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### July/August 2010 Issue

#### Eating Disorders Not Otherwise Specified — Real Disorders, Real Risks

By Jennifer Mellace  
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For years, anorexia nervosa and bulimia nervosa have been researched, written about, diagnosed, and treated. But what about those who suffer from varying degrees of bulimia or anorexia—individuals struggling with eating-disordered thoughts, feelings, or behaviors but who lack all the symptoms of a traditional diagnosis? How are they diagnosed and treated?

The unfortunate answer is that for years they weren't. People with eating disorders not otherwise specified (EDNOS) went unnoticed and therefore untreated until about a decade ago. But since then, more studies have been conducted, and more people with these issues have come forward, helping EDNOS to be recognized and classified as a real problem.

#### Alarming Statistics

Statistics tell us eating disorders are real and can be deadly. The Renfrew Center Foundation has found that up to 24 million people in the United States alone experience some variation of an eating disorder, and The Alliance for Eating Disorders Awareness states that over one person's lifetime at least 50,000 individuals will die as a direct result of their eating disorder. Furthermore, information presented in *Eating Disorders, The Journal of Treatment & Prevention* indicates that EDNOS develop in 4% to 6% of the general population, with 50% to 70% of the individuals who present for treatment of an eating disorder being diagnosed with such.

With these statistics it's fair to say that individuals with EDNOS are at equal risk of experiencing adverse effects as those with a more specific eating disorder. And they may be at an even higher risk since some clinicians may underestimate their symptoms, causing them to go untreated.

[EatingDisordersOnline.com](#), an online community bringing people together around the issues of eating disorders, notes that the "not otherwise specified" label often suggests these disorders are not as important, as serious, or as common as anorexia or bulimia nervosa, even though this is untrue. Far more individuals suffer from EDNOS than from bulimia and anorexia combined, and the risks associated with having EDNOS are often just as profound; many people with EDNOS engage in the same dangerous, damaging behaviors seen in other eating disorders.

"EDNOS may have a similar etiology as other eating disorders, which includes a combination of biological/genetic influences and environmental factors—for instance, the social pressure to diet," says Nicole Siegfried, PhD, executive director at Magnolia Creek Treatment Center for Eating Disorders in Birmingham, AL. "I think by focusing on how the symptoms are interfering specifically in that person's life (e.g., disrupting family relationships, interfering with school performance) can be a helpful way to help the person recognize the severity of their symptoms."

James Greenblatt, MD, chief medical officer at Walden Behavioral Care in Waltham, MA, says it's critical for social workers and other healthcare professionals to understand that EDNOS are most common among people who suffer from eating disorders, but it just happens that these people don't meet the strict criteria set forth by the *DSM*. "It's important to remember that these individuals are just as ill, if not more. A recent study shows that EDNOS has as high a mortality rate as anorexia, but unfortunately many insurance companies won't cover these patients, leaving those who are sick to either not seek treatment or, worse, make themselves sicker so they can get the diagnosis that will afford them coverage," he explains.

Often overlooked by patients and their doctors, eating disorders have the highest mortality rate of any mental health condition. A study by the National Association of Anorexia Nervosa and Associated Disorders reports that 5% to 10% of people with anorexia die within 10 years of developing the disease, 18% to 20% of those with anorexia will be dead after 20 years, and only 30% to 40% ever fully recover.

Some long-term effects of all eating disorders include electrolyte imbalances, the growth of lanugo (soft downy hair on the face, back, and arms), edema, muscle atrophy, impaired neuromuscular

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function due to vitamin and mineral deficiencies (specifically potassium), paralysis, tearing of the esophagus caused by self-induced vomiting, cancer of the throat and larynx due to acid reflux disorders, and malnutrition, which alone can lead to respiratory infections, kidney failure, blindness, heart attack, and eventually death.

### Signs and Symptoms

With the signs and symptoms so closely related to the classic eating disorders, how does a healthcare professional know what to look for? Keep in mind that the signs and symptoms of EDNOS are the same as those of any other eating disorder, just not all of the signs and symptoms required to fully meet a diagnosis of another disorder. They may also be a combination of two or more eating disorders, such as severe restrictions on calories as well as purging after only a small meal or snack.

“EDNOS is often misunderstood as a disorder that is not as severe or as serious as other eating disorders,” says Siegfried. “EDNOS interferes significantly with the life goals and activities of individuals with this diagnosis. Recent research indicates that EDNOS is not subthreshold anorexia or subthreshold bulimia but rather associated with specific pathology that may be better classified as separate disorders rather than one ‘catch-all’ category. Based on current *DSM* criteria, EDNOS symptoms may include any or some of the following: restriction, bingeing, purging, fasting, etc., and individuals with EDNOS—as with some other eating disorders—may be underweight, normal weight, or overweight. They may have physical symptoms or they may not. They may demonstrate multiple eating disorder behaviors or just one (e.g., restricting, purging). The main criterion for EDNOS is that the individual has eating behaviors that somehow interfere with their relationships, work, or general life functioning.”

Some common signs of EDNOS include the following:

- obsessive calorie counting and knowledge of calories in almost all foods;
- skipping meals, often eating only small snacks;
- pushing food around on a plate rather than eating it;
- exercising excessively, particularly after or “to make up for” eating;
- ingesting an excessive amount of food, even when not hungry;
- “grazing” for as long as food is available;
- hiding eating habits due to shame or embarrassment; and
- showing excessive interest in weight, body image, and fasting.

It’s important to know that people diagnosed with EDNOS may frequently switch between different eating patterns—for instance, someone who may eat a normal amount of food but then become exceedingly obsessed with healthful eating or strictly categorizing normal foods or entire food groups as “safe” and “off-limits.”

The following are behaviors of those with EDNOS as indicated by the current *DSM*:

- For females, all the criteria for anorexia nervosa are met except that the individual has regular menses.
- All the criteria for anorexia nervosa are met except that, despite significant weight loss, the individual’s current weight is in the normal range.
- All the criteria for bulimia nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice per week or for the duration of less than three months.
- There is regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two biscuits).
- The person repeatedly chews and spits out but does not swallow large amounts of food.
- Binge-eating disorder, recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviors characteristic of bulimia nervosa, is present.

### Treating EDNOS

While treatment plans are generally tailored to an individual, most will focus on first reestablishing a nutritional balance through a healthful meal plan, exploring factors that contributed to the development of the eating disorder, and learning new ways to cope with distress.

Rebecca Cooper, MFT, CCH, CEDS, founder of Rebecca’s House Eating Disorders Treatment Program in southern California, says it is most important to ask your patients about how much time they spend thinking about food, their weight, diets, or how their body looks. “People with EDNOS or eating disorders will tell you [this information] 90% to 100% of the time,” says Cooper. “Just this fact alone shows them how their relationship with food must be affecting other parts of their life. If you are always occupied with these thoughts, you are constantly at war with yourself. It makes it hard to enjoy your life and live in the now.”

When establishing a recovery program, Cooper says counseling alone may not be enough. “Some people need a structured environment to get through the initial stages of recovery. Regardless of the level of care, it is necessary to work with a team consisting of a medical doctor, registered dietitian, social worker/therapist, exercise physiologist, and a good support group,” she explains.

Having suffered from EDNOS, Constance Rhodes, author of *Life Inside the 'Thin' Cage*, writes, "If your motivations regarding food and exercise are based on 'psychic' rather than 'physical' needs, you need to know that your struggle is important, and worthy of seeking out appropriate medical and/or therapeutic assistance."

Rhodes says individuals must understand that what they're experiencing is real and stems from something significant in their life, be it physical or psychological. It is important to remember that EDNOS is a clinical definition and that those suffering need just as much help and assistance as someone with any other eating disorder.

"The name EDNOS given to these disorders is very powerful," says Greenblatt. "Social workers and other professionals need to keep this in mind when telling patients they have an eating disorder not otherwise specified. They need to be sensitive and make the patients realize that this definition is not seen as less severe than, say, anorexia or bulimia.

"There is a lot of confusion among professionals," he continues. "And if professionals don't understand, imagine what patients and families seeking treatment feel like."

So what needs to change? Greenblatt says loosening of criteria on anorexia and bulimia nervosa diagnoses and refining the **DSM** categories. "Most people in my profession are hopeful that eventually the criteria for classifying eating disorders will broaden, allowing these very common disorders to be diagnosed and studied. Until then, healthcare professionals just need to remember that EDNOS shouldn't be seen as a less-lethal illness."

— Jennifer Mellace is a Maryland-based freelance writer whose articles have been published in various regional and national publications.

### Proposed Revisions to **DSM-V**

Walden Behavioral Care in Waltham, MA, and other similar facilities advocate broadening guidelines so individuals classified as having an eating disorder not otherwise specified (EDNOS) can receive coverage for the treatment they need. Current guidelines give those with EDNOS a reason not to seek treatment—or an incentive to get worse. And while it's difficult for those with eating disorders to achieve recovery, the earlier treatment begins, the greater the probability of recovery.

In May 2013, publication of the fifth edition of the **DSM**, the standard classification of mental disorders used by mental health professionals in the United States that contains a listing of diagnostic criteria for every psychiatric disorder recognized by the U.S. healthcare system, will mark one of the most anticipated events in the mental health field.

"Most important is that the **DSM-V** will finally include binge-eating disorder," says Rebecca Cooper, MFT, CCH, CEDS, founder of Rebecca's House Eating Disorders Treatment Program in southern California. "Those of us who have been working with eating disorders know that binge-eating disorder can be just as damaging as the other recognized eating disorders. We have been forced to use EDNOS because there was not a named **DSM** diagnosis for this disorder and EDNOS was not covered by insurance. Patients were not able to get help unless they were obese enough to get gastric bypass surgery or dying of starvation."

The draft criteria for eating disorders includes two very important changes. The first is listing binge-eating disorder as a stand-alone diagnosis, and the second is the removal of the amenorrhea, or the absence of a menstruation cycle, criteria for anorexia nervosa. There is a consensus that EDNOS is used more frequently in clinical settings than is desirable. The recommended changes should reduce the need for this category. Recommended changes in the criteria for anorexia nervosa, bulimia nervosa, and eating and feeding disorders usually beginning in childhood should also reduce the need for EDNOS. If these recommendations are accepted, the examples in EDNOS will be changed accordingly.

"**DSM-V** is supposed to address some of the problems with the EDNOS diagnosis, which includes that the disorder is 'too big' and too much of a catch-all category," says Nicole Siegfried, PhD, executive director at Magnolia Creek Treatment Center for Eating Disorders in Birmingham, AL. "The new **DSM** has broader definitions for anorexia (e.g., not a specific body weight requirement, amenorrhea is no longer a requirement), which will allow individuals with true anorexia symptoms to be diagnosed with anorexia instead of EDNOS. Also, the **DSM-V** will have a separate category for binge-eating disorder, which was subsumed under EDNOS in the previous version of the **DSM**. These changes will allow for a 'cleaner' categorization of eating disorders and better diagnostic and treatment."

The workgroup is also considering whether it may be useful and appropriate to describe other eating problems such as purging disorder, or recurrent purging in the absence of binge eating, and night-eating syndrome as conditions that may be the focus of clinical attention. Measures of severity would be required, and these conditions might be listed in an appendix of the **DSM-V**.

To see the proposed criteria for binge-eating disorder and EDNOS as stated by the American Psychiatric Association, visit [www.dsm5.org](http://www.dsm5.org).

— JM