clinical interview with a psychologist on her first day of admission, Josephine explained that she had lost 30 pounds over six months, with 10 of those pounds being lost in the past month. Prior to ED development, she explained a desire to lose weight for two reasons. The first being that she was teased by peers on her track team about her body weight. She also reported the desire to lose weight after a medical visit where a physician told her that she was "overweight" and needed to lose weight for her health. Josephine felt ashamed and worried about what this meant for her health and as a result, started exercising more (running up to three miles every day) on top of track practice and reducing food intake (particularly carbohydrates and fats) to lose weight. She reported her restriction over the past two months then intensified; she started

cutting down to 400 to 1000 calories a day. She denied other compensatory behaviors such as purging or laxative use. She reported an intense fear of gaining weight and frequently checked her weight as a result. She was struggling in school (poor grades and concentration) and had little motivation to socialize with friends. Her mother shared that Josephine was not herself; she appeared depressed, irritable, and anxious. Her mother reported guilt at missing her daughter's rapid weight loss but shared that her daughter refused to eat with the family and her daughter was always at track practice.

As Josephine neared medical stability, the psychologist and medical team on the inpatient unit recommended that Josephine continue ED treatment as an outpatient given that she had not been in ED treatment prior, there was no imminent safety risks (e.g. suicidal plan or intent), and she ate most meals successfully albeit with significant anxiety and distress. Her mother and father brought her to outpatient appointments and the psychologist used Family Based Treatment (FBT) to help her work toward weight restoration. Parents supervised all meals during Phase 1 and Josephine's weight trend improved until she reached 140 lb. Josephine started to fixate on her weight, was demonstrably more anxious, and her parents discovered she started to skip lunch at school. Josephine explained that she looked different than friends on her track team and could not take gaining any more weight. This occurred at the same time that she was cleared by medical providers to return to track given medical improvements. Ultimately, Josephine's parents decided with the consultation from the psychologist to limit activity until Josephine continued to progress to her target weight of 150 lb. Further discussion of Josephine's case as it relates to the assessment and treatment of AAN continues throughout the paper.

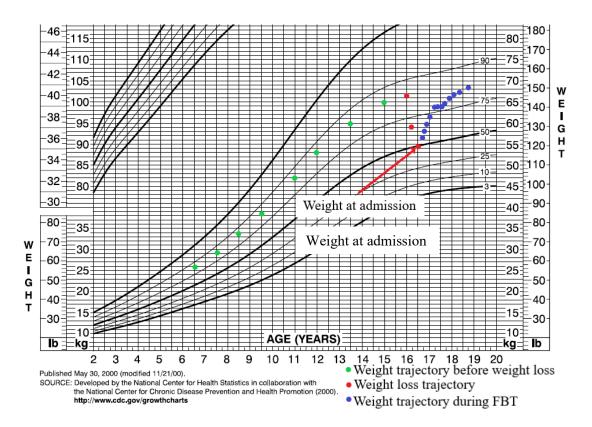


Figure 1. Patient growth chart – with data on weight pre-ED diagnosis and weight at treatment presentation (admission) and end of treatment. Growth chart is taken from (Center for Disease Control and Prevention, 2000).

# **Key Background**

Eating disorders (ED) are psychological disorders that occur in combination with many causal factors including genetic and biological (genes and heritable personality traits), sociocultural (thin ideal internalization), and psychological (Schaumberg et al., 2017) factors.

While the average onset of ED appears to occur during adolescence and early adulthood, all ages can experience ED. Similarly, EDs were once believed to be diagnoses predominantly experienced by cisgender females, yet research indicates that EDs occur across diverse demographics including gender identities, races, ethnicities, and socioeconomic statuses (Anderson et al., 2017). EDs are considered to have some of the highest medical complications and risks for mortality among all DSM-5 psychiatric disorders with significant impact on

individuals, families, and society (Peebles & Sieke, 2019). Further, ED rates have significantly increased due to the COVID-19 pandemic (Matthews et al., 2021).

Historically, diagnosis of AN appeared to be exclusive. For instance, the DSM-IV-TR classification of anorexia nervosa (AN) specified that patients weigh below 85% of ideal body weight (IBW, determined by BMI), endorse significant fear of weight gain and body image distress, and if female sex – to have lost their menstrual cycle to meet diagnostic criteria for AN (Moskowitz & Weiselberg, 2017; Peebles & Sieke, 2019). There were several concerns that arose with this diagnostic classification. For one, there was minimal definition for how to determine IBW, especially among adolescents, given BMI is used for adults and not adolescents. This resulted in vague interpretations of what the DSM-IV-TR meant about weight loss for adolescents. Further, including loss of menstruation increased the perception that AN is a female-related psychological disorder and did not consider findings that menstrual loss occurs at different weight loss trajectories for each person. Most importantly, adolescents and adults who did not fit the criteria for AN (or bulimia nervosa) were then diagnosed with Eating Disorders Not Otherwise Specified (EDNOS); a catch-all diagnosis for all other ED presentations. Thus, separate patients endorsing ED severity for just one month, purging for two years without bingeeating, losing 15% of total body mass but not meeting underweight criteria, or with lack of "weight loss" but exhibiting stunted growth related to poor food intake could have all been diagnosed with EDNOS but with very different stories. The heterogeneity of EDNOS made it difficult to understand the severity of ED pathology and medical risk or conduct effective research among those diagnosed with EDNOS (Harrop et al., 2021). Historically, a diagnosis of EDNOS was then considered less severe, associated with poorer insurance coverage, and lower treatment accessibility (Moskowitz & Weiselberg, 2017). Lastly, the weight criterion in the

DSM-IV-TR (and one may argue DSM-5) is problematic in that it only considers an individual's weight when they are diagnosed with disregard for overall weight loss or individual growth history. Indeed, if Josephine was diagnosed according to the DSM-IV-TR, she would have been classified as having EDNOS. Yet, her medical instability and report of ED symptoms are alarming.

To address concerns noted above, the DSM-5 modified the subcategory EDNOS by creating a new subcategory of ED, Other Specified Eating and Feeding Disorders (OSFED), and added the diagnosis of atypical anorexia nervosa as an ED in this category (APA, 2013). Atypical anorexia nervosa (AAN) has the same diagnostic criteria as AN per the DSM-5 with the qualification that individuals with AAN, despite significant weight loss, are presenting at "normal to above normal weight" (APA, 2013) at the time of diagnosis. As AAN is a "newer" diagnosis, there has been less research devoted to it (Strand et al., 2020). However, research findings suggest AAN is similar in severity to AN. For one, medical complications (e.g., bradycardia, electrolyte imbalance, low heartrate nadir) appear to be commensurate among medically hospitalized adolescents diagnosed with either AAN or AN. In fact, a patient's diagnosis (i.e., weight at presentation) is less of an indicator of medical risk than the rate or amount of weight loss an individual experiences (Garber et al., 2019). Thus, while someone with AAN may not be "underweight" per normative standards (BMI percentile based on age-and-sexbased norms) they could have lost significantly more weight than an individual with AN and be at greater medical risk (Garber et al., 2019; Sawyer et al., 2016). Indeed, Josephine under the DSM-5 would meet the criteria for AAN as she presented with a BMI percentile of 47.1 down from 86.

Additional research indicates that AAN is more common than AN with a two to threetimes greater prevalence rate than AN (Harrop et al., 2021) and that there has been a five-fold
increase in medical hospitalizations among patients with AAN in recent years (Whitelaw, et al.,
2014). Again, this suggests that there is growing recognition of the medical risks associated with
AAN and that EDs, when inclusive of all weight statuses, may be more common than originally
thought. When comparing diagnoses, adolescents with AAN endorse higher ED pathology,
anxiety, depression, and body dissatisfaction compared to adolescents with AN (Garber et al.,
2019; Sawyer et al., 2016) when they present for treatment. Reasons for differences between
groups have not been examined thoroughly, however, research suggests that a greater portion of
patients with AAN have histories of higher weight (often defined as overweight (between 85<sup>th</sup>
and 95<sup>th</sup> BMI percentile) or obese (above the 95<sup>th</sup> BMI percentile) in previous research studies
and per the CDC). For instance, one study found that 77% of adolescents with AAN and 23.3%
of patients with AN had histories of higher weight (Matthews et al., 2022).

Thus, unique experiences related to historic or current weight status or being diagnosed with AAN might contribute to heightened distress among adolescents diagnosed with AAN compared to AN. For one, adolescents with histories of higher weight prior to their ED development or AAN may face greater weight stigma and bias than individuals in less marginalized bodies (Harrop et al., 2021). Peers, society, or even medical providers may not view AAN as severely and may respond accordingly. The medical field's attention to weight status, fear of obesity (given the "obesity epidemic"), encouragement for weight loss or aims to prevent weight gain perpetuate the incorrect notion that weight is correlated with health. Often medical risks associated with higher weight are explained by stigma and stressors related to weight over weight itself (Puhl & Heuer, 2009). Thus, adolescents with histories of higher

weight may have been instructed by medical teams about the need to lose weight which could have negative impacts ranging from ED behaviors, body dissatisfaction, and shame. Further, weight-based teasing, a noted factor for ED development, is also noted to be higher among individuals with AAN or a history of higher weight (Matthews et al., 2022). Receiving a diagnosis of AAN at treatment presentation may also feel less validating, as adolescents and caregivers may feel this suggests they are not "underweight", have the same medical risk, or have as severe ED symptoms due to misconceptions about weight and health (Kimber et al., 2019).

The following portions of this paper introduce recommendations for psychologists and collaborating providers (physicians, nurses, teachers, etc.) on assessment and treatment for AAN, considerations for providing diversity-informed care, and expanding research among those with AAN.

### **Evidence-Based Assessment Recommendations**

While not exhaustive, the main goals during assessment for AAN include clarifying ED diagnosis, determining the level of care appropriate for treatment, assessing caregiver needs, and consulting or referring a patient to medical services ideally to providers with formal ED training or knowledge. Since the diagnostic classification of AAN appears to be more nebulous, with research studies having different definitions and given the newness of AAN (Harrop et al., 2021) a psychologist will first want to be mindful of accurate diagnosis. When assessing for an ED, even if a patient is not in the "underweight" category of less than 85 percent of BMI percentile (age and sex-matched norms), weight loss and restrictive/compensatory behaviors should lead a psychologist to diagnose AAN versus a diagnosis of OSFED or EDNOS.

Additionally, given the medical risk associated with AAN, an assessment for ED diagnosis can be conducted with a therapist but should closely coincide with a medical visit (Peebles & Sieke, 2019). As noted above, weight at presentation is only one marker of severity. It is imperative that providers also understand the degree of weight loss (in Josephine's case 30 lbs.), rate of loss (over 6 months with 10 lbs. of weight loss occurring in the last month), degree of restriction (400 to 1000 calories daily), and compensatory behaviors on top of heartrate, menstruation status (among adolescents with female sex), and electrolytes imbalances (Garber et al., 2019; Peebles & Sieke, 2019). Beyond medical stability at intake, it is also important to assess for risk of refeeding syndrome, which can occur as a patient is renourished regardless of weight at presentation. Again, this assessment needs to be done by a medical team, yet psychologists should refer patients for medical workups (if they have not already received one) as they make recommendations for improving nutrition. Another benefit of interdisciplinary assessment involves understanding an individual's growth curve and weight trajectory necessary for establishing an estimated target goal weight (TGW). This helps to clarify natural versus aberrant weight fluctuations related to medical concerns (i.e., chronic illness, other psychological concerns) to set TGW.

Additionally, depending on whether patients are seen by a psychologist in private practice, at a medical center, or elsewhere, a psychologist's role during an assessment is to assess caregivers' understanding of medical risks associated with AAN and awareness of their child's ED behaviors (as adolescents may under-report ED behaviors), patient safety (suicidal behaviors and self-harm), and the amount of time and resources caregivers can allocate to supervising meals and treatment. It is often at this juncture that psychologists provide caregivers with

referrals to appropriate providers including medical providers, psychiatrists (to help with comorbid mental health concerns), and sometimes dietitians.

#### **Evidence-Based Treatment**

While there are helpful case studies (Hughes et al., 2017) and qualitative studies of provider perspectives on treatment for AAN (Dimitropoulos et al., 2019; Kimber et al., 2019), there have been few formal studies or randomized controlled trials assessing treatment for adolescents diagnosed with AAN (Harrop et al., 2021; Strand et al., 2020). Given symptom overlap and commensurate medical risk between AN and AAN, providers have been using evidence-based treatments for AN with adolescents diagnosed with AAN (see Dimitropoulos et al., 2019; Hughes et al., 2017; Kimber et al., 2019) and have discussed special considerations as it relates to AAN.

Among adolescents diagnosed with AN, research demonstrates that rapid reversal of weight loss and ED symptoms and early detection of ED (i.e. shorter illness duration) are some of the best predictors of recovery (Steinhausen, 2009). While treatments such as Enhanced Cognitive Behavioral Therapy (CBT-E) are most utilized among adults, Family Based Treatment (FBT; Lock & Le Grange, 2015) appears to demonstrate the greatest efficacy among adolescents with AN. For example, weight gain is considerably faster among adolescents with AN receiving FBT compared to other treatments (Lock & Le Grange, 2019). Further, medical hospitalizations appear to be lower among adolescents receiving FBT compared to treatment as usual. Predictors for best outcome among adolescents with AN during FBT include four lb of weight gain in the first month, caregiver self-efficacy, and lower degree of expressed emotion (e.g. less criticism) among family members (Lock & Le Grange, 2019).

FBT is a treatment involving all family members and emphasizes five main tenets (Lock & Le Grange, 2015). During FBT, clinicians a) emphasize weight and nutritional restoration as the key ingredient for recovery and b) act as consultants to the family who knows their child best. Clinicians also aim to c) increase caregiver self-efficacy so they may feel autonomous and confident about increasing their child's nutrition despite likely pushback from adolescents reticent about changing ED behaviors and fearful of gaining weight. Lastly, during FBT, the clinician aims to d) help caregivers separate their child from their ED to reduce any criticism and minimize caregiver strain, while e) encouraging an agnostic stance on the causes for the development of the ED. FBT typically progresses over three phases of treatment. The first phase of treatment is considered Phase I and is the most intensive – it emphasizes that caregivers take over nutrition for their child whose ED has stood in their way of making appropriate eating decisions important for health and helping them renourish weight lost. During this phase, psychologists are considered the central treatment provider whom the patient sees weekly. Psychologists coordinate with medical providers and often empower parents to supervise and choose all meals and snacks and determine when their child can have more autonomy with nutrition (e.g., eat unsupervised at school and return to sports (not typically during Phase I)). Psychologists often have to take a firm and compassionate stance with patients and families on the need for weight restoration, normalizing distress endorsed by adolescents with AN/AAN during the refeeding process, while working to help families understand the importance of FBT versus individualized therapy.

Phase II involves providing more and more developmentally appropriate autonomy with eating back to adolescents based on caregiver input as the adolescent reaches weight stability and a reduction of ED behaviors. Often psychologists meet with patients every other week given

progress and take on a less involved stance, being slightly more deferential to caregivers. Phase III involves a wrap-up to care, relapse prevention with the goal of returning youth to their lives separated from their ED, and referral for any additional psychological concerns (e.g., to treat anxiety, OCD).

FBT sessions at all phases involve a 10-to-15-minute meeting between the psychologist and adolescent followed by a meeting among all family members (ideally including siblings as well as caregivers) to discuss progress with improved nutrition and challenges that arose. To reiterate, the main goals of FBT are weight restoration and normalization of eating despite considerable distress and anxiety related to increasing nutrition and reduction of ED behaviors.

To tailor FBT towards treatment among individuals with AAN, psychologists should be cognizant of several concerns including non-blind weights with adolescents, setting goal-weights, weight stigma and body image, caregiver distress and support, and the importance of advocating for care for patients. The first consideration may be in-session weighing which occurs between the psychologist and adolescent and separately from caregivers (while caregivers get weight feedback during the conjoint portion of the session). Adolescents with premorbid histories of higher weight or AAN may be particularly sensitive to unblinded weights related to experiences associated with being higher weight and/or receiving the diagnosis of AAN versus AN and not seeing themselves as "thin" or "sick" enough. This may include previous traumatic weigh-ins at doctors where similar to Josephine's case, doctors sound a medical "alarm" and tell adolescents they have gained weight, need to lose weight, etc. for their health. While AN and AAN likely lead adolescents to focus on changes to their weight and body shape due to fear of weight gain and body dissatisfaction, emphasizing weight gain among adolescents with AAN may feel equally distressing and perhaps a parallel experience to being told they need to lose

weight. While there are no studies that have evaluated whether sharing weights with patients is necessary for recovery during FBT, weight feedback is part of manualized FBT and there is evidence supporting weighing in other ED treatments (i.e., CBT-E). Thus, one may consider not sharing weights with adolescents with AAN, but this would deviate from evidence-based care. Avoiding sharing weight with adolescents with AAN could further weight stigma and shame by making an adolescent's weight seem more untouchable than it is or damage trust and rapport between the adolescent and provider if the adolescent feels the provider is being secretive. It may also maintain an anxiety/avoidance cycle in seeing weight gain necessary for recovery. While there is no clear answer, in adhering to manualized treatment, it is important to consider the individual impact of sharing weights with patients and to appreciate an individual's previous experience related to weight status. Some providers have recommended graphing weight trajectories without emphasizing population norms or discussing weight trends (weight up one lb. from last week) as a potential modification (Dimitropoulos et al., 2019) to this conundrum.

In addition to in-session weigh-ins, it is also imperative to remain diligent about setting TGW among adolescents with AAN that are in line with an adolescent's growth curve prior to ED development, although there is still not a firm consensus about this in the field (Jhe et al., 2022). While research has predominantly reported recovery based on BMI percentile (having patients get to 50<sup>th</sup> BMI percentile), many individuals with AAN need to be at higher BMI percentiles to get back to their goal weight (Jhe et al., 2022), particularly as cognitive recovery from AN/AAN occurs after weight restoration. Given weight stigma, patients with AAN may be at greater risk of having TGW being set lower in line with population versus individual weight norms, and there may be inconsistent understanding of a patient's TGW among all providers. In Josephine's case, where she was encouraged to lose weight by a medical provider, it would be

essential to collaborate with their PCP to ensure that they do not encourage Josephine to remain at the 41.7 BMI percentile but rather return Josephine's weight to her historic growth curve. Lastly, like patients with AN, it is important to not stall weight gain even if an adolescent appears to be at a "normal" weight compared to population norms given the significant medical risk associated with their weight loss versus presentation weight (Dimitropoulos et al., 2019; Sawyer et al., 2016).

Given that caregivers are responsible for weight restoration during FBT, it is also essential that beliefs around weight and nutrition among caregivers are congruent with the goals of FBT. Caregivers of adolescents with AAN, in addition to their children, could have also been inundated with anti-obesity messaging and worry about their child's weight. FBT providers may need to undo some of this messaging and provide considerable psychoeducation on the importance of returning youth to their growth curve for ED recovery. Other ways that psychologists can support caregivers of adolescents with AAN during FBT include increasing self-efficacy, trouble-shooting meals (especially in Phase I), and helping caregivers become more aligned. Typically caregivers feel guilty for their child's ED development which may go under-detected; sometimes adolescents are reluctant to share or even hide their ED behaviors out of shame or fear of having to eat more. Caregivers could also feel frustrated by any attempts to seek and establish medical care. Psychologists at this point also strive to help caregivers regain a sense of competence and self-efficacy in helping their child. In Josephine's case, the psychologist might find examples of how caregivers have helped her get over other medical or developmental hurdles and will actively provide positive feedback for any progress in getting Josephine to gain weight, eat a variety of foods, etc.

For trouble-shooting meals, psychologists lead a meal coaching session at session 2 where families in FBT bring a meal that will help "renourish" their kid and the psychologist coaches caregivers on behavioral strategies (encouragement, deflection of negotiating how much an adolescent with eat, physically cutting food and handing their child a utensil). This is set up to also increase caregiver self-efficacy and the psychologist can also model strategies parents can use to increase nutrition.

Lastly, psychologists can help support caregivers by helping them supportone another (encouraging alignment in strategies for renourishing their kid and improved communication) and recruiting support from family and friends. This may include discussing how to explain the diagnosis of AAN, increase support for their child and themselves, and even provide education to family members on combatting societal weight bias and body image comments. Psychologists can also advocate for families by helping them use the best language while seeking insurance reimbursement or even with appeals for uncovered hospital or outpatient stays as sometimes AAN is associated with poorer insurance coverage. Psychologists can also help facilitate referrals to psychiatrists and nurse practitioners for medication management of comorbid conditions and significant distress and to dietitians if caregivers are seeking more support with meal planning and nutrition.

Often youth and caregivers experience significant distress during FBT. Adolescents may feel anxious and angry about eating as much, related to fear of weight gain and adolescents may try to engage in ED behaviors despite caregiver oversight. Caregivers may experience significant anxiety about the level of distress and tensions that occur due to taking over nutrition for their child. In the attempt to reduce distress, sometimes caregivers will make adjustments to meals based on requests by their child (or their child's ED thoughts). This could include less food or

providing only "safe" foods. Given potential misconceptions related to the severity of ED based on AAN diagnosis, caregivers of adolescents with AAN may make greater alterations in nutrition as a result (Kimber et al., 2019). Caregivers could also shy away from providing foods that are considered "less healthy" again due to mixed messaging around health and nutrition. It is beneficial for providers and families to introduce all foods back and avoid the trap of focusing on foods being "good" or bad". Caregivers may also provide more autonomy in food choices to their adolescents because of seeing the ED as less severe; this is likely less helpful as an adolescent's ED will likely still encourage adolescents to choose "safer" options or engage in ED behaviors. Should a psychologist notice caregiver's tendency to adjust what they are providing to reduce anxiety, psychologists can provide psychoeducation about the importance of normalizing eating (encouraging a return to eating all food groups) and the importance of renourishment (e.g. weight gain) for recovery mindful of any past messaging from medical providers and society on eating behaviors, and even some of the parents' dieting behaviors.

Psychologists meeting with adolescents with AAN may also need to be cognizant of heightened body image concerns in this demographic given western culture's emphasis on weight, the prevalence of the thin ideal (or muscular ideal for males), and weight stigma in society. Adolescents with AAN may experience valid fears about weight gain necessary for recovery. Caregivers may equally worry about weight gain. Thus, it may also be important for psychologists to discuss diet culture and the media's inaccurate depiction of idealized bodies during treatment with adolescents with AAN. Distress during weight restoration among adolescents with AN and AAN is also unfortunately normative. Providers should be empathetic and firm in treatment goals of weight recovery and help caregivers and adolescents understand that body dissatisfaction is an artifact of the ED but potentially also societal norms making it

difficult for almost anyone to be accepting of their physical body. Adolescents with AAN often have reported histories of weight-based teasing (Kimber et al., 2019) which may also impact their fear of weight gain. Discussing these experiences while simultaneously staying committed to weight restoration may also help adolescents and their families cope with distress about weight gain and body dissatisfaction. In Josephine's case, it may be important to discuss her experiences of teasing by peers on her track team while still sharing the importance that despite this, she gains weight for recovery particularly when she was pushing back about need for continued weight gain. Not unique to diagnosis, several families and adolescents may desire or assert a need to take an individual therapy approach to ED treatment. Clinicians working with patients with AAN, similar to those with AN, should encourage caregivers and adolescents to focus on weight restoration over seeking a cause for ED and greater motivation before weight restoration efforts.

# **Clinical and Ethical Challenges**

In addition to general considerations during treatment and assessment, there are several ethical and clinical challenges related to the prevention and diagnosis of AAN. The diagnosis of AAN itself may be stigmatizing; describing AAN as "atypical" provides a label that may insinuate that it is different from AN yet adolescents with AAN have still lost significant degrees of weight and exhibit similar if not greater ED symptoms than AN (Sawyer et al., 2016). Adolescents with AAN and their families may also experience significantly less validation for their ED and experience stigma as a result. Historically, research demonstrates this given longer illness duration (e.g. treatment delays and slower ED detection (Sawyer et al., 2016; Whitelaw et al., 2014). It is therefore essential that interdisciplinary providers really ask about ED behaviors and restriction (e.g., calories eaten, meals per day, compensatory behaviors engaged in), overall weight loss, among adolescents regardless of weight history to not miss AAN diagnosis.

ED treatment also involves considerable care coordination and collaboration. While a clinician may be confident in providing care to adolescents with AAN, it may not mean that other collaborating providers are adherent to medical recommendations related to ED, FBT principles, or special considerations related to AAN. Therefore, it is essential for routine collaboration and clarification. Team members should be sure that there is an agreed strategy for sharing TGW and how weight gain will be shared with adolescents with AAN and their families. There could be instances where one member of the care team does not want an adolescent to know their weight which can cause a rift between providers given FBT's emphasis on sharing weight with youth. Additionally, care teams should discuss TGW early in treatment to be aligned and send consistent messages about the need for weight recovery among adolescents with AAN families. In Josephine's case, one member of the care team may be pushing her to remain at a BMI percentile below the 85<sup>th</sup> percentile, while the current accepted practice would be to return her to her baseline growth trajectory tracking at the 86<sup>th</sup> percentile (Jhe et al., 2022). This likely needs to be reconciled and may require advocating on a therapist's part. While some ED treatment occurs within an interdisciplinary team of ED providers, individuals in private practice or other settings not embedded in an ED clinic may need to provide considerable education to an adolescent's additional care team members. Differences related to perceived medical concerns of AAN may also contribute to different recommendations related to exercise privileges among adolescents with AAN. This was demonstrated in the vignette where the medical team said that Josephine could exercise given medical stability. During FBT among adolescents with AN, exercise is typically not recommended until an adolescent is closer to goal weight, is demonstrating minimal ED behaviors, or has close medical and psychological oversight ensuring confidence that the adolescent will continue to remain medically stable and gain weight.

Psychologists once knowledgeable about medical stability are usually the providers encouraged at discussing exercise privileges with families. Josephine was restricting nutrition when approved for exercise and not at goal weight. A psychologist would likely recommend troubleshooting lunch supervision or recommending that Josephine halt exercise until back on track or even at her goal weight and would coordinate with her medical team to explain the psychological impact of exercise under these circumstances.

Discussion of weight and shape can generally be a sensitive topic among all patients with ED. It is not uncommon that individuals with ED hear benign comments aimed at encouraging them or helping them to feel better about their bodies as being told they are gaining weight, do not look good, or the stigmatized word, getting "fat." Providers may be even more reticent in discussing weight with patients with AAN versus AN out of concerns for invalidation, discomfort in discussing weight status, and fear of affecting adolescent's mood negatively. It is still important for clinicians to be able to discuss weight and shape concerns despite this. Yet, clinicians should be mindful to avoid making inaccurate claims about what weight and body shape recovery means for patients with AAN. For instance, while the amount of weight gain or exact TGW may not be imperative to share, adolescents should not be blinded about the need to gain weight, told their weight or body shape will not need to change, or that they will not need to return to their premorbid body weight. It is ineffective for providers to avoid sharing this truth or minimize the importance of weight gain since this could encourage adolescents with AAN to feel their baseline weight is undesirable and providers cannot control actual weight trajectories for any patient during recovery. Additionally, clinical anecdotes indicate that some adolescents with AAN or histories of higher weight have been told that once their ED improves, they can work towards weight loss. This may also feel invalidating and harmful. This message suggests to

adolescents with AAN that their premorbid weight is not acceptable and may lead to poorer treatment outcomes since dieting is both ineffective and a risk factor for ED development and relapse.

It is important to consider how to discuss weight status (both current or past) among all adolescents to be validating, inclusive, and respectful. In general, it is helpful to discuss an adolescent's weight status relative to their weight history. For Josephine, providers could share she is under her expected weight for recovery. Yet there is no consensus on which terms are most effective and least stigmatizing when describing weight status (Meadows & Danielsdóttir, 2016). The words "fat", "heavy", and "unhealthy" are generally agreed to be pejorative with less consistent approval/disproval of the words overweight/obese/underweight. While the terms overweight and obese/obesity were described as labels per the CDC based on BMI percentile, they may be harmful and misleading since being at or above the 85th BMI percentile in and of itself does not indicate medical risk yet the obesity epidemic has contributed to this negative and erroneous connotation. Lastly, many journals suggest using person-first language, hence our utilization of the phrase "adolescents with AAN", however using person-first language for weight status may imply negative judgment (Meadows & Danielsdóttir, 2016). Thus, it may be best to ask adolescents how they prefer to discuss their current weight and weight history to be most affirming.

Interdisciplinary providers can be advocates for adolescents at risk for ED development and strive for prevention against AAN (and thus AN) in many ways. Providers should be aware of any implicit or explicit weight bias they may possess and should avoid making comments about patient weight or shape or even their own among adolescents (Neumark-Sztainer et al., 2010). When it comes to changes in weight, interdisciplinary providers may want to avoid

praising patients for weight loss itself or diet changes (e.g., eating "healthier") for health to avoid reinforcing diet culture, the thin ideal, and orthorexic eating patterns. It is recommended that providers avoid promoting foods as good or bad or bodies as healthy and unhealthy based on weight alone. Further, if a provider is recommending weight loss to adolescents, they should avoid discussing generic goals to lose weight or specific quantities of weight loss (i.e., 10 lbs.) with adolescents. It is more beneficial to discuss the need for weight loss in terms of balancing eating behaviors, not restricting specific food groups, and engaging in movement that feels good in their body. Providers should also avoid instilling fear about weight gain or being at a higher weight as this will be less effective at engendering behavior change and could perpetuate extreme dieting behaviors predictive of ED development.

Schools are another environment influential to adolescents and environments that could perpetuate incorrect messaging around weight, contribute to risk for ED development, and cause distress among adolescents with AAN diagnoses. For one, health classes may instruct youth about counting calories, encourage avoidance of sugary foods high in fat, and insist youth measure their BMI while discussing the link between weight and health. Adolescents may start to worry more about their health, become more rigid about food intake, or commence a diet placing them at greater risk for ED development. Experiences such as these at school may also have an effect of calling out adolescents of higher body weights providing yet another potential traumatic experience related to weight status. It may be essential for providers to work with schools to alter their curriculum or even excuse patients (regardless of AN/AAN) diagnoses from coursework related to nutrition and weight.

# **EDs and Diversity-Informed Care**

Emerging research has been conducted to understand EDs among demographics beyond cisgender adolescent females which research and diagnostic criteria are largely based on (Anderson et al., 2017). Findings suggest there are several important considerations in order to provide competent and diversity-informed assessment and treatment for AAN (and other EDs) particularly since EDs are not "one size fits all" (Schaumberg et al., 2017). During the assessment process, psychologists assessing for body image concerns (a key criteria for diagnosis of ED) should appreciate the nuances in body image concerns specific to varied gender identities, cultures, and demographics (e.g. athletes). For instance, cisgender males may not endorse a desire to achieve thinness or a flat stomach, but rather muscularity and defined abs. Adolescents who identify as transgender or non-binary may report gender dysphoria and greater distress about having physical features incongruent with their gender identity in addition or in lieu of thin or muscle ideal internalization. Further, different cultures such as Latinx may not endorse a greater desire for thinness, aiming for more curvaceous but toned bodies. Similarly, ED behaviors may vary based on demographic factors; athletes may not restrict calories but may restrict food groups (e.g. carbs or fats), cisgender males may report eating significantly more food and exercising more to achieve muscular ideals, and certain cultures may report greater distress related to ED behaviors as food may be more central to family events and cultural norms.

Providers should also be cognizant of the high demands of commitment of time and resources required for FBT and be accommodating to family needs dependent on financial and employment factors in addition to cultural beliefs (more separated parental roles versus shared roles). Providers using FBT should also be aware of divergent eating habits and preferences (e.g. large family meals, vegetarian diet), and religious rites (e.g. keeping kosher) to adapt FBT based

on cultural and individual family values. Furthermore, certain demographics may be less likely to seek care or ED detection is delayed. Matthews and colleagues (2022) for instance noted that males are more likely to be diagnosed in urgent medical visits versus ED assessments, are more likely to be diagnosed with AAN, and have histories of higher weight suggesting slower detection of ED or lower treatment seeking among this demographic. This highlights the need for psychologists to assess for ED among all demographics, particularly cisgender males, transgender individuals, and athletes who may not seek support for ED as regularly or who present at different weights, shapes, etc. (Anderson et al., 2017).

# **Future Research and Clinical Innovations**

Given the increased recognition that AAN is medically concerning, researchers in the field have made many recommendations for future research regarding AAN (Harrop et al., 2021; Strand et al., 2020). First, researchers should further understand the epidemiology and natural course of AAN (Strand et al., 2020). Additionally, research is needed to explore treatment among AAN by specifically assessing if FBT is as effective for individuals with AAN (using experimental and RCT designs) and whether any modifications would ameliorate treatment implementation and outcome (e.g. including open weighing). This would include patient acceptability and accessibility to receive FBT. A further understanding of the impact of weight stigma and bias before or during ED treatment would also be beneficial so the field can continue to combat "anti-fat" bias. This may include examining the impact of receiving a diagnosis of AAN on families. Yet this list is not all-inclusive (see (Harrop et al., 2021; Strand et al., 2020)).

#### **Conclusions and Lessons Learned**

While the clinical vignette depicted does not discuss a comprehensive treatment course for Josephine, several considerations related to assessment and treatment were presented in this

paper. First, Josephine's case illustrates the importance of not relying solely on an individual's weight status (relative to population norms) when they present for treatment. For instance, Josephine was at the 41.7 BMI percentile when she presented for treatment. That data point alone does not suggest medical risk. However, Josephine's degree of weight loss over a rapid period (20% of her weight over six months) is extremely medically concerning and contributed to her medical instability and need for inpatient hospitalization for bradycardia.

Josephine's weight loss was rapid, and her illness duration was short (6 months). Unlike research findings that suggest that adolescents with AAN have longer illness duration, Josephine's case is a bit aberrant (Harrop et al., 2021), yet promising since illness duration is related to prognosis (Steinhausen, 2009). Yet the degree of weight loss in the period of time that she lost weight is concerning and could have been related to the societal perception that weight loss is valuable and medically helpful. Had Josephine's weight been in the BMI percentile of 50<sup>th</sup>, her weight loss may have "appeared" more alarming and potentially been more easily detected. While not discussed, there are several reasons not to associate blame for ED development among caregivers or Josephine. Adolescents with ED may engage in ED behaviors in secret and try to appear "normal" often related to shame and fear of their ED being detected. Dieting and weight loss behaviors are seemingly normative, and society is unclear on where to draw the line between "healthy" and "unhealthy" weight management behaviors and when behaviors go too far making it hard for adolescents and families to know when ED gets out of hand and EDs typically develop through a chain of behavior changes that increase in severity and frequency. Further, Josephine and her family were under the impression that weight loss was necessary from their last visit with their PCP with little direction on the best strategies to do so. If Josephine had presented for medical visits where providers could have observed her rapid

weight loss, and when medical providers note weight loss trends in general, it may be important to understand what adolescents are doing to achieve weight loss. Had Josephine reported a caloric intake of 400 to 1000 calories daily, the restriction of certain food groups, daily weighing, or degree of exercise (running 3 to 5 miles daily) providers may have been able to intervene if they viewed these behaviors as concerning.

Experiences before Josephine's ED also could have influenced Josephine's changes in eating and exercise. Josephine reported weight-based teasing among peers on her track team and having a medical provider share the concern about her weight and health despite her continued growth development at the 86<sup>th</sup> BMI percentile. Research and clinical observation have demonstrated similar scenarios among other adolescents with AAN. This is unfortunate since teasing and negative weight comments are associated with ED risk and may impact adolescents with AAN during treatment (Matthews et al., 2022). For instance, Josephine may report significant fear of her weight increasing and a fear of loss of acceptance by peers which may be important to work through during treatment. Josephine and even her parents could also be confused about her medical provider's recommendations for weight loss. It would be important to provide education that weight status is not likely responsible for medical risk alone while discussing the impact of societal norms around body image and views on weight and health. Clinicians providing BBT to adolescents AAN should be diligent to stay the course and help caregivers continue to work towards weight restoration without delay. Weight restoration for adolescents with AAN should be based on historic growth curves through collaboration with medical providers' understanding of markers of medical recovery and risk for ED (Moskowitz & Weiselberg, 2017; Peebles & Sieke, 2019).

ED treatment involves interdisciplinary collaboration. This is essential for managing medical risk, providing adequate psychological support, and helping a patient holistically. Care providers with ED experiences and knowledge of AAN may need to advocate for their patient's TGW to be set higher than BMI percentile norms and based on growth chart history (Jhe et al., 2022; Peebles & Sieke, 2019). Care providers may also need to discuss goals related to exercise, school activities, etc. to ensure that all providers are understanding the medical severity of AAN and working to reduce and not enforce ED behaviors (Dimitropoulos et al., 2019). In terms of prevention, providers can be self-reflective on their own biases related to weight and shape. Providers noticing weight loss among adolescents at higher BMI percentiles may strive to be just as diligent about assessing ED behaviors and medical risk for earlier detection and given the medical risk associated with weight loss. Providers may also strive to minimize labeling of weight as underweight or overweight and avoid using other stigmatizing terms such as "fat", "heavy", etc. Generally speaking, asking adolescents which terms they prefer to use for weight and shape and asking about past experiences they have had related to weight status and body image may feel more affirming to adolescents with AAN (and AN). In conclusion, it is key to validate that regardless of an individual's weight status when they present for ED treatment, their ED is real, and medically concerning, and weight restoration is necessary for recovery.

# **Key Clinical Considerations**

- 1. In assessing severity and medical risk, AN and AAN are both concerning ED diagnoses. AAN carries significant medical risk and an adolescent's weight may not predict medical risk as much as how far their weight is from their developmental growth curve or rate of weight loss.
- 2. It is helpful to understand any experience of weight bias, stigma, weight-based teasing, and medical recommendations for weight loss from medical providers among adolescents with AAN or other diagnoses.
- 3. Providers should ensure an adolescent's whole treatment team is on board with recovery goals, specifically related to target goal weight and treatment interventions.
- 4. Providers should aspire to be mindful of any of their own biases related to weight and body image and be sensitive about the language used to describe weight and body shape.

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