Chapter 4

Epidemiology, course, and outcome of eating disorders

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ABSTRACT

Purpose of review
To review the recent literature about the epidemiology, course, and outcome of eating disorders in accordance with the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

Recent findings
The residual category ‘eating disorder not otherwise specified’ (EDNOS) was the most common DSM-IV eating disorder diagnosis in both clinical and community samples. Several studies have confirmed that the DSM-5 criteria for eating disorders effectively reduce the proportion of EDNOS diagnoses. The lifetime prevalence of DSM-5 anorexia nervosa among women might be up to 4%, and of bulimia nervosa 2%. In a cross-national survey, the average lifetime prevalence of binge-eating disorder (BED) was 2%. Both anorexia nervosa and bulimia nervosa are associated with increased mortality. Data on long-term outcome, including mortality, are limited for BED. Follow-up studies of BED are scarce; remission rates in randomized controlled trials ranged from 19% to 65% across studies. On a community level, 5-year recovery rates for DSM-5 anorexia nervosa and bulimia nervosa are 69% and 55%, respectively; little is known about the course and outcome of BED in the community.

Summary
Applying the DSM-5 criteria effectively reduces the frequency of the residual diagnosis EDNOS, by lowering the threshold for anorexia nervosa and bulimia nervosa, and adding BED as a specified eating disorder. Course and outcome studies of both anorexia nervosa and bulimia nervosa show that no significant differences exist between DSM-5 and DSM-IV definitions.
INTRODUCTION

Epidemiological studies provide information about the occurrence of disorders and trends in the frequency of disorders over time, which knowledge is crucial to unraveling the etiology of (mental) disorders and for the purpose of planning treatment services. Course and outcome studies also serve to inform patients, clinicians, and policy makers on the prognosis of disorders, including the duration, effectiveness, and costs of treatment. This review aims to provide an overview of the recently published studies on the epidemiology, course, and outcome of eating disorders, including anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), and the residual diagnosis ‘eating disorder not otherwise specified’ (EDNOS, renamed ‘other specified feeding or eating disorder’ (OSFED) in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5). We will update the reviews on this subject published in recent years by Keel & Brown and Smink and colleagues. In the first part, we define and describe the incidence and prevalence - the basic epidemiological measures - for AN, BN, BED, and EDNOS / OSFED in accordance with DSM-5 criteria. In the second part, we review course and outcome studies regarding the three eating disorders specified in the DSM-5: AN, BN, and BED.

EPIDEMIOLOGY OF EATING DISORDERS

Incidence is the number of new cases of a disorder in a population divided by the total time experienced for the population followed. For eating disorders, the incidence rate is commonly expressed per 100,000 persons per year (100,000 person-years). Prevalence is the proportion of a population that has a disorder at a specific point or interval in time, for example, at a certain date (point prevalence), in a certain year (12-month prevalence; often used in the DSM-5), or at any point in life (lifetime prevalence).

The DSM-5, published in May 2013, includes a revised eating disorder section. A major problem with diagnosing eating disorders using the fourth edition (DSM-IV) was the observation that the residual diagnosis EDNOS was the most common diagnosis in both clinical and community samples. In order to reduce the frequency of EDNOS, the thresholds for AN and BN were lowered and BED was added as a specified eating disorder. The revised definitions of the diagnostic categories will thus alter the disorder frequencies reported earlier. In this section,
the epidemiological studies specifically focusing on eating disorders according to – or in line with – the DSM-5 criteria are discussed. For a more comprehensive review of the incidence and prevalence of AN, BN, BED, and EDNOS according to the DSM-IV criteria, see our recent review.³

**Anorexia nervosa**

Incidence studies of eating disorders on a community level are scarce. In a community study of female Finnish twins of the 1975-1979 birth cohort,⁸ the incidence rate of a broad definition of AN (which is close to the DSM-5 definition of AN) was 490 per 100,000 person-years among 15-19-year-old girls, an increase of 81.5% compared with the incidence rate of DSM-IV AN (270 per 100,000 person-years). In the same study, the lifetime prevalence of AN almost doubled when the broad definition was used: 4.2% (broad AN) versus 2.2% (DSM-IV AN), which is in line with other community studies among women.⁹,¹⁰ Stice et al.¹¹ followed a relatively small sample of 496 adolescent girls and found a lifetime prevalence of 0.8% for DSM-5 AN by age 20 (n= only 4). In a Portuguese sample of female college and university students,¹² DSM-IV cases of eating disorders were reclassified under the DSM-5 criteria. The point prevalence of DSM-5 AN was 0.7% with a cutoff point of body mass index (BMI) less than 17.5 kg/m² and 1.0% with a cutoff point of BMI less than 18.5 kg/m², compared with 0.6% for DSM-IV AN. The 12-month prevalence among young women is approximately 0.4%.²

**Bulimia nervosa**

For BN, the incidence rate among 16-20-year-old women from the Finnish female twin cohort increased by 50% from 200 to 300 per 100,000 person-years when symptom frequency was relaxed to once a week, in accordance with the DSM-5 criteria.¹³ Several community studies found that the prevalence of BN increased by 30% when DSM-5 criteria were used, leading to a point prevalence of 0.6% for DSM-5 BN among adolescent girls and young women,¹² and a lifetime prevalence of around 2% for women.¹¹,¹³,¹⁴ The 12-month prevalence of BN among young women is 1-1.5%.²,³

**Binge-eating disorder**

To our knowledge, no incidence studies on BED yet exist. The 12-month prevalence of BED among US adult women and men is 1.6 and 0.8%, respectively.² Several population studies among adults found only very small increases in the lifetime prevalence of BED under the DSM-5 criteria,¹⁴,¹⁵ leading to an estimated 12-month
prevalence for DSM-5 BED of 1.7% in US women, with the 12-month prevalence of men remaining at 0.8%.\textsuperscript{15} In the first cross-national community survey including low-income, middle-income, and high-income countries\textsuperscript{16} an average lifetime prevalence of 1.9% for BED was found across the surveys. Lifetime prevalence estimates ranged from less than 1% in several European countries to 2.6% in the USA and 4.7% in Brazil; the sample from the latter country being limited to one urbanized area (Sao Paulo). Binge frequency had to be at least twice a week (in line with DSM-IV criteria), with a minimum duration of the disorder of 3 months (DSM-5).\textsuperscript{16}

**Eating disorder not otherwise specified / other specified feeding or eating disorder**

The residual diagnosis EDNOS is a heterogeneous category, with different operationalizations across studies. Accordingly, the reported prevalence rates vary considerably.\textsuperscript{2,17-19} The DSM-5 specifies five disorders in the residual OSFED category: atypical AN, BN of low frequency and/or limited duration, BED of low frequency and/or limited duration, purging disorder, and night eating syndrome. Little epidemiological data exist for most of these conditions. In a large community cohort of US adolescent girls and young women, the prevalence of purging disorder was 2-2.5%.\textsuperscript{19} In another sample of 496 US adolescent girls, the lifetime prevalence by age 20 was 2.8% for atypical AN, 4.4% for subthreshold BN, 3.6% for subthreshold BED, and 3.4% for purging disorder; these conditions accounted for 68.9% of all DSM-5 eating disorder diagnoses.\textsuperscript{11} However, several studies have confirmed that the DSM-5 criteria for eating disorders effectively reduce the proportion of EDNOS diagnoses, although the magnitude of the reduction varies across the studies.\textsuperscript{12,20-23}

**COURSE AND OUTCOME OF EATING DISORDERS**

In the last decade, comprehensive reviews on the course and outcome of AN and BN have been published,\textsuperscript{1,24-27} though of course they are based on studies using DSM-IV or DSM-III-R diagnostic criteria. Less is known about the course and outcome of BED because of a lack of long-term follow-up studies.\textsuperscript{1} As BED is newly recognized as an official diagnosis in the DSM-5, we will relatively pay more attention in this review to the course and outcome studies of BED.

Important parameters of good outcome are remission and recovery. On the other end of the spectrum, mortality is the most extreme parameter of poor outcome.
Because mortality is such a salient and unambiguous outcome of eating disorders, we will review the recent studies on mortality in AN, BN, and BED irrespective of which DSM edition diagnostic criteria were used.

**Anorexia nervosa**

The crude mortality rate (CMR) is the number of deaths within the study population over a specified period. The standardized mortality ratio (SMR) is the percentage of observed deaths in the study population (e.g., AN patients) divided by the percentage of expected deaths in the population of origin (e.g., all women between 15 and 45 years of age). In a meta-analysis of excess mortality in the 1990s, AN was associated with the highest rate of mortality among all mental disorders. In a more recent meta-analysis of 35 published studies describing mortality rates for AN, the CMR for AN was 5.1 deaths per 1,000 person-years and the overall SMR was 5.9 with a mean follow-up period of 14.2 years. A common cause of death in AN is suicide. According to two meta-analyses (covering largely the same studies), the suicide rate for AN was 1.3 per 1,000 person-years; thus, one in five AN patients who die have committed suicide. Other common causes of death in AN are the direct consequences of starvation and alcohol-related diseases. Two recent studies using the Swedish Hospital Discharge Register found that fecundity is reduced in both men and women with (a history of) AN, compared with the general population, but that women with a history of AN who do have children (before or after hospital admission for AN) have a better prognosis in terms of mortality. This seems a rather straightforward finding, as infertility (amenorrhea) was a diagnostic criterion in the earlier editions of the DSM and is regarded as an indicator of physiological dysfunction in the DSM-5. However, in the population-based study of the female Finnish twin birth cohort, the 5-year clinical recovery rate did not differ between AN patients with and without amenorrhea, being 66.8 and 69.1%, respectively. This finding was replicated in a prospective study of an outpatient sample treated with cognitive-behavioral therapy (CBT): at 6-year follow-up, the recovery rate for AN according to both DSM-5 and DSM-IV criteria was 52%. These results provide additional evidence for the validity of the deletion of the amenorrhea criterion in terms of treatment outcome. However, the majority of AN patients in the community are not detected by the health care system or referred to mental health care.
Bulimia nervosa

Mortality and suicide risk are elevated in BN as well, albeit not as marked as in AN.\textsuperscript{31,33} According to a meta-analysis of 12 studies describing mortality rates for BN, CMR was 1.7 per 1,000 person-years and SMR was 1.9 for a mean follow-up duration of 9.7 years.\textsuperscript{31} Another recent meta-analysis of the risk of suicide in eating disorders\textsuperscript{32} reported a suicide rate of 0.3 per 1,000 person-years for BN; thus, as is the case for AN, about one in five deaths in BN are the result of suicide. Several studies\textsuperscript{15,41} report that recovery rates are the same for BN according to the DSM-5 and DSM-IV criteria. In a study of a treatment sample receiving CBT, recovery rate was around 50\% for both DSM-5 and DSM-IV BN after 6 years of follow-up. Patients were considered recovered when they no longer fulfilled the criteria of any eating disorder at follow-up.\textsuperscript{41} In the community study of female Finnish twins,\textsuperscript{13} 55\% of patients with BN according to the DSM-5 criteria were recovered 5 years after the onset of the disorder (DSM-IV: 57\%). In this study, a more stringent definition of recovery was used: the absence of bingeing and purging for at least one year prior to assessment. Fewer than a third of the cases had been detected by health care professionals.\textsuperscript{13} Keel et al.\textsuperscript{44} reported that 20-year remission rates in a sample of college students did not differ significantly between DSM-IV BN and related EDNOS, such as BN of lower frequency and/or limited duration, BED, and purging disorder, suggesting that thresholds that distinguish BN from related EDNOS may have poor predictive validity.

Binge-eating disorder

Data on the long-term outcome of BED, including mortality, are scarce. None of the included studies in the meta-analysis of mortality rates in EDNOS by Arcelus et al.\textsuperscript{31} stated explicitly that BED was part of the EDNOS category.\textsuperscript{3,31} In a sample of 68 female inpatients with BED, CMR was 2.9\% after 12 years of follow-up, with a nonsignificant SMR of 2.3 (95\% CI: 0.0-5.5).\textsuperscript{45} In a meta-analysis of three studies, no suicide had occurred among 246 BED patients after a relatively short mean follow-up of 5.3 years.\textsuperscript{32}

Most outcome data on BED are (derived from) randomized controlled trials (RCTs) comparing different forms of psychotherapy and behavioral weight loss (BWL) treatment in overweight or obese BED patients. Duration of follow-up across the studies ranges from 1 to 6 years.\textsuperscript{46-53} These studies address several important issues and priorities in BED research, such as the lack of long-term outcome studies\textsuperscript{46,48,52,53} and the identification of predictors and moderators of treatment outcome.\textsuperscript{48,51,53} In an RCT comparing cognitive-behavioral therapy-guided self-help
(CBT gsh), interpersonal therapy (IPT), and BWL, at 2-year follow-up significantly higher remission rates for binge eating were reported for both CBT gsh and IPT (62 and 67%, respectively) than for BWL (43%).48 In a study examining the long-term efficacy of CBT and IPT, similar remission rates of 52.0% and 76.7%, respectively (non-significant difference; mean 64.4%), were observed after a mean follow-up duration of almost 4 years. Over the course of follow-up, remission rates declined significantly in the CBT group.52 The attenuated efficacy of CBT over time was also observed in another study: whereas CBT provided better outcomes at the end of treatment compared with BWL, after 6 years of follow-up (retention rate 65%), remission rates in both treatment arms were around 19% only.53 An Italian study comparing individual and group CBT in a treatment-seeking sample of both BED and subthreshold BED patients reported a relatively low remission rate of 32% after 3 years of follow-up; subthreshold BED was defined by a minimum binge frequency of once a week (in line with the DSM-5 criteria), for at least 6 months (DSM-IV).46

BED is associated with overweight and obesity.48 The psychological treatments of BED do not produce substantial weight loss, although the elimination of binge eating might protect against future weight gain.48,52,54,55 BWL leads to short-term weight loss,48,49,51,53,55 but long-term weight loss has yet to be demonstrated.53,55

However, in morbidly obese BED patients undergoing bariatric surgery, after 1 year the same amount of (substantial) weight loss was achieved as in surgically treated patients without BED, and, compared with BED patients receiving BWL, there were similar improvements in eating behaviors and risk factors for cardiovascular diseases.56 BED may confer a risk of components of the metabolic syndrome (a cluster of related risk factors for cardiovascular disease, including abdominal obesity, dyslipidemia, hypertension, and abnormal glucose metabolism),16,57 over and above the risk attributable to obesity alone.57 Despite the important findings of these studies and their methodological rigor, including accurate assessment of BED with valid and reliable diagnostic instruments, it is important to note that from an epidemiological point of view they provide a limited picture of the true outcome of BED, as a substantial proportion of the total population of BED patients are not obese and the majority of BED patients do not seek treatment.16

There is a lack of longitudinal community studies on BED in adults, but for adolescents some studies of interest have been published recently.11,19,58 In a prospective study of 8,594 adolescent girls evaluating whether BED predicted the development of adverse outcomes,19 girls with BED had a twofold risk of becoming overweight or obese, or developing high depressive symptoms compared with nondisordered
girls, but the risk of starting to binge drink or use drugs was not increased. In another study of the same cohort in which boys were also included, weekly binge eating predicted drug use as well.\textsuperscript{58} The presence of BED was ascertained by means of self-report and not all DSM-diagnostic criteria of BED were systematically assessed before making the diagnosis, which might have led to some misclassification.\textsuperscript{19,58} Finally, in a community study of a sample of 496 female adolescents followed over 8 years with yearly assessment of eating disorders by means of a semi-structured interview, 3\% developed DSM-5 BED, with a 1-year remission rate of 93\%.\textsuperscript{11} This most likely reflects the typical remission-relapse course of mild, self-limiting forms of BED in the community, for which no treatment is sought.\textsuperscript{11}

**CONCLUSION**

The DSM-5 criteria for eating disorders effectively reduce the frequency of the residual diagnosis EDNOS, by lowering the threshold for AN and BN, and adding BED as a specified eating disorder. Both AN and BN are associated with increased mortality; for BED, however, data on the long-term outcome, including mortality, are scarce. The course and outcome studies of both AN and BN show that no significant differences exist between DSM-5 and DSM-IV definitions. For BED, most outcome data are derived from RCTs, whereas less is known about BED on a community level.
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