

Insight May Limit Identification of Eating Disorders

To the Editor:

We write in regard to the recent publication “Prevalence and Correlates of DSM-5–Defined Eating Disorders in a Nationally Representative Sample of U.S. Adults” (1). We previously obtained the same dataset from the National Epidemiologic Survey on Alcohol and Related Conditions and became concerned about the ability of this structured phone interview (Alcohol Use Disorder and Associated Disabilities Interview Schedule-5) to assess eating disorders. These results are reported both here and previously in Afifi *et al.* (2). Both studies reported markedly lower prevalence rates of both bulimia nervosa (BN) and binge-eating disorder (BED) and a lower persistence rate in anorexia nervosa (AN) compared with prior published studies on the epidemiology, course, and outcome of eating disorders (3–7). As physician scientists with clinical expertise in eating disorder diagnosis and a translational neuroimaging research program examining social perception in patients with eating disorders, we believe these differences emerge because this interview was not validated for eating disorders. Patients with eating disorders are often unaware of their disease, making direct symptom queries much more challenging than in many other psychiatric illnesses. Here, we highlight two major problems related to the use of this clinical survey to diagnose and assess clinical trajectory in eating disorders.

First, the binge-eating section starts with the question, “Have you EVER eaten an UNUSUALLY LARGE AMOUNT of food within any 2-hour period, not including the holidays? That is, eating more food than most people would eat during a 2-hour period under similar circumstances.” If the answer is no, then the screen and evaluation for BN and BED ends. In contrast, during a clinical eating disorder interview, the description of the participant provides of his or her typical eating patterns, not the participant’s a priori beliefs about typical eating behaviors, determines psychopathology. Not only is the ability to accurately assess other people’s behaviors in relation to one’s own behavior difficult for most people, but nearly all patients with BN and BED have relatives and friends that also eat large amounts of food in short periods of time. With most fast-food restaurants serving portions that are two to three times a recommended serving size, the amount of food consumed in relation to other people in the United States is a poor model of healthy eating. Thus, the use of this question as a screen is expected to reduce detection of both BN and BED, just as observed: the prevalence of both BN (DSM-5: 12 months 0.14%, lifetime 0.28%) and BED (DSM-5: 12 months 0.44%, lifetime 0.85%) are three to five times lower than previously reported (3–5). Importantly, another survey, the National Health and Wellness Survey, conducted during the same time period, found increases in both the 12-month and lifetime BED prevalence after comparing DSM-IV-TR and DSM-5 criteria (DSM-IV-TR: 12 months 1.15%, lifetime 1.52%; DSM-5: 12 months 1.64%, lifetime 2.03%) (6).

Second, the AN section starts with “What has been your LOWEST weight in pounds since you reached your current height, not counting times when you were ill?” If a subject recognizes that he or she was ill when he or she had AN, the subject would screen out. We posed this question to five individuals that are recovered from AN; all answered the question with a minimum weight worked out with their treatment team as being healthy for them. Not one responded with a weight that was <90% of his or her ideal body mass index because they were all very sick at lower weights. That means that recovered participants with AN with insight into their disease are missed. Conversely, this question might screen in people that were at low weights while engaging in severe, short-term diet/exercise programs who did not consider themselves ill at the time perhaps because they were making a temporary choice related to some lifestyle goal (marathon, wedding, reunion). Some of these people may develop an eating disorder but many do not. This interview also reported that most of those people with AN did not believe their disordered eating behaviors interfered with their lives and that AN participants had a low persistence of the disease. Both of these results are, again, the opposite of the existing literature and seem more consistent with an individual’s mistakenly screening positive for AN based on behaviors related to a short-term diet than with the actual psychopathology that clinicians observe in patients with AN. This very low persistence of AN (9.4%) is inconsistent with the chronicity and severity reported in the literature in studies examining patients who have sought treatment for AN (7).

The implications of underestimating the prevalence and psychosocial impairment and misrepresenting the expected clinical course of individuals with eating disorders is profound. The majority of individuals with eating disorders do not receive adequate treatment (8). One of the “nine truths” about eating disorders is that an eating disorder is not a choice (9). In our clinical experience, many patients with eating disorders seek treatment only when they realize that they cannot stop; many people who have temporarily engaged in dieting and stop, assume that every patient with an eating disorder could also just stop. Unfortunately, the mortality rate for AN is the highest of all psychiatric illnesses (10), and any results that support beliefs that eating disorders will just stop may diminish motivation to seek as well as access to treatment. Eating disorder research receives a small fraction of the funding in comparison with other psychiatric illnesses. In 2015, the volume of federal support for eating disorder research equated to approximately \$0.73 per affected individual. In contrast, autism research received \$58.65 per affected individual and schizophrenia research obtained \$86.97 per affected individual (11). In summary, we recognize the need for epidemiologic studies focused on eating disorders, but we recommend that future interviews are validated clinically before use. The knowledge necessary for a layperson to accurately self-reflect and answer these screening questions is unlikely to be present in most individuals with eating disorders, as lack of insight is a substantial part of these diseases (12). Accurate assessments of

the psychosocial, medical, and financial burden of eating disorders are desperately needed.

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