

Overview of eating disorders: diagnosis and epidemiology

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Introduction

This overview of eating disorders will reflect on the way that eating disorder diagnosis, conceptualisation, public perception and the clinical and research landscape has changed over the past 30 years and how this has impacted estimates of incidence and prevalence. Despite these changes, some consistencies remain; the core pathologies of eating disorders, namely dietary restriction, binge eating behaviours and harmful weight loss strategies resulting in clinically significant impairment or distress remain at the centre of all the main eating disorder diagnoses.

Yet, what were once considered rare disorders presenting to, and managed by, specialists, have become a major public health issue; one Finnish twin study reported around 10% of young men and women (17.9% for females and 2.4% for males) as meeting criteria for an eating disorder (1). There are a number of possible explanations for this change in the demography. The first is the evolving definition of what constitutes an eating disorder. A field that once focused almost exclusively on patients with anorexia nervosa incorporated bulimia nervosa into its thinking in the 1980s and 1990s. A proposal was made to rename these disorders collectively as "dieting disorders", given the overvaluation of weight and shape concerns and strong influence of the cultural thin ideal in the aetiology of both (2). From the late 1990s onwards, binge eating disorder (BED) increasingly became recognised as the most common eating disorder (3, 4), and with it came the complex relationship between eating disorders and higher weight; where the thin ideal once dominated, the culture of weight stigma came more into focus. BED was subsequently included, not uncontroversially, in the DSM-5 in 2013.

Add into the mix avoidant/restrictive food intake disorder (ARFID), in which dietary restriction is no longer associated with high importance of weight and shape, and we start to see a fundamental shift in conceptualisation of what is, and what is not, an eating disorder. Originally intended as an umbrella diagnosis to capture a variety of presentations and idiosyncratic terminologies and to stimulate research, ARFID has served its purpose. As of October 2024, there are 684 journal articles about ARFID, of which 560 were published within the previous five years. With little epidemiological data, no limits in terms of age and significant challenges in terms of differentiation from its common comorbidities, ARFID poses challenges from both a clinical and a research perspective. Presentations within an ARFID diagnosis include those that would once have been classified as feeding disorders of infancy and early childhood, specific phobias, somatisation disorder, and what are understood as core symptoms of developmental disorders such as autism. In a large autism cohort, 21% of participants and 17% of their parents presented with avoidant-restrictive features (5). Of children diagnosed with ARFID, 8.2% to 54.8% are autistic and more than half of individuals with ARFID also have other neurodevelopmental, psychiatric or somatic diagnoses, with anxiety, depression, sleep disorders and learning difficulties being the most common. Feeding difficulties are particularly related to sensory sensitivities, food preferences and mealtime rituals and routines which can persist into adulthood. Research to understand how and when interventions may be most effective in this population is scarce as yet (6), although various strategies have been developed to support autistic children with feeding difficulties (7).

What the addition of ARFID to our diagnostic lexicon has also highlighted, in addition to a group of patients previously neglected in research and practice, is a clearer understanding of the features of anorexia nervosa that are associated with dietary restriction and not simply with overvaluation of low body weight. These include the importance of neophobia (an irrational fear or dislike of anything new or unfamiliar), alexithymia (the inability to recognise or describe one's own emotions), sensory sensitivity, the tendency to premorbid low weight and the relationship between restrictive eating and autism spectrum disorders. Combined with another major theoretical breakthrough in the field, that of "big data" genetic analyses, the reconceptualisation of eating disorders as metabo-psychiatric disorders (8) has shifted thinking around personal responsibility, blame and shame, all of which have been hallmarks of public and professional perspectives on eating disorders.

Genetic and neurobiological factors

Together, genetic studies and neuroscience are moving us towards an era in which the "bulimic or binge eating disorders" and the "restrictive eating disorders" are emerging as having distinctive genetic and neurobiological underpinnings, acknowledging, of course, that the two can co-occur. A transdiagnostic approach offers potential for development of interventions targeting, for example, cognitive biases (such as rejection sensitivity or negative interpretation bias) (9) or processes (such as rumination or impulsivity) across eating disorder diagnoses. Some important distinctions between diagnoses remain, however, such as the explicit and implicit overvaluation of weight and shape in self-evaluation seen in anorexia nervosa and bulimia nervosa that distinguishes these disorders from ARFID (10), which is implicated as a maintaining factor in theoretical models, such as outlined in Kaye's seminal paper (citing su-

permodel Kate Moss), "Nothing Tastes as Good as Skinny Feels: the neurobiology of anorexia nervosa" (11).

Diagnostic criteria

The current diagnostic classification of eating disorders was designed to minimise the number of patients presenting with clinically significant eating difficulties who did not meet the criteria for a specified eating disorders diagnosis (12) and to align the diagnostic categories in the DSM-5 and ICD-11 with one another more closely. To address the excess of "Eating disorders not otherwise specified" diagnoses using DSM-IV criteria, the DSM-5, and more recently the ICD-11, added other specified feeding and eating disorders (OSFED) to the diagnostic family. OSFED specifies clinically significant variants of eating disorder presentations, including purging disorder and night eating syndrome. The final diagnoses in the feeding and eating disorders family are pica and rumination disorder/syndrome, both of which are relatively under-researched in large samples.

Some updates to the diagnostic criteria of eating disorders have been nuanced, with the aim of making them less stigmatising, more inclusive and developmentally sensitive. These include the removal of words like "refusal", the potential to imply cognitions from behaviour, the removal of specific weight criteria which were leading to very rigid diagnostic profiling, reduction in the frequency criteria of specific behaviours (e.g., bingeing) for a diagnostic threshold to be reached, and the removal of amenorrhoea as a diagnostic feature due to its limited application and prognostic significance. Other amendments have been more substantial and controversial. In the ICD-11, the criteria for anorexia nervosa allow the diagnosis to be made if there is evidence of significant weight loss in a short amount of time and typical cognitions; thus, the diagnosis can be made in persons of any weight. In the DSM-5, this presentation would be diagnosed as atypical anorexia nervosa, but this, in turn, calls into question the weight threshold between anorexia nervosa and atypical anorexia nervosa. Nonetheless, the overall trend is for the centrality of weight status (i.e., BMI) in eating disorder diagnosis and treatment to have diminished. Consequently, the prevalence of disordered eating across the weight range, and the cultural and ethnic biases that weight-based definitions introduce, has become more apparent.

Despite increasing consensus on diagnostic categories across classification systems, the limited range of behaviours and cognitions across the range of eating disorder diagnoses are thought by some to outweigh their differences. This view is the basis of the transdiagnostic framework underlying enhanced cognitive behavioural therapy for eating disorders (CBT-E) (13) and, as noted above, is increasingly supported by neuroscience showing shared deficits underlying, for example, cognitive processing biases, metacognition and emotional dysregulation (14, 15). Nonetheless, evidence-based approaches, much of the research agenda and, to some extent, clinical services remain very diagnosis-specific in recognition of the differential biological, psychological and social aetiological and prognostic distinctions between these presentations. Meanwhile, new clinical presentations continue to challenge the validity of current diagnostic categories, introducing new terminology such as orthorexia (a restrictive and unhealthy focus on healthy eating), diabulimia (a form of purging disorder seen in people with type 1 diabetes mellitus who misuse insulin for the purpose of weight management) and bigorexia, in recognition that weight gain and muscle bulking, typically in males, can be associated with psychopathology and risk. None of these terms is currently included in the DSM or ICD classifications.

One diagnostic dilemma, not exclusive to eating disorders, has been the extent to which diagnoses, and therefore prevalence estimates, are based on self-reporting using psychometrically validated measures as opposed to third-party or clinician assessment. This is illustrated by the sudden increase in prevalence of probable eating disorders seen at the age of 16 years when the instrument used to assess caseness in the English national children and young people's prevalence surveys changed from parent report to self-report. In 2023, eating disorders were identified in 12.5% of 17-to-19-year-olds by self-report, with rates four times higher in young women (20.8%) than young men (5.1%) (16). This compared with 2.6% of 11-to-16-year-olds by parent report, although rates remained four times higher in girls (4.3%) than boys (1.0%). By the age of 20 to 25, prevalence reduced again to 5.9% by self-report, with no difference in rates evident between women and men. This difference in prevalence may accurately reflect the degree of disordered eating behaviours and cognitions between the ages of 17 and 19, which is the median age of onset for eating disorders (17), or it may be that young people see their behaviours as more pathological than their parents do. Of course, distress is primarily a subjective construct, although impairment and behavioural disturbance may be better assessed objectively.

Nonetheless, the optimal method of determining diagnostic thresholds and the value of categorical diagnostic boundaries continue to be challenged in eating disorders (18), especially in the context of comorbidities in which dietary restraint and/or food preoccupation is the norm, such as type 1 diabetes, obesity and autism. In such disorders, questions arise about when disordered eating becomes an eating disorder; for example, "What is appropriate dietary restriction in a person of higher weight who is attempting to manage their weight?", "When does loss-of-control eating or emotional overeating become a binge?", and "When does the sensory-based dietary restriction seen in people with autism become ARFID?". The term "disordered eating" is increasingly used to describe these disturbances of eating, although it is used differently in different contexts. Some use the term to describe behaviours found in the population that have not reached, or not assessed as reaching, clinical thresholds. For example, 40% of 16-year-old girls in

one cohort study showed disordered eating behaviours, 11% of which reached the diagnostic threshold on screening tools (19). Other examples include emotional overeating in people living at higher weight (20) or the approximately 26% of subjects with type 1 diabetes who have some form of disordered eating or weight control behaviour, the majority of whom also misuse insulin for the purposes of weight control (21). Eating disorder clinicians often use the term disordered eating to describe overt eating disorder behaviours where the persistence of the symptoms or their frequency/severity, often in the context of other psychopathology such as emotionally unstable personality disorder, suggests that an eating disorder diagnosis may not be appropriate or helpful in terms of getting the patient the care they need. Nonetheless, given the widespread prevalence of disordered eating behaviour and its comorbidities, it is vital that clinicians across the healthcare system are familiar with identifying, assessing and signposting people with disordered eating to appropriate care.

Prevalence and incidence

Sadly, alongside the increased recognition of eating disorders has come a rise in their incidence and prevalence, a phenomenon exacerbated by the COVID-19 pandemic (22). Debate continues about whether this is due to the expansion of the conceptualisation of eating disorders, as outlined above, or whether the increases are "real". There has always been a discrepancy between the population prevalence of eating disorders and that of people presenting to clinical care. Profile and awareness raising, increasing the evidence-based interventions on offer and removal of barriers to care may account for why the numbers presenting to clinical care have risen. Other explanations for increased prevalence include the promotion of body image-related perfectionism together with new ways to experience social rejection and bullying and to access potentially harmful material that social media presents (23). Another likely factor is the parallel rise in obesity over a similar period (24). A link with obesity prevalence is logical given the centrality of "fear of obesity" to the psychopathology of eating disorders, and the association between higher weight, dieting behaviour, body dissatisfaction, weight stigma (and associated teasing/bullying) and shame that characterise all eating disorders. Yet, the dialogue between the obesity and eating disorders fields and the current evidence base that might result in a shared public health approach remains limited and challenging (25, 26).

These caveats and the diagnostic dilemmas outlined above aside, where good epidemiological studies exist, they show a picture of relative consistency within Western cultures. The incidence and prevalence of anorexia nervosa remains relatively stable (27, 28), apart perhaps from in younger age groups (28, 29). For bulimia nervosa, there has been a decline in overall incidence rate over time (27). Lifetime prevalence rates for anorexia nervosa are estimated to be up to 4% among females and 0.3% among males, and for bulimia nervosa, up to 3% of females and more than 1% of males. All eating disorders are reported worldwide among males and females of all ages, although estimates in non-Western cultures remain more limited, and many such cultures are rapidly evolving. Twenty-two epidemiological studies on eating disorders in five different countries in the Arab world reported a 12-month eating disorder prevalence of 3.2% and an eating disorder lifetime prevalence of 6.1% (30). BED was the most common eating disorder (12-month prevalence = 2.1%, lifetime prevalence = 2.6%). Across the studies, between 23.8 and 34.8% of participants were at high risk for any eating disorder, with body dissatisfaction, high BMI and separated/widowed/single marital status being associated with eating disorder pathology. These figures are comparable to many Western cultures. Other populations recognised as being at higher risk of eating disorders compared to their peers are sexual and gender minority young people (31), with 16.6% of a sample of over 8000 sexual and gender minority adolescents aged 13 to 17 years from the United States reporting at least one disordered eating behaviour, binge eating being the most prevalent (9.7%), followed by caloric restriction (6.2%), purging (3.2%), diet pill use (1.4%) and, less commonly, laxative use (0.8%) (32).

The incidence and prevalence of ARFID has been harder to determine because of the lack, until recently, of diagnostic instruments, the lack of routine administrative data containing the diagnosis, since it was not included in the ICD-10, and the differences in settings in which it has been measured. Thirty studies included in a systematic review found that most estimates came from specialised eating disorder settings, where prevalence rates were 5% to 22.5% (33). Three studies from specialist feeding clinics showed the highest prevalence rates, ranging from 32% to 64%, while studies from non-clinical samples reported prevalence estimates ranging from 0.3% to 15.5%. Only two studies, using the same methodology, have estimated incidence, one in Canada and one in the UK. Both found an incidence of around 2 to 3 children or adolescents per 100,000 reaching clinical care (34, 35). In all studies, psychiatric comorbidity was common, especially anxiety disorders (9.1–72%) and autism spectrum disorder (8.2–54.75%).

In addition to considering the incidence and prevalence of eating disorders, it is important to acknowledge the burden of disease they present to those affected. The burden associated with mental disorder has reached prominence, in part thanks to the extensive Global Burden of Disease (GBD) studies. In 2019, anorexia nervosa and bulimia nervosa were the only eating disorders included in the GBD estimates (36). A subsequent analysis included BED and OSFED, on the basis that they are more prevalent. In the updated estimate, data from 54 studies (36 from high-income countries) found that 41.9 million people (17.3 million with BED and 24.6 million with OSFED), had been omitted from the previous GBD estimate of 13.6 million people (37), making a total of 55.5 million people and thus confirming the need to consider all eating disorder diagnoses in prevalence estimates. Together, these data suggest that eating disorders

are among the commonest mental disorders affecting young people and working-age adults and that their prevalence and impact are increasing. What has, until now, been largely considered a specialist clinical problem needs to be addressed as a public health concern, adopting approaches aligned to, rather than at odds with, obesity policy.

Conclusions

Feeding and eating disorders occur across the weight spectrum and diagnoses are evolving to recognise and capture a wider range of disordered eating behaviours and associated cognitions. Thus, eating disorders diagnosed with contemporary diagnostic criteria are common. BED is consistently the most prevalent disorder in non-clinical populations and in people at higher weight, although accurate estimates are sparse in some countries and incidence has not been accurately determined. The incidence and prevalence of anorexia nervosa is relatively stable except in children and young adolescents, where rises are observed. The incidence of bulimia nervosa may be declining. The population incidence of ARFID is unknown, although preliminary data are available for clinical cases and prevalence estimates vary widely depending on the setting. Research into the outcomes of people with disordered eating behaviour might help inform when it is useful to make a diagnosis of eating disorder or describe it disordered eating.

With each iteration of diagnostic criteria, the limitations of diagnostic categorisation emerge. For example, phenotypic descriptions of eating disorders (such as ARFID) can mask aetiological heterogeneity, which may be relevant to treatment selection and efficacy as well as to scientific advances in understanding. Whatever the precise prevalence and incidence of eating disorders and whatever the diagnostic challenges might be, it has become clear that these disorders are common and present a major public health challenge as well as a continued challenge to clinical services because of the high rate of comorbidities and, particularly for anorexia nervosa, the high mortality rate.

References

1. Silen Y, Sipila PN, Raevuori A, Mustelin L, Marttunen M, Kaprio J, et al. DSM-5 eating disorders among adolescents and young adults in Finland: a public health concern. *Int J Eat Disord*. 2020;53(5):520-31.
2. Beumont PJ, Garner DM, Touyz SW. Diagnoses of eating or dieting disorders: what may we learn from past mistakes? *Int J Eat Disord*. 1994;16(4):349-62.
3. Yanovski SZ. Binge eating disorder: current knowledge and future directions. *Obes Res*. 1993;1(4):306-24.
4. Hay P. The epidemiology of eating disorder behaviors: an Australian community-based survey. *Int J Eat Disord*. 1998;23(4):371-82.
5. Keski-Rahkonen A, Ruusunen A. Avoidant-restrictive food intake disorder and autism: epidemiology, etiology, complications, treatment, and outcome. *Curr Opin Psychiatry*. 2023;36(6):438-42.
6. Connor ZL, Atkinson L, Bryant-Waugh R, Maidment I, Blissett J. Development of a toolkit to help parents/caregivers manage feeding problems in autistic children: a protocol for a realist synthesis and toolkit co-design. *PLoS One*. 2024;19(10):e0309410.
7. Hodges AK, Hathaway KL, McMahon MXH, Volkert VM, Sharp WG. Treatment of feeding concerns in children with autism spectrum disorder: a systematic review of behavioral interventions with caregiver training. *Behav Modif*. 2023;47(4):936-58.
8. Watson HJ, Yilmaz Z, Thornton LM, Hubel C, Coleman JRI, Gaspar HA, et al. Genome-wide association study identifies eight risk loci and implicates metabo-psychiatric origins for anorexia nervosa. *Nat Genet*. 2019;51(8):1207-14.
9. Rowlands K, Beaty T, Simic M, Grafton B, Hirsch C, Treasure J, et al. Cognitive bias modification training of attention and interpretation to reduce expectations of social rejection in adolescents with eating disorders: a small efficacy randomized controlled trial. *Int J Eat Disord*. 2022;55(11):1506-20.
10. Izquierdo A, Plessow F, Becker KR, Mancuso CJ, Slattery M, Murray HB, et al. Implicit attitudes toward dieting and thinness distinguish fat-phobic and non-fat-phobic anorexia nervosa from avoidant/restrictive food intake disorder in adolescents. *Int J Eat Disord*. 2019;52(4):419-27.
11. Kaye WH, Wierenga CE, Bailer UF, Simmons AN, Bischoff-Grethe A. Nothing tastes as good as skinny feels: the neurobiology of anorexia nervosa. *Trends Neurosci*. 2013;36(2):110-20.
12. Fairburn CG, Bohn K. Eating disorder NOS (EDNOS): an example of the troublesome "not otherwise specified" (NOS) category in DSM-IV. *Behav Res Ther*. 2005;43(6):691-701.
13. Fairburn CG, Cooper Z, Shafran R. Cognitive behaviour therapy for eating disorders: a "transdiagnostic" theory and treatment. *Behav Res Ther*. 2003;41(5):509-28.
14. Aloï M, Carcione A, Lo Coco G, Rania M, Carbone EA, de Filippis R, et al. Metacognition as a transdiagnostic factor across eating disorders: a latent profile analysis study. *Front Psychol*. 2024;15:1391715.
15. Sloan E, Hall K, Moulding R, Bryce S, Mildred H, Staiger PK. Emotion regulation as a transdiagnostic treatment construct across anxiety, depression, substance, eating and borderline personality disorders: a systematic review. *Clin Psychol Rev*. 2017;57:141-63.
16. Newglove-Delgado TM, F; Williams, T; Mandalia, D; Dennes, M; McManus, S; Savic, M; Treloar, W; Croft, K; Ford, T.. Mental Health of Children and Young People in England. Leeds. NHS England (2023).
17. Solmi M, Radua J, Olivola M, Croce E, Soardo L, Salazar de Pablo G, et al. Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. *Mol Psychiatry*. 2022;27(1):281-95.
18. Tournayre L, Balbinotti MAA, Monthuy-Blanc J. Some hope for a dimensional assessment? A critical review of psychometric validated (semi-) structured interview to assess eating disorders. *Eur Eat Disord Rev*. 2024;32(6):1138-56.
19. Bould H, De Stavola B, Lewis G, Micali N. Do disordered eating behaviours in girls vary by school characteristics? A UK cohort study. *Eur Child Adolesc Psychiatry*. 2018.
20. Chaves E, DiPangrazio A, Paponetti M, Stout G. Disordered eating in pediatric obesity. *Pediatr Clin North Am*. 2024;71(5):879-96.
21. Peveler RC, Bryden KS, Neil HA, Fairburn CG, Mayou RA, Dunger DB, et al. The relationship of disordered eating habits and attitudes to clinical outcomes in young adult females with type 1 diabetes. *Diabetes Care*. 2005;28(1):84-8.

22. Meier K, van Hoeken D, Hoek HW. Review of the unprecedented impact of the COVID-19 pandemic on the occurrence of eating disorders. *Curr Opin Psychiatry*. 2022;35(6):353-61.
23. Keski-Rahkonen A. Eating disorders: etiology, risk factors, and suggestions for prevention. *Curr Opin Psychiatry*. 2024;37(6):381-7.
24. da Luz FQ, Sainsbury A, Mannan H, Touyz S, Mitchison D, Hay P. Prevalence of obesity and comorbid eating disorder behaviors in South Australia from 1995 to 2015. *Int J Obes (Lond)*. 2017;41(7):1148-53.
25. Turner SL, Libert AM, Haase G, Pan Z, Austin A, Timko CA. The unintended consequences of school-based health and nutrition policies: a systematic review. *Front Psychol*. 2024;15:1356663.
26. Le LK, Tan EJ, Perez JK, Chiotelis O, Hay P, Ananthapavan J, et al. Prevention of high body mass index and eating disorders: a systematic review and meta-analysis. *Eat Weight Disord*. 2022;27(8):2989-3003.
27. van Eeden AE, van Hoeken D, Hoek HW. Incidence, prevalence and mortality of anorexia nervosa and bulimia nervosa. *Curr Opin Psychiatry*. 2021;34(6):515-24.
28. Petkova H, Simic M, Nicholls D, Ford T, Prina AM, Stuart R, et al. Incidence of anorexia nervosa in young people in the UK and Ireland: a national surveillance study. *BMJ Open*. 2019;9(10):e027339.
29. van Eeden AE, van Hoeken D, Hendriksen JMT, Hoek HW. Increase in incidence of anorexia nervosa among 10- to 14-year-old girls: a nationwide study in the Netherlands over four decades. *Int J Eat Disord*. 2023;56(12):2295-303.
30. Melisse B, van Furth E, Hoek HW. Systematic review of the epidemiology of eating disorders in the Arab world. *Curr Opin Psychiatry*. 2024;37(6):388-96.
31. O'Shea J, James R, Nicholls D, Downs J, Hudson LD. Prevalence, severity and risk factors of psychiatric disorders amongst sexual and gender diverse young people during the COVID-19 pandemic: a systematic review. *Clin Child Psychol Psychiatry*. 2024;29(3):1213-27.
32. Nagata JM, Stuart E, Hur JO, Panchal S, Low P, Chaphekar AV, et al. Eating disorders in sexual and gender minority adolescents. *Curr Psychiatry Rep*. 2024;26(7):340-50.
33. Sanchez-Cerezo J, Nagularaj L, Gledhill J, Nicholls D. What do we know about the epidemiology of avoidant/restrictive food intake disorder in children and adolescents? A systematic review of the literature. *Eur Eat Disord Rev*. 2023;31(2):226-46.
34. Katzman DK, Spettigue W, Agostino H, Couturier J, Dominic A, Findlay SM, et al. Incidence and age- and sex-specific differences in the clinical presentation of children and adolescents with avoidant restrictive food intake disorder. *JAMA Pediatr*. 2021;175(12):e213861.
35. Sanchez-Cerezo J, Neale J, Julius N, Lynn RM, Hudson L, Nicholls D. Incidence of avoidant/restrictive food intake disorder in children and adolescents across the UK and Ireland: a BPSU and CAPSS surveillance study. *BMJ Open*. 2024;14(11):e088129.
36. Ali M, Abbasifard M, Abbasi-Kangevari M, Abbastabar H, Abd-Allah F, Abdelalim A, et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020;396(10258):1204-22.
37. Santomauro DF, Melen S, Mitchison D, Vos T, Whiteford H, Ferrari AJ. The hidden burden of eating disorders: an extension of estimates from the Global Burden of Disease Study 2019. *Lancet Psychiatry*. 2021;8(4):320-8.