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Sorry. Your Eating Disorder Doesn't Meet Our Criteria.

By ROBIN MARANTZ HENIG

Imagine a 20-year-old woman who refuses to eat anything except carrots and toast because she is afraid of gaining weight, even though she is 5-foot-8 and weighs only 99 pounds. She exercises to the point of exhaustion five mornings a week because, though she is bone-thin, she thinks her thighs are too flabby. Her periods are irregular, but she has never gone more than three months without menstruating.

Another woman, who is also 20 and also 5-foot-8, has an opposite eating pattern. She goes without eating all day, and starting at 6 p.m. she eats nonstop, whatever she can get her hands on. Her favorite pastime is to sit in front of the television with a gallon of mocha-chip ice cream. She maintains a normal weight of 130 by occasionally forcing herself to vomit. But purging is not always easy in her college dormitory, with four young women sharing a single bathroom, so she ends up vomiting, on average, about once a week.

Everyone can agree that these women have some sort of disordered eating.

But psychiatrists would say that neither one falls into the strict definition of anorexia nervosa, the most severe eating disorder, or its relative, bulimia nervosa. According to the bible of psychiatric diagnosis, the American Psychiatric Association's Diagnostic and Statistical Manual, anorexia must be accompanied by cessation of menstrual periods for at least three months in a row, and bulimia must involve vomiting or other forms of purging at least two times a week, on average.

Instead these women, and thousands like them, would fall into a category that doctors have been relying on for years, a vague nondiagnosis known by the acronym Ednos: eating disorder not otherwise specified.

Diagnosing psychiatric conditions is more of an art than a science, and the Not Otherwise Specified label reflects the imprecision of that art. The American Psychiatric Association's manual has a Not Otherwise Specified category for many disorders, whenever symptoms are so vague, so mild or so untreatable that it doesn't seem to warrant the full-fledged diagnosis. With the manual continually under revision, the Not Otherwise Specified grab bag is the place where new diagnoses emerge.

For instance, the diagnosis of Asperger's syndrome, a variant of autism, was pulled from a collection of disorders previously labeled Pervasive Personality Disorder Not Otherwise Specified.

Much is at stake in whether a condition is elevated to the status of a full-fledged diagnosis. Because no laboratory tests or other objective criteria exist for making psychiatric diagnoses, the American Psychiatric Association's manual is the definitive arbiter of the line between normal and abnormal. Its definitions help determine such practical matters as insurance reimbursement, competence and eligibility for disability. But they also help determine something more elusive, and probably more

important: whether someone's behavior should be considered a personality quirk or a symptom of mental illness.

Now, in the diagnostic category of eating disorders, the search for greater specificity in the Not Otherwise Specified grab bag is generating much attention.

"The Future of Ednos" was a topic at an international meeting on eating disorders in Amsterdam last month, and it is the title of a book expected to be released in Europe next year.

To some observers, this new attention comes not a moment too soon.

"Ednos right now is a real hodgepodge," said Dr. B. Timothy Walsh, professor of pediatric psychopharmacology at Columbia. "We have people in that category with anorexia nervosa," but they still menstruate so they don't meet all the criteria for a formal diagnosis.

Similarly, Dr. Walsh said, "we have people who are obese and binge but don't vomit," so they don't fit into the strict definition of bulimia nervosa, which requires both bingeing and purging. Or they might binge and vomit once a week, but to qualify as bulimic they would have to vomit at least twice a week.

"What we really need to do is collect data," Dr. Walsh said. "All the knowledge base we currently have relates to people who vomit twice a week. But if it turns out that the characteristics of those who binge and vomit once a week are similar to those who do so twice a week, then we can loosen the criteria for bulimia nervosa."

The history of eating disorders has been a gradual one as the Diagnostic and Statistical Manual has been revised through the years. Anorexia nervosa first appeared in the version of the manual known published in 1980, and bulimia appeared for the first time in the same edition. Bulimia was renamed bulimia nervosa in the next edition, which came out in 1987.

Anorexia nervosa affects 0.5 to 3.7 percent - or about 1.5 million to 11 million American women - at some point in life, according to the National Institute of Mental Health. Rates are lower among men and teenage boys.

The lifetime prevalence of bulimia is higher - from 1.1 to 4.2 percent of women - with a similar age and sex distribution.

In the current version of the diagnostic manual, published in 1994, one condition - binge eating disorder - was pulled out of Ednos and listed as a "provisional diagnostic category," the first step in the process of achieving its own diagnosis. The disorder is much like bulimia nervosa, but without the purging.

The "provisional" designation highlights the need for more research into a condition's prevalence and treatment, and highlighting binge eating disorder in this way was a prelude to its being named as a separate diagnosis in the manual that is to appear in 2012.

"That's one of most compelling reasons to get something out of the Not Otherwise Specified category," said Dr. Michael First, associate professor of clinical psychiatry at Columbia. Dr. First is a member of the planning group that is directing the enormous undertaking of revising the manual for its fifth edition.

"If you feel that there's a homogeneous group of patients in there for which there's a treatment, the fact

that it's called Not Otherwise Specified really obscures it, hindering treatment, hindering research," he said.

Another candidate for a new eating disorder in the fifth edition of the manual can be thought of as the flip side of binge eating, a condition that has been labeled "purging disorder" by Dr. Pamela Keel, an associate professor of psychology at the University of Iowa. Just as binge eating disorder has many of the characteristics of bulimia, so does purging disorder. But neither meets the strict criteria for bulimia nervosa.

People with purging disorder, Dr. Keel said, are of normal weight, and they purge after eating normal or even small amounts of food.

Right now, purging disorder is relatively hidden, buried in the Ednos category. And until the Diagnostic and Statistical Manual panelists ask for more data, as they have for binge eating disorder, not much more will be known, Dr. Keel said.

"Within widely used diagnostic interviews, if a person has never had a low weight and denies a history of binge eating, the interviewer skips all questions regarding the use of vomiting, laxatives or diuretics to control weight," Dr. Keel wrote in an e-mail message. "It's very difficult to learn more about a problem if you never ask any questions about it."

As Dr. First sees it, several criteria must be met before a diagnosis is pulled out of the Not Otherwise Specified category and into a stand-alone diagnosis. These criteria have to be met before binge eating disorder, purging disorder or any other condition emerges out of the Ednos grab bag.

The first requirement is that a significant number of patients must be affected, he said. Second, there has to be evidence of an existing and effective treatment.

The criterion of an effective treatment has prevented many conditions from being entered in the Diagnostic and Statistical Manual. In the 1980's, there was an effort to include "sadistic personality disorder." But it failed, said Dr. First, because no treatment existed. "We could have decided to call something sadistic personality disorder," he said, "but if there's no treatment, what would be the point?"

The third criterion for removing a condition from the Not Otherwise Specified category is the trickiest to meet. It relates to a kind of diagnosis-creep. Experts working on Diagnostic and Statistical Manual panels must ask how close the condition is to behavior that could be considered normal. For binge eating disorder, for instance, they must ask: When is such behavior a true psychiatric condition, and when is it the kind of thing that almost everyone engages in every Thanksgiving?

"This is the matter of what we call false positives," Dr. First said. "It's the danger of defining as a psychiatric syndrome a set of symptoms that normal people have."

When a new category is created in the manual, he said, "you're trying to identify a category that will help patients get treatment."

"But," he continued, "you're worried that this category is going to be applied to normal people as well."

Some psychiatrists want to create a different label for Ednos, calling it instead "mixed eating disorder" or "atypical eating disorder." But Dr. Walsh of Columbia said that would be merely a cosmetic change.

"If I'm a clinician and I get a call from a school saying, 'Hey, I've got a person with mixed eating disorder coming over,' I don't know if I'm going to be seeing someone who weighs 80 pounds or 280 pounds," he said. "The whole belief that diagnoses are useful things rests on their ability to put together under one umbrella a relatively homogeneous set of syndromes, which gives the clinician the ability to shortcut a full assessment."

Diagnostic labels, said Dr. Walsh, "allow big shortcuts."

Dr. Keel, on the other hand, prefers the term "mixed eating disorder" over Ednos. She said the mixed eating disorder label "may have the benefit of eliminating the false impression that Ednos is somehow less severe or less clinically significant than so-called full-threshold eating disorders." But she expressed concern that the term would limit the enthusiasm for teasing out what other identifiable conditions lie within the Ednos category.

As experts debate what to do about Ednos - pull out distinct disorders from the grab bag category, change the diagnostic criteria for the existing disorder, give the grab bag a more scientific-sounding name - people with disordered eating are left in a kind of therapeutic limbo.

Eventually, the hope is, the uncertainties will be resolved, and the woman with anorexia who still menstruates and the woman with bulimia who only purges once a week, will be able to get the diagnosis and treatment that they need.

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