Advances in Adolescent and Young Adult Eating Disorder Care in Rhode Island

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INTRODUCTION

Medical providers in primary care practice are at the forefront of diagnosis and management of adolescents and young adults with eating disorders (ED). As a result, they play a critical role in establishing an interdisciplinary treatment plan that will help stabilize patients and move them towards recovery. While ED are prevalent among adolescents and young adults in the United States[1] and are among the most common chronic illnesses of adolescence, they can present a diagnostic challenge in the primary care setting. Diagnostic criteria for ED were recently modified in the Diagnostic and Statistical Manual, 5th Edition,[2] allowing clinicians to more accurately identify a variety of ED including anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant-restrictive food intake disorder, and feeding or eating disorder not elsewhere classified (**Table 1**). Clinicians are increasingly recognizing ED in previously overlooked groups, including males,[3] transgender individuals,[4,5] and overweight/obese adolescents.[6]

This article briefly describes strategies to identify ED in the primary care setting. We include treatment options available for adolescents and young adults with ED in Rhode Island, and summarize the inpatient treatment approach at Hasbro Children's Hospital for ED patients in medical crisis. We provide an overview of Family Based Treatment, a new evidence-based treatment approach for adolescents and young adults with ED.[7]

Identification of Eating Disorders in the primary care setting

Given the high prevalence of ED in the second and third decades of life, pediatric and young adult providers should stay alert to signs and symptoms that might indicate an ED (**Table 2**). Eating disorders can be difficult to diagnose for many reasons, including the secretive nature of the illness and wide variability

Table 1. DSM V diagnostic criteria for Eating Disorders

Anorexia Nervosa	Restriction of food intake leading to weight loss, or maintenance of weight < 85% of ideal body weight (BMI<17.5) Fear of fatness or weight gain Distorted body image *Restricting type:* no binge behavior *Binge/Purge type:* binge purge behavior in setting of low weight or weight loss
Bulimia Nervosa	Binge eating (at least once per week for at least 3 months) • Discrete period of time (2h) • Definitively more food consumed than appropriate (>2000 kcal) Sense of lack of control with eating behavior Purging/other compensatory behaviors to avoid weight gain/promote weight loss
Binge Eating Disorder	Recurring episodes of binge eating Must meet at least three of the following: • Eating more quickly than "normal" • Eating until so full that it is uncomfortable • Eating large amounts when not hungry • Eating alone because of embarrassment about volume • Feeling negative emotions about binge (disgust, depression, guilt) Distressed emotions around eating Binges occur at least once per week for at least 3 months No recurrent behaviors to avoid weight gain
Avoidant/Restrictive Food Intake Disorder	An eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with at least one of the following: • Significant weight loss, or failure to gain developmentally appropriate weight • Significant nutritional deficiency • Dependence on enteral feeding or oral nutritional supplements • Marked interference with psychosocial functioning. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no associated body image disturbance The disturbance is not better explained by • lack of available food • associated culturally sanctioned practice • attributable to/better explained by concurrent medical or psychiatric condition
Feeding or Eating Disorders Not Elsewhere Classified	Sub-threshold Anorexia Nervosa/Bulimia Nervosa "Atypical" eating disorders

American Psychiatric Association DSM-5

Table 2. Signs/symptoms that could suggest ED

Crossing growth curves
Functional GI disorders
Presyncope or syncope
Unexplained hypokalemia or other electrolyte disturbance
BMI ≤ 17.5 kg/m2
Abrupt change in dietary or exercise habits
Secretive behavior around food
Hyperglycemia in a type I diabetic easily controlled in the hospital

Table 3. SCOFF questionnaire for eating disorder screening

Do you make yourself Sick (vomit) because you feel uncomfortably full?
Do you worry you have lost Control over how much you eat?
Have you lost more than One stone (14lbs) over the last 3 months?
Do you believe yourself to be Fat when others say you are thin?
Would you say that Food dominates your life?
2 or more positive responses suggest further exploration into ED is indicated

Morgan et al., 1999

in associated behaviors. For instance, while weight loss in an overweight or obese patient may be medically appropriate, literature suggests that overweight/obese individuals are at particularly high risk for developing an ED.[6] In a healthcare environment strongly focused on helping patients lose weight and avoid obesity, clinicians can find it hard to determine which patients are engaged in healthy weight-loss behaviors and which are adopting life-threatening strategies. In addition to using clinical judgment, providers can apply a simple, five-question validated screening tool to determine whether further evaluation is warranted (**Table 3**).[8] When in doubt, close monitoring of patients over time can help establish a trajectory of weight change when an ED is suspected. More frequent follow-up can also help build trust between patient and provider, encouraging honesty in disclosure of unhealthy attitudes and behaviors. Connecting the family to a dietician and a family counselor familiar with eating disorders may be sufficient to treat ED.

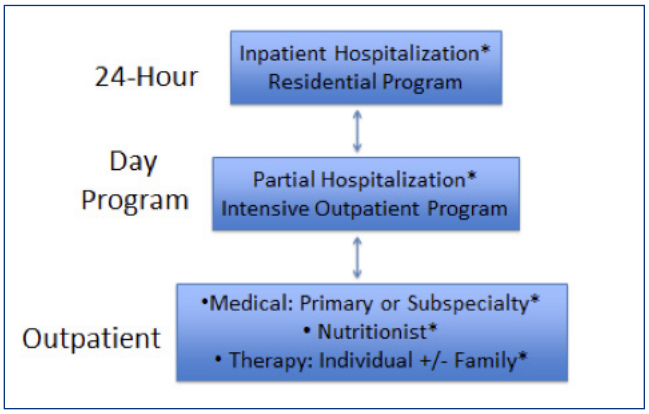
Eating disorder treatment options in Rhode Island

Many clinicians in Rhode Island effectively diagnose and treat adolescents and young adults with ED within the primary care setting. For patients requiring subspecialty support or access to a higher level of care, there are multiple levels of care available in our state. The Hasbro Eating Disorders Program (HEDP) offers multidisciplinary outpatient and inpatient medical and nutritional services, in addition to care coordination. For patients who have more complicated psychiatric pathology related to their ED or a co-morbid condition, the Hasbro Behavioral Health Inpatient Unit and Partial Hospital Program offer more intensive psychiatric management along with medical and nutritional support for medically stable patients with ED (**Figure 1**). As patients move between these levels of care, close coordination and communication between teams help facilitate seamless transitions across the continuum. While these services meet the needs of many individuals struggling with ED, it is important to note that in Rhode Island, we do not have access to local, long-term residential or intensive outpatient ED treatment settings. However, there are multiple programs in neighboring states who serve this need.

Inpatient Hospitalization

The Society for Adolescent Health and Medicine revised their guideline statement on hospitalization of eating disordered patients in 2015.[7] Despite having clear admission criteria articulated in this guideline (**Figure 2**), treatment

Figure 1. Overview of different levels of ED care



*Indicates treatment currently available in Rhode Island

Figure 2. Society for Adolescent Health and Medicine hospital admission criteria for ED

Electrolyte disturbance
Cardiac dysrhythmia
Acute medical complications (syncope, seizures, pancreatitis, etc)
Severe malnutrition (<75% goal weight)
Other physiologic instability • HR <50bpm awake, 45bpm asleep • BP < 80/50 mmHg • Temp < 97 F • Orthostatic changes in pulse (>20 bpm) or BP (>10 mmHg)
Food refusal
Dehydration
Arrested growth/development
Uncontrolled binging/purging
Failure of outpatient treatment
Co-morbid conditions that complicate outpatient care (depression, OCD, family dysfunction, etc)
Acute psychiatric emergency (self-harm, suicidality)

Society for Adolescent Health and Medicine, 2015

of ED patients in the medical inpatient setting without an interdisciplinary team which includes eating disorder trained nursing staff can be a challenge. In Rhode Island and the surrounding area, adolescent and young adult patients can access inpatient medical services at Hasbro Children's Hospital (HCH).

The HEDP admits over 100 ED patients to the hospital each year for medical stabilization of complications related to ED. The average inpatient length of stay is 7 days, during which time patients receive daily care from the medical, psychiatry, social work, nutrition, and nursing teams. Patients can also access Child Life and academic services during their hospitalization.

The primary goal during an admission for a medically unstable ED patient is to nourish, closely monitor, and ultimately stabilize the individual for discharge to an alternative level of care (outpatient, partial hospital, residential, or psychiatric inpatient). In addition to the medical complications that may arise during the re-feeding process, the experience of re-feeding often causes significant discomfort. Fluid and electrolytes shift encountered in feeding malnourished youth can be life-threatening. Close monitoring of electrolytes and fluids, and slow judicious refeeding are essential for safety. Chronically malnourished patients often have bradycardia and orthostatic instability which requires close monitoring. For example, starvation leads to decreased intestinal motility, and as nutrition is re-introduced and for days or weeks thereafter, individuals may feel physical fullness, nausea, bloating, and constipation. The re-introduction of nutrition can also prove emotionally challenging, leading to psychological distress as well as refusal to participate in treatment. Family members who witness a loved one in distress are often challenged in supporting a treatment plan that can be difficult and protracted.

The HEDP employs a multidisciplinary approach to care including psychiatric evaluation and daily treatment; extensive nutritional assessment and ongoing education with patients and families; psycho education regarding the function of the eating disorder and available treatments; and support regarding adjustment to illness. Both patients and families are integrally involved in all aspects of care during the hospitalization; this allows them to develop an understanding of the ED disease and to receive the best possible treatment options for discharge. For many patients and families, hospitalization is the first step on their road to recovery from the ED. The knowledge patients and families gain during their hospitalization has the potential to significantly impact treatment compliance following discharge.

Including Families in Eating Disorder Care

In their 2015 review of ED practice guidelines, the Society for Adolescent Health and Medicine clearly recommends hospitalization as an acute, short-term period of stabilization, acknowledging that an individual struggling with ED must rely on supports available to them in their home environment to ultimately succeed in recovery.[7] For most adolescents and young adults, this support system is comprised primarily of parents and other close family members.

Table 4. Phases of Family Based Treatment

Treatment Phases	Sessions	Task/ Focus of Treatment
Phase 1	Sessions 1–10	Parents in charge of weight restoration
Phase 2	Sessions 11–16	Parents gradually give control over eating back to adolescent
Phase 3	Sessions 17–20	Focus on adolescent development issues

Lock & LeGrange, 2013

Table 5. Tenets of Family Based Treatment

An agnostic view about the cause of anorexia nervosa
Initial symptom focus (pragmatic)
Non-authoritarian consultative stance as therapist
An ability to separate disorder of anorexia nervosa from the adolescent (externalization)
An emphasis on parental symptom management (empowerment)

Lock & LeGrange, 2013

Family-Based Treatment (FBT) is a promising, evidence-based therapy for the treatment of ED in adolescents. FBT has been found to be effective among children and adolescents who have been ill for less than three years, are under age eighteen, and are medically stable for outpatient treatment.[9] Through its empowering of parents to manage their child's ED, and its firm, consistent, yet compassionate focus on re-feeding, FBT signifies a paradigm shift in the treatment of ED. FBT informs, prepares and equips parents to become the best resource and strongest tool in their child's treatment.

Encompassing three phases over six to twelve months (**Table 4**), FBT helps family members mobilize to take charge of their child's eating during the initial phases; afterward, the adolescent is gradually given back control. Throughout the treatment, care givers support parents to "fight the eating disorder" with a "food as medicine" approach. By getting the adolescent "back on track" and returned to normal development, care givers and parents treat the ED and prevent relapses. Although FBT was developed for an outpatient setting, its principles (**Table 5**) have begun to be adapted for use across levels of care, including inpatient, partial hospitalization and intensive outpatient treatment.[10,11,12]

CONCLUSIONS

When establishing a treatment plan, patients and families with ED often embark on a long treatment/recovery process marked by both setbacks and success. As with any pediatric chronic illness, treatment ultimately aims to help individuals recover and transition to a healthy adulthood. In Rhode Island, services exist that support many levels of ED care and acuity.

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