

NASPAG Papers

FIGIJ and NASPAG Advocacy Statement: Recognize Eating Disorders Early and Intervene!



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ABSTRACT

Eating disorders (EDs) are life-threatening biopsychosocial illnesses that impact a growing number of children, adolescents and young adults globally. Clinicians who address the reproductive health of adolescents and young adults are uniquely positioned to recognize EDs, with oligomenorrhea and amenorrhea often heralding the development or progression of disordered eating. Early detection and prompt referral to multidisciplinary care where available can lead to improved outcomes. FIGIJ, NASPAG and ACOG recognize menses as a key vital sign; an additional vital sign can include use of the growth chart to track changes that might indicate disordered eating. When weight or height cross 2 or more major percentiles, further assessment for disordered eating or other etiology is indicated.

Keywords: Eating disorders, Advocacy, Menses as a vital sign, Reproductive health, Bone health

Introduction

Eating disorders (EDs) are biopsychosocial illnesses that affect children, adolescents, and young adults in increasing numbers. The global prevalence of EDs in adolescence in the last decade has grown to 6-8%; 60-87% of people with EDs go unrecognized and/or untreated.¹ EDs affect all organs in the body, leading to impaired physical health and quality of life, impaired cognition, decreased bone formation with increased resorption, bone marrow suppression with resultant anemia, and increased mortality.²⁻⁵ Clinicians who address the reproductive health of adolescents are uniquely positioned to recognize EDs in their patients, as changes to the menstrual cycle may be a presenting symptom of an ED with low energy availability. Clinicians can provide appropriate referrals to the multidisciplinary care, when accessible, and resources to address expediently

the medical and psychological consequences of EDs. Early intervention leads to improved outcomes.^{2,6,7} FIGIJ, NASPAG, and ACOG recognize menses as an important vital sign, with many youth with EDs presenting with amenorrhea, oligomenorrhea, or other evidence of menstrual dysfunction.⁸⁻¹⁰ Use of the growth chart to identify crossing of 2 or more percentiles can also serve as a vital sign that marks potential disordered eating or another physiologic cause that warrants investigation.

The most common EDs are anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED). EDs are not the result of an individual's choice but rather a result of interaction between genetic and environmental factors at critical time points in development. Adolescents, particularly girls, are increasingly conscious of their body, and this has a bearing on their diet. An acute change in eating practices, such as restricting entire food groups, may be a red flag for an emerging ED. Transgender and gender-diverse youths are vulnerable to EDs with an up to 2- to 4-fold increased prevalence of these disorders compared with cisgendered youths. In the adolescent gynecology setting, EDs

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may present with weight loss, menstrual disturbances, unexplained growth or pubertal delay, restrictive or abnormal eating behaviors, overexercising, or recurrent vomiting. Although formal diagnosis and treatment of EDs are outside the scope of practice for pediatric and adolescent gynecologists, it is critical that providers are comfortable in recognizing and screening for EDs, thereby enabling referral for appropriate treatment, giving the opportunity for better health outcomes. Treatment of EDs should be individually tailored and requires a holistic approach including counselors, dietary or nutritional support, patients, and patients' families.

The Spectrum of EDs in Youth

The most easily recognized, AN presents with marked weight loss or failure to grow along expected parameters for developmental stage. Although amenorrhea has been removed as a criterion for DSM-5 and ICD-11 definitions, the presence of regular menses remains a vital sign of reproductive health, which tends to turn off in the presence of the physiologic stress of disordered eating.^{11,12} Less recognizable but identical in physiologic findings is atypical AN, first defined in DSM-5 in 2013, where patients present similarly to those with AN but are of normal or higher weight.¹² Youth with atypical AN may lose menses while still being overweight or obese or, more accurately, at weights reflecting higher visceral adiposity and may resume menses at higher weights than same-aged patients presenting with secondary amenorrhea in the context of AN.¹³ These patients can still have significant medical compromise despite being normal weight/overweight. BED also goes unrecognized, with a prevalence of 26.3% in children and adolescents who are overweight and obese ages 5–21 years.^{14,15}

BN refers to binge eating accompanied by shame, guilt, and compensatory behaviors including vomiting, diet pills, laxatives, or diuretics; fasting intermittently; or hyperexercising. Other diagnoses new to DSM-5 include avoidant/restrictive food intake disorder, which presents similarly to AN and similar physiologically but without the desire to lose weight. In fact, most patients with avoidant/restrictive food intake disorder want to gain weight but may chronically undereat due to avoidance of pain or other aversive outcomes, such as a fear of choking or vomiting, lack of interest in food, and/or extreme pickiness. Also new to DSM-5 is night eating syndrome, characterized by excessive food consumption either after dinner or on awakening from sleep, resulting in significant distress to the individual. For a full review, see the AAP position statement on eating disorders and comparison of ICD-11 to DSM-5 diagnoses for eating disorders.^{2,11}

A diagnosis commonly used is relative energy deficiency in sports (RED-S), historically called the female athlete triad. Recognized by the International Olympic Committee in 2014, RED-S is defined by impaired physiologic functioning due to insufficient energy intake relative to energy expenditure, resulting in medical compromise, including menstrual dysfunction, osteopenia, cardiac compromise, and other medical complications.¹⁶ The term RED-S is more

inclusive of males, and amenorrhea was removed as a requirement to be more inclusive diagnostically. A diagnosis of RED-S provides an entryway for families of youth who hyperexercise and restrict energy intake, either intentionally or unintentionally due to lack of awareness of appropriate intake, to address recovery. This definition can be especially useful in situations in which the adolescent's or young adult's sports performance has high value for the young person and/or the family. Clinicians can remain vigilant not just to identify RED-S but also to intervene and ensure appropriate care to address nutritional depletion and disordered eating.

Independent of socioeconomic status, EDs also remain under-recognized in diverse populations, including LGBTQ+ youth and those with poor access to health care.^{17,18} The weight-shaming and stigma associated with obesity may also predispose children and adolescents to develop EDs.¹⁹

The Role of Social Media

As found in youth with AN, many individuals with EDs may not recognize their own restrictive eating patterns and, on the basis of unrealistic beauty standards promoted by social media, peer, and/or family influences, believe their diet patterns are healthy and normal. The diet industry markets to this audience, with social media creating opportunities for patients to spend time and money on strategies that may sabotage health or contribute to disordered eating. Although messages of body positivity can be found on TikTok or other social media, the numbers overwhelmingly point to a preponderance of diet strategies and language or images that may trigger abnormal eating attitudes and behaviors.²⁰

Adolescents at Risk for Polycystic Ovary Syndrome as a Red Flag for Potential Disordered Eating

Youth presenting with secondary amenorrhea or oligomenorrhea, evidence of androgen excess such as hirsutism and acne, and weight gain may be at risk for polycystic ovary syndrome (PCOS). In a scoping review of 38 studies, the prevalence of EDs in girls and women with PCOS ranged from 0 to 62%, with a 3- to 6-fold increased likelihood of having an ED.²¹ Adolescents and women with PCOS were found to have a 30% increased odds ratio of BN and BED. These findings make sense, as PCOS is often accompanied by weight gain and disturbed body image, with abnormal eating attitudes and behaviors being a common response. Accordingly, adolescents of risk for PCOS should trigger screening for EDs at diagnosis and in subsequent follow-up visits.

Medical Complications That Accompany AN/BN

Medical sequelae of EDs may go unrecognized yet be life-threatening. Individuals at any weight may experience the medical complications of malnourishment.^{2,4,5} Bradycardia may represent loss of heart mass and decreased cardiac function rather than the efficiency of an athlete's heart. Constipation, early satiety, bloating, and abdominal

Table 1
Medical Criteria for Hospitalization for Acute Medical Stabilization²⁻⁴

Bradycardia (heart rate <50 beats per minute)
Other cardiac arrhythmia (prolonged QTc defined as >450 for <18 yo, >460 for >18 yo)
Orthostatic hypotension (20-point increase in heart rate from lying to standing and/or 10-point decrease in diastolic BP)
Hypothermia (≤ 95 degrees Fahrenheit)
Precipitous weight loss (a loss of 10% of their body weight in the last 3 months, or crossing growth curve centiles in weeks or months)
Hypokalemia, hypoglycemia, other electrolyte imbalance
High risk for refeeding syndrome (eg, those who have lost 10% of their body weight in the last 3-6 months or who have had no nutritional intake for 50 or more consecutive days)
Failure of outpatient management
Acute suicidality with 1 of the above, requiring medical floor before psychiatric floor

pain may occur due to slowed movement through the gut as the body tries to absorb necessary nutrients in a starvation phase. Low sex drive, amenorrhea, oligomenorrhea, and stress fractures and/or bone stress injuries may point to hypogonadotropic hypoenestrogen states in natal females. Euthyroid sick syndrome may occur in malnutrition, with normal TSH, decreased T3 levels, and elevated reverse T3, with or without decreased T4, and will correct with refeeding alone. Red flags for admission for acute medical stabilization can be found in [Table 1](#).

Medical Management of the Reproductive Health of Individuals with EDs

The accrual of bone density in adolescents is dependent on the hormonal environment and adequate energy availability. In addition to adequate calcium and vitamin D intake, low bone mineral density requires weight gain in youth with restrictive eating patterns and osteopenia, with some benefit observed with use of transdermal estrogens (and oral progesterone) in severe cases.^{2,4} Combined oral contraception, in contrast to transdermal estrogen, does not improve bone mineral density in these patients with EDs and is not indicated for management of bone health but may be prescribed for contraception. Long-term fertility is preserved, and amenorrhea does not mean a young person cannot get pregnant; clinicians still need to counsel on adequate contraception to prevent unintended pregnancy. Life-threatening depression, anxiety, and other mental health diagnoses may also impact health and well-being.

The Reproductive Health Clinician's Role: What Can We Do?

Good clinical practice includes review of the growth curves of individuals presenting with menstrual disorders, with attention paid to any patient crossing centiles in weight and height in either direction. To put this in more user-friendly terms, the CDC and WHO growth charts reveal standard centiles, or percentiles, along which to follow growth trajectories. The major centile curves include 3%, 5%, 10%, 25%, 50%, 75%, 90%, and 97%. For instance, crossing two major centile curves could mean having weight, height, and/or BMI moving from the 10% to the 50% centile or downward from the 90% to the 50% centile.²² Accelerated weight gain may be an indication to investigate further for BED, night eating syndrome, BN, or other forms of disordered eating. Similarly, weight loss in a patient who is

overweight or obese may be praised by family and health care providers but warrants further questioning on what strategies the young person utilized; such weight loss may be a sign of atypical AN or another ED. Referral to an ED multidisciplinary team and close follow-up are warranted whenever an ED is considered. Awareness of local or online resources can help facilitate prompt referrals for multidisciplinary care.

Awareness of implicit weight bias in medical care can lead to necessary change; all staff can be trained to create a weight-inclusive environment including properly sized gowns, avoidance of weight shaming, and role-modeling of positive body talk. Encouragement of family-centric strategies that promote healthy lifestyles, family dinners whenever possible, and use of motivational interviewing to elicit positive change can be first steps in the prevention and treatment of EDs.

Often, clinicians face patient and/or family resistance to the diagnosis of an ED, particularly when coming to the gynecologist's office to address amenorrhea or irregular menses and not expecting a discussion on disordered eating. Both patients and parents may state, "We eat a healthy diet" or "She's always been lean." The provider can acknowledge and validate their resistance to change, reflecting back what is observed and acknowledging that recognition and treatment of disordered eating can be scary or new and unwelcome concepts to embrace. Optimally, conversations can be open, honest, and collaborative, addressing fears and concerns while mythbusting. For instance, when a patient or parent says, "We eat a low-fat diet due to our family history of high cholesterol and my spouse's recent heart attack," the clinician can acknowledge the value of family meal changes to support that parent's wellness while noting that the energy needs of a child, adolescent, and young adult differ from those of an adult. The adolescent brain from ages 15 to 26 years requires 50-90 g of fat a day to myelinate neural pathways, whereas an adult brain can exist on little to no fat grams per day, with less myelination expected (hence the proverb "You can't teach an old dog new tricks"). Discuss the use of a team approach, engaging a dietitian versed in eating disorders, as well as specialists in the care of youth with eating disorders, including Adolescent Medicine providers, therapists, websites such as FEAST (<https://feast-ed.org/>) and NEDA (<https://www.nationaleatingdisorders.org/>), and other resources. The clinician can also use motivational interviewing skills to partner with the patient and parent to

align motivations. For instance, when a patient presents with RED-S, appealing to the young person's desire to improve their athletic performance and not to be sidelined by a stress fracture may have more traction than simply stating that they need to eat more or gain weight. Express your concern and arrange follow-up as appropriate, optimally with a multidisciplinary team approach. These discussions can be challenging, requiring honesty, patience, a nonjudgemental approach without weight shaming or bias by the provider or parent, with validation of fears and concerns, and close follow-up to promote positive change.

Recommended Action Steps

For Clinicians and Professional Societies

- Recognize EDs in all settings, including where young people present for reproductive health care.
- Use the growth charts! Screen for EDs whenever a child, adolescent, or young adult crosses percentiles in weight and height, including situations of weight gain as well as weight loss.
- EDs affect individuals of all shapes, sizes, and socioeconomic status. Look for disordered eating in youth who are overweight and obese, in sexual minority youth, and in those from low-income settings who may otherwise go undetected.
- Urge caution in the use of dietary supplements and weight-loss medications in adolescents with EDs. Further research is encouraged in this area.

For Communities and Schools

- Educate youth and families on social media, guiding them toward sites that endorse body positivity and avoiding those that promote weight stigma or body shaming.
- Encourage social media creators to focus on creating diverse body-inclusive and body-positive content.

For Government and Policy Makers

- Educate medical students, trainees, colleagues, caregivers, and clinic staff on EDs as well as on weight-inclusive strategies that promote health and eliminate weight shaming or stigma.
- Nutrition guidelines should primarily focus on a healthy lifestyle rather than weight.
- Encourage diversity in clothing size and advertising.

This advocacy statement has been endorsed by the NASPAG Advocacy Committee

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Conflicts of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

1. Galmiche M, Déchelotte P, Lamber G, Tavolacci MP: Prevalence of eating disorders over the 2000–2018 period: a systematic literature review. *Am J Clin Nutr* 2019; 109:1402–13.

2. Hornberger LL, Lane MA: COMMITTEE ON ADOLESCENCE: Identification and management of eating disorders in children and adolescents. *Pediatrics* 2021; 147(1):e2020040279.
3. Golden NH, Schneider M, Wood C, et al: Preventing obesity and eating disorders in adolescents. *Pediatrics* 2016; 138(3):e1–e10.
4. Medical Guidelines Committee, Academy for Eating Disorders: Eating Disorders: A Guide to Medical Care. AED Report 2021–4th ed. Published online 2021. https://higherlogicdownload.s3.amazonaws.com/AEDWEB/27a3b69a-8aae-45b2-a04c-2a078d02145d/UploadedImages/Publications_Slider/2120_AED_Medical_Care_4th_Ed_FINAL.pdf
5. Society for Adolescent Health and Medicine: Medical management of restrictive eating disorders in adolescents and young adults. *J Adolesc Health* 2022; 71:648–54.
6. Rome ES, Strandjord SE: Eating disorders. *Pediatr Rev* 2016; 37(8):323–36.
7. Forman SF, McKenzie N, Hehn R, et al: Predictors of outcome at 1 year in adolescents with DSM-5 restrictive eating disorders: report of the National Eating Disorders Quality Improvement Collaborative. *J Adolesc Health* 2014; 55(6):750–6.
8. Hillard PJA: Using the menstrual cycle as a vital sign: what we still want to know about adolescent menstrual cycles. *J Pediatr Adolesc Gynecol* 2022; 35:413–14.
9. Sanfilippo JS: Is the menstrual cycle truly a vital sign? *J Pediatr Adolesc Gynecol* 2014; 27(6):307–8.
10. Adams Hillard PJ: Menstruation in adolescents: what do we know? And what do we do with the information? *J Pediatr Adolesc Gynecol* 2014; 27(6):309–19.
11. Quadflieg N, Voderholzer U, Meule A, Fichter MM: Comparing ICD -11 and DSM -5 eating disorder diagnoses with the Munich eating and feeding disorder questionnaire (ED-QUEST). *Int J Eat Disord* 2023; 56(9):1826–31.
12. American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders. 5th edition. Arlington, VA, American Psychiatric Association, 2013.
13. Rastogi R, Sieke EH, Nahra A, et al: Return of menses in previously overweight patients with eating disorders. *J Pediatr Adolesc Gynecol* 2020; 33(2):133–8.
14. He J, Cai Z, Fan X: Prevalence of binge and loss of control eating among children and adolescents with overweight and obesity: an exploratory meta-analysis. *Int J Eat Disord* 2017; 50(2):91–103.
15. Kjeldbjerg ML, Clausen L: Prevalence of binge-eating disorder among children and adolescents: a systematic review and meta-analysis. *Eur Child Adolesc Psychiatry* 2023; 32(4):549–74.
16. Mountjoy M, Sundgot-Borgen JK, Burke LM, et al: IOC consensus statement on relative energy deficiency in sport (RED-S): 2018 update. *Br J Sports Med* 2018; 52(11):687–97.
17. Guss CE, Williams DN, Reisner SL, et al: Disordered weight management behaviors, nonprescription steroid use, and weight perception in transgender youth. *J Adolesc Health* 2017; 60(1):17–22.
18. Watson RJ, Adjei J, Saewyc E, et al: Trends and disparities in disordered eating among heterosexual and sexual minority adolescents. *Int J Eat Disord* 2017; 50(1):22–31.
19. Leme ACB, Haines J, Tang L, et al: Impact of strategies for preventing obesity and risk factors for eating disorders among adolescents: a systematic review. *Nutrients* 2020; 12(10):3134.
20. Barakat S, McLean SA, Bryant E, et al: Risk factors for eating disorders: findings from a rapid review. *J Eat Disord* 2023; 11(1):8.
21. Lalonde-Bester S, Malik M, Masoumi R, et al: Prevalence and etiology of eating disorders in polycystic ovary syndrome: a scoping review. *Adv Nutr* 2024; 15(4):100193.
22. Growth charts from the Centers for Disease Control and Prevention. Available: https://www.cdc.gov/growthcharts/cdc-growth-charts.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fgrowthcharts%2Fclinical_charts.htm. Accessed November 25, 2024