

Working with Youth with Eating Disorders: What Every Resident Needs to Know

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Eating Disorders (ED) are severe mental illnesses with significant medical complications. They typically begin in adolescents, with the highest risk in those ages 15 – 19 years of age¹¹. Eating disorders as strictly defined in DSM-IV affect up to 5% of adolescent females;^{8,7} prevalence rates are expected to increase using the broader DSM-5 criteria.¹⁸ These illnesses carry with them an increased risk of both medical and psychiatric morbidity, and an increased risk of mortality^{9,20}. Given their prevalence and serious nature, it is essential for trainees in pediatrics and psychiatry to know how to manage EDs. However, working with youth with eating disorders can feel intimidating at first, whether you are on call and seeing someone with anorexia nervosa in the emergency room, assessing a new patient in an outpatient clinic, or assigned to work on the Eating Disorders inpatient unit. Having a better understanding of these illnesses is the first step to overcoming this anxiety. The following are our tips on what every resident should know about pediatric eating disorders:

1) Eating Disorders are not a ‘lifestyle choice’; the illness, not the patient, is in control.

In order to work with patients with eating disorders you need to understand what they are experiencing. It can seem difficult to understand why a thin, medically unstable girl would say she can't eat because she's "too fat", or why a patient with bulimia nervosa won't stop bingeing and purging. However, Eating Disorders are not a lifestyle choice; they are severe mental illnesses, associated with anxiety, depression, stress and low self-esteem. In fact, EDs can be conceptualized as a combination of four different mental illnesses: a phobia, an addiction, a delusional disorder and a form of obsessive-compulsive disorder.

You need only observe hospitalized patients with anorexia nervosa during meal time to see how terrified they are of eating and gaining weight. The anxiety starts just before meal time, when they become extremely agitated, glancing constantly at the clock, anticipating the arrival of the dreaded nutrition. They eat slowly and chew the food with fear and disgust, as if it contains poison. They may run away, get angry, or cry, because they are completely terrified. Compare this presentation to a more common phobia, such as a fear of heights. Imagine a person who is terrified of heights trembling on the edge of the highest diving board. Would we think they are crazy and wonder why they can't "just jump?" So why do some people expect patients with EDs to "just eat?"

Though EDs resemble phobias, they can also be compared to addictions. Patients with anorexia nervosa get 'addicted' to seeing the numbers go down on the scale: when they lose weight, they feel relieved and successful, but when they gain weight, they feel anxious, guilty, disgusting and a sense of failure. In order to feel good, they need to see

the numbers continuing to go down, no matter how malnourished they become. Patients with bulimia nervosa also become ‘addicted’ to bingeing and purging: restricting leads to overwhelming hunger which leads to bingeing; bingeing is followed by feelings of anxiety, disgust and guilt, which are relieved by purging. Soon, the patient comes to depend on purging as a way to relieve themselves not just of unwanted calories, but of unwanted emotions too.

Anorexia nervosa appears to have a ‘delusional’ component as well, as evidenced by studies of body image misperception in which patients with anorexia nervosa are asked to identify the female silhouette which most closely resembles their own shape: a significant portion of patients overestimate their body size⁶. Clinically, we have seen patients with severe anorexia nervosa who genuinely believed that they were too fat to be seen in public, that the chair might break if they sat on it, that they might not fit through the doorframe, and that the size tags on clothes at the mall had been ‘faked’ to trick them into thinking that they are thinner than they really are.

Finally, and probably the easiest way, to understand our patients with eating disorders is to see the illness as a form of Obsessive-Compulsive Disorder (OCD). OCD consists of obsessive worries (such as worrying that there are germs on your hands that are going to make you sick) and feeling compelled to do something to try to decrease those intolerable, terrifying thoughts (such as washing your hands over and over again). Anorexia Nervosa is similar: a person develops obsessive thoughts constantly telling them that they are fat and disgusting, they are eating too much, and are gaining too much weight. These thoughts cause intolerable distress and fear. The only thing that will decrease the intensity of these thoughts and of the distress, are symptoms directed at weight loss, such as restricting intake, exercising, and purging. When the person eats or tries to rest, the thoughts become much ‘louder’ and stronger in their head, causing terrible fear and agitation, to the point that it is unbearable (“I’m eating too much, I’m gaining too much weight, I’m getting fat, I mustn’t eat any more!”). When they have symptoms directed at weight loss, the thoughts and the distress decrease. This is just like patients with OCD who feel compelled to wash their hands in order to decrease the intensity of their obsessive thoughts of germs. In other words, the symptoms aren’t about how dirty the hands are, but about how strong the obsessions are. Similarly, the symptoms of a patient with an ED may seem on the surface to be about weight, but really are a reflection of the intensity of the obsessive thoughts that are torturing them. Understanding this point is key to understanding why a medically unstable and underweight patient can be terrified of eating and of gaining weight. Telling such a patient to “just eat” is as helpful as telling a patient with severe OCD to “just stop washing your hands.”

One important distinction between the two illnesses is that AN can often be associated with less insight and less motivation for treatment. Patients themselves often don’t realize that they have an illness similar to OCD. They thus “believe” the thoughts (experienced as their own thoughts) telling them that they are overweight and eating too much food. The illness convinces them that this is true, such that they truly experience themselves as looking heavier than they are. Weight loss in patients with EDs is

associated with a temporary quieting of their obsessive worries and with feelings of relief, satisfaction, success, and accomplishment (of feeling 'good enough'). In contrast, eating or weight gain is associated with strong feelings of fear, agitation, guilt, shame and failure. To make matters worse, the side effects of starvation and weight loss are increased obsessiveness, such that the 'OCD'-like nature of the illness worsens as patients lose weight (see side effects of starvation below). This knowledge helps us to understand why underweight patients aren't happy when they reach their goal weight, and why they can't just stop having symptoms to avoid hospitalization or to please parents. It also explains why anorexia nervosa has the highest mortality rate of any psychiatric illness ⁵.

Bulimia nervosa is a similar illness, but one in which patients carry an extra burden because these youth experience themselves as 'failed anorexics,' associated with strong feelings of shame, due to their inability to resist the strong feelings of hunger brought about by symptoms directed at weight loss, such as restricting, exercising or purging. These patients may have stronger hunger cues, be more impulsive, or less rigidly perfectionistic, despite their equally strong body dissatisfaction and desire to lose weight. Patients are unable to 'just stop' the pattern of restricting, bingeing and purging, due to their terrible fear that if they eat normally they won't be able to lose weight, which they feel is necessary in order to be attractive and 'good enough.' They thus feel compelled to keep dieting (eg. skipping meals), which in turn leads to bingeing and purging, and so on; the cycle is extremely difficult to stop.

2) Families do not cause eating disorders.

Once you understand that eating disorders are similar to a form of Obsessive-Compulsive Disorder, and made worse in anorexia nervosa by the effects of increased weight loss and starvation, it is easier to appreciate that these illnesses are not the fault of either the patient or the parents. We now know that there is a strong genetic predisposition to developing an ED. In the case of anorexia nervosa, a girl or boy starts out wanting to lose weight (to improve self-esteem or body image, or to avoid the judgment of peers) or wanting to eat healthier foods (out of an anxious or perfectionistic desire to improve oneself, to eat "good" foods and avoid "bad" foods). Many hundreds of thousands of young females, and males, in Western society have tried dieting. It is the ones who are able to be successful and to lose a certain percentage of body weight, either due to decreased hunger cues, strong perfectionistic tendencies, or very strong unhappiness and body dissatisfaction, who then develop the increased obsessiveness caused by the effects of malnutrition on the brain. It is these strong obsessions and compulsions that maintain and drive the illness.

Distraught parents may watch helplessly as their child loses more and more weight, or may try unsuccessfully to force their child to eat, or they may cope with denial about the seriousness of the weight loss. In the vast majority of cases, these are loving, caring, good parents who have suddenly been 'blind-sided' by the effects of this devastating illness on their teenager. These parents should not be judged when they present to you. Don't

assume that they must have done something to cause this, or that they are over-protective or harsh or negligent.

3) Families are an essential part of the treatment team.

Recognizing anorexia nervosa as a form of OCD means understanding that the patient is compelled to have symptoms, and thus, that individual therapy can't be expected to work on its own. The child can't just 'choose' to stop restricting, exercising or purging. If ignored, the child may die. As such the recommended treatment for anorexia nervosa is to help families to understand this: to educate them, externalize the illness, lift guilt or blame, and raise parental anxiety in order to mobilize and empower parents "to be stronger than the ED" and take control over the child's nutrition. Parents need to compassionately help their child to feel that s/he has no 'choice' because parents have made taking nutrition and gaining weight 'mandatory,' (like taking insulin when you have juvenile diabetes, even if you are afraid of needles). These are the principles behind 'Maudsley' family therapy (also known as Family-Based Therapy or 'FBT'), which is the recommended treatment for adolescent EDs ^{8,15}.

Of course, asking parents to take charge of their child's nutrition is much easier said than done. A skilled family therapist helps parents to work together to provide structured, supervised meals and post-meal supervision; to be firm against the eating disorder but compassionate towards the child, who may react with anger or defiance, or may express great distress. Siblings will be included in therapy sessions to provide support for the ill child, and to help focus the entire family on the need to help the adolescent to recover from his/her eating disorder. As with a diagnosis of cancer (in which treatment is also unpleasant but crucial), parents may need to take time off work in order to provide the necessary support and supervision of meals. (To learn more about FBT for adolescent AN, read Lock and Le Grange's *Treatment Manual for Anorexia Nervosa: A Family-Based Approach*. Second Edition, 2012. Parents should be directed towards helpful resources, including www.canped.ca, www.maudsleyparents.org, and the book *Help Your Teenager Beat an Eating Disorder* by Lock and Le Grange.)

Unfortunately, not all parents are able to be "stronger than the eating disorder," either because the illness is too strong, or because of other stressors, including conflict at home or physical or mental illness, so that even with skilled family therapists only about 65-70% of patients are able to fully recover with FBT, and the process may take years ^{12,13}. However, even though you will meet a few parents who are fragile or unable to provide the support that their child needs to recover, this does not mean that these parents have "caused" the ED, any more than the inadequate or struggling parents that you will meet in the endocrine clinic have caused their child's juvenile diabetes.

We do not have as much evidence regarding the best treatments for adolescent Bulimia Nervosa, which may respond to a combination of FBT, cognitive behavior therapy (CBT) and dialectical behavior therapy (DBT). Nonetheless, even in BN, parents should be treated with respect and not blamed, educated about the illness, and included in the treatment team so that they can help to externalize and separate the illness from their

child, support their child to challenge and resist the ED thoughts and urges, praise their child and help the child to feel “good enough,” help him or her to find better ways to cope with negative emotions, provide structured supervised meals at home, and help to contain ED symptoms ¹⁴.

4) Assessment of an adolescent with an eating disorder requires some modifications to the standard psychiatric interview.

When you first meet them, remember that these young patients are having ‘abusive’ self-critical thoughts in their head every day telling them that they are fat, ugly, disgusting, eating too much, and gaining too much weight; these thoughts make them feel guilty, ashamed, anxious and ‘not good enough.’ They probably have social anxiety and worry about negative judgment from others. They will assume that you are thinking critical things, and this can make it difficult for them to open up to you. Therefore, we are not as ‘neutral’ in doing our assessment of a young person with an eating disorder as you might be on an adult medical or psychiatry rotation. Lean forward, look concerned, smile warmly, nod, and praise the patient during the interview. Help them to feel cared about, listened to, understood, and admired. Externalize the illness and use language in your questions that helps them to feel that you understand what they are going through, such as “And as you lost weight, did the eating disorder thoughts in your head continue to tell you that you needed to lose more weight, as though it was never enough?” “Did the eating disorder ever make you feel guilty for eating, or like you deserved to be punished? And finally: “Given how scared you must be of treatment, it was very brave of you to open up to me today about your story, and you did a wonderful job.”

Following the individual psychiatric and medical assessment ^{10,12,13}, we would strongly recommend a separate meeting with parents, as sometimes the stories can be surprisingly different. A desperate and terrified patient may smoothly and articulately convince you that she used to have trouble eating, but that she has now realized the problem and is eating normally again, such that you leave the interview impressed by her insight and improvement. You then meet with parents who say that she is avoiding foods with any fat, is exercising excessively, and has increased her intake from 500 to 1000 calories per day. The patient, too tortured by her ED, could not be open about her symptoms because of her terrible fear that treatment will cause weight gain.

5) Starvation and malnutrition have devastating consequences on the body and brain.

One of the most difficult things for a trainee to recognize when treating a youth with anorexia nervosa is how starvation and weight loss have affected the young person in front of them. The patient is likely bright and articulate. They may still be doing well in school. Many of them are pleasant and cooperative. They may describe severe depression or anxiety. It can be tempting to diagnose a Major Depressive Episode or Anxiety Disorder and to want to start an SSRI.

Alternatively, the patient may say very little, not elaborate on answers, and have difficulty putting feelings and experiences into words. She may be angry, irritable, or even rude and belligerent. She may actively resist treatment. She may be emotionally fragile, have mood swings, or cry through much of the interview. She will be completely preoccupied with thoughts of food and weight. All of these symptoms tend to be attributed by trainees to mental illness or personality or even adolescence. However, it is only with the advantage of following such patients over time, and watching the effects of weight gain, that one learns the huge effects that weight loss and starvation have on a person's personality. Working with such youth, we are reminded of images of buds "blossoming" into flowers when watching a young person go from a state of starvation, at 65%, 75% or 85% of their predicted healthy weight (or ideal body weight, IBW) to when they reach 100% of their target weight. Weight-restored youth smile, are more energetic, have a sparkle in their eyes, have a sense of humor, they are more insightful and flexible in their thinking, are less labile or irritable and better able to cope, they have 'warmer' personalities, and they have more interesting facets to their personality beyond thoughts of food and weight. All of this change is thanks to the effects of weight gain and renourishment.

Much of what we know about the effects of starvation on the brain comes from the infamous 'Minnesota starvation study' ¹¹. This study described the psychological and cognitive effects of starvation on healthy young male volunteers, including irritability and anger, mood swings, depression, anxiety, obsessiveness, rigidity, inflexibility, narrow focus, loss of humour, social withdrawal and isolation, breakdown of relationships and marriages, poor coping skills and emotional fragility, decreased sleep, decreased concentration, memory problems, preoccupation with food, meal rituals, and even psychosis in two unfortunate subjects. Parents may be frustrated by conflict at home and their child's irritability and 'bad attitude.' Some parents describe their child as if 'possessed,' because their personality is so different, compared to prior to the ED. Parents may be distressed by their child's low mood and afraid to make him or her eat in case it makes the depression worse. Our job is to help parents to see that all of this is caused by starvation, so is not the fault of the child, and that food is the treatment.

After weight gain, there are bound to be ongoing body image concerns, and there may well be ongoing co-morbidities of depression and anxiety, separate from the ED, which require treatment with an SSRI. However, for many patients, mood will have improved significantly with renourishment, (despite their strong fear and insistence at admission to hospital that they would "rather die" than gain weight). Over time, clinicians who work with this population learn the effects of different degrees of malnourishment, such that one of the most important pieces of clinical information that your supervisor will want to know is the patient's "percentage IBW:" an answer of "70% IBW," as opposed to "90% IBW," will immediately be associated with certain assumptions about the patient's fragile medical and psychological state. Many patients who fall below "80% IBW" will need to be hospitalized, while patients who are 80% IBW or above and medically stable can be treated as outpatients, but will need close medical monitoring and FBT focused on the need for weight gain.

Patients are often considered weight restored when their weight is above 95% IBW, though in our program we consider patients to be weight-restored only when they have reached 100% of their minimum healthy weight range. In post-pubertal girls who are not on oral contraceptives, reaching a healthy weight is associated with normal vital signs, estradiol levels that are generally over 100 pmol/L (although a small proportion will menstruate with levels below 100 pmol/L) and a return of normalized menstrual function. For most adolescent females, hormone levels normalize when they reach 92-96% IBW ⁷.

We often counsel families that when a person loses weight, they don't just lose weight from the parts that we can see, they also lose weight 'on the inside,' including losing mass from the heart and the brain. Medical consequences of malnutrition are numerous and include hypothermia, bradycardia, orthostatic hypotension, pubertal and growth delay, osteoporosis, and a risk of cardiac arrhythmia to name just a few. Skin becomes dry, and hair falls out. Lanugo hair may develop as weight falls off. Constipation and digestive issues become common problems. Endocrine abnormalities include low levels of estrogen in females and of testosterone in males, and amenorrhea acts synergistically with the effects of starvation on bone growth and bone density to result in osteopenia and osteoporosis. Purging can result in inflammation of the salivary glands or esophagus, decay of tooth enamel, and dangerous electrolyte imbalances, such as hypokalemia. Ongoing severe starvation affects all organs, including the heart, bowels and kidneys, and can lead eventually to single or multi-organ failure ^{1,9,10}

For severely ill patients who require hospitalization, there are also medical risks associated with renourishment, including the risk of hypophosphatemia and electrolyte imbalances associated with the 'refeeding syndrome.' There are risks associated with gaining weight too slowly or too quickly; at present the target for weight gain in hospitalized youth with anorexia nervosa is 1-2 kg/week ¹⁰. The effects of weight loss and starvation are more acute and dangerous in young people compared to adults, and are especially dangerous in pre-pubertal children, who tend to have fewer fat stores, and who can become dehydrated and medically compromised more quickly, and whose bone health and growth are also at greater risk of compromise ¹⁹.

6) Knowledge of basic psycho-education related to eating disorders, nutrition, weight and dieting will help you to answer many common questions asked by patients and parents.

Residents, and physicians in general, have usually been taught more about the dangers of obesity and metabolic syndrome than they have about the dangers of dieting and malnutrition. Many trainees, for example, have been taught that a healthy BMI is "between 18.5 and 25." However, they often do not know how a person's IBW is determined, or understand that a person can be dangerously ill at a BMI of 20. For example, it is easy to tell that a person with a BMI of 14 is severely ill, because of their emaciated state. However, if a person's healthy BMI is usually 24, then that individual can be very ill at a BMI of 20. Such patients may not be recognized as ill by their primary caregivers, especially if they are not well known to that physician, or if they are

secretive about their symptoms. Healthy bodies come in all different shapes and sizes, and slimmer does not necessarily mean healthier. Unfortunately, our society celebrates the 'thin ideal' for females, so patients with severe eating disorders and low self-esteem whose IBW is a BMI of 24 often receive many compliments as the eating disorder progresses and weight drops.

Understanding the importance of being at one's individual healthy weight for their body, and learning the consequences of being undernourished, can help you to answer many questions from patients and parents. For example, understanding the obsessive and terrifying thoughts that tell every girl with anorexia nervosa that she is eating too much food and gaining too much weight, will help you to anticipate our hospitalized patients' constant complaints that they are being given too much food. You can then help to reassure a patient and her concerned family that as long as the eating disorder is putting such obsessive worries into her head, it will always feel like she is eating too much food, and the illness will always tell her that she is gaining too much weight. If we were to respond to these thoughts and feelings, the illness would never allow her to eat enough or to gain enough weight to recover. Learn the answers to a few questions that patients will ask over and over again: "You can't expect me to eat all that; you're giving me too much food! I can't eat it because my stomach hurts; If you make me gain all that weight I'll just feel worse and have to lose it all again; why can't I just stay at this weight?"

Knowing the medical and psychological consequences of malnutrition can help you answer the question of "why can't I just stay at this weight?" while understanding the concept of ideal body weight for each individual, and how we determine a person's healthy weight, can help you to answer questions about why we are making our patients "gain so much weight," when this is "only making me feel worse." Sometimes, even parents have been affected by our society's acceptance of the 'thin ideal,' and have difficulty understanding why we would expect a girl with a pre-morbid BMI of 24 to go back to that weight, rather than "letting her" stay at a BMI of 20.

Finally, given all the messages we hear about "healthy eating," "bad foods" and "sugar as a toxin," we often get questions about why we make our patients eat dessert after meals. The answer lies in understanding the illness as a phobia. If an adult without an ED chooses to eat 'healthy' or to avoid certain foods, we would hope it would be done in a balanced and moderate, rather than an extreme, way: eating a wide variety of foods, taking pleasure in what one eats, and perhaps choosing to generally avoid certain foods, but not being afraid to eat them. We would hope that they could still enjoy pumpkin pie at Thanksgiving, cake on their birthday, or chocolate on Valentine's Day. A person with an ED is terrified of eating these foods. The treatment for a phobia is exposure: learning that these foods provide nutrition and pleasure, that no one food will make a person fat, that desserts and treats are part of a normal, healthy, balanced and varied meal plan, and that one can enjoy them without getting obese or sick: these are all important messages to challenge the rigid and anxious eating disorder beliefs about these foods as "bad" or "making me fat." In an eating disorder program there are "no bad foods."

7) ARFID is a "new" pediatric eating disorder.

The most common types of eating disorders that you will see in an adolescent eating disorder clinic include anorexia nervosa, bulimia nervosa, and other “unspecified” eating disorders that are similar to, but do not meet all diagnostic criteria for AN or BN. The next most common type of restrictive pediatric eating disorder is now known as “ARFID” for Avoidant/Restrictive Food Intake Disorder (DSM-5). ARFID patients are underweight, but their feeding disturbances do not exhibit the classic preoccupation with weight, body image or weight loss¹⁷. Their restricted intake seems related more to feelings of “stress” and anxiety than to “feeling fat.” They tend to be younger than the adolescents who present with AN or BN (eg. in our program, the average age for adolescents presenting with AN is 15 years, while the average age of our ARFID patients is 13 years). These patients are malnourished and underweight, like our AN patients, but not because they feel compelled to lose weight. Their weight loss is a form of an anxiety disorder, either caused by the feelings of nausea or ‘knots’ in the stomach associated with severe anxiety, or by a fear of eating “bad” foods (eg. after learning in school about the “dangers” of fats and/or sugars), by a fear of vomiting or choking or of developing abdominal pain if they eat, or by a variety of other causes generally associated with stress or anxiety.

To date there is little research to guide our understanding or treatment of ARFID, but like patients with anorexia nervosa, these patients need to be renourished back to their healthy weight, families need to be provided with psycho-education, and parents need to be compassionately empowered to take control of the child’s nutrition. In treating a child with ARFID, as with AN, we compare it to a child with juvenile diabetes who is terrified of needles: we don’t blame or criticize the child, we have empathy and compassion for their anxiety, and we provide support, encouragement and ways to cope, but despite the fear, taking the insulin (or the nutrition) cannot be optional.

Conclusion:

Eating disorders are complex, serious mental illnesses associated with significant medical complications and psychiatric comorbidities. Youth with eating disorders may be resistant to treatment due to their severe anxiety. Treatment of eating disorders can be difficult, and it can sometimes take years for patients to recover. Working closely with families is important, but can be stressful and time-consuming. For all of these reasons, treating youth with eating disorders can be daunting. Nonetheless, we hope that, armed with the information provided here, you will approach this population feeling informed rather than intimidated. Connecting with young patients who are frightened and suffering, offering empathy, understanding and compassion while teaming with their families to help them recover from the devastating medical and psychological consequences of an eating disorder, is as rewarding an experience as you will encounter in your career in medicine.

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