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Issue 6 Winter 2024

Cutting Edge Psychiatry in Practice

Focus Issue

Eating Disorders

Guest Editor: Dr Erica Cini
Consulting Editor: Professor Dasha Nicholls
Editor-in-Chief: Professor Frank M C Besag
ISSN 2047-1882 (Print) 2047-1890 (Online)

NHS East London NHS Foundation Trust

The front and back cover images for this issue were created by young people with eating disorders and were originally featured on the Butterfly Foundation website, butterfly.org.au.

The creator of the front cover image, **Audrey Kouris**, described her work in the following way.

"To create this drawing I thought about what it feels like to go through an eating disorder. In my experience it made me feel like I was trapped or in jail. The tally marks on the drawing is meant to represent jail. I often felt no matter how unwell I was it was never "bad enough". The hands reaching at this person body and pulling at the at the skin is like the voices and the disorder always telling me how I could "improve". My head is full of negative voices and it's like a tornado which I expressed in my drawing. I find drawing or writing is a really good way to understand my feeling and I hope other people will use art as a form of therapy like I did." – Audrey Kouris

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Cutting Edge Psychiatry in Practice is an initiative of East London NHS Foundation Trust

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Foreword

I am delighted to introduce this edition of the journal that is dedicated to synthesising some of the rich clinical knowledge and scientific evidence about these disorders which have only recently found their home within psychiatry. The span of topics that are addressed in this volume, and the wide range of expertise that has been garnered, together speaks to the complexity of these conditions, and the need for a broad understanding. The volume considers issues and approaches that are outside the standard "box" and includes an international perspective with a wide range of authors proficient in many disciplines. Within my lifetime of working in the realm of eating disorders, the most rewarding aspect is the long-term partnerships that we have forged with patients and their supporters. This collaboration of those with lived experience with their diverse skills, has ensured that the direction and delivery of research and development, and the form and evidence base of treatment, is informed by expertise and evidence. It is internationally recognised that funding for services and research into this area has been woefully inadequate. However, the diversity of voices, and the breadth and depth of the knowledge base within this volume, illustrates both the need, and the challenge, of working in this area, and the hope that informed help is now at hand.

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Editorial

It has been a wonderful experience to edit this eating disorders focus issue of Cutting Edge Psychiatry in Practice. The 94 contributors from seven different countries have informed, educated, updated, inspired and moved us. The topics range widely, covering history, current practice, leading edge advances such as neurosurgery, pharmacotherapy and virtual reality, together with the promise of genetics/epigenetics and the challenges of ethics. The paper on ethics highlights the difficulties in making decisions in a field in which many patients refuse treatment but a high proportion will die without it.

The concept of what should be included in the category of eating disorders has changed recently, with recognised eating disorders currently comprising anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, other specified feeding and eating disorders, pica and rumination disorder. The previous requirement that the individual had to have concerns about weight, body shape or body image no longer apply to all the eating disorders. Related conditions such as body dysmorphia are also considered in this issue and the high prevalence of co-existing conditions, notably autism, is highlighted.

The authorship includes several world leaders in the field, those with extensive clinical experience, current practitioners and, most important, those with lived experience of eating disorders. With such a range of wonderful papers, it might seem inappropriate to draw attention to one in particular, but Katharine Lazenby's writings on her own very challenging experience of having both anorexia nervosa and autism set the scene with such clarity and impact, it cannot be recommended too highly.

We remain profoundly indebted to the many committed authors, peer reviewers, service users and others, including our brilliant Design and Copy Editor, our invaluable Consulting Editor and our indefatigable professional proofreader, who have made this publication possible. We hope that you will find it of value and that, like us, you will be informed, educated, updated, inspired and moved.

Professor Frank M C Besag FRCP FRCPsych FRCPCH (Editor-in-Chief)

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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.

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Lived experience of an eating disorder

Katharine Lazenby†

A common misconception of anorexia is that it is a faddy, vanity-driven diet that has gone too far; a wilful lifestyle choice that simply requires a decision to "just eat" in order to recover. I would have saved myself years of agony and time lost in inpatient care if it were really that simple.

Between the ages of 19 and 32 I had more inpatient admissions in specialist eating disorders units than I am able to count (some of which lasted as long as a year or 18 months). One of my consultant psychiatrists calculated that in my 20s I spent more time locked in a hospital ward than I did living in my own home. Having slipped into the merciless grips of an eating disorder, I found it impossible to prise myself free. For many years it felt like trying to escape quicksand – the more I struggled to find solid ground, the deeper I sank.

If you get to know and understand eating disorders, you'll come to realise that they serve a powerful function for the individual; some of us may go so far as to say the illnesses are in many ways beneficial, rewarding even. They are often a response to a deep and profound unmet need or buried conflict. Providing a sense of control, escape or comfort, they often arise in an attempt to cope with things that feel overwhelming, chaotic or frightening. They are the answer to an unresolved question, the solution to a knotty problem.

I felt both suffocated and comforted by the python-like grip of my anorexia. I had many moments of clarity where I could see it was destroying me, jeopardising everything in my life, and yet I still wanted to be held in its embrace.

It was dangerous, but felt safe. So, for years it kept pulling me down. The paradox is that to others my eating disorder looked like I was giving up on life, a slow suicide, but I believe that on some level it was my way of trying to save myself.

Retreating into my eating disorder numbed my emotions and fogged my mind: anorexia was the perversely literal solution to having "a lot on my plate", thoughts that are too much to bear and emotions that are impossible to swallow. My eating disorder steadily disconnected me from reality, turning down the volume on a deafening world and providing an escape from unwanted responsibilities and feelings of powerlessness and insecurity. It gave me a language to communicate how I felt about myself, a channel through which to process how overwhelming I found life. Since I was a young child I had struggled with a painful feeling that I didn't fit in and would never belong. I felt inadequate, like I was constantly failing, consumed by a belief that there was a right way and wrong way to behave and that, somehow, I was never getting it right. Wracked with obsessive anxiety, as I reached my late teens, managing life felt increasingly puzzling and difficult to grasp and my feeling of being a misfit had turned into extreme self-loathing. This was compounded by unprocessed anger and trauma from homelife challenges I'd faced growing up, which I turned inwards, fueling a toxic belief that self-destruction was the only answer. Whilst I did not consciously choose to develop an eating disorder, it makes sense that an eating disorder chose me – the roots of the disorder were growing thick and strong long before my anorexia surfaced. Life, and being me, felt intolerable; the eating disorder offered an enticing escape.

Hyperfixating on calorie control or weight loss provided a powerful distraction, and something I could have command and control over – a way of turning away from the seemingly unsolvable problems that really ate away at me: "Who am I? What do I want? Why do I feel like I never fit in? How do I cope with existing?" or managing the feelings that threatened to drown me: self-loathing, guilt, anger, fear, anxiety. For a long time, I chased self-worth through the destructive behaviours of my eating disorder, and I built an identity around it.

But I do not want to romanticise the illness or sugarcoat its actual cost and impact. I nearly died, a number of times, because of it. My first breakdown forced me to drop out of university and whilst friends were graduating, moving house, building careers and settling down, I was circling in and out of hospital, my physical and mental health unravelling over and over again. I lost friendships along the way and family members were devastated, witnessing my seeming inability to remain stable and the increasingly intensive forms of treatment being introduced to try and save me. I was sectioned multiple times, was too unwell to work during my 20s and deemed too unstable to live independently, so for many years I lived in supported housing. Inpatient care saved my life, but the admissions were also soul-destroying and traumatising. Disconnected from the outside world for extremely long periods of time, I found it hard to see myself as anything more than a patient or diagnosis, or to believe in the possibility of a future beyond the hospital walls.

I often became more unwell upon admission, with an intensification of my anorexic behaviours and other issues such as self-harm. The reasons for this are complex but the hospital environment had a major part to play. In the intensely distressing, frightening and restrictive world of the ward, the comfort of my strict anorexia rules and behaviours felt to me more essential and "lifesaving" than ever, the only way to hold on to a sense of autonomy and control. I knew there was no way out without complying with treatment and yet letting go of my eating disorder felt impossible. The upshot would be, however, extreme forms of treatment used by my care teams to keep me alive (sectioning, physical restraint, antipsychotic medication, nasogastric feeding). Sometimes the grip of care felt like it echoed the grip of my illness.

The "escape" my eating disorder offered in reality kept me in a prison; life moved on without me. In lots of ways my anorexia has been an illness of paradox and tangled contradictions, trapping me in a labyrinth of back-to-front thinking. At times, not consuming food has been an all-consuming preoccupation. In the doctrine of anorexia, "need" is redefined as "greed", appetite becomes denied, displaced and demonised. Anorexia made me desperate to disappear and yet terrified of being abandoned or ignored. I felt the drive to both achieve, stand out, be exceptional but also to self-destruct.

Anorexia laid down strict rules for me to obey, punitive standards to attain, but also kept moving the goalposts; nothing – quite literally – was ever good enough. These rules brought me comfort, but they also tied me in agonising knots and attempting to bend or break them triggered overwhelming anxiety and panic. The fears my anorexia induced were irrational, but they were also crippling and deeply rooted, impossible to battle with reasoning or logic alone. Family and healthcare professionals often tried to rationalise with my thoughts and behaviours, the apparent symptoms of my eating disorder, by telling me why I should eat more and offering practical advice on how. But I knew the reasons why recovery made sense. I knew that the things I wanted – to complete a degree, have a job, a relationship, a home – were incompatible with the unwavering commitment to denying myself nourishment and keeping myself teetering on the edge of starvation. I was not lacking in knowledge about the needs of my body, and I understood the concept of self-compassion and self-care. Reason was not enough because it responded to the eating disorder at the level of symptom rather than cause, like cutting down a tree and leaving its roots intact.

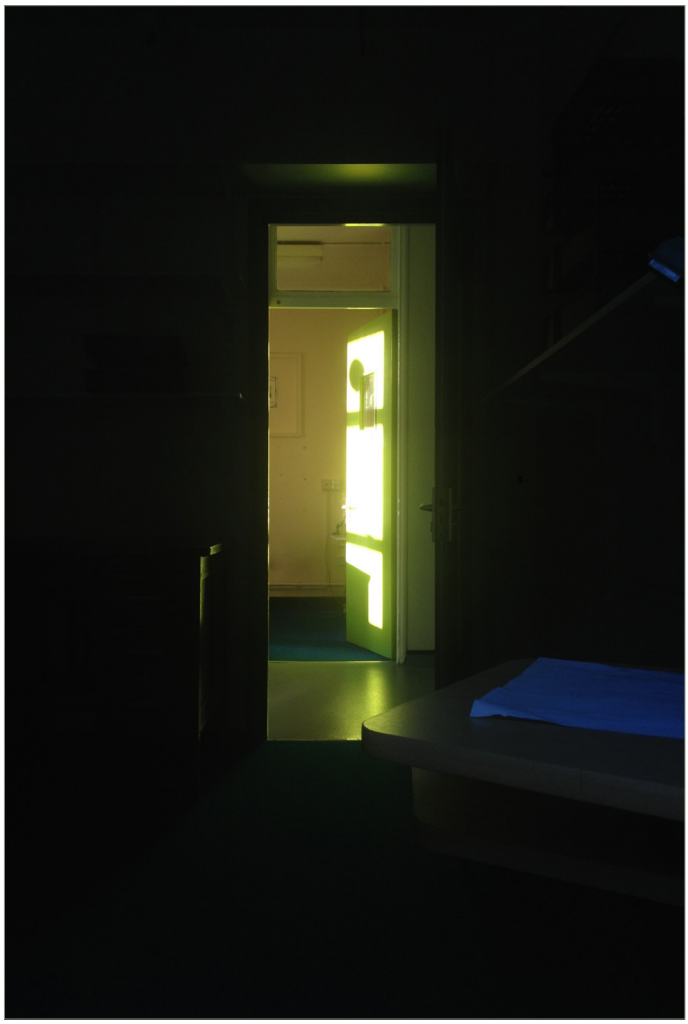
When I tried to resist the demands of my illness, anorexia would tell me I was losing control. Family would plead with me to "fight", but, in the grip of anorexia, fighting felt like losing and "winning" against the disorder felt like failing. I wanted freedom beyond the constraints of illness and hospitalisation. I wanted to stop wounding my family, and to stop being weighed down with the shame I felt at being stuck in a stagnating life. But "complying" with treatment plans and turning my back on my eating disorder threatened the loss of my most potent coping mechanisms. So, for years, I was filled with ambivalence about recovery and could not see a way out.

"And the day came, when the risk it took to remain tight in a bud was greater than the risk it took to blossom" - Anaïs Nin

I carried that quote around with me, in and out of hospital, for years before I started to embody its truth. Just as each

person's eating disorder is unique to them, so too is each recovery. I made promises – to myself and to others – that I would get better, that I would not end up in hospital again, over and over. Shame and grief wore me down with each broken promise and as years went by, hope slipped through my fingers. I didn't make a conscious decision to walk away from, rather than towards, anorexia. I didn't consciously commit myself to weight restoration or put into practice a concerted plan to steadfastly rid myself of self-destructive urges. Yet somehow, in the last six years, the balance of my health and behaviour has started to tip more towards recovery than illness. I started, almost without fully realising it was happening, to say "yes" to life.

My last hospital admission was in 2017. That year I was diagnosed with cancer. The psychological and physical devastation of this triggered another major eating disorder relapse and I ended up, once again, sectioned in an eating disorders unit. I was transported daily by ambulance to a hospital on the other side of London to receive chemo and radiotherapy. I frankly can't find the words to describe how bleak that time was, how utterly broken and hopeless I felt. That year I came face to face with the precarious fragility of life, with the brevity of the time we have, in a way I hadn't felt before. I came out of the experience with a feeling that perhaps I didn't want to keep depriving myself, that I was tired of being disconnected from my own life and fed up surviving in the smallest confines. I think that there has always been a spark within me that wanted to live, but for a long time I kept it small, barely perceptible at times; perhaps I was afraid of it, or protecting it too carefully.



Anorexia has been that protection, but in recent years I have come to resist its deadly constriction and take back the life it threatened to suffocate. I actively want to live rather than just survive. This has meant saying yes to pleasure, to appetite, to fun, to taking risks and having adventures, to finding my voice, my power, my strength and feeling my emotions in their full and terrifying force. I have a successful career, a marriage, qualifications, a home, passions, hobbies and friends. I have been places and done things I never thought I would ever be capable of achieving. My life, compared with a decade ago, is so dramatically different that sometimes I cannot fathom the trajectory.

I would be lying if I said I was recovered. The truth is I would still describe myself as someone who lives with disordered eating and who is working on understanding and loosening the knots of my behaviour. But I have freed myself enough to be able to grow and heal, and this gives me hope and optimism for the future.

I am often asked how I have changed direction, what has enabled me to move forwards. Inpatient care caught me in crisis and kept me alive, and the wide variety of therapy I received has been instrumental in helping me to understand myself and process things I couldn't face alone. But there were times being in treatment compounded my issues and kept me disempowered and lost to myself. I had to find ways of meeting my needs for connection, fulfilment, control and autonomy that weren't tied to illness or clinical care. So, for me, recovery has also been nurtured by creativity, relationships, travel, by the discovery of hidden talents and passions, finding work I enjoy and opportunities to own the story of my experiences free from shame.

I have spent the entirety of my adult life attempting to understand myself, trying in particular to get to the heart of why I became so unwell and why life, even today, often feels like an immense and perplexing struggle. I have spent hours unpicking my thoughts, feelings and behaviours with therapists, doctors, nurses and anyone else I felt safe enough to open up to. I have talked and talked, rationalised and made connections, "processed" and linked event A to reaction B, over and over again. It has been undeniably useful in many ways but also demoralising; despite all the talking, my challenges – particularly my crippling anxiety, low self-esteem and anorexic tendencies – stubbornly persisted. In all that time though something crucial was overlooked.

Then in 2023 I was diagnosed as autistic, and a key missing link fell into place. Research conducted by the PEACE pathway, specifically developed for the treatment of eating disorders and autism, has found that around 35% of people

struggling with eating disorders are autistic or display autistic traits. I worked extremely hard to camouflage most of the difficulties associated with my neurodivergence, so it is not surprising that it took so long for me to be diagnosed. But without a doubt autism has played a key part in my eating disorder, underpinning many factors that led to its development in the first place and exacerbating the immense challenges I have faced in trying to recover. It is painful to realise now how much misunderstanding I have encountered – staff and patients who criticised and judged my meltdowns as attention-seeking and histrionic, the misdiagnosis of my autism as borderline personality disorder, or failures to appreciate how devastatingly destabilising I found change or transition.

Reflecting back on my life now, applying autism as a context, I cannot help but wonder whether the years I spent in the care of mental health services might have unfolded very differently had people understood this fundamental aspect of who I am.

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Katharine is also a visiting scholar at London Southbank University, where she lectures on psychologically informed environments and eating disorders, and has spoken at a number of national conferences about her lived experience of mental health care and recovery.

She sits on the board of directors for the Design in Mental Health Network (https://dimhn.org) and is a trustee for the art and mental health charity, Hospital Rooms (https://hospital-rooms.com).

Katharine is also a practicing artist, exhibiting when she can find the time! She is passionate about the importance of centring lived experience in mental health training and education and the power of creativity in nurturing growth and recovery.

The photographs accompanying this article were taken by Katharine while she was an inpatient receiving treatment for anorexia nervosa. More of Katharine's photography is featured on the Cutting Edge Psychiatry in Practice website.

Epigenetics and eating disorders: from genetic and molecular pathways to therapeutic possibilities

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Abstract

Eating disorders (EDs) are complex, multifactorial conditions influenced by biological, psychological and environmental factors. Recent discoveries in genetic epidemiology research have confirmed a genetic component in EDs, particularly in anorexia nervosa. However, the biological processes underlying the causal pathways to disease onset remain poorly understood and biomarker research in this area significantly lags behind. Emerging empirical evidence from the past decade suggests that epigenetic mechanisms serve as key mediators of environmental and genetic risk factors that underlie major mental health conditions, including EDs. This article highlights recent findings from genetic studies on EDs and emphasises the emerging role of epigenetic mechanisms. It introduces epigenetic mechanisms, in particularly DNA methylation, and explores how dynamic DNA methylation changes may influence disordered eating behaviours through alterations in gene expression, offering a fresh perspective on the interplay between genetics, environment and epigenetics in EDs. Recent findings in the field of ED epigenetics provide promising insights into the development of these conditions, despite current limitations in epigenomic coverage, sample size and the identification of reliable biomarkers. Future studies employing comprehensive epigenomic scans across a broader spectrum of EDs are crucial for uncovering the mechanistic relevance of epigenetics and advancing biomarker research, ultimately enabling the development of improved, novel and more personalised clinical treatments.

Keywords: epigenetics, eating disorders, anorexia nervosa, binge eating disorders, gene-environment interaction, epigenome-wide association studies (EWAS)

Introduction

Eating disorders (EDs), including anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and avoidant/restrictive food intake disorder (ARFID), are severe, and often chronic, psychiatric illnesses that have a devastating impact on those affected, as well as their families and friends. All EDs are marked by some disturbances in eating behaviours (e.g., fasting, vomiting, binge eating) and often come with dissatisfaction with body shape and size. Despite their chronic nature and high comorbidity with other psychiatric disorders, our understanding of the risk factors and treatment for EDs is still lacking (1) and biomarker research is lagging (2). Such research is especially urgent, as the COVID-19 pandemic and lockdown measures have resulted in a spike of new ED diagnoses, as well as hospitalisations and deteriorations in symptoms (3). Empirical evidence from research in the past two decades has highlighted a complex interplay between biological, psychological and environmental factors in the development of EDs (4).

This review introduces the fundamental concepts of epigenetics and explores evidence supporting the role of environmental regulation, through epigenetic mechanisms, in shaping susceptibilities to EDs. Our aim is not to conduct a systematic review of epigenetics in EDs, as such reviews already exist elsewhere (e.g., 5-9), but rather to offer an informed update on recent discoveries, especially those from epigenome-wide association studies (EWAS), and provide key takeaways, ongoing advancements and emerging themes. As published work in this area is relatively scarce, we also draw upon concepts and discoveries from related disciplines, exploring their potential relevance for the epigenetics of EDs field. Our discussion concludes with suggestions for advancing the field and potential translational research that could influence clinical practice.

The aetiology of eating disorders

Family, twin and adoption research has consistently highlighted the heritable nature of EDs. Heritability estimates from twin studies range from 48% to 74% for AN, from 55% to 62% for BN and from 39% to 45% for BED, establishing the genetic underpinnings (10-14). Recent genome-wide association studies (GWAS) enabled the identification of novel common human variants associated with AN. The largest recent GWAS conducted on a European ancestry sample including 16,992 AN cases and 55,525 controls identified eight AN-associated genome-wide significant loci, with 11% to 17% of the heritability being attributed to common genetic variants (14). These AN-associated genetic

loci exhibited a significant positive association with other psychiatric disorders including obsessive-compulsive disorder, major depression, schizophrenia and anxiety, and a significant negative correlation with anthropometric and metabolic traits such as body mass index (BMI), body fat percentage, insulin and leptin (14). These findings suggested reconceptualising AN as a metabo-psychiatric disorder (15). Apart from common genetic variants, genetic studies of rare and structure variants in EDs have revealed enrichment of structural 13q12 deletion (1.5 Mb) and copy number variations disrupting the CNTN6/CNTN4 region in several AN cases (16). Whole-genome sequencing analyses in AN also identified novel variants in seven genes including TTC22, MRPS9, DNAJC30, HEPACAM2, USP20, ESF1 and CDK5RAP1 (17).

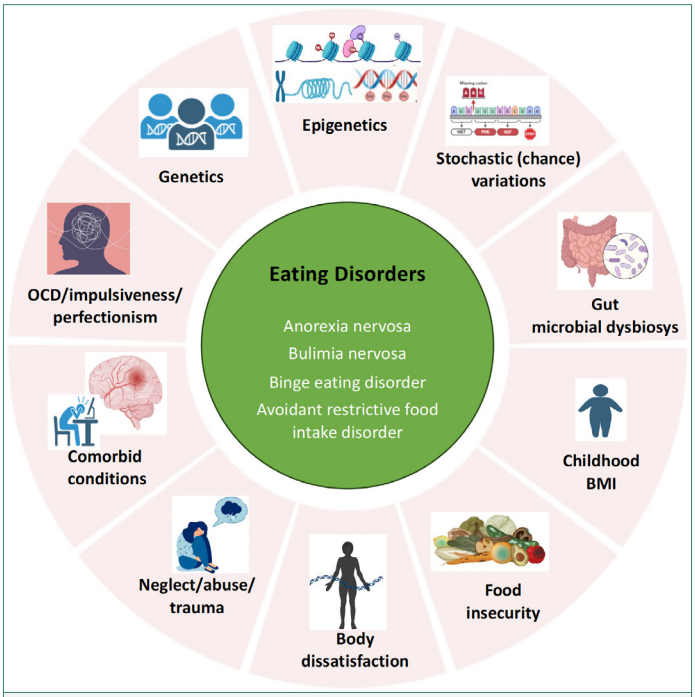

Figure 1. Developmental and risk factors for eating disorders

Given the complex nature of EDs, environmental factors, from socio-cultural influences to personal experiences, as well as stochastic chance variations in cells and biological factors such as gut microbiota in appetite regulation and epigenetics, also contribute to ED development (18). Examples of key risk factors for EDs are illustrated in Figure 1.

An introduction to epigenetics

Epigenetics ("epi" meaning "on top of" in Greek) acts as a crucial bridge between genetics and the environment, offering a nuanced perspective on how external and internal stimuli interact with genetic variations, influencing gene expression and downstream phenotypes. The term "epigenetics" and the concept of an epigenetic landscape were first coined in 1942 by the British biologist, Conrad Waddington, to describe the relationship between genotype (i.e., the sequence of genes) and phenotype (i.e., the way they are expressed in the organism), mainly during early embryonic development. Currently, epigenetics, as proposed by the National Institutes of Health Epigenomics Roadmap Project initiative, is defined as "both heritable changes in gene activity and expression (in the progeny of cells or of individuals) and also stable, long-term alterations in the transcriptional potential of a cell that are not necessarily heritable" (19). This biological mechanism is essential for normal cellular development and differentiation and has important implications on the long-term regulations of gene expression and chromatin packaging (20).

There are three main epigenetic mechanisms: DNA methylation, histone modification and non-coding RNA. In this article we will focus mainly on DNA methylation (DNAm), one of the best understood and the most stable epigenetic modification that regulates gene expression. Typically, DNAm level in the gene promoter region is often inversely correlated with gene expression level due to transcriptional silencing; that is, hypermethylation of the gene promoter region is associated with reduced gene expression, and vice versa (21). DNAm is the intricate interplay between two families of enzymes, DNA methyltransferases (DNMTs) and ten-eleven translocation (TET) methylcytosine dioxygenases, which control DNAm and demethylation, respectively (22, 23). DNAm occurs when DNMTs transfer a methyl (CH3) group from S-adenosylmethionine (SAM) to the 5 position of cytosine, one of the four bases of DNA, to generate 5-methylcytosine (5mC). DNA demethylation takes place when TET

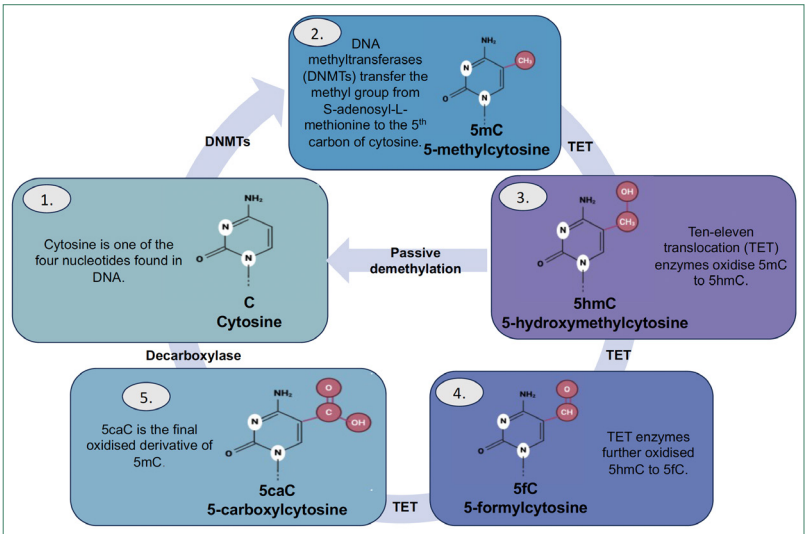

Figure 2. The dynamic cycle of DNA methylation and demethylation

DNA methyltransferases (DNMTs) catalyse the formation of 5-methylcytosine (5mC), while TET enzymes oxidise 5mC to 5hmC and initiate DNA demethylation, which can take place actively or passively. Active DNA demethylation involves an enzymatic process that eliminates or alters the methyl group from 5mC, whereas passive DNA demethylation refers to the loss of 5mC during successive rounds of replication when functional DNA methylation maintenance machinery is absent.

enzymes oxidise the methyl group of 5mC to 5-hydroxymethylcytosine (5hmC), 5-formylcytosine (5fC) and 5-carboxylcytosine (5caC) in DNA (Figure 2). DNAm predominantly targets cytosines followed by guanine residues (CpG), a phenomenon commonly referred to as CpG methylation (24). However, non-CpG methylation, such as methylation at cytosines followed by adenine, thymine or another cytosine, has also been observed in specific cell types such as pluripotent stem cells and glial cells (25, 26).

There is now growing evidence that suggests a link between DNA methylation dysregulation and a range of mental health disorders, including depression, anxiety, psychosis, autism spectrum disorders and addiction (27-31). Due to its prevalence in the human brain and its potential role in human brain development, 5hmC has also gained increasing attention in the mechanistic studies of neurodevelopmental and neurodegenerative disorders (32). While conventionally considered independent of the DNA sequence, findings from recent research have revealed widespread effects of genetic variants on variation in DNAm between individuals. The genetic variants that may affect the DNAm patterns of CpG sites are called methylation quantitative trait loci (mQTLs). By incorporating mQTLs with GWAS data, studies have identified a potential role for DNAm in genetic regulatory mechanisms as well as molecular links between genetic variation and complex traits (33, 34).

While the genome and associated genetic alterations persist throughout an organism's lifespan, the epigenome and DNAm are dynamic and reversible, as well as varying across tissue/cell types, development and age. Epigenetic processes can also be affected by exposure to various external environmental factors, either broadly or at specific epigenetic sites. For instance, DNAm has been demonstrated to fluctuate in response to nutritional, chemical (e.g., smoking), physical and psychosocial factors (e.g., exposure to severe stress). DNAm levels have also been shown to correlate highly with chronological age, and such DNAm-based age estimators are commonly known as epigenetic age. Intriguingly, the difference between epigenetic age and chronological age, termed epigenetic age acceleration or deceleration, has been associated with environmental exposures (35), BMI (36, 37), functional and cognitive aging (38), psychiatric disorders (39) and mortality (including cardiovascular mortality and all-cause mortality) (40, 41).

Since epigenetic modifications are inherited mitotically in somatic cells, they offer a potential mechanism through which the impacts of external environmental factors during specific developmental stages can induce enduring changes in behaviour and/or phenotype. The malleability of the epigenome thus offers a mechanism for understanding the gene–environment interactions that are fundamental in psychiatry, including those interactions underlying predisposition to EDs.

Of particular interest are nutrition and diet, which are known to have a direct effect on epigenetic processes (42) and these alterations may contribute to the biological and molecular basis of the development of EDs. One important example of epigenetic processes is the Agouti viable yellow allele (Avy) inbred mouse strain. This strain showcases various coat-colour phenotypes, depending on the epigenetic state of a large transposable element positioned upstream of the Agouti gene. Within this transposon lies a hidden promoter that triggers a phenotype characterised by yellow fur and metabolic issues such as obesity (43). DNA methylation of the transposon suppresses this phenotype, resulting in mice with agouti (brown) fur and healthier metabolic profiles. Intriguingly, the DNA methylation pattern across this region, and consequently the phenotype, can be altered in offspring by modifying the diet of pregnant mothers (44, 45). Prenatal supplementation of the diet of pregnant mice with methyl donors such as folic acid, vitamin B12, choline, betaine and genistein (the primary phytoestrogen in soy) has been shown to increase DNA methylation in offspring postnatally, leading to gene expression associated with brown fur and improved metabolic health. In humans, the impact of maternal nutritional effect on the epigenome of the unborn offspring has also been observed, for example in the Dutch Hunger Winter study. Individuals exposed to prenatal undernutrition during periconception have altered DNA methylation signatures of the insulin-like growth factor II (IGF2) gene (with known importance in growth and metabolism regulation) when compared with their unexposed same-sex siblings 60 years after the exposure (46).

DNA methylation studies in eating disorders

The malleability of the epigenome represents a plausible biological mechanism with the potential to make important contributions to improving our understanding of the development of and susceptibility to EDs. For example, the exposure of a social environment that promotes thinness and unattainable body image could result in disordered eating behaviours which in turn trigger epigenetic changes and downstream upregulation of genes suppressing appetite or weight. Similarly, in individuals susceptible to obesity, environmental factors such as exposure to stressful life events and the availability of high-fat and high-carbohydrate foods might lead to epigenetics and expression changes to genes related to adiposity (47-49). Figure 3 illustrates how such epigenetic changes mediated by the interaction of inherited predispositions, environmental stimuli, stochastic epigenetic variations and disordered eating can trigger the long-lasting alterations in gene expression that influence susceptibility to EDs.

Despite the potential role of epigenetic mechanisms in the development of EDs, research in this field is still in early development. Akin to the beginning of genetic research in EDs, the majority of earlier epigenetic studies undertook a hypothesis-driven, candidate-gene approach with particular focus on genes related to potential ED-associated

pathways, including the dopaminergic pathway, which regulates reward (50, 51), the cannabinoid system, which is involved in appetite regulation (52), and the oxytocin system, which is associated with psychosocial modulation (53). Much of these candidate epigenetic studies focus on AN, with a minority including individuals with BN. In addition to candidate gene studies, ED-associated global DNA methylation differences have also been investigated with some inconsistent findings reported, for example, both global hypomethylation as well as hypermethylation were associated with AN (54-57). Despite some promising findings, these studies offer limited conclusions due to their narrow focus on DNAm, primarily examining promoter regions of selected candidate genes. Additionally, sample sizes have been small, with the largest study including fewer than 150 participants (8).

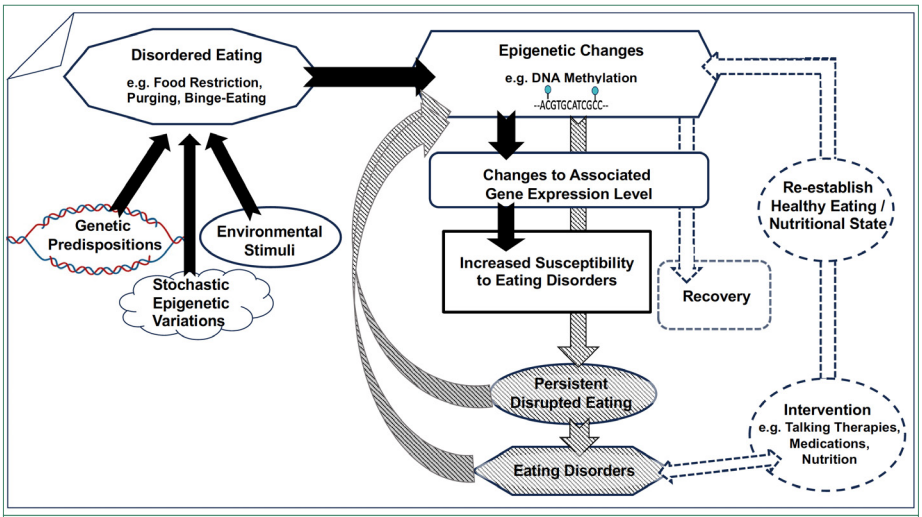

Figure 3. The intricate relationship between environmental factors, genetic predispositions, stochastic (chance) epigenetic variations, disordered eating behaviours, epigenetic changes and vulnerability to eating disorders

Exposure to adverse environmental stimuli and stochastic epigenetic variations may elevate the risk of disordered eating behaviours in individuals who carry susceptibility genes predisposing to eating disorders. Disordered eating may produce enduring alterations to gene expression via epigenetic (e.g., DNA methylation) changes that influence vulnerability to eating disorders. Increased susceptibility to eating disorders will subsequently contribute to ongoing disrupted eating behaviours (as depicted by the arrow filled with lines), leading to additional modifications in the epigenome and gene expression. The malleability of the epigenome offers a potential "reset" with the remission of the illness (as depicted by the dashed arrows) via intervention and re-establishment of healthy eating and nutritional state.

The human epigenetic research field has seen a significant rise of EWAS across health research disciplines in the past two decades due to technical advancement and the decreasing laboratory cost of measuring epigenome-wide DNAm (58). The most widely used technology for EWAS is the Illumina DNAm microarray, with its latest edition enabling a high-throughput quantification of up to 900K DNA methylation CpG sites within a single experiment (59). To our knowledge, there have been five published EWAS that investigated genome-wide DNAm profiles in AN with four presented findings using the Illumina Infinium® HumanMethylation450 BeadChip and one using the Illumina Infinium® HumanMethylation EPIC v1.0 BeadChip, which provide quantitative DNAm data on over 450K and 850K CpG, respectively (60, 61).

The first ED EWAS analysed genome-wide DNAm profiles from lymphocytes of 29 women with AN and 15 normal-weight, sex-matched controls (54). The authors reported a total of 14 differentially methylated AN-associated sites, annotated to 11 genes, including PRDM16, HDAC4, TNXB, FTSJD2, PXDNL, DLGAP2, FAM83A, NR1H3, DDX10, ARHGAP1 and PIWIL1. Interestingly, some of these reported genes have known psychological, metabolic and physical relevance to AN. For example, NR1H3 is involved in lipid metabolism and inflammation (62), and TNXB and DSE have been associated with Ehlers-Danlos syndrome, a connective tissue disorder linked to EDs (63). Kesselmeier et al. (64) examined DNAm levels in whole-blood DNA from 47 women with AN, 47 lean women without AN and 100 population-based women. Given the known potential cell-type composition effect on DNAm signals, careful considerations and adjustments were applied for the data analyses. The authors reported a total of 51 and 81 AN-associated differentially methylated sites when comparing 22 AN-active women with 24 lean women and 30 non-AN women, respectively. Approximately two-thirds of these AN-associated sites also exhibited directionally consistent differential DNAm differences in a comparison of five pairs of twins discordant for AN. The authors also reported a replication of TNXB hypermethylation associated with AN (54). It is worthy of note that the cohort analysed had significant age differences (mean ages for AN and control samples were 16 and 60 years, respectively), which is a potential confounder when interpreting the results, given the known effect of age on DNAm profiles (65). Steiger et al. (66) quantified genome-wide DNAm in leukocyte DNA from 75 AN-active women, 31 AN-remitted and 41 with no ED. The authors reported a total of 58 AN-associated differentially methylated sites, when comparing the AN-active and no ED groups, with an enrichment of genes that are relevant to metabolic and nutritional status (lipid and glucose metabolism), psychiatric status (serotonin receptor activity) and immune function. Interestingly, in a subset analysis focusing on 28 differentially methylated sites that were common to "AN-active versus no ED" and "AN-active versus AN-remitted" comparisons, effects across the analyses were consistently in opposite directions. Specifically, when group DNAm was higher in AN-active versus no ED, it was lower in AN-remitted versus AN-active, and vice versa. The authors proposed that these findings suggest an average shift toward restored DNAm levels in people who are remitted. Similar analyses were conducted by the same research group but with a slightly extended sample size consisting of 145

women with AN, 49 showing stable one-year remission of AN and 64 with no ED (67). A total of 205 and 162 AN-associated differentially methylated sites were reported when compared between "AN-active vs no ED" and "AN-active vs AN-remitted" groups, respectively. Interestingly, amongst these AN-associated differentially methylated sites, very comparable group DNAm levels between AN-remitted and no ED groups were reported. The authors concluded that this observation replicates previous findings (66) and indicates a restoration to normal levels following remission, suggesting the presence of state-dependent changes in DNAm levels that can be positively "reset" with the remission of the illness (Figure 3). In addition, the authors explored the potential relationships between DNAm profile, duration of exposure, malnutrition (as reflected by chronicity of illness) and the severity of malnutrition (as reflected by low BMI). Intriguingly, there was a significant association between 18 and 20 sites with chronicity of illness and BMI, respectively. These findings confirm the effect of dietary nutrition on the epigenome. It is worthy of note that this study, although it contains an expanded sample size compared to other ED epigenetic studies, is still small compared to EWAS in other psychiatric fields.

The study of disease-discordant monozygotic twins represents a powerful strategy in epigenetic epidemiology because they are matched for genotype, age, sex, maternal environment, population cohort effects and exposure to many shared environmental factors (68). Iranzo-Tatay et al. (69) combined this unique study design with the Illumina Infinium® HumanMethylation EPIC v1.0 BeadChip to dissect potential AN-associated differentially methylated sites in a small cohort of seven discordant twin pairs for AN. The authors of this discovery study reported nine AN-associated differentially methylated sites, including two validated in a replication cohort (consisting of seven AN patients and seven controls) and mapped onto genes associated with metabolic traits PPP2R2C and CHST1. There is, to our knowledge, no EWAS study published on other EDs.

Future perspectives and conclusions

Epigenetic research in EDs is still in its infancy, yet preliminary findings are revealing the potential relevance and impact this field of study could hold for enhancing our understanding of the aetiology and development of these disorders. Findings from hypothesis-free EWAS studies conducted thus far have indicated an interesting overlap with recent GWAS meta-analysis studies (14), highlighting the enrichment of AN-associated genetic and epigenetic dysregulation of genes enriched in psychiatric and metabolic pathways. The resemblance in methylation signatures between the AN-remitted and no ED groups, as opposed to the AN-active groups identified by Steiger et al. (67), emphasises the potential adaptability of AN-associated differential methylation signatures and the clinical application of epigenetic biomarkers. These observations add to the growing body of evidence that DNAm dysregulation plays a fundamental role in psychiatric phenotypes and that large-scale epigenetic research in EDs is warranted.

ED epigenetic research conducted thus far has primarily focused on AN and with small sample sizes; it is crucial for future EWAS studies to increase their cohort size as well as to widen the research scope to other subtypes, including BN, BEDs and ARFID. Large sample sizes (N > 1000) are fundamental for detecting small individual (epi)genetic effects; the consolidation of samples within research consortia has been instrumental in the successful execution of GWAS and EWAS across numerous human traits, as well as psychiatric phenotypes (70-72). National and international initiatives, such as the UK Eating Disorders Genetics Initiative (EDGI) (73), the Binge Eating Genetics Initiative (BEGIN) (74) and the ARFID Genes and Environment (ARFID-GEN) study (75), which are collecting both deep phenotypic data and biological samples from different subtypes of ED, have been established in the past few years. These innovative cohorts pave the way for future large-scale (epi)genetic research to be conducted, shedding light on the biological mechanism of EDs.

Expanding from ED subtypes, studying diverse populations is vital for comprehending the aetiology and risk factors of EDs. In line with genetic and epigenetic research across psychiatry, the majority of ED research published is Eurocentric with a lack of racial or ethnic diversity (76-78). Future research effort that enhances diversity in population representation within epigenomics research is essential for interpreting epigenetic biomarkers associated with EDs as well as providing crucial insights into underlying biological mechanisms (76).

Preliminary findings from AN-focused EWAS have provided insightful contributions to the epigenetic basis of EDs, highlighting potential enrichment of the DNAm dysregulations of genes involved in psychiatric and metabolic traits. However, due to technical limitations, only a very small fraction of the DNA methylome (less than 3%) has been captured and studied so far. Recent technological advances in long-read sequencing technology, including Oxford Nanopore sequencing, have greatly expanded the capacity of long-range, single-molecule DNA-modification detection, providing reliable and quantitative data of up to 97% of the DNA methylome (79). Epigenetic studies on EDs employing long-read sequencing are poised to offer valuable insights into the genetic variations contributing to EDs while deepening our understanding of their complex genetic and epigenetic landscapes. This approach could also illuminate disrupted biological pathways associated with EDs and advance the discovery of potential biomarkers. While much of the focus has been on DNA methylation, expanding ED research to include other epigenetic mechanisms, such as histone modifications and non-coding RNAs, could provide valuable insights.

Epigenetic changes associated with EDs hold significant potential as targets for personalised treatment. While psy-

chological therapies remain the cornerstone of ED management, pharmacological interventions are also recognised in clinical guidelines (80), for example, fluoxetine for BN and comorbid anxiety or depression (81), and lisdexamfetamine (82) and topiramate for BED (83, 84). Emerging evidence suggests that epigenetic mechanisms may influence the efficacy of these medications (85, 86). For example, fluoxetine has been shown to regulate brain-derived neurotrophic factor via epigenetic mechanisms (87), potentially alleviating and preventing depressive symptoms. Understanding an individual's epigenomic profile could enable clinicians to make more informed decisions, tailoring pharmacological treatments to optimise personalised management plans for EDs.

In conclusion, epigenetics represents a crucial biological mechanism and a promising innovative biomarker for EDs. Advancing epigenetic research in this field is essential to enhance our understanding of the origins of EDs and to identify intervention targets, paving the way for the development of more effective and personalised treatments.

Acknowledgements and disclosures

CCYW, SHL and GB receive salary support from the National Institute for Health and Care Research (NIHR) Biomedical Research Centre for Mental Health, South London and Maudsley National Health Service (NHS) Foundation Trust and Institute of Psychiatry, Psychology, and Neuroscience, Kings College London. YYH receives salary support from Preventicum. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR, Preventicum or the UK Department of Health.

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Cultural differences in eating disorders with particular emphasis on British South Asian communities

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Abstract

Eating disorders have historically been considered "culture-bound" phenomena, confined to Western societies and, specifically, young White females with, predominantly, anorexia nervosa. Eating disorder research tended to align with these perceptions and, until relatively recently, few studies had been conducted to establish the prevalence of eating disorders in non-Western countries. Evidence from epidemiological surveys, undertaken largely in the last three decades, have shown that eating disorders are present in African, Asian, Middle Eastern and South American societies and, in many cases, the prevalence estimates are comparable to those in the West. However, there is evidence to suggest that precipitating factors, presentations and cultural perceptions of eating disorders differ between sociocultural contexts. This may result in underdiagnosis of eating disorders in non-White individuals and may be a barrier to successful management. These considerations are exemplified by studies in the South Asian population in the UK which have shown a different symptom profile than that found in White individuals. Clinicians who are not attuned to these cultural differences may fail to recognise an eating disorder diagnosis. South Asian populations may present with somatic concerns and the absence of "fat phobia". Culture-specific familial expectations, religious observances and issues of self-identity may have a greater role in the development and maintenance of eating pathologies in this, and other, minority ethnic groups. Greater awareness of these factors among clinicians would increase the prospects for recognition, diagnosis and successful outcomes.

Keywords: prevalence, minority ethnic, risk factors, presentation, body image

1. Introduction

Historically, eating disorders have been considered a culture-bound phenomenon associated specifically with Western societies and, predominantly, with White girls and young women belonging to the middle and upper socioeconomic classes (1). The widely held misconception that eating disorders are much less common, or absent, in other sociocultural settings led Beat, the national eating disorder charity in the UK, to campaign for greater recognition of eating disorders, disordered eating and body image concerns in other demographic groups.

In a recent landmark position paper by Landor et al. (2), the authors emphasised how body image is shaped by "multiple axes of oppression that exist within systemic and structural systems, ultimately privileging certain bodies above others", and described the development of the Sociocultural-Intersectionality Body Image framework. The levels of the framework, which address historical, contemporary and sociopolitical contexts, were designed to go beyond "white supremacy" to make body image research and practice applicable, and relevant, to other ethnicities, and more fully to "understand the body image experiences of those with racialised and minoritised bodies to challenge inequities" (2).

The COVID-19 pandemic further exacerbated the existing health inequalities in the recognition, referral and treatment of eating disorders. Data from NHS England (3) demonstrated an increase in hospital admissions among Asian and British Asian groups of 62% between 2018/19 and 2020/21, a proportionally higher increase than for other ethnicities including White British (43.5%) and Black African (34%) over the same period. Detailed figures for the Asian and British Asian groups showed the increase in admissions for 2020/21 compared with 2018/19 was 51% for people of Pakistani ethnicity and 49% for people of Indian ethnicity, suggesting that South Asians in particular, who make up the largest ethnic minority group in the UK, are presenting in increasing numbers to acute eating disorder services. Such data suggest that prevention and early intervention needs to be prioritised in people from these backgrounds.

This article summarises recent research on eating disorders in non-Western countries and in minority ethnic groups in majority White populations. In section 3, research conducted in the last three decades on eating disorders and body image concerns in the South Asian population in the UK is examined in greater detail.

2. Eating disorders in non-Western cultures

Consistent with the historic characterisation of eating disorders as a culture-bound, Western-centric phenomenon (1, 4, 5), much of the English language eating disorder literature has, until relatively recently, focused almost exclusively on Western White populations, predominantly young, middle-to-upper-class females with anorexia nervosa (AN) (1, 5, 6). More recently, however, increased eating disorder research in previously neglected cultures has suggested that, contrary to earlier perceptions, eating disorders are prevalent in all societies and among all demographic groups, and that eating disorder typologies that have long been recognised in Western countries are similarly represented in non-Western countries (4, 7). Moreover, evidence suggests that the prevalence of eating disorders in non-Western countries and among non-White ethnic groups has increased over the three or four decades covered by the research (1, 8-13), in line with, or exceeding, that in the White population (14-16). Epidemiological data for major global regions including Eastern Europe, Latin America, South Asia, Africa, the Middle East and the Pacific Islands remain sparse (9, 17-19).

Studies have described both marked similarities and important differences between cultural contexts in eating disorder prevalence, presentation, risk factors and outcomes (1, 4, 5). Findings are inconsistent (1, 9) and comparisons between countries are confounded by methodological differences between the studies (1, 20). Few studies have compared epidemiological data directly across different cultural contexts (9). More commonly, comparisons have focused on ethnic minority populations within individual Western countries, predominantly the United States and the UK. These have suggested that ethnic minorities have a generally lower risk of developing an eating disorder (1). However, some studies have found no difference between White and other ethnicities (9, 21, 22), and others have even found a higher level of eating disorders, disordered eating and unhealthy eating attitudes in specific minority ethnic populations. For example, higher rates have been found among school-age females of South Asian heritage in the UK (23, 24), and among Hispanic American and African American women in the US (25-28). In a recent cross-sectional study in a national sample of 286,720 young adults in the US (29), statistically significantly higher rates of current probable eating disorders were reported for Asian/Asian American, Hispanic/Latinx, Native Hawaiian/Pacific Islander and Middle Eastern/Arab/Arab American groups than for White individuals (odds ratios = 1.3, 1.3, 2.1 and 1.5, respectively; all $p < 0.001$). The rate of current probable eating disorders in Black/African American individuals was lower than that in White individuals (odds ratio = 0.8; $p < 0.001$). Where lower rates have been reported among ethnic minorities in clinical samples, an additional potential confounding factor is the lower likelihood of referral in these groups, suggesting the possibility of underdiagnosis (30, 31).

2.1 Prevalence and incidence of eating disorders in non-Western cultures

Irrespective of the specific cultural context, studies have tended to focus on demographic subgroups considered to be at greatest risk, typically adolescent or young adult females, implying that prevalence and incidence data for the general population in many countries are limited (20).

2.1.1 Estimates of lifetime prevalence

A meta-analysis published in 2013 (15) reported estimates of lifetime prevalence from cross-cultural studies in the general population but the analysis was based on data from a relatively small pool of studies (n = 15) with a narrow geographical distribution limited primarily to the United States, Western Europe, South Korea, Brazil, Mexico and New Zealand. Overall, the estimated lifetime prevalence for any eating disorder was 1.01% (95% confidence interval (CI): 0.54–1.89), with a higher lifetime prevalence reported for binge eating disorder (2.22%, 95% CI: 1.78–2.76) than for bulimia nervosa (BN) (0.81%, 95% CI: 0.59–1.09) and AN (0.21%, 95% CI: 0.11–0.38). The comparison of lifetime prevalence between Western and non-Western countries was notably limited by South Korea being the only non-Western country for which data were available but suggested a six-fold higher prevalence in the group of Western countries (1.29% vs 0.21%; $p < 0.001$). A previous systematic review published nearly a decade earlier (20) reported eating disorder prevalences from a methodologically disparate group of studies in diverse population-based and clinic-based samples. The prevalence of AN in these studies was between 0.1% and 5.7% in Western countries and between 0.002% and 0.9% in non-Western countries. The prevalence of BN was between 0% and 7.3% in Western countries and 0.46% and 3.2% in non-Western countries. The authors of the review did not differentiate figures for different groups or point prevalence figures from those for lifetime prevalence. Without this context, the data are difficult to interpret meaningfully.

2.2.2 Estimates of point prevalence

A meta-analysis published in 2022 investigated the global point prevalence of eating disorders and disordered eating specifically among university students based on data from studies that used standard screening measures including the EAT-26 (Eating Attitude Test), EAT-40, EDE-Q (Eating Disorder Examination Questionnaire) and SCOFF (Sick, Control, One Stone, Fat, Food) (14). The overall analysis included 89 studies from 40 countries and found a prevalence of 19.7% (95% CI: 17.9–21.6%) for any screen-based disordered eating (SBDE). Among the seven countries for which the most data were available, prevalence was highest in the United States (37.1%), followed by Lebanon (33.2%), Palestine (32.8%), Spain (31.7%), Saudi Arabia (21.2%), France (21.0%) and India (18.1%). Analysis based on a grouped

comparison of "Western" and "non-Western" countries found a numerically higher prevalence of SBDE in non-Western countries (18.4% vs 20.9%), but the difference was not statistically significant.

More recently, an analysis of data from the 2017 Global Burden of Disease Study (16) reported age-standardised point prevalences for any eating disorder per 100,000 population by global region. Estimates for 2017 (per 100,000 population) were 807.1 for Australasia, 525.2 for Western Europe, 463.5 for high-income North America and 404.8 for high-income Asia Pacific, compared with 140.9 for Southeast Asia, 249.8 for the Caribbean, 205.7 for North Africa and the Middle East and 270.8 for Central Latin America. Eating disorder point prevalence and disability-adjusted life-years increased in all global regions between 1990 and 2017, with the exception of Central Sub-Saharan Africa.

None of these analyses compared prevalence between non-Western countries and ethnic minority populations in Western countries.

Table 1 summarises general population prevalence estimates from original studies, reviews and meta-analyses published in the last 25 years. Although far from comprehensive, these studies are illustrative of the wider literature and, saliently, have reported prevalence rates for some non-Western countries that are broadly commensurate with, and in some cases higher than, those reported in Western countries.

For example, reported point prevalence estimates for AN ranged from <0.1% in Kuwait (32), 0.1% in Latin America (Argentina, Brazil, Chile, Colombia, Mexico and Venezuela) (33) and 0.8% in Malaysia (34) and Iran (35), to as high as 4.8% in Japan (36), compared with <1–4% in recent studies in European countries (37, 38) and 0.05% in a nationally representative sample of adults (aged ≥18 years) in the US (39).

Point prevalence rates for BN were 0.7% in Brazil (40), 0.87% in African countries (19), 1.0% in Japan (36) and Saudi Arabia (41), 1.2% in Latin America (33), 1.4% in Malaysia (34) and 6.2% in Iran (35), compared with recent estimates from studies in the West of 0.3% in the US (42), 0.4% in Australia (43) and <1–2% in European countries (37, 38).

Conversely, estimates of point prevalence for binge eating disorder were just 0.1% in Malaysia (34) compared with 1.4% in Brazil (40), 2.1% in Saudi Arabia (41) and 3.5% in Latin America (33), whereas recent estimates have suggested point prevalence of between 0.31–1.2% in European countries (42, 44), 1.0% in New Zealand (42) and 0.4–1.2% in the US (39, 42).

As mentioned previously, these findings should be interpreted with caution in light of the methodological differences between studies; the data do not support direct comparisons between studies. It has also been questioned whether the standard screening and diagnostic assessment scales for eating disorders developed in Western countries are appropriate for non-Western populations (5, 9, 45-47) and, correspondingly, whether the findings from studies that have employed these scales in non-Western contexts are reliable.

2.2 Factors associated with development of eating disorders in non-Western cultures

Notwithstanding these considerations, the results summarised in Table 1 appear to contradict the historic perception of eating disorders as an almost entirely Western cultural phenomenon, predicated on the Western idealisation of the "thin" body type (6, 48). An extension of this theory proposes that the increase in eating disorders observed in non-Western countries over recent decades can be explained largely by exposure in these countries to Western culture, specifically notions of the "thin ideal" and "body instrumentality" as a means of self-actualisation (5, 7), and, further, that eating disorder prevalence to a substantial degree corresponds to the extent of "Westernisation" in a given country.

These ideas were exemplified in the case of Japan, a society that underwent a rapid process of Westernisation in the latter half of the 20th century, and in which the prevalence of eating disorders reported in studies in the 1980s, 1990s and 2000s showed a consistent increase, broadly commensurate with that in the West (4, 5, 7, 48-52).

Similarly, studies in ethnic minorities and immigrants in Western countries have focused on the degree of "acculturation", that is, adoption of the values of a different, or host, culture, to explain the relative risk of developing an eating disorder for individuals belonging to these groups (53-55). According to this idea, individuals from non-Western cultures, which might have widely contrasting ideals with respect to body type, are at increasing risk of developing an eating disorder the greater their exposure to, and adoption of, perceived Western cultural norms (4-6, 26, 56, 57).

Multiple studies, both in individuals in non-Western countries and among immigrants to Western countries, have provided evidence for this hypothesis (4, 7, 58-66). However, the overarching theory has been questioned as a result of studies suggesting a similar, or higher, prevalence of eating disorders, disordered eating and body image concerns in non-Western settings (4, 67-72) and in ethnic minority groups in Western countries, including among recent immigrants (73-77). There is also increasing evidence that the precipitating factors associated with the onset of eating disorders in these groups may be distinct from those that characterise eating disorders in White populations (1, 5, 7, 78-82). In particular, the "fat phobia" or preoccupation with an ideal "thin" body type that is thought to underpin the development of eating disorders in the majority of cases in Western White individuals may be a less central concern, or completely absent, in those who are not White (7, 71, 83-86). Instead, other psychological and/or somatic impetus-

								Prevalence	
Author	Year	Study type/data source	Country/Region	N	Age range (yrs)	Eating disorder	Assessment scale	Measure	Estimate
Al-Hadi (41)	2022	Saudi National Mental Health Survey	Saudi Arabia	4,004	15-65	Any ED	CIDI 3.0	Lifetime	6.1%
						AN			0.6%
						BN			2.8%
						BED			2.6%
						Any ED		12-month	3.2%
						BN			1.0%
						BED			2.1%
Appolinario (40)	2022	Cross-sectional, population-based survey	Brazil	2,297	18-60	BN	QEWP-5	Point	0.7%
						BED			1.4%
Chua (34)	2022	Randomised selection online survey	Malaysia	818	18-73	AN	SWED	Point	0.8%
						BN			1.4%
						BED			0.1%
						ARFID			4.8%
						OSFED			51.4%
Safiri (32)	2022	Data from GBD study (2019)	MENA[1]	NA	NA	AN	DSM or ICD	Point	49.3/100,000
			Kuwait[2]						78.7/100,000
			Afghanistan[3]						29.2/100,000
Wu (16)	2020	Data from GBD study (2017)	Global	NA	NA	Any ED	DSM or ICD	Point	203.2/100,000
			H-I North America						463.4/100,000
			H-I Asia Pacific						404.8/100,000
			Australasia						807.1/100,000
			Western Europe						525.2/100,000
			Southeast Asia						140.9/100,000
			Central Latin America						270.8/100,000
			Caribbean						249.8/100,000
			MENA						205.7/100,000
			Central Sub-Saharan Africa						116.2/100,000
			Oceania						108.6/100,000
Kolar (33)	2016	Systematic review and meta-analysis	Latin America[4]	10,840	10-28	AN	Various	Point	0.1%
				14,816	10 to adult (≥ 18)	BN			1.2%
				10,363	12 to adult (≥ 18)	BED			3.5%

								Prevalence	
Author	Year	Study type/data source	Country/Region	N	Age range (yrs)	Eating disorder	Assessment scale	Measure	Estimate
Van Hoeken (19)	2016	Review	Africa	1,476	NA	AN	DSM-IV	Point	0%
						BN			0.87%
						EDNOS			4.45%
Kessler (42)	2013	WHO Community Mental Health Surveys	Global[5]	24,124	≥ 18	BN	CIDI	Lifetime	1.0%
			Colombia						0.4%
			Brazil						2.0%
			Belgium						1.0%
			Italy						0.1%
			New Zealand						1.3%
			United States						1.0%
			Global					12-month	0.4%
			Colombia						0.2%
			Brazil						0.9%
			Belgium						0.3%
			Italy						0.0%
			New Zealand						0.5%
			United States						0.3%
			Global			BED		Lifetime	1.9%
			Colombia						0.9%
			Brazil						4.7%
			Belgium						1.2%
			Italy						0.7%
			New Zealand						1.9%
			United States						2.6%
			Global					12-month	0.8%
			Colombia						0.3%
			Brazil						1.8%
			Belgium						0.7%
			Italy						0.2%
			New Zealand						1.0%
			United States						1.2%

								Prevalence	
Author	Year	Study type/data source	Country/Region	N	Age range (yrs)	Eating disorder	Assessment scale	Measure	Estimate
Qian (15)	2013	Systematic review	Global[6]	35,247	≥ 15	Any ED	DSM or ICD	Lifetime	1.01%
			Western countries	28,972					1.29%
			South Korea	6,275					0.21%
			Global	38,544		AN			0.21%
			Western countries	25,705					0.32%
			South Korea	11,375					0.13%
			Global	59,683		BN			0.81%
			Western countries	44,192					0.90%
			South Korea	6,275					0.05%
Garrusi (35)	2012	Cross-sectional, population-based survey	Iran	1,181	14-55	Any ED	EDDS	Point	11.5%
						AN			0.8%
						BN			6.2%
						ST-AN			1.4%
						ST-BED			35.0%
Larrañaga (92)	2012	Prospective population-based study	Spain	NA	≥ 15	Any ED	NA	20-year	82.8/100,000
						AN			18.6/100,000
						BN			25.7/100,000
						EDNOS			38.3/100,000
Preti (44)	2009	Cross-sectional, population-based survey	Europe[7]	4,139	≥ 18	Any ED	CIDI 3.0	Lifetime	2.51%
						AN			0.48%
						BN			0.51%
						BED			1.12%
						ST-BED			0.72%
						Any BE			2.15%
						Any ED		12-month	0.56%
						AN			0.0%
						BN			0.15%
						BED			0.31%
						ST-BED			0.09%
						Any BE			0.54%
K-Rahkonen (93)	2007	Longitudinal cohort study	Finland	2,881 (F)	24-26	AN	SCID	Lifetime	2.2%

Author	Year	Study type/data source	Country/Region	N	Age range (yrs)	Eating disorder	Assessment scale	Prevalence	
								Measure	Estimate
Nakamura (36)	2000	Prospective cross-sectional study	Japan	NA	12-57	AN	DSM-IV	Point	4.8%
						BN			1.0%

Table 1. Prevalence estimates for eating disorders in general population samples.

Abbreviations: AN = Anorexia nervosa; ARFID = Avoidant/restrictive food intake disorder; BE = Binge eating; BED = Binge eating disorder; BN = Bulimia nervosa; CIDI = Composite International Diagnostic Interview; DSM = Diagnostic and Statistical Manual of Mental Disorders; ED = Eating disorder; EDDS = Eating Disorder Diagnostic Scale; EDNOS = Eating disorder not otherwise specified; GBD = Global Burden of Disease; H-I = High-income; ICD = International Classification of Diseases; MENA = Middle East and North Africa; NA = Not applicable; OSFED = Other specified feeding or eating disorder; QEWP = Questionnaire on Eating and Weight Patterns; SCID = Structured Clinical Interview for DSM-IV; ST = Subthreshold; SWED = Stanford-Washington Eating Disorder Screen; WHO = World Health Organization

Notes: **1.** Afghanistan, Algeria, Bahrain, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Sudan, Syria, Tunisia, Türkiye, United Arab Emirates, Yemen **2.** Country with highest prevalence **3.** Country with lowest prevalence **4.** Argentina, Brazil, Chile, Colombia, Mexico, Venezuela **5.** Belgium, Brazil, Colombia, France, Germany, Italy, Mexico, the Netherlands, New Zealand, Northern Ireland, Portugal, Romania, Spain, United States **6.** Latin America, New Zealand, South Korea, United States, Western Europe **7.** Belgium, France, Germany, Italy, the Netherlands, Spain

es might be more relevant, for example, familial pressures, conflict due to bicultural identity, competitive impulses, desire for conformity with the perceived norms of the host society, religious observances or low motivation to eat due to feelings of "fullness" or lack of hunger (6, 7, 26, 87).

Alternative explanations for the worldwide increase in eating disorders and body dissatisfaction have implicated globalisation, industrialisation and urbanisation and the attendant changes in socioeconomic status, sociocultural trends and traditional family and societal roles, in particular for women, rather than Westernisation per se (1, 4-6, 17, 20, 88-90). As such, the increased prevalence of eating disorders may be considered a feature of "cultures in transition" (4). It has been suggested that this influence is particularly apparent where sociocultural change takes place over short timeframes, whether this be societal change in rapidly developing economies or on the individual level among recent immigrants to Western countries (91). As important as social and cultural factors may be in creating a set of normative, if unrealistic, values for physical appearance, compliance with which may contribute to eating disorder susceptibility, individual risk factors and their interaction with societal influences are likely to have an equally determining role.

A comprehensive review of these factors is beyond the scope of this article, but some of the underlying ideas are discussed further in the next section in the context of eating disorder research in South Asian ethnic minority groups in the UK.

3. Eating disorders in South Asian ethnic groups in the UK

Clinical work in East London, which has a large British South Asian (mainly Bangladeshi) community (94, 95), led to one of the current authors conducting a service evaluation to better understand the presentations of eating disorders in this group. An initial exploratory evaluation (96) investigated the ethnicities of 215 users presenting to the East London Community Eating Disorder Service for Children and Young People between January 2017 and January 2019. Of the 215 service users, 84 (39.1%) were Asian, of which 55 (25.6% of the total sample) were Bangladeshi; 70 (32.6%) were White, of which 43 (20.0% of the total sample) identified as White British; 12 (5.6%) were Black; and 35 (16.3%) were from other ethnic groups. Eating disorder diagnostic categories and symptom profiles differed across ethnicities. It was concluded that the findings suggested the need for a re-examination of eating disorder stereotypes, specifically the prevailing Western White bias in presumed risk, and for greater awareness of ethnicity-specific presentations.

Research exploring body dissatisfaction in the South Asian population in the UK has historically been limited. However, over the past three decades, there have been efforts to investigate differences in prevalence, presentation and aetiology between South Asian ethnic groups and the White British population. For example, a study conducted in 1991 in schoolgirls in the northern city of Bradford found that those from a South Asian background had a more than five times greater risk of bulimic symptoms than their White counterparts (3.4% and 0.6%, respectively) (97). Similarly, in a study conducted in South Asian young people in Bolton, those identifying as female and Muslim scored higher on the EAT-26 eating pathology measure than White females (mean scores of 10.4 and 8.91, respectively). However, the White group had notably higher scores on the bulimic symptom subscale than the South Asian group (1.31 and 0.57, respectively) (98). A subsequent paper reported that adolescent Asian females in the UK showed high levels of eating psychopathology and were more likely to fast than their White peers, but were less likely to exhibit binge eating behaviour (99). Results from subsequent research in East London were only partially consistent with these findings; Bhugra and Bhui (100) observed that South Asian teenagers were more likely than teenagers from either White or African-Caribbean backgrounds to experience "abnormal eating behaviours", but found that these were indicative of sub-clinical bulimia, showing patterns of compulsive eating, dietary restraint and the perception that "food dominated their lives",

and suggested, as had previously been proposed, the existence of "ethnic differences in the aetiology of these conditions" (101). More recently, the South East London Community Health (SELCoH) study explored eating pathology in individuals in South East London and concluded that people of South Asian decent were more likely to exhibit bulimic pathology than their White counterparts (73). Broader Asian ethnicity was associated with purging, loss of control eating and preoccupation with food.

Four qualitative studies have been conducted in which potential factors associated with the differing eating disorder presentations in South Asian groups in the UK, and barriers and facilitators to accessing eating disorder services, have been explored (30, 102-104). These studies recruited South Asian participants from similar geographical areas as the quantitative prevalence studies (predominantly the Midlands and northern England (97, 98)), specifically Leicestershire and Birmingham (30, 102), Greater Manchester (103) and Yorkshire (104). The findings have begun to illuminate the often complex, interacting factors which influence the body image and disordered eating behaviours of South Asian women, and shortcomings in cultural understanding in current eating disorder service provision. Common themes such as the importance of navigating identity, unique South Asian family dynamics (often centred around marriage and reputation), the symbolic meaning of food and the shame and stigma surrounding mental health issues compared to the prestige of good physical health, were consistently reported in all four studies. The distinct presentation of body dissatisfaction and disordered eating among South Asian individuals was also highlighted, for example, "loss of appetite" rather than overt "fear of fatness" (102).

Hoque explored how body image and eating disorders were recognised and understood within the South Asian cultural context and found that ease or difficulty in accessing eating disorder services was influenced by the inherently critical tendencies in Asian society, parental response, self-agency and individual effectiveness in seeking help (102). Self-referral for help with disordered eating in minority ethnic groups is typically low; only 36% of those identified as having symptoms of disordered eating in the SELCoH study had sought professional help in the previous 12 months (73).

Mishra et al. (104) explored sociocultural influences on body image in South Asian women and found that navigating (often marriage-related) appearance pressures from elders, negotiating cultural and societal standards across different aspects of the individual's cultural identity, the representation of South Asian women in the wider societal context and forms of healing from the pressures imposed on South Asian women were important factors. While these studies explored influences on the development of body image and disordered eating in the general South Asian population, none focused specifically on the perspective of individuals in the age groups considered at greatest risk, namely adolescents and young adults, who were the main focus of the quantitative prevalence studies. An earlier retrospective case series drawn from this population, however, found similar patterns in motivating factors for AN to those reported by Hoque et al. (105). Specifically, British South Asian adolescent females presenting to psychiatric clinics with weight loss or AN were statistically significantly more likely to report loss of appetite ($p = 0.01$) and less likely to report fat phobia ($p = 0.032$) and weight preoccupation ($p = 0.001$) in connection with their eating disorder than matched White British peers (105).

Despite the findings which suggest a higher prevalence of disordered eating in South Asian populations compared with other ethnicities, particularly for bulimic spectrum disorders, overall referrals from members of this community to specialist eating disorder services are still lower than for other groups (31, 106-108). In a study that explored potential barriers to treatment access among South Asians in Leicester, themes such as differing views of thinness, the role of the family, lack of knowledge of eating disorders, stigma and concerns over confidentiality when approaching primary care services were prevalent (30). Where minority ethnic individuals do seek help, the differing presentations of body dissatisfaction and disordered eating described earlier may present a challenge to diagnosis (102).

Comparable studies conducted in minority ethnic South Asian populations in other countries have identified common themes. For example, a study conducted in the US found similar sociocultural pressures to those reported in the UK, with South Asian women describing being subject to weight stigma from multiple sources, in particular older female relatives (109). Participants reported competitive pressure to achieve body and appearance ideals including light skin, dark black hair and minimal body hair, and to marry at a young age (109). These findings suggest that cultural nuances should be considered in the discourse surrounding cognitive dissonance–based interventions. More generally, greater awareness among clinicians of culture-specific factors is likely to increase the prospects for recognition and effective management.

In this section, we have focused on studies in South Asian groups because of the relatively extensive research in this population. However, the findings that suggest distinct eating disorder presentations and precipitating factors are likely to be more generally applicable to other minority ethnic groups (see previous section). Similarly, the challenges to diagnosis and management identified among South Asians in the UK and US may also be relevant to other ethnicities, suggesting the need for greater awareness among clinicians and for further research into the effectiveness of management strategies in non-Western cultural settings.

Summary

Contrary to historic perceptions, eating disorders are not "culture-bound" phenomena predominantly confined to young White female populations in Western countries, but occur at similar rates in minority ethnic groups and in the general populations of non-Western countries. AN, BN and binge eating disorder have been documented in Asia, Africa, South America and the Middle East, as well as in individuals of Asian, African, Latinx, Hispanic and Middle Eastern ethnicities in Europe, the US and Australia.

Despite comparable point prevalence rates for eating disorders in Western and non-Western countries, and between White and non-White groups within Western societies, differences exist in cultural attitudes to food, body image perceptions and precipitating factors for eating disorders that may complicate diagnosis in minority ethnic groups and confound effective management.

Although research in this previously neglected area has increased markedly in recent decades, further studies are needed to better understand eating disorders across ethnicities, particularly regarding assessment, risk factors and potential adaptations to established interventions. For example, one of the authors (EC) is conducting work on symptom profiling of eating disorders within the Bangladeshi population. This research aims to inform the development of a clinical tool to aid earlier identification of eating disorders in this group. Similar initiatives are needed to enhance clinicians' awareness of the varying presentations of eating disorders across diverse populations. Such awareness would improve the prospects for earlier recognition, diagnosis and treatment, ultimately leading to better outcomes.

Box 1. Key points

1. Research on eating disorders in non-Western countries is historically limited.
2. Eating disorders are not limited to White Western populations and occur at similar rates in minority ethnic groups and in individuals native to non-Western countries.
3. Eating disorders may have distinct presentations among non-White ethnicities, for example, "non-fat-phobic" anorexia nervosa.
4. There is uncertainty as to whether eating disorder screening, assessment and diagnostic tools developed in Western cultural contexts are reliable in other populations.
5. Diagnoses may be missed if clinicians do not recognise cultural differences in eating disorder presentations and modify criteria for diagnosis accordingly.
6. Further research on the characteristics, risk factors, assessment and interventions for eating disorders in non-Western populations is needed.

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Gender differences in eating disorders: the role of medicalisation

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Abstract

Had a paper on gender differences in eating disorders (EDs) been written in the 1970s, it would likely have included discussion of whether males should be eligible for the diagnosis of the sole eating disorder that was recognised at that time, namely, anorexia nervosa. There might also have been discussion of the clinical characteristics of male patients and whether and how these differed from those of female patients. Otherwise, the focus would have been on the factors that led some young women to develop the "morbid preoccupation with weight loss" that was considered the defining characteristic of the condition. Since this time, the issue of gender differences in EDs has become increasingly complex as the number and diversity of conditions deemed to constitute an ED has proliferated and the proportion of these conditions accounted for by males has increased. In the current contribution, it is proposed that gender differences in EDs should be viewed in the context of an ongoing process of medicalisation, whereby problems that were previously deemed to be societal in nature or, indeed, not problems at all, have come to be seen as disorders demanding clinical and public health attention. It is suggested that medicalisation should be viewed as a key variable accounting for change in the gender distribution of EDs over time and that the occurrence, drivers and ramifications of this process warrant greater attention in future discussions of this issue.

Keywords: eating disorders, gender, medicalisation, social constructionist, feminist

Introduction and scope

The issue of gender differences in eating disorders (EDs) has become increasingly topical, and complex, in the past half-century as the number and diversity of conditions recognised as EDs in the Diagnostic and Statistical Manual of Mental Disorders (DSM) has proliferated (1, 2). One or two conditions, namely, anorexia nervosa (AN) and bulimia nervosa (BN), that were believed to be uncommon and largely confined to adolescent and young adult women have become numerous conditions and some, such as binge eating disorder (BED), are relatively common in both men and women (1, 2).

In the current paper, an attempt is made to distil this complexity while also highlighting issues that the author believes warrant greater consideration in future discussions of the topic. The text that follows is divided into three broad sections. First, an outline of the recent history of ED nosology is provided. Second, findings from the most recent reviews of epidemiological studies bearing on gender differences in EDs are summarised. Third, an attempt is made to interpret these findings in light of historical developments and to highlight key implications and directions for research, policy and practice moving forward.

Reflecting the author's interests and expertise, the focus is on gender differences in "cases" of EDs as these occur in the general population. Gender differences in the clinical presentation of individuals with specific ED diagnoses adds a further level of complexity, on account of the range of factors that determine whether or not individuals with "mental health disorders" choose to seek help and, if so, from whom. These factors include gender but also levels of distress and disability, and various aspects of "eating disorders mental health literacy" (2-4).

Also reflecting the author's expertise, interests and intellectual journey, the current contribution is influenced by sociological and critical feminist approaches to EDs and to "mental health disorders" more generally. Thus, a key contention of the current paper is that gender differences in EDs – and change in these over time – need to be interpreted in light of an ongoing process of medicalisation, whereby problems that were previously deemed to be societal in nature or, indeed, not problems at all, have come to be seen as disorders demanding clinical and public health attention (1, 2).

It should also be noted that certain considerations likely to be of interest to some readers are not addressed in the current contribution. For example, there is no coverage of the putative role of "biological" factors in accounting for gender differences in EDs. This is because research demonstrating gender differences in the associations between certain forms of eating and/or weight-control behaviours and certain biological variables (e.g., brain activity, genetic characteristics) is, in the author's view, of limited heuristic value. Indeed, continued efforts to highlight putative biological causes of EDs can be seen as another manifestation of medicalisation, the benefits of which are debatable (2,

5, 6).

There is also no consideration of whether and how gender differences in EDs are moderated by other socio-demographic variables, such as age, ethnicity and sexual orientation. This is because information from epidemiological studies remains largely confined to adult, Caucasian, "cisgender" persons (7, 8) and because there is only so much that can be covered in this relatively brief contribution. For the same reasons, no attempt is made to address gender differences in ED diagnoses specific to infancy or early childhood, namely, pica, rumination disorder and avoidant/restrictive food intake disorder (ARFID) (9, 10).

Gender differences in eating disorders in the medical literature: a potted history

The first "eating disorder": anorexia nervosa

Some of the earliest descriptions of self-starvation to appear in the medical literature involved male patients. These include cases of adolescent males described by the English physician Richard Morton in 1689 and the Scottish physician Robert Whytt in 1764 (11, 12). Further, it was because the "disease" was known to occur in males as well as females that William Gull advocated use of the term "anorexia nervosa" in preference to "apepsia hysterica" or "anorexia hysterica" (13). However, Gull also believed that AN was "a disease occurring mostly in young women" and in both his case series (13) and those of Charles Lasegue (14) only cases involving females were reported. This is significant because Gull, an English physician, and Lasegue, a French psychiatrist, are typically credited with having provided the first full medical descriptions of the condition now recognised in the DSM as AN (15, 16).

Serious interest in epidemiological studies of AN began only in the 1960s (17). Prompted by speculation that the prevalence of AN might be increasing, researchers began to document trends in incidence, relying on registers of patients attending psychiatric services and/or on hospital records. This research stimulated interest in the development of explicit diagnostic criteria, which in turn provided a platform for studies of population prevalence. However, the very low base rate of AN was such that estimates of population prevalence remained problematic (18, 19). Efforts to circumvent this problem entailed sampling of "high-risk" sub-groups, namely, adolescent and young adult women, identification of "partial-syndrome" cases and deriving estimates of population prevalence from studies of prevalence in primary care. In one, the first comprehensive reviews of the epidemiology of EDs, Hoek (18) concluded that the average point prevalence of AN among young females was 0.28%.

The issue of gender differences in AN received little or no scholarly attention at this time (20, 21). Case series conducted in the decades prior to the publication of DSM-III (22) consistently suggested that males comprised between 5% and 15% of individuals deemed to have AN (18, 23). Complicating interpretation of these findings is the fact that the diagnostic criteria for AN in use at the time were developed on the premise that this was – or should be – a condition solely or largely confined to females. In several case series, males were simply excluded because the diagnostic criteria included amenorrhea (20, 24).

When it came to attempts to develop standardised criteria, while some authorities (e.g., 25) continued to stipulate the occurrence of amenorrhea, Russell (26) proposed the occurrence of "amenorrhea in the female or loss of sexual interest in the male". Ultimately, Russell's view prevailed and males have remained eligible for the diagnosis of AN in successive editions of the DSM. Loss of sexual interest has never been required for the DSM diagnosis of AN in males; however, for females, amenorrhea was required for the diagnosis of AN in DSM-III-R (27) and DSM-IV (28) but not in DSM-III (22) or DSM-5 (9).

Second and third disorders: bulimia nervosa and binge eating disorder

The occurrence of episodes of "binge eating" and/or purging had been noted in several early clinical descriptions of AN (29) and was familiar to clinicians in the 1960s and 1970s (e.g., 26, 30, 31). However, the observation of recurrent episodes of both binge eating and purging among women of "normal weight" led to the description of BN as a disorder distinct from AN (32) and its inclusion as "bulimia" in DSM-III (22) and as BN in DSM-III-R (27).

The fact that BN appeared to be more common than AN reinvigorated interest in population-based surveys of prevalence. Nevertheless, BN, like AN, appeared to be largely confined to young women and most population-based prevalence studies were conducted in or entailed oversampling of this demographic (33). The consensus from initial reviews was that BN affected approximately 1% of adolescent and young adult women with a gender distribution similar to that of AN (18, 33). As with AN, preconceptions concerning the nature and occurrence of BN complicate interpretation of such estimates. Nevertheless, Fairburn and Beglin (33) felt justified in concluding that "the comparatively small number of men who present for the treatment of bulimia nervosa reflects a genuine difference in the prevalence of the disorder between the sexes rather than being an artifact attributable to factors such as differential case detection and referral".

Also relevant when considering gender differences in the prevalence of BN is the distinction between purging and non-purging weight-control behaviours. Like binge eating, but unlike purging, "excessive exercise" is relatively common in men with EDs (34, 35). Had the diagnosis of BN been confined to individuals engaging in purging behaviours, as Russell and others had envisaged, then the prevalence of BN in males would be lower still. A similar consideration

arises in relation to gender differences in the occurrence of so-called "purging disorder" (PD) (36).

While episodes of binge eating among obese individuals has been described for decades, the observation of a subgroup of individuals who otherwise met criteria for BN but whose episodes of binge eating occurred in the absence of purging or other extreme weight-control behaviours, and who may or may not be obese, prompted calls from some authorities for the recognition of a third ED, namely, BED (37). In an initial validation study, led by the Chair of the DSM-III task force, Robert Spitzer, "full-syndrome BED" was observed among 2.5% and 1.1% of female and male community participants, respectively (37). Thus, BED was not only more common than AN and BN but relatively common among men. This likely reflected, in part, the fact that the proposed diagnostic criteria for BED did not include a "body image disturbance" criterion of the kind required for the diagnoses of AN and BN (38, 39). It is well known that the extreme concerns about weight or shape characteristic of AN and BN are more common in women than in men (4, 35). Subsequently, BED was included as provisional diagnosis in DSM-IV (28) and as a formal diagnosis, alongside AN and BN, in DSM-5 (9).

Other disorders and potential disorders

Provision for conditions that do not satisfy all criteria for a given ED diagnosis has been made in the DSM since the third revision (DSM-III) (22). In DSM-III, the term "atypical eating disorder" was introduced as a residual category for EDs that could not be adequately classified in any of the specific categories recognised at the time, namely, AN, BN, pica and rumination disorder of infancy. Examples were not provided, however. In DSM-III-R (27), the "eating disorders not otherwise specified" (EDNOS) category included the examples of "a person of average weight who does not have binge eating episodes, but frequently engages in self-induced vomiting for fear of gaining weight" (subsequently known, among other things, as PD), "all of the features of anorexia nervosa in a female except absence of menses" and "all of the features of bulimia nervosa except the frequency of binge eating episodes". In DSM-IV (28), these and several other examples of EDNOS are mentioned, including a variant of AN in which "despite significant weight loss, the individual's current weight is in the normal range" and the (then) provisional diagnosis of BED. In the DSM-5 other specified feeding or eating disorder (OSFED) category (9), all of the abovementioned examples are retained while two new exemplars, namely, "binge eating disorder of low frequency and/or limited duration" and "night eating syndrome" (NES), are introduced. Further, a second residual category, "unspecified feeding or eating disorder" (UFED), is introduced for situations in which "the clinician chooses not to specify the reason that the criteria are not met for a specific feeding and eating disorder". This conspicuous increase in the number of, and attention given to, specific exemplars of the DSM EDNOS/OSFED categories is a key component of the medicalisation process (1).

The inclusion of a sub-threshold form of BED and of NES as exemplars of the OSFED category is notable in the current context because, like BED, these conditions are relatively common in males. In the US National Comorbidity Survey Replication Study (40), for example, the lifetime prevalence of "sub-threshold BED" was 1.9% in men and 0.6% in women. While epidemiological studies of NES have been hampered by a lack of agreed-upon criteria, available evidence suggests that the prevalence of NES in the general population is approximately 1% to 1.5% with little or no gender difference (41, 42). NES, like BED, was first described in the 1950s (43, 44).

At least two other conditions may be considered for inclusion in future revisions of the DSM. Muscle dysmorphia (MD), also known as "bigorexia" and "reverse anorexia", is a condition characterised by a morbid concern that one's body is not sufficiently muscular. It was included as a subtype of "body dysmorphic disorder" in the DSM-5 "obsessive-compulsive and related disorders" section, although some authorities have argued that it should instead be classified as an ED and it is invariably included in reviews of EDs in men (45-48). A recent large-scale study of adolescents (49) found that the point prevalence of MD was 2.2% among boys and 1.4% among girls. The status of "orthorexia nervosa" (ON), a putative new ED involving obsessive preoccupation with the consumption of foods deemed to be "healthy", has also been a focus of attention in the academic literature, and popular media, in recent years (50, 51). Issues of high – and highly variable – estimates of prevalence aside, ON appears to be equally common in men and women (52, 53).

Gender differences in eating disorders: current status

Readers familiar with the history of epidemiological studies of EDs will know that interpretation of findings from these studies is replete with difficulties (19, 54). These findings vary widely depending on the population sampled, the operational criteria for specific diagnoses employed, the measures used to assess these criteria, response rates and the various biases inherent in the use of survey and/or interview methods. Further, as noted above, the low base rates of AN and BN – and very low rates in males – were such that early estimates of gender differences in prevalence relied solely on treatment-seeking samples. However, more reliable information concerning gender differences in the population prevalence of EDs – and change in this over time – continues to accumulate.

Since the early 1990s, population-based studies of the prevalence of EDs that have included both women and men have increasingly been conducted and the best available evidence concerning gender differences in ED prevalence comes from systematic reviews of findings from these studies. As with findings from individual studies, findings from reviews are difficult to interpret and compare due to variability in the study methods employed (see (8, 55)). For the present purpose, the 2019 Galmiche et al. review of ED prevalence for the period 2000 to 2018 (7) is most useful

	AN		BN		BED		EDNOS/OSFED		Any ED	
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women
Point prevalence	0.3% (0 - 0.4%)	2.8% (0 - 4.8%)	0.1% (0 - 1.3%)	1.5% (0 - 8.4%)	0.3% (0 - 0.5%)	2.3% (0 - 9.8%)	0.9% (0 - 1.7%)	10.1% (0.5 - 31.1%)	2.2% (0.2 - 7.3%)	5.7% (0.9 - 13.5%)
12-month prevalence	0.1% (0 - 0.2%)	0.5% (0 - 0.8%)	0.4% (0 - 1.1%)	0.7% (0.3 - 2.2%)	0.6% (0 - 1.2%)	1.4% (0.5 - 3.0%)	NA	NA	0.7% (0.3 - 0.9%)	2.2% (0.8 - 13.1%)
Lifetime prevalence	0.2% (0 - 0.3%)	1.4% (0.1 - 3.6%)	0.6% (0.1 - 1.3%)	1.9% (0.3 - 4.6%)	1.0% (0.3 - 2.0%)	2.8% (0.6 - 5.8%)	3.6% (0.3 - 5.0%)	4.3% (0.6 - 14.6%)	2.2% (0.8 - 6.5%)	8.4% (3.3 - 18.6%)

Table 1. Weighted means (ranges) for point, 12-month and lifetime prevalence (%) of DSM eating disorder diagnoses by sex for the period 2000 to 2018 as reported by Galmiche et al. (7)
Abbreviations: AN = anorexia nervosa; BED = binge eating disorder; BN = bulimia nervosa; ED = eating disorder; EDNOS = eating disorder not otherwise specified; NA = not available; OSFED = other specified feeding or eating disorder

because it is the only recent review that includes point, 12-month and lifetime prevalence data stratified by sex for most DSM-5 ED diagnoses. The findings from this review are summarised in Table 1.

While the variability within and between rows highlights the difficulties inherent in interpreting findings from population-based epidemiological studies, the consistency of findings relating to sex differences in the prevalence of any ED across rows is impressive. These findings, when taken with those from early epidemiological studies as outlined above, suggest that the proportion of cases of ED in the general population accounted for by males has changed from approximately 5% to 10% to approximately 25% to 30% in recent decades. Since very few studies including the DSM-5 OSFED (or UFED) category were available at this time, males would likely account for a higher proportion of EDs still were this study to be updated.

Additionally, Galmiche and colleagues considered change in ED prevalence over time (7). In this regard, the authors reported that the average weighted point prevalence of any ED increased from 3.5% for the period 2000–2006 to 4.9% for the period 2007–2012 and 7.8% for the period 2013–2018. While data for the latter findings were not stratified by either sex or diagnosis, it would be reasonable, given the considerations outlined above, to infer that the prevalence of EDs has increased more rapidly in males than in females over time. It is also reasonable to speculate that, if current trends continue then, at some point in the future, the population prevalence of EDs will no longer differ by gender.

Gender differences in eating disorders: the role of medicalisation

Medicalisation, a term originating in the sociology literature in the early 1970s, has been defined as the process by which previously nonmedical aspects of appearance or behaviour become defined, and treated, as medical problems, usually as diseases or disorders (56, 57). Often-cited examples include behaviour issues in children and adolescents, shyness, sadness, reactions to traumatic experiences, sexual performance and mood changes associated with menstruation (56, 57).

As suggested above, the most conspicuous manifestation of the increasing medicalisation of eating and weight-control behaviours in recent years is the proliferation of conditions included as EDs in successive editions of the DSM (1, 2). This has occurred alongside a conspicuous increase in the number of, and attention given to, specific exemplars of the DSM residual categories of EDNOS and OSFED (1). The net effect of these changes is a progressive lowering of thresholds such that previously normative behaviours become "risk factors", risk factors become "sub-threshold disorders" and sub-threshold disorders become "full-syndrome disorders" (58-61). Further, there is a well-worn path by which each new development gives rise to new rounds of activity on the part of researchers, clinicians, lobby groups, public health agencies and the media, thereby consolidating and perpetuating the medicalisation process (57, 62, 63).

It is important to note that medicalisation, as conceptualised by Conrad and others, is a neutral term used to describe a process that may be associated with both positive (e.g., improved treatment) and negative (e.g., unnecessary or potentially harmful treatment or intervention) outcomes (2, 56, 57). Hence, when applied to "mental health problems", medicalisation is distinct from the "anti-psychiatry" movement, exemplified in the work of Szasz and others and more recent work in the critical psychiatry and critical public health fields (see 2, 64, 65). This "neutrality" may be one reason why the construct of medicalisation remains a central theme in medical sociology and popular discourse (66, 67).

Challenges to medicalisation

In theory then, both positive and negative outcomes might follow from the increasing medicalisation of eating and weight-control behaviours evident in changes to the DSM classifications of EDs over time. In the currently dominant discourse, evident in the ED, clinical psychology and psychiatry literatures, the increasing number and range of conditions recognised as EDs in the DSM is apt to be seen as a welcome development affording sufferers the promise of improved quality of life through diagnosis and appropriate intervention (e.g., 47, 68-70). Nevertheless, alternative views have periodically been expressed (1, 2).

Concerns relating to the medicalisation of eating and weight-control behaviours have been expressed in the feminist literature for at least three decades (71-74) alongside con-

cerns relating to the medicalisation of women's health and mental health issues more generally (75-78). These accounts have focused on the construction of eating and weight-control behaviours as a form of "individual pathology", a construction that is seen to obscure the roles of sociocultural and political factors in shaping the occurrence of EDs and their over-representation among young women. However, concerns of this kind have been expressed less often in recent years. This likely reflects, at least in part, the success of efforts to portray EDs as "brain-based diseases" or "illnesses" in the academic literature and popular media (2, 74) and consequent diminution of the role of sociocultural factors (79-81). Additionally, medicalisation may be less salient from a feminist perspective now that both men and women are affected.

There have also been pockets of resistance to the proliferation of ED diagnoses in the ED and general psychiatry fields. Following Russell's (32) description of BN and the inclusion of bulimia in DSM-III, there was considerable debate as to the status of these conditions as disorders distinct from AN (29, 82). Some authors questioned whether AN, BN and variants of these conditions might better be viewed as different manifestations of or points on a spectrum rather than as discrete entities (e.g., 83-85). Others questioned whether the emergence of BN might reflect iatrogenic effects (e.g., 86, 87). Beumont and colleagues (88) argued that the time had come to apply Occam's Razor to the classification of EDs and recognise just a single disorder with the defining characteristic of a "morbid preoccupation with weight loss". Others have argued that EDs are best viewed as variants of an underlying anxiety and/or affective disorder (e.g., 89, 90).

Proposals for the inclusion of BED as a provisional diagnosis in DSM-IV and as a formal diagnosis in DSM-5 raised concerns about "trivializing the construct mental disorder" and turning over-eating from "a manifestation of gluttony and the easy availability of really great tasting food into a psychiatric illness" (60, 61, 91). More recently, Vandereycken (63) questioned whether conditions such as purging disorder, NES, MD and ON should be viewed as examples of "diagnostic fads produced by media hype" rather than as "genuine disorders" and whether research addressing the occurrence and correlates of these conditions merely consolidates the process of reification. The status of ON provides particularly fertile ground for research informed by these different perspectives. In the ED, general psychiatry and public health literatures, attention has focused on the occurrence and correlates of, refinement of diagnostic criteria for, causes of and risk factors for, and clinical management of ON (e.g., 51, 92). Social science scholars, by contrast, have considered whether ON might constitute an example of "over-medicalisation" and its relation to the construct, well known in the sociology literature, of "healthism" (e.g., 50, 93).

These challenges notwithstanding, there has been surprisingly little critical analysis of the ramifications of the increasing medicalisation of eating and weight-control behaviours evident in changes to the classification of EDs over time. In particular, there has been virtually no analysis of whether, to what extent and how these changes have been beneficial for the increasingly large and diverse group of people deemed to suffer from an ED (1, 2, 8). It is also striking that while the role of sociocultural factors in driving changes in the occurrence and manifestation of EDs over time has consistently been highlighted in the ED literature (94, 95), the role of medicalisation as such a factor has been largely ignored (1, 2).

Implications and future directions

A key goal of the current contribution has been to highlight the way in which the process of medicalisation, often driven by the work of influential advocates at key points in time, has influenced gender differences in ED prevalence. Had AN and BN remained the only ED recognised in classification schemes, then attention would have remained focused on the factors that led some young women to develop a morbid preoccupation with weight loss (96). The inclusion of BED was a turning point, in that it cemented the view that this preoccupation need not be a sine qua non for ED diagnosis (97). Similarly, whether diagnostic criteria for EDs, and the measures used to assess these, are unduly "female-centric", as some authors have suggested (e.g., 46, 48), depends on one's view concerning the nature and definition of "eating disorder".

If, as has been suggested, gender differences in the occurrence of EDs continue to diminish, then a key concern becomes how best to respond to the increasingly large number of males who believe that they have a mental health problem for which treatment is required (2, 4). The role of medicalisation is again key in this regard because adherence to a biomedical model has implications for the types of intervention deemed most likely to be helpful by researchers, health professionals, public health agencies and the public (2, 98). In the currently dominant, medical-model approaches to intervention, EDs are conceived of as diseases that must be prevented through targeting of "high-risk" individuals or managed by medical and allied health professionals. As noted elsewhere (2, 98), the dominance of these approaches has been maintained despite their benefits being debatable. As would be expected, evidence for the benefits of prevention and treatment programs for EDs in males is particularly limited (45, 48, 99).

At the same time, possible alternative approaches, focused on health promotion, have been marginalised (2, 98). Such approaches include population-based interventions designed to address stigma and other aspects of ED mental health literacy, bolster resilience and tolerance of distress, draw on the engagement of peers and, perhaps, reduce reliance on health services (2, 100-102). Ideally, approaches of this kind would extend to the education of health and

allied health professionals and those training in these professions (46, 101). This might include, for example, improving awareness and understanding not only of the increased demand for services entailed in the expansion of EDs in males but also the need to consider alternative perspectives when considering the drivers of this demand and different possible approaches to intervention.

Of course, these different approaches are not mutually exclusive (2, 98, 103). With public health resources perennially limited, however, priorities typically need to be designated. As noted above, there has, thus far, been virtually no critical analysis of whether and how the increasing medicalisation of eating and weight-control behaviours evident in changes to the classification of EDs over time has been beneficial for people deemed to suffer from these conditions. In the absence of such analysis, it is difficult to know which approaches to intervention should be prioritised in either males or females. Addressing this gap in the literature may be the most pressing direction for future research.

Conclusion

What was once a single ED largely confined to adolescent and young adult women has become numerous conditions, some of which are relatively common in males. A key factor in this change has been an ongoing process of medicalisation by which patterns of behaviour previously deemed to be normative have become EDs, demanding clinical and public health attention. If these trends continue, then it is reasonable to hypothesise that, at some point in the future, the population prevalence of EDs will not differ by gender. If so, then this would serve as a striking example of the influence of sociocultural and political factors on "illness presentation". The occurrence, drivers and ramifications of the medicalisation process warrant greater consideration in future research addressing gender differences in EDs.

Declarations of interest

The author declares that he has no conflicts of interest.

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Eating disorders and autism: extension of the PEACE pathway to children and young people

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Abstract

A greater susceptibility to development of eating disorders (EDs) has been recognised among people with autism since the 1980s. Standard treatment approaches for EDs can be less effective for those with autism or autistic features, but there are no separate guidelines for the management of EDs in this population. The clinical need for autism to be understood and accommodated better in ED services has become increasingly apparent in recent years. The PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience) pathway, was launched by the London Maudsley Hospital in 2017 and is the first treatment approach to be developed specifically for autistic adults receiving inpatient treatment for an eating disorder. Following the success of the PEACE pathway in London, three years of innovation funding was granted to child and adolescent ED services in Buckinghamshire, Oxfordshire and Berkshire (BOB) to support the local implementation of this approach in community services. The aim was to apply similar principles while offering reasonable adjustments and ensuring the delivery of neuroinclusive care. Initial evidence suggests that the proactive, neuro-affirming approach to ED treatment in young people with autism emphasised by PEACE can improve treatment experience, reduce risk and shorten or avoid higher-intensity treatments for some patients. It is hoped that the care delivery model, adaptations and resources developed as part of the BOB PEACE implementation will be adopted more widely to benefit many more autistic children, young people, adults and families struggling with EDs.

Keywords: autism, anorexia nervosa, bulimia nervosa, binge eating disorder, ARFID, pica, eating disorder services, PEACE pathway

1. Introduction

Autism is a neurodevelopmental condition in which persistent deficits in social communication and social interaction, and behavioural patterns characterised by restrictive or repetitive interests or activities, emerge in early childhood (1). Although the features of autism must be present during the early developmental period, functional impairment may not be apparent immediately and may only emerge when social demands exceed ability (1). Estimates based on the updated diagnostic criteria for autism suggest that global prevalence in the general population is approximately 1% to 3% (2, 3). Autism is disproportionately diagnosed in males, with a male:female ratio of between 3:1 and 4:1 (3, 4).

This article is divided into two parts. In the first part, we provide an overview of current research on autism in eating disorders (EDs) and discuss the implications for treatment of EDs in people who also have autism. In the second part, the development and implementation of a specialised treatment approach for people with coexisting autism and anorexia nervosa (AN), bulimia nervosa (BN) or binge eating disorder (BED), the Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE), is described in detail.

2. Review of autism in individuals with eating disorders

2.1 Background

An association between autism and ED susceptibility was first proposed in 1983 by Christopher L. Gillberg (5), who later suggested that infants who showed low empathy during early development were predisposed to EDs in later life (6). Decades later, the results of an analysis of data from the Avon Longitudinal Study of Parents and Children (ALSPAC) (7) found that adolescents who developed disordered eating patterns at age 14 years had overall higher Social and Communication Disorders Checklist (SCDC) scores, and a 20% increase in SCDC scores from the age of 7 years, compared to those who did not develop disordered eating. The authors concluded that autistic social deficits in childhood may increase the risk of disordered eating in adolescence. Since Gillberg's original observations, numerous studies have described various autism-like features in individuals with EDs, including weak central coherence and cognitive inflexibility (8-10), obsessive-compulsive features (11, 12) and broad social difficulties (13-15), as well as similar theory of mind deficits in people with autism and those with AN (16). These findings have even led some authors to question whether AN, the ED for which there is most evidence, may be a "female form" of autism (17, 18).

There is now extensive evidence that individuals with EDs are more likely to exhibit autistic features or to meet autism diagnostic thresholds than those without EDs (19), and a growing consensus that coexisting autism is associated with more severe ED presentations, greater chronicity and poorer outcomes (19-23).

A clear determination of the extent of co-occurring autism–ED is still lacking, however, and estimates of the prevalence of autism among people with EDs vary. This partly reflects differences in diagnostic criteria, study methodologies and populations between studies (24). Many studies lack comprehensive assessment of autism, despite growing recognition of the association and the implications for management (19). Diagnosis may also be confounded by the overrepresentation of females among those with EDs, which is in contrast to the preponderance of males diagnosed with autism; it has been suggested that assessment scales may not be as reliable in diagnosing autism in females (25), implying that autism may be more prominent in this group than previously thought.

The picture is further complicated by the findings from studies that suggest observed autistic traits may more accurately be characterised as state-dependent features of the ED, rather than indicative of true autism, which is a pervasive disorder implying that it persists over time (22, 26-28). However, there is good evidence that, in many cases, autistic features are present before the emergence of the ED (22, 25), and persist after recovery (29-32), supporting the conclusion that autism is likely to be a risk factor for disordered eating. The authors of a recent longitudinal study in 24 adolescents with AN (23) concluded that autistic characteristics showed evidence of both trait and state phenomena, observing that underweight and starvation in the acute phase of the ED might have an exacerbatory influence on pre-existing autistic features. These findings were largely consistent with the conclusions of an earlier systematic review (25) that found evidence that at least some autistic features in individuals with AN remain stable over time and are not related to body weight.

Evidence for the association is further strengthened by studies showing familial patterns of coexisting autism and AN (33, 34), suggesting the possibility of a shared genetic susceptibility. An analysis of Danish registry data (34) found that both coexisting autism and a family history of autism are more common in people with AN than in the general population. In this study, data for 5006 individuals with AN and 12,606 individuals with autism were analysed together with data for their parents and full and half siblings. Probands who were first diagnosed with AN had a greater risk of a later autism diagnosis (hazard ratio [HR] = 15.08; 95% CI, 12.23–18.58), and probands who were first diagnosed with autism had a greater risk of a later AN diagnosis (HR = 5.39; 95% CI, 4.37–6.64). AN in a first-degree relative also increased the risk of autism in probands (HR = 1.80; 95% CI, 1.43–2.28), and autism in a first-degree relative increased the risk of AN (HR = 1.45; 95% CI, 1.09–1.94). However, the elevated risk of coexisting autism in AN probands, and of autism diagnosis in relatives of AN probands, did not differ significantly from that for other psychiatric disorders, suggesting that the association may not be specific to autism.

2.2 Prevalence of autism in individuals with eating disorders

Much of the current research on autism and EDs is limited to studies of AN; the association between autism and other EDs has been much less extensively investigated and few data are available on the prevalence of autism and autistic traits in, for example, BN, BED or avoidant/restrictive food intake disorder (ARFID). Estimates of autism prevalence in the general population have changed markedly over recent years, largely as a result of the revised diagnostic criteria as well as increasing awareness. This implies that the recognition of autism in individuals with EDs may also have increased, and correspondingly that autism prevalence figures reported in older studies may underestimate the extent of co-occurring autism–ED.

2.2.1 Anorexia nervosa

Estimates based on self-report using the autism quotient (AQ) suggest that up to 40% of adolescents and 26% of adults with AN meet the diagnostic cutoff for autism (35, 36). Studies using clinician-administered assessments, such as the Autism Diagnostic Observation Schedule (ADOS), have reported similar figures overall, but with some variability in item subscores, suggesting a narrower autistic profile in some individuals. For example, a study in 60 women with severe AN (37) found that 14 (23%) met the clinical cutoff for autism on the revised ADOS (ADOS-2), but while all showed social impairments, only eight (13%) demonstrated repetitive or restrictive behaviours. Another study by the same authors (38) found that out of 40 adolescent females with AN attending inpatient and day-patient ED services, four (10%) met full research criteria for autism, based on ADOS-2 scores and a review of their developmental histories. A further 17 (40%) met the ADOS-2 diagnostic cutoff without fulfilling the developmental criterion. A study in 150 adolescent outpatients with AN or subthreshold AN (14) reported below-average scores on measures of social aptitude and above-average scores on measures of peer relationship problems and obsessive-compulsive symptoms, but only six individuals (4%) were considered to meet diagnostic criteria for "possible" (n = 5) or "definite" (n = 1) autism. Similarly, a study comparing AQ, ADOS and Social Responsiveness Scale scores in 218 young females (aged 12–30 years) with either current or recovered AN (without a previous diagnosis of autism), or autism, and a "typically developing" control group (39), found that, while the AN groups had higher levels of autism features than the control group, they were less likely to show impairments in verbal and non-verbal communication, social interaction and imagination/creativity than the autism group. However, the AN groups were only reliably differentiated from the autism group on

the ADOS-2 "quality of social response" item.

The importance of using appropriate criteria for assessment of autistic features in older adolescents and adults with AN was demonstrated in a study by Sedgewick et al. (40). The authors used a revised version of the ADOS-2, which was specifically developed for use in this population, and compared diagnostic outcomes with those obtained using the original version of the scale in a sample that included 66 women and girls with current AN (AN group), 46 in recovery from AN (REC group), and 63 controls who had never had an ED (HC group). Using the original algorithm, five of the HC group, 13 in the AN group and seven in the REC group scored above the diagnostic cutoff for autism. The revised algorithm resulted in a greater number meeting the diagnostic cutoff in each of the three groups: six in the HC group, 18 in the AN group and nine in the REC group. Notably, the revised ADOS-2 scores were not significantly correlated with ED symptomatology, suggesting they were indicative of underlying autism and not state-dependent features of AN.

In summary, autistic features are common in individuals with AN. The studies summarised above, and recent reviews (24, 25), suggest that 20% to 35% may meet ADOS-2 diagnostic criteria for autism. However, the autistic profile of individuals with AN appears to differ in many cases from that of individuals with autism without AN. This may partly reflect the largely female samples in AN studies but also suggests a distinct autism presentation in AN.

2.2.2 Bulimia nervosa and binge eating disorder

While relatively few data are available for other EDs, study samples that have included individuals with AN, BN and BED have suggested that the numbers meeting diagnostic criteria for autism are similar across ED types. Gesi et al. (41) were the first to identify a higher degree of autistic features in individuals with BN and BED than in healthy controls. A later systematic review of studies investigating autism and ADHD in individuals with AN, BN or BED (42) reported that, overall, 4.7% had a DSM-III, DSM-IV, DSM-5 or ADOS-2 diagnosis of autism, which was the same rate as that for the AN subgroup when analysed separately. Similarly, among 71 ED outpatients attending a specialised ED hospital (43), 28%, 40% and 31% of those with AN, BN and BED, respectively, were classified as having "high level autistic traits" (HAST), according to DSM-5 criteria and clinical assessment. The difference between the rates of HAST in AN and other EDs combined was not statistically significant.

2.2.3 Avoidant/restrictive food intake disorder

Since 2013, when it was first defined as a distinct ED in the DSM-5, several studies have investigated coexisting autism in ARFID. A systematic review of ARFID in children and adolescents (44) reported prevalence estimates of coexisting autism in children with ARFID of between 8.2% and 54.8% across six studies. Between 21% and 28% of children with autism were considered to be at high risk of developing ARFID. The DSM-5 characterises food restriction in ARFID as resulting primarily from heightened sensitivity to the sensory aspects of food (e.g., appearance, colour, smell, texture, temperature or taste), rather than a preoccupation with body weight or shape (1). Similar restrictive eating behaviours and sensory sensitivities are commonly seen in individuals with autism without a diagnosed ED, which may contribute to a particular risk of developing ARFID in this population (45). However, differences in social functioning, sensory processing and eating attitudes have been reported in children with coexisting ARFID-autism, compared to children with autism only (46). Unusually among EDs, ARFID is diagnosed equally in males and females; however, coexisting ARFID-autism is more common in males (1).

2.2.4 Pica

Pica is characterised as persistent (>1 month) consumption of non-nutritive, non-food substances (1). As with ARFID, the impetus for abnormal eating behaviours in pica is not a preoccupation with weight or body image. Analysis of data from the ALSPAC study (47) showed pica behaviours were present in 3% of children at one or more regular follow-up reviews between the ages of 36 months and 115 months (9 years, 7 months). Pica was most commonly reported at 36 months and decreased later in development. At all five follow-ups (at 36, 54, 65, 77 and 115 months), pica was significantly associated with autism ($p < 0.001$). The percentage of children with pica who also had a diagnosis of autism was not reported, however.

2.3 Treatment approaches to eating disorders in individuals with autism

There is a consensus that standard treatment approaches for EDs can be less effective for those who also have autism or autistic features (20, 22, 48). Autism is associated with greater ED severity, longer-term treatment, risk of admission to intensive inpatient care (49, 50) and negative treatment outcomes (48, 51), further emphasising the need for interventions adapted to their particular requirements. However, there are no separate guidelines for the treatment of EDs in people with autism (49) and approaches to treatment have typically been informed by individual clinician experience (52). It is worth noting, given the relatively high prevalence of autism in those with EDs, that many of the published treatment studies will have included autistic individuals. What is lacking is further research evidence to identify adaptations that may improve treatment efficacy in this group.

Starting in 2017, the views of individuals with autism-AN, carers and clinicians were collected in a series of interviews conducted as part of a wider clinical improvement project by South London and Maudsley NHS Trust (49, 52). The sur-

veys identified a set of priorities for adjustments to routine care and clinician engagement with people with autism-AN (49, 50, 52, 53). The main conclusions are summarised in Box 1.

Box 1. Outcomes of needs assessment for the treatment of autism-AN according to patients, carers and clinicians (49)

1. Importance of recognising sensory differences
2. Recognition that therapeutic engagement with therapists takes longer to achieve
3. Need for an individualised and flexible approach to treatment
4. Difficulty in receiving a diagnosis
5. Lack of a clear treatment pathway
6. Need for clinician training and support
7. Need for adjustment to outpatient and inpatient treatment environments to reduce stress

The themes identified formed the basis for the development of the first specialised care pathway for EDs in people with autism, the "PEACE" pathway (see earlier). Changes to the clinical care model that were introduced as a result included: autism training for ED specialist clinicians, including the use of autism assessment tools; adaptation of treatment approaches and environments for people with autism; development of psychoeducation materials for patients; and enhanced clinician and carer support (49). Within two years of the introduction of the pathway, the mean duration of hospital admission for patients with autism-AN had fallen from 133 days to 90 days, with an attendant reduction in the cost of each admission of almost £23,000 (54). Preliminary indications also suggest a reduction in readmission rates, although data are yet to be published. The success of the project has led to interest in its further development with the aim of expanding the service to patients with autism and EDs other than AN (49), and to those in different treatment settings. In the following section, the development and implementation of the PEACE pathway within community child and adolescent mental health services (CAMHS) is described in more detail and key learning shared to enable further dissemination of this approach.

3. Development of the Buckinghamshire, Oxfordshire and Berkshire (BOB) PEACE initiative

3.1 Background and inception

Following the positive outcomes reported by the South London and Maudsley group in adapting care for autistic adults receiving inpatient treatment for AN, there has been much interest in expanding the PEACE initiative to benefit a wider group of patients. The pioneering work in South London and Maudsley demonstrated that a specific focus on improving care for this group can greatly enhance treatment outcomes and care experience (55). In our local child and adolescent ED services, we observed that young people – especially girls – often present with an ED first, before their autism is recognised. This is in keeping with recent research findings (7, 52). In addition to this, there is a risk that the common restructuring of CAMHS into specialist pathways, while carrying obvious advantages, can disadvantage those with overlapping needs by potentially separating different areas into "silos" of expertise, including neurodevelopmental conditions and EDs. Clinicians working in ED services noted the importance of enabling the identification of autism earlier in an individual's treatment journey and the need to adjust standard treatment protocols to consider suspected autism. This is described by the second author, below.

"I've always felt different, odd, like I didn't belong in the world. I didn't understand why for years. Not knowing why led me to believe I was broken, flawed, wrong. My mental health nose-dived, along with my self-confidence, and I developed anorexia at 14. I spent nearly a decade in services feeling like I was going nowhere, if anything, getting worse. Years spent in hospitals experiencing invasive treatment methods, every possible medication and therapy tried, I genuinely believed I was just broken beyond repair and that there was no chance of it ever getting better.

That all changed when autism was proposed. At first, I didn't accept it – I had a narrow stereotype of what autism was and I didn't fit it. But eventually I did my research and it felt like finally, something made sense. I finally understood why I felt the way I did, why I processed the world in a different way to those around me, why I struggled with aspects of life but excelled in other areas too.

Having my autism recognised meant reasonable adjustments were made within my eating disorder treatment too, which initiated firm strides in my recovery. After 10+ years of going around in circles, I started making real progress.

Since receiving my autism diagnosis, my life has changed significantly. Some of this has been obvious external things, like sensory adaptations, having more time to process change and using different ways to communicate. But the biggest and most meaningful changes have been those I've felt within myself. I stopped being so harsh with myself, so angry. I started feeling compassion to my younger self, discovering who I truly am, advocating for my autistic needs and discovering my autistic identity.

Discovering I was autistic saved my life, but it has also given me a life because the explanation it offered has guided me to not just survive but thrive."

On the basis of these observations and experiences, a group working within the BOB Integrated Care System (ICS) secured three years of NHS innovation funding in 2021 to extend the benefits of the PEACE initiative to children and young people in a community setting. Within this ICS, two provider Trusts deliver three county-wide child and adolescent eating disorder teams, covering a population of approximately 1.8 million. In the BOB PEACE project, we

set out to improve local care pathways for autistic young people with eating disorders by raising awareness of the needs of this group and supporting the integration of expertise to facilitate better care. The aim of the project was to identify, evaluate and disseminate changes in practice that could then form part of an ongoing core offer. To deliver this project we recruited, to a specialist PEACE implementation team of clinicians, experts by experience and support staff. This group worked both across the ICS footprint to transform care as well as developing a local offer embedded within our existing CAMHS ED services. The project was organised into three workstreams: (1) developing early help for autistic young people at risk of developing an ED; (2) improving the identification and experience of autistic young people first accessing ED services; and (3) enhancing the care of autistic young people with complex needs already receiving treatment.

Building on the South London and Maudsley findings outlined in Box 1, above (49), and additional local needs identified through early scoping work, the BOB PEACE project developed a range of interventions to address the additional challenges that may be encountered by patients, families and clinicians and services when working with an ED in the context of autism (see Table 1).

3.2 Identified shortcomings in existing eating disorder management for people with autism and specific aims of the BOB PEACE Pathway

3.2.1 Autism not routinely screened for in eating disorder services

Prior to the implementation of the PEACE project, we did not know how prevalent autistic traits were in our local children and young people (CYP) ED population. Moreover, as a service, we observed that autism was often not recognised as early as it could be in ED treatment. This is in keeping with the research literature (57). Therefore, an early adaptation we made was to introduce the AQ-10, a short 10-item screening measure of autistic traits. Using this measure, alongside a standard clinical assessment interview, enabled us to identify any reasonable adjustments for

Perspective	Challenge identified	PEACE intervention
Service level and clinicians	Autism not recognised early in treatment history, leading to poorer experience and outcomes.	Introduced screening and training for clinicians; PEACE champion roles embedded within ED teams; early-help resources developed and disseminated via dedicated website.
	Lack of confidence in ED services in identifying autism, and in neurodevelopmental services in treating EDs.	Strengthened links between neurodevelopment and ED services to ensure integrated care; complex case panel set up.
Service level	Ensuring our eating disorder services are neuroinclusive and in line with key standards.	NAS accreditation achieved, resulting from improvements to clinical settings, reasonable adjustments offered and inclusive care plans.
	No specific resources offering early help to autistic CYP at risk of developing an ED.	Psychoeducational resources developed and distributed to schools and doctor surgeries.
All	Evidencing improved outcomes and care amongst autistic CYP with eating disorders.	Clinical outcome measures indicated improvement in CGAS, GBOs and reduction in risk for CYP.
	Missed opportunities to learn from lived experience and improve care.	Patient and parent EbyEs embedded in PEACE throughout the project.
CYP, clinicians and carers	**Communication** between CYP and clinician, and within the families.	Communication passports completed and embedded into care plans; advocating different styles of communication.
Service, CYP and clinicians	**Sensory processing differences** not accommodated for by traditional ED treatment models or are they accounted for in the clinical environment.	Reasonable adjustments webinar series delivered surrounding sensory sensitivities with regard to food and meal plans. Sensory boxes were put into clinic waiting rooms and appointment rooms.
CYP	**Loneliness, social difficulties and masking** commonly described by autistic individuals, which have been identified as causal and maintaining factors for an ED (56), and not addressed by current treatment pathways.	Low-intensity interventions were designed to explore how autistic people could learn to unmask, empower their autistic self and find connections with others.
	Preference for **sameness and routine**, with difficulties in navigating and tolerating change.	PEACE advocates for using the strengths of the autism, such as the ability to plan and adhere to plans, in recovery. Additionally, low-intensity intervention was created surrounding skills for tolerating uncertainty and change.

Table 1. How the BOB PEACE project set out to improve care for autistic children and young people with eating disorders

Abbreviations: CGAS = Children's Global Assessment Scale; CYP = children and young people; EbyEs = experts by experience; ED = eating disorder; GBO = goal-based outcomes; NAS = National Autistic Society; PEACE = Pathway for Eating disorders in Autism developed from Clinical Experience

possible autism to be made early in their care, improving their experience of services (52). It is important to note that starvation-induced changes can mimic some features commonly seen in autism. Our approach was needs-led rather than diagnosis-led, and any reasonable adjustments were made and reviewed following collaborative conversations with the young person and their family. We know from the original London study that many of the reasonable adjustments were beneficial to patients irrespective of autistic status and did no harm. As a secondary benefit, introducing screening allowed for early referral for neurodevelopmental assessment in cases where this was deemed appropriate.

3.2.2 Lack of confidence in managing autism and eating disorders

Toward the start of the BOB PEACE initiative, a training needs analysis revealed that expertise across EDs and autism had become increasingly "siloed" with the development of specific CAMHS pathways. Neurodevelopmental teams lacked confidence in identifying and responding to ED needs, and clinicians in ED teams lacked knowledge and confidence around autism. In addition, the overlap of EDs and autism was poorly understood. Therefore, the project set out to offer information, training and resources to bridge the knowledge and confidence gaps across teams. This included offering monthly webinar training for different areas of the overlap between autism and EDs, publishing a monthly newsletter, developing a website where information could be disseminated and creating resource leaflets on different aspects of the overlap, such as emotional processing and sensory needs.

The monthly webinars were extremely successful, with between 60 and 150 attendees each month. Topic areas addressed included: communication differences, the interplay between autism and EDs, spotting the signs, reasonable adjustments that could be made to standard family therapy for anorexia nervosa and supporting autistic young people with EDs in school.

Webinars were well attended and got excellent feedback.

"The webinar was absolutely amazing! It was informative and [speakers] were brilliant! Have gained lots of valuable knowledge through the webinar!"

"Great to have expert clinicians and researchers presenting. So valuable listening to the experts by experience – brilliant contribution from them."

Both the website and monthly newsletter contained more information and insights gained throughout the project, as well as achievements and progress made as a PEACE team. The website offered information on the overlap between autism and EDs through lived experience videos, animations and pages to read, alongside resources for clinicians to access when working with an autistic or possibly autistic young person.

3.2.3 Empowering clinicians and carers in autism and eating disorders

A goal for the BOB PEACE team was not only to improve the service experience for the young person, but also to empower clinicians treating young people who they suspected were autistic. As a team, this was achieved through information dissemination and resources, but also through direct involvement of PEACE clinicians in consultations, assessment and care planning, tailoring evidence-based interventions and supporting autism assessment referrals.

Direct work had very positive outcomes; below are quotes from clinicians and carers.

"I now have a clear plan and knowledge to confidently support this young person, which includes signposting, giving resources and advice around psychoeducation, and setting up a communication passport." (Clinician feedback)

"After battling for many years, this is the first time my child has responded so positively to treatment."

"The PEACE team have brought a unique understanding of my daughter's [autism spectrum disorder] and anorexia, and the complex relationship between the two." (Parent/carer feedback)

Figure 1 demonstrates the positive impact PEACE had on clinicians' understanding of the overlap between autism and EDs and the efficacy of direct consultation work.

3.2.4 Ensuring eating disorder services are neuroinclusive and in line with key standards – National Autistic Society accreditation

Demonstrating the commitment of ensuring our services are neuroinclusive, and as an external marker of the reasonable adjustments described, we sought and achieved National Autistic Society (NAS) accreditation across all three ED services. These included adjustments such as: sensory accommodations in clinic settings, an active approach to adapting therapies and treatment approaches with autism in mind and the development and distribution of resources about autism, EDs and the overlap. This also has the benefit of communicating our neuroaffirmative ethos to new CYP and families and inspiring other parts of the CAMHS system to do the same.

3.2.5 No specific pathway offering early help for autistic people at risk of developing an eating disorder

It is well documented that autistic individuals are at a greater risk of developing mental health problems, including

EDs (58, 59). We aimed to improve the knowledge and understanding of why autistic people may develop EDs, help parents and carers to spot the early warning signs of disordered eating and EDs and provide advice on avenues of support for CYP and those supporting CYP. One of the biggest achievements of the innovation project was raising awareness of the needs of this group and how care can be improved using the PEACE framework.

This was achieved through creating psychoeducational resources offering information on why autistic people may be at a higher risk of developing an ED and when difficulties with food may need a more intensive support intervention. Further information was also disseminated through the monthly newsletter and accessible on the website for ease of access. Many of these resources were also shared with schools and GP surgeries to ensure autistic CYP were offered neuroinclusive care and reasonable adjustments as early on into their experience of eating difficulties as possible.

3.2.6 Improving outcomes and care experiences

Prior research had indicated that without reasonable adjustments, autistic people are more likely to have a negative experience of ED treatment and poorer outcomes than their neurotypical peers (48-50). Thus, it was important to monitor clinical outcomes to ensure the care provided was effective and beneficial. Our outcome measures indicated improvements across the Children's Global Assessment Scale (CGAS) and Goal Based Outcomes for CYP utilising the pathway. CGAS measures completed to date showed that 85% (n = 13/15) of the young people with the highest level of need, receiving direct support from a PEACE clinician, showed an improvement in overall functioning between pre-PEACE and post-PEACE intervention scores. In our initial pilot of the targeted modular interventions delivered by assistant psychologists, 100% (n = 14) demonstrated improved scores following delivery of the module, highlighting that all young people felt closer to achieving their individualised goals. Following PEACE consultations, clinicians reported at least one improved outcome (reduced admission length, need for escalation or risk to/from self and others, improvements to physical health, or improvements in engagement with the young person) in 77% (n = 114) of cases. Of applicable high-risk cases receiving PEACE consultation, clinicians reported a reduction in the length of admission to paediatric or acute inpatient care or crisis services in 42% (n = 5) of cases, and reduced need for escalation or admission to paediatric or acute inpatient care or crisis services in 47% (n = 9) of cases. Of the responding clinicians, 94% (n = 46) also reported better understanding of their young person's needs following PEACE input, with 80% (n = 39) reporting increased confidence in working with the young person and 86% (n = 42) reporting that PEACE input led to a better treatment plan being developed. Furthermore, qualitative feedback from both patients and parents/carers of CYP with EDs reflected the positive impact of PEACE, captured by the quotes below.

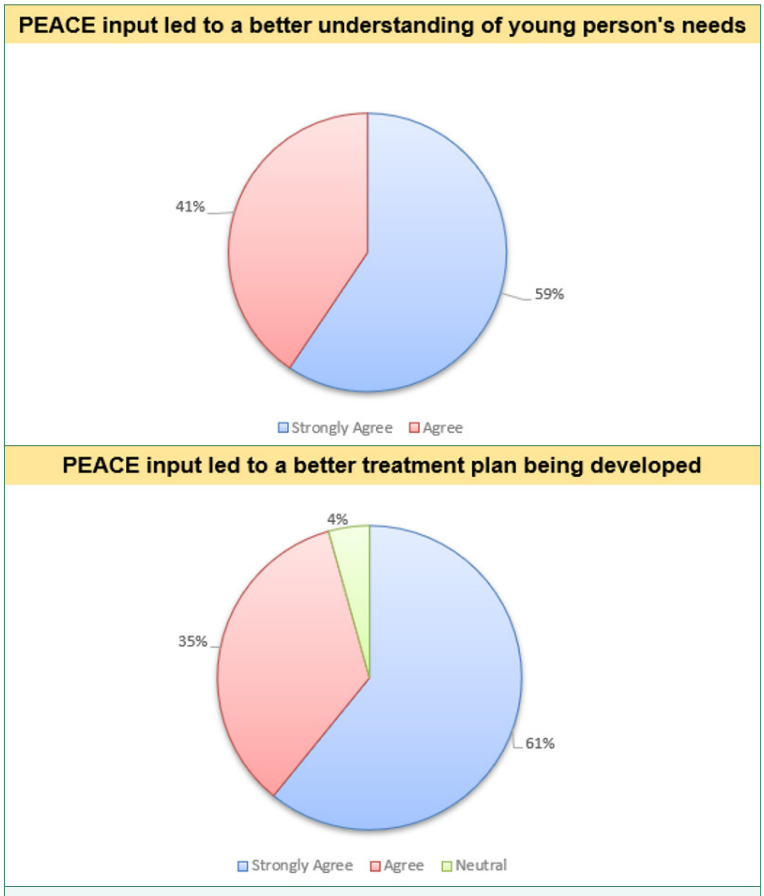

Figure 1. Distribution of responses to key clinician feedback questions

"My daughter has had four years of inconsistency of care, leaving her feeling hopeless and that the system doesn't care. At last, she feels that she has found someone who truly understands her needs."

"As my daughter would not engage directly with any professionals, the PEACE clinician has had regular sessions to advise and coach me in how best to support her. These sessions have been invaluable and have been a significant part of my child's steps towards recovery. The PEACE team have brought a unique understanding of my daughter's ASD and anorexia, and the complex relationship between the two."

3.2.7 Missed opportunities to learn from lived experience

Recognising and listening to the voices of those with lived experience of EDs, and autistic individuals, has been advocated for in recent years in response to a lack of evidence for treatment efficacy (7) and meaningful change in understanding the conditions (60, 61). The inclusion of lived experience has been found to promote inclusivity of otherwise relegated voices, reduce the power dynamic between service providers and users and offer inspiration for recovery (60, 62).

In light of this, Experts by experience (EbyEs) were embedded in the PEACE project throughout, encompassing a wide range of tasks and responsibilities. For example, representation on the project board; co-producing project workstreams; speaking at conferences and contributing to the webinar series; offering continuing professional development training slots; answering clinicians' questions; assisting in the research being conducted; helping design and produce the website, newsletter and resources; and helping develop the low-intensity therapeutic interventions. The feedback from clinicians of having the lived experience perspective was profound, often referred to as the most helpful aspect of training and learning. EbyEs were able to offer valuable insights into their experience and presentation of their EDs as autistic individuals, specifically surrounding symptomology that may not align within traditional diagnostic frameworks, enabling a broader understanding of EDs and facilitating relevant considerations for diagnosis and treatment. Furthermore, the EbyEs reported feeling heard and validated as well as having improvements to their own recovery journey and self-understanding through using their lived experience to shape treatment and research.

3.2.8 Communication differences

The social communication difficulties that autistic people experience may impact their ability to engage in treatment, especially due to the heavy reliance on verbal articulation and conversational interaction within traditional ED treatment, such as in therapy. Clinicians had identified that communication differences made building rapport more difficult (50), and parents have expressed how the types of language used impacted their child's engagement with services (57). Alongside this, autistic people expressed the benefit of adaptations made to typical communication styles to meet their needs, such as offering written information (57). It is important to note that autistic people can benefit just as much from evidence-based treatment models when additional consideration is given to how these are communicated and other aspects of care, such as the therapy environment.

PEACE advocated the use of communication passports which explore how an autistic person prefers to communicate, such as through writing or art, alternative ways of communicating how they are feeling and areas in which they need more support. Communication passports have previously been shown to be effective for patients with EDs, as well as those with co-occurring autism and EDs, by documenting their communication preferences and offering insights into their identity and who they are outside of the ED (63). Communication passports were completed for each CYP seen and embedded into care plans so that each clinician was able to access and make reasonable adjustments when working with the young person.

Additionally, training was delivered to clinicians about the importance of using clear, unambiguous language and refraining from using metaphors or abstract concepts that autistic people may find more difficult to understand (64).

3.2.9 Masking and social interactions

Difficulties in social interaction are commonly reported among autistic individuals; struggling to fit in, bullying and loneliness have been found to be directly and indirectly linked with the development of EDs (56). Moreover, autistic people may engage in masking or camouflaging behaviours to try to gain social acceptance and fit in with peers. The negative impacts of masking are multifactorial, including exhaustion leading to "burnout", anxiety and depression. These negative impacts can impede identity development and have been found to predict ED symptomology (65). These may act as additional maintaining factors which receive less attention in traditional models of treatment. We developed additional modular interventions of one to seven sessions, deliverable by assistant psychologists or similar staff, to address these specific areas of challenge. These modules were developed to be delivered alongside routine treatment to address areas identified as important to a specific young person. We are currently in the process of evaluating their efficacy.

In CAMHS services, it is important to consider the young person's social experience, especially in navigating the school environment. As a PEACE team, we developed a four-session modular intervention called "Finding Connections", which explored what masking is and its impact, empowered the young person to feel able to unmask and explored ways to find and make them feel connected to others as their authentic autistic self.

For clinicians, a webinar was delivered offering information on masking and the impact of masking for autistic people, and strategies that could be used to encourage an autistic person to feel able to unmask.

3.2.10 Sensory processing differences

Differences in sensory processing experienced by autistic people can include being hypersensitive and hyposensitive to stimuli and sensations (1, 66). For an autistic person experiencing an ED, this may be shown through a limited variety of foods being deemed "safe" due to their texture or temperature, struggling to process busy, noisy and bright waiting room areas in hospital settings and being hypersensitive to feelings of fullness and bodily sensations. Hyposensitivity may incorporate difficulties in recognising and interpreting interoceptive cues, such as bodily signals of hunger and thirst. Autistic individuals have expressed the importance of understanding and accommodating for sensory processing differences in ED treatment, where it currently does not (52, 53). Moreover, a lack of sensory processing adjustments can impede an autistic person's ability to adhere to treatment (57) and may cause individuals to feel unable to engage in treatment due to overstimulating clinical spaces (67).

In response to this need, PEACE offered information and resources to improve the understanding of the autistic person's sensory world and how this may impact eating behaviour. It also facilitated making reasonable adjustments within the clinic environment and dietetic support with meal planning and food preferences. This was done through delivering webinars with ideas on how to make clinical areas autism friendly; a "sensory checklist" was also developed as a quick guide for clinics to refer to, so as to ensure that sensory accommodations were being made.

Within BOB ED services, clinic settings were de-cluttered with an optional quiet waiting area. Sensory boxes were put into all waiting rooms, with the option of using sensory tools within appointments to help the autistic person regulate themselves. For young people, a three-session modular intervention was made with information about their autistic sensory world, understanding and advocating for their sensory needs.

3.2.11 Preference for sameness

Autistic people may rely more heavily on a routine and struggle with change more than their non-autistic counterparts (68). Understanding that effective planning and predictability can help an autistic person meant that it was important for PEACE to implement strategies that work with the autistic mind to aid their recovery.

In ED services, clinicians were informed of the importance of making and adhering to plans made with the autistic young person, and to give as much notice as possible about any upcoming changes. It was advised that meal plans may be required for a longer amount of time than for non-autistic individuals, and changes in treatment may occur at a slower rate. Importantly, it was highlighted that an autistic person's preference for sameness does not mean that evidence-based treatment would be more difficult or less effective, as effective planning can actually improve treatment adherence, as supported by previous literature (69).

Where change does need to occur, especially during the initial stages of treatment, the individual is trained in additional skills around tolerating uncertainty and change, delivered through a further modular intervention.

3.3 The process in practice: a case example

The efficacy of the direct PEACE approach that clinicians were able to offer and implement has been captured in case studies, such as the one described below.

J was a 13-year-old girl who presented to the local paediatric ward following a deterioration in her physical health having engaged in significant dietary restriction over the course of several months. J was suspected to be on the autistic spectrum and was already waiting for a diagnostic assessment by the local neurodevelopmental team.

The PEACE clinician joined the primary ED assessment, which took place on the ward, offered an initial consultation and agreed ongoing complex consultation. J and her family struggled significantly with managing discharge from the paediatric ward and J required a lengthy second admission. The PEACE clinician brought a combined knowledge of autism and EDs to support effective multidisciplinary working, with the aim of avoiding admission to an inpatient psychiatric hospital.

Professionals' meetings commenced weekly, including both ED and neurodevelopmental staff to support thinking around discharge from the hospital. Paediatric staff became instrumental in helping achieve this. Following J's successful discharge and improvement in her physical health, avoiding psychiatric admission, the PEACE clinician supported access to a formal neurodevelopmental assessment. The PEACE clinician continued to offer regular contact with J's parents, alongside her key worker, to complete her transition back to community treatment.

The positive impact of the indirect interventions and adaptations from PEACE pathway has also been captured, reflected in the feedback from a patient below:

"The work that PEACE do save lives like mine. By raising awareness of autism, we can better identify those who are autistic and sooner. Implementing reasonable adjustments for autistic individuals in eating disorder treatment pathways improves engagement, patient experience and recovery outcomes. As an autistic patient, I can only celebrate the work that PEACE does and is doing."

3.4 Reflections, learning and future directions

On reflection, many of the targets set out at the beginning of the BOB PEACE innovation project were achieved. At the end of our three-year innovation period, most clinical staff working in CAMHS and Adult Eating Disorders were aware of the PEACE initiative and related resources. This impact continues to help empower clinical staff to identify possible autism and make reasonable adjustments early on in care. As most experiences of mental health difficulties begin in childhood and adolescence (70), enabling a positive experience of help-seeking and treatment can be crucial in creating positive mental health outcomes both in childhood and later life. We have accrued initial evidence that a proactive, neuro-affirming approach to ED treatment in CAMHS can improve treatment experience and potentially both reduce risk and shorten or avoid higher-intensity treatments, such as hospital admission. This is particularly important as inpatient admissions can carry additional risks to the wellbeing of autistic people, including the risk of a poorer outcome. Our project was not about changing the core evidence-based treatment models, many of which probably included autistic people in their research studies. Instead, it set out to support those delivering treatment

to do so in an autism-informed capacity. Achieving NAS accreditation was a key achievement in evidencing this approach. Qualitative feedback and case studies, such as the one previously described, indicate the positive impact the project has made. We acknowledge that autistic individuals often present with atypical symptomatology that does not align neatly with traditional diagnostic frameworks. This requires the need for ongoing flexibility in diagnostic and treatment approaches, such as those set out in this paper. We hope that demonstrating the positive influence of being curious about autism in ED treatment and the initiatives of PEACE will continue across relevant mental health services.

An aspect that proved integral to the PEACE implementation was the embedding of people with lived experience from the beginning which was repeatedly cited as a highlight of the training and psychoeducational content delivered. Our innovation project acted as a flagship for the value of including lived experience in service design and improvement and inspired other areas to do the same. We were also struck by the positive personal impact on the EbyEs, who contributed so much to the project's success.

Capturing the impact of PEACE-driven changes was not always easy. Evidencing impact across heterogeneous individuals in a complex multifaceted treatment system is correspondingly complex. We are aware we may not have captured all aspects of intersectionality between autism and EDs, for example, the intersection of physical health, particularly gastrointestinal conditions (71) and broader demographic factors such as ethnicity and socioeconomic status. We undoubtedly developed more effective ways to capture impact as the project developed over its three-year lifespan. This meant that we missed some opportunities fully to evidence impact early on in delivery. While our data were able to demonstrate a positive effect, we recognise that even with additional funding and staff resource, evidencing value in busy NHS settings can be a challenge. We hope that by disseminating our findings, this will support commissioners and service providers in other areas to adopt and continue to evidence the effects of the PEACE initiative.

Our final area of work has been to embed findings from the funded project into the core service offer, so that future CYP, families and staff continue to benefit from the innovative work, resources and knowledge accrued. Innovation funding was fundamental to allow us to adapt and demonstrate the benefits of PEACE in our community CYP population. However, we leave a legacy of a care delivery model, website, adaptations and resources that other providers can adopt easily with minimal cost to benefit many more autistic CYP and adults and their families who are struggling with EDs. Arguably, this is, perhaps, our greatest achievement.

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Exploring the overlap between eating disorders and addiction disorders: implications for treatment

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Abstract

Eating disorders (EDs) are complex psychiatric conditions characterised by disturbances in eating behaviours and associated psychological impairments. Despite being traditionally distinct from addiction disorders, increasing evidence highlights significant overlaps in their neurobiological and behavioural underpinnings. This article explores the potential for EDs to be conceptualised, in part, as addiction disorders. It examines mechanisms such as the activation of dopamine reward pathways, endorphin release and the anxiolytic effects of starvation-induced ketosis, which may create addictive processes within EDs. Behavioural parallels, including impulsivity, compulsivity and neurochemical alterations in bulimia nervosa (BN) and binge eating disorder (BED), further align these disorders with substance use disorders. Additionally, food and exercise addiction, often comorbid with EDs, are evaluated in the context of their shared neural circuits and psychosocial drivers. Distinctions between EDs and addictions are also discussed, highlighting differences in aetiology, reward mechanisms, social acceptability and recovery dynamics. Understanding EDs through the lens of addiction has profound implications for treatment, including the integration of addiction-focused therapeutic strategies and pharmacological interventions targeting dopaminergic and opioid pathways. This framework offers new insights into the aetiology, psychopathology and treatment of EDs, with the potential to improve outcomes for individuals suffering from these life-threatening disorders.

Introduction

Eating disorders (EDs) are a group of conditions characterised by persistent disturbances in eating behaviours and associated psychological impairment. EDs have high mortality rates and are frequently comorbid with other psychiatric disorders, including addiction (1).

Key points

1. EDs share significant neurobiological overlap with addiction disorders
2. Starvation triggers homeostatic adaptations that may produce anxiolytic and euphoric effects
3. Impulsivity in BN and BED mirrors behaviours observed in addiction disorders
4. Distinctions between EDs and addiction are discussed
5. Viewing EDs as addiction disorders informs developing therapies and treatment approaches

Anorexia nervosa (AN) is defined by the restriction of energy intake, leading to significantly low body weight, accompanied by an intense fear of weight gain and disturbances in the perception of one's body shape or weight. Bulimia nervosa (BN) is characterised by recurrent episodes of binge eating followed by inappropriate compensatory behaviours, such as self-induced vomiting, excessive exercise or the misuse of diuretics and laxatives. Binge eating disorder (BED) shares the binge eating component of BN but lacks compensatory behaviours (2).

The cognitive-behavioural theory of EDs suggests that overvaluation of shape and weight is central to ED psychopathology. Consequently, behaviours such as food restriction, exercise, purging and bingeing are seen as manifestations of these disordered cognitions.

Goodman defined addiction as a process in which a behaviour provides both pleasure and relief from negative affect. This behaviour is characterised by a recurrent inability to control or stop it, despite negative consequences (3).

The DSM-5 introduced significant changes to the categorisation of addictions, renaming the Substance-Related Abuse and Dependency category as Substance-Related and Addictive Disorders with two subdivisions: substance-related disorders and non-substance-related disorders. The latter, currently exemplified only by gambling disorder, encompasses addictive behaviours that do not involve the ingestion of psychoactive substances (2).

The co-occurrence of EDs and addiction has been a topic of interest in psychiatry. Compared to the general population prevalence of addiction (approximately 9%), studies suggest that up to 50% of individuals with an ED also abuse or depend on substances such as alcohol or psychoactive drugs (4). Furthermore, 35% of individuals diagnosed with a substance use disorder (SUD) report ED behaviours, compared to 5% of women in the general population (5).

This article explores whether certain ED behaviours may stem from behavioural addiction or induce physiological changes that mimic substance dependence, producing withdrawal symptoms and physical dependence. Mechanisms such as dopamine (DA)-mediated reward pathways, endogenous opioid activation (e.g., through purging or

exercise) and the GABAergic effects of starvation ketosis (mediated by beta-hydroxybutyrate (BHB)) are discussed. These insights could enhance our understanding of ED aetiology, psychopathology and treatment.

Is starvation addictive?

Dysfunctional reward processes have been proposed as a basis for the compulsive behaviours observed in AN. Imaging studies and animal models provide evidence for this hypothesis (6). Bergh et al. suggested that starvation and overactivity elevate glucocorticoid hormones released from the adrenal grand in response to stress which may induce euphoria through DA pathway activation (7).

Starvation-induced ketosis produces BHB, a ketone body produced from the breakdown of fats in the liver in response to glucose scarcity, to serve as an alternative fuel source for the brain. BHB has anxiolytic and euphoric effects mediated through modulation of the inhibitory neurotransmitter GABA (8). These effects may explain why individuals with AN report a sense of calm or euphoria during prolonged fasting, reinforcing starvation behaviours.

Alterations in the brain's reward systems also contribute. Wagner et al. and Park et al. demonstrated structural and functional abnormalities in reward-related brain regions in individuals with AN. These alterations shift initial food restriction from being positively reinforcing to becoming habitual and negatively reinforced through maladaptive cognitive control and excessive habit formation (6, 9).

Chronic stress and the hypothalamic-pituitary-adrenal (HPA) axis also play roles. Corticotropin-releasing hormone, the primary regulator of the stress response, is released excessively following dysregulation of the HPA axis. This reduces appetite and enhances the drive for food avoidance. Starvation-induced hormonal shifts, including increased glucocorticoids and reduced insulin sensitivity, further reinforce altered reward pathways (10, 11).

Impulsivity and dopaminergic neural circuits

Impulsivity, a multidimensional construct, has been implicated in BN and associated with psychiatric complications such as SUDs and personality disorders (12). Impulsivity correlates with DA imbalances in the frontal cortex and striatum, impairing cognition, self-regulation and planning (13).

In BN, disruptions in striatal DA and reduced dopamine D_2 receptor availability have been observed. Broft et al. reported significant differences in DA response between individuals with BN and healthy controls, with greater binge-purge frequency correlating with reduced DA response (14).

Food addiction

Food addiction, characterised by compulsive overconsumption of highly palatable foods (rich in sugar, fat and salt), parallels substance addiction in its neurobiological underpinnings (15). Neuroimaging studies show that such foods activate DA reward pathways (16). The Yale Food Addiction Scale (YFAS) assesses food addiction based on DSM-5 addiction criteria (15).

Meule et al. found that all BN participants in their study met YFAS food addiction criteria, while remission of BN corresponded to a remission of addictive behaviours. Furthermore, a study conducted by Cassin et al. found that 92% of participants with BED also met the DSM-5 criteria for substance addiction (17). Recent reviews highlight marked parallels between overconsumption of highly palatable foods and SUDs in terms of DA, opioid, acetylcholine and serotonin pathways (18). While phenotypic overlap exists, this does not necessarily indicate that both disorders are identical. Evidence is lacking to support the translation of all addiction criteria to food addiction and further research is needed.

Exercise addiction

Exercise addiction, with a comorbidity rate of up to 48% in EDs, is characterised by compulsive, excessive exercise often driven by weight-loss motivations or avoidance of negative affect (19). High-intensity exercise releases endogenous opioids, creating a euphoria that can lead to "auto-addiction" (20). Rodent studies suggest that exercise may also impair reward circuitry, reducing the hedonic effects of other rewarding stimuli (21, 22).

Distinctions between eating disorders and addictions

1. **Aetiology**

   EDs, particularly AN and BN, are underpinned by disturbances in body image and weight-related beliefs, absent in traditional addiction models.

2. **Immediate versus sustained reward**

   Addictions involve acute, immediate reward, while restrictive EDs rely on prolonged reinforcement. BN and BED share impulsive traits resembling addiction (23).

3. **Social acceptability**

   Pursuit of thinness in EDs often garners social approval, whereas substance addiction frequently leads to social rejection.

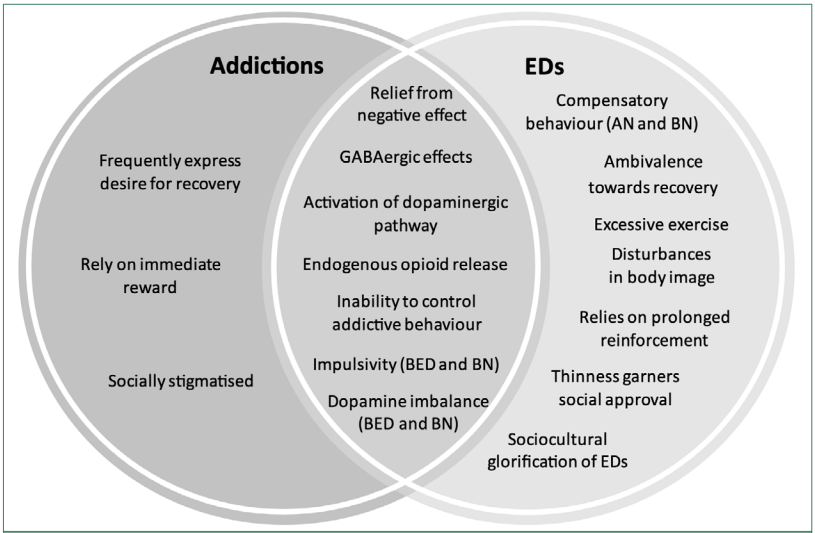

Figure 1. Conceptual model of overlap between addiction disorders and eating disorders

4. Recovery

Individuals with EDs often exhibit ambivalence toward recovery, contrasting with the abstinence-focused goals in addiction recovery (24).

5. Sociocultural factors

Diet culture and the glamourisation of thinness within Western society often aid in the development of ED ideals from a young age, while addictions are often cautioned against (25).

Treatment implications

Conceptualising EDs as addictions could inform novel treatment approaches. Addiction-focused interventions such as DA-targeted pharmacotherapy or opioid antagonists like naltrexone may hold promise for ED-related behaviours (26).

Enhanced cognitive behavioural therapy remains the first-line treatment for EDs, but integrating SUD-focused modules (e.g., reward sensitivity and impulsivity management) could improve outcomes in dual-diagnosis cases (27).

Self-help programs, such as Overeaters Anonymous, provide structured recovery frameworks, though risks of pathological competition among ED patients in group settings must be carefully managed (24).

Conclusion

While EDs and addictions are distinct entities, significant overlaps in neurobiology and behaviour suggest a continuum. Conceptualising EDs within an addiction framework could deepen our understanding of their aetiology and psychopathology, offering new directions for treatment and management of these complex disorders.

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Medical aspects of anorexia nervosa and bulimia nervosa

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Abstract

Eating disorders (EDs) have a lifetime prevalence of 8.4% for women and 2.2% for men. Anorexia nervosa (AN) and bulimia nervosa (BN) are commonly encountered in medical practice.

The main medical issue for BN and the binge-purge subtype of AN is electrolyte disturbance associated with purging and vomiting, which untreated can be fatal. This loss of K^+ and Cl^- with associated hypovolaemia may lead to hypokalaemic alkalosis. Treatment is by fluid and electrolyte replacement. Damage to the upper gastrointestinal (GI) tract, including reflux oesophagitis, dental problems, aspiration and, occasionally, oesophageal rupture, can occur.

In patients with the restrictive form of AN, the biggest risks are weight loss and malnutrition, which can have profound effects on the heart, gut, endocrine system and bone. Safe refeeding is essential. The risk to the person should be assessed using comprehensive, graded, multifactorial assessment tools, for example, Medical Emergencies in Eating Disorders (MEED). There is increasing evidence that patients can be safely refed at higher rates than was previously recommended, but it is important to assess the risk of refeeding syndrome and reduce the rate of refeeding if it is high.

Underfeeding syndrome, where patients fail to establish an adequate intake, is equally important. It is critical to manage anorexic behaviour on the ward to prevent it from frustrating the process of refeeding and stabilisation. Using established protocols, communicating effectively with the patient and their family, and being aware of the methods that may be used to avoid weight gain is important, as is an understanding of mental health legislation if the least-restrictive measures fail.

Recognising that the ED drives the behaviour of the patient and externalising the disorder, rather than blaming the patient, is important.

Patients with EDs have high rates of functional GI disorders and bone problems. A multidisciplinary approach to treatment is essential.

Introduction

Eating disorders (EDs) are common and most clinicians will encounter people with them during their careers. In EDs, the physical and psychological consequences are inseparable, and one can directly influence the other. Addressing both the physical and psychiatric aspects of EDs is essential for their management.

Patients with EDs are usually looked after by mental health and primary care teams and, with early diagnosis, attentive monitoring and careful follow-up, their physical problems can often be managed without the need for hospitalisation or the involvement of general medical specialists. In EDs, however, physical complications can arise which may be life-threatening or pose a significant risk to the long-term health of the person. In some cases, admission to a specialist eating disorder unit (SEDU) may be a possibility, but these are not always available and they may not be able to look after patients who require close laboratory monitoring, complex nutritional support or those who have severe malnutrition. Consequently, ED patients may come under the care of acute medical teams, particularly those specialising in gastroenterology or general medicine.

This review is directed towards acute medical specialists, and to guide psychiatrists, mental health teams and general practitioners who have patients whose physical condition is deteriorating. It concentrates principally on the medical problems associated with anorexia nervosa (AN) and bulimia nervosa (BN), but patients with any eating disorder can develop physical complications. People with avoidant/restrictive food intake disorder (ARFID) or autism spectrum disorder may have very disordered eating patterns and significant nutritional problems, but unlike in AN or BN, weight control is not usually the dominant motivation (1).

In AN and BN, concern about potential weight gain drives compensatory behaviours, and the balance between the primary drivers and the compensatory behaviours determines the presentation of the disease (Box 1). In AN, fear of weight gain is obsessive and the compensatory behaviours and calorie restrictions are disproportionate, leading to weight loss and undernutrition. In BN, the binging and compensatory behaviours are in balance, and the patient remains at normal or near-normal weight. In both conditions "the disease drives the behaviour" of the patient, which, in turn, may frustrate the medical treatment of the underlying condition (1). Similarly, the physical condition of the patient affects their mental state, particularly in AN where malnutrition can have a significant effect on the patient's

Box 1. Eating disorder definitions based on ICD-11 classifications (4)

Feeding and eating disorders

Involve abnormal eating or feeding behaviours that are not explained by another health condition and are not developmentally appropriate or culturally sanctioned. Eating disorders involve abnormal eating behaviour and preoccupation with food as well as prominent body weight and shape concerns.

Anorexia nervosa (6B80)

Characterised by significantly low body weight for the individual's height, age and developmental stage that is not due to another health condition or to the unavailability of food. A commonly used threshold is body mass index (BMI) less than 18.5 kg/m^2 in adults and BMI-for-age under the 5th percentile in children and adolescents. Rapid weight loss (e.g., more than 20% of total body weight within 6 months) may replace the low body weight guideline as long as other diagnostic requirements are met.

Bulimia nervosa (6B81)

Characterised by frequent, recurrent episodes of binge eating (e.g., once a week or more over a period of at least one month). A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eating notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten. Binge eating is accompanied by repeated inappropriate compensatory behaviours aimed at preventing weight gain (e.g., self-induced vomiting, misuse of laxatives or enemas, strenuous exercise). The individual is preoccupied with body shape or weight, which strongly influences self-evaluation. There is marked distress about the pattern of binge eating and inappropriate compensatory behaviour or significant impairment in personal, family, social, educational, occupational or other important areas of functioning. The individual does not meet the diagnostic requirements of anorexia nervosa.

Avoidant/restrictive food intake disorder (6B83)

Characterised by avoidance or restriction of food intake that results in: (1) the intake of an insufficient quantity or variety of food to meet adequate energy or nutritional requirements that has resulted in significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or has otherwise negatively affected the physical health of the individual; or (2) significant impairment in personal, family, social, educational, occupational or other important areas of functioning (e.g., due to avoidance or distress related to participating in social experiences involving eating). The pattern of eating behaviour is not motivated by preoccupation with body weight or shape. Restricted food intake and its effects on weight, other aspects of health, or functioning are not due to unavailability of food, not a manifestation of another medical condition (e.g., food allergies, hyperthyroidism) or mental disorder, and are not due to the effect of a substance or medication on the central nervous system, including withdrawal effects.

cognitive abilities (2). Whilst it is difficult to quantify this effect, the classic studies of Ancel Keys in which young, healthy male volunteers who agreed to be starved experienced profound effects on their cognition and mood as their weight fell by 20%, at which point they were all successfully refed (3).

Twin and other genetic studies suggest that both AN and BN have strong genetic predispositions. The female relatives of individuals with AN are 11 times more likely to develop AN than those without. Twin studies suggest a heritability of between 0.28 and 0.744, which is significantly higher than for many purely "physical" conditions. Less is known about the genetics of BN, but the heritability is thought to be 0.6 and there is a strong correlation with AN, at 0.46 to 0.79. EDs are, therefore, very similar to other conditions where a polygenetic predisposition interacts with the environment to produce disease (5, 6).

The lifetime prevalence of EDs has been estimated at 8.4% for women and 2.2% for men. In women, it is estimated that the lifetime risk of AN may be 1.4% and BN 1.9%, with lower rates in men, at 0.2% for AN and 0.6% for BN (7). AN is believed to carry the highest mortality rate of any psychiatric disorder (8).

Basic principles of medical care

Some people, including clinicians, who may not have encountered a person with an ED before, may view the person's food history as being a "lifestyle choice" rather than the consequence of a serious disease. Often, it suits the person with the ED to encourage this and to underplay the intense controlling influence that the condition has on them (1).

Non-psychiatric medical teams (NPMT) with little experience in managing AN and BN can, therefore, underestimate the seriousness of the conditions and the risks they pose to their patients. This may make them less willing to challenge ED behaviours, more inclined to discharge patients early and less familiar with and willing to use mental health legislation.

The most important roles of psychiatric teams and ED specialists are to:

- help NPMTs understand the conditions
- support the medical team whilst ED patients are in the hospital
- advise on mental health legislation
- offer more specific treatment and ongoing psychiatric care.

The complex psycho-pathophysiology of EDs makes them challenging to manage, particularly for medical teams.

The basic principles of medical management (9) are:

- recognise the disease and initiate a multidisciplinary approach, including liaison psychiatry, dietitians and nurses
- assess the risks that the disease poses to the patient
- stabilise the physical condition, initiate safe refeeding and other appropriate treatments
- recognise and manage ED behaviours likely to impact recovery, understanding that they are part of the condition and that "the disease drives the behaviours"
- be prepared to use mental health legislation if required
- manage transitions between care providers, being aware that these are points in the pathway where patients may become lost (10)
- communicate effectively with the patient and their family, whilst recognising that patients still have a right to confidentiality.

Assessing risk

Risk is multifactorial in both AN and BN. Deaths occur from many different causes, including suicide, accidents, undernutrition, hypoglycaemia and electrolyte disturbances. Consequently, any risk framework must consider a range of factors, rather than simply concentrating on the psychological or physical danger. In general, patients are in very considerable danger when their disease results in homeostatic failure in any system, if their behaviours are uncontrolled or their mental health is deteriorating.

One of the most comprehensive risk assessments available at present is Medical Emergencies in Eating Disorders (MEED), which has an all-age, graded, risk assessment applicable to all EDs, including ARFID (11).

The risk to life is graded using a traffic-light system into three categories:

- red flags imply "a high risk of impending risk to life"
- amber categories are "an alert for impending risk to life"
- green flags imply a "low impending risk to life"

BMI and weight
Weight loss
Heart rate
Cardiovascular system health
Hydration
Temperature
Muscular weakness
Electrocardiogram
Biochemical
Haematology
Behaviours
Engagement
Activity and exercise
Purging
Self-harm

Table 1. Risk domains in MEED

All the risks are integrated with a comprehensive guide to immediate management. MEED offers a useful framework to discuss patients with an acute medical team and has replaced the previous guidance, the Management of Really Sick People with Anorexia Nervosa, or MARSIPAN, which is now obsolete and should no longer be used (12). MEED has been widely endorsed by expert groups including the UK Academy of Royal Colleges and is, therefore, likely to be cited by legal and disciplinary bodies such as coroners and ombudsmen should a complaint be made (13).

MEED assesses risk across 15 separate fields, which include physical parameters such as weight, BMI, weight loss and cardiovascular parameters but also exercise and self-harm (see Table 1).

The medical management of bulimia nervosa

BN is characterised by recurrent binge eating and loss of control, which triggers compensatory behaviours, particularly self-induced vomiting and purging with laxatives. Over-exercise can occur but is less common than in AN. Although not included in ICD-11 (4), patients with BN are usually of normal or near-normal weight. The most common medical complications relate to plasma electrolyte disturbances due to purging, which can be severe and life-threatening.

Patients with BN do not look malnourished and may have a pseudo-Cushing appearance due to hypertrophy of the parotid glands caused by recurrent purging. BN is frequently associated with feelings of shame and the extent of the purging behaviour can often be understated, meaning the risk to the patient may be underestimated.

Vomiting results in the loss of H^+ and Cl^- ions. It can also be associated with fluid loss and hypovolaemia, which lead to activation of the renin-angiotensin-aldosterone system, with a paradoxical further renal loss of H^+ and K^+ ions. The result is a hypokalaemic metabolic alkalosis sometimes presenting as a pseudo-Bartter syndrome (14). If the rise in pH occurs quickly, as a result of massive purging, the plasma Ca^{2+} may also fall. The net result in severe cases is a complex electrolyte disturbance that cannot be corrected by simply prescribing potassium supplements.

Most K^+ is intracellular, meaning that if plasma levels of K^+ are reduced, the intracellular deficit will be even greater. Failure to correct this adequately, and to address the binge-purge behaviour, can lead to multiple presentations to the emergency department. The symptoms of hypokalaemia may be difficult to pick up and can include muscular weakness, lethargy, fainting and dizziness, cardiac arrhythmias and sudden death.

Correcting a hypokalaemic alkalosis requires recognition of the underlying condition, whether it be BN or the binge-purge subtype of AN.

Key measures include the following.

- A reduction or ideally cessation of the binge-purge activity by addressing the patient's psychological issues and by arranging appropriate follow-up and monitoring.
- Monitoring of plasma urea and electrolytes, including K^+, Ca^{2+}, Mg^{2+} and PO_4^{2-}.
- Correction of hypovolaemia, which may be achieved by reducing the purging and re-establishing a normal oral fluid intake.
- In severe cases with tachycardia and a postural drop in blood pressure, admission will be required for careful monitoring and intravenous fluids.
- Hypokalaemia with a plasma K^+ of less than 3 mmol/L requires expert medical or paediatric assessment and usually admission for oral and intravenous K^+ replacement. This requires access to appropriate nursing, laboratory facilities and ECG monitoring and is usually an indication for admission to a medical ward or a medical high-dependency unit. It is important to continue potassium supplementation after discharge, bearing in mind that if vomiting continues, oral potassium may not be absorbed.
- A proton pump inhibitor, such as lansoprazole or omeprazole, will reduce acid secretion and may help correct the alkalosis but must be combined with the measures above.
- A psychiatric review is essential to start treating the underlying behaviours.

Other complications of BN and purging

- Recurrent vomiting in ED patients is often effortless and can be carried out quickly and surreptitiously. It can be very difficult to detect. It can quickly lead to oesophagitis and features associated with reflux. Prolonged reflux in predisposed individuals may lead to a Barrett's oesophagus, which is potentially a pre-malignant condition (15).
- Reflux can also cause chronic laryngitis, cough and hoarseness. Recurrent vomiting can also lead to a risk of aspiration pneumonia.
- There can be loss of enamel on teeth and severe dental decay (16).
- Parotid and salivary gland enlargement may mimic a tumour but is almost invariably bilateral. Patients may also have reduced salivary flow and xerostomia (16).
- Calluses on the hands are caused by placing fingers down the throat (Russell's sign) (17).
- Rarely, a severe episode of vomiting may lead to spontaneous disruption of an organ. Rupture of the oesophagus, Boerhaave syndrome, usually occurs in the lower segment of the oesophagus and is associated with pleuritic pain, free gas on x-ray and signs of sepsis (18, 19). A chest x-ray may show free gas, but CT scanning is usually more accurate and helpful. It constitutes a medical emergency and has a high mortality without proper treatment (18).
- Spontaneous gastric rupture is more common in AN where the stomach can become very thin due to starvation. It carries a high mortality even if diagnosed quickly (18, 19). Surgery is extremely hazardous if the patient is malnourished but may be the only option to control peritonitis.

A patient with established purging behaviour who is suddenly unable to vomit as usual, or develops unusual pain, requires urgent assessment and should be suspected of having a perforation until proven otherwise.

Perforation of an organ is one of the few indications for intravenous nutrition in patients with EDs.

Laxative abuse

Laxative abuse can occur in both AN and BN (20) and usually involves stimulant laxatives purchased over the counter, although the increased availability of online pharmacies, where the patient does not have to be present in person or see anyone, has made access to laxatives much easier. Most laxative abuse is surreptitious and may require a urine laxative screen to confirm. It can be a condition in its own right and may result in a lengthy and potentially invasive investigation of the gastrointestinal (GI) tract. Undetected, it can lead to long-term renal damage. Confronting a patient with evidence of laxative abuse requires care and sensitivity, particularly if it has been hidden from family and care staff for long periods.

The medical management of anorexia nervosa

AN has two subtypes, restrictive (AN-R) and binge-purge (AN-BP). Neither is a completely distinct condition and patients may move between types or have aspects of each.

The complications of AN-BP are similar those described for BN but, by definition, with the added complexities of weight loss and malnutrition. In general, the binges are smaller than in BN and the restrictive compensatory behaviours disproportionate.

In AN-R, the complications relate to the acute and chronic effects of malnutrition and the hazards of refeeding.

Malnutrition and starvation

Malnutrition is a sub-acute or chronic state of disordered nutrition in which a combination of varying degrees of over- or undernutrition and inflammatory activity leads to a change in body composition and diminished function (21).

The definition includes both under- and over-nutrition, which emphasises that whilst patients with BN, binge eating disorder or ARFID may have a normal weight, or even be overweight, they can still be malnourished and have for example, significant micronutrient deficiencies.

Patients with AN are, by definition, undernourished but do not typically have an active inflammatory response. Consequently, the C-reactive protein (CRP) and plasma albumin levels are usually normal, sometimes right up to the point of death. There is no universal blood test that either detects or excludes malnutrition. It remains a clinical diagnosis, based on weight, BMI, weight loss, dietary assessment and the overall clinical picture.

Human beings are "heat engines" and obey the first law of thermodynamics. If a person reports an adequate food intake but continues to lose weight, then either their intake is less than reported, or their energy expenditure is greater than has been estimated. In the absence of any food intake, weight loss is linear and progressive, as shown in the Minnesota studies of Ancel Keys (3), and the classic analysis of hunger strikers by Allison, where the loss of 40% of the initial body mass took approximately 70 days with a 30% mortality (22). Any intake of food will slow the rate of loss, whilst exercise and the onset of any illness will increase it, particularly if that illness involves an acute inflammatory response, such as sepsis.

Refeeding patients with AN

Patients with AN face two distinct hazards associated with refeeding. If refeeding is introduced too quickly or in an uncontrolled way, then they can be subject to refeeding syndrome, where sudden changes in electrolytes can be life-threatening. If refeeding is introduced too slowly or attempts to refeed are thwarted by uncontrolled anorexic behaviours, then they may be subject to the underfeeding syndrome, where their nutritional requirements are not met and their nutritional status continues to decline (11).

Refeeding syndrome

A person with little or no intake of nutrients enters a state of adapted starvation, where the body's metabolic processes are progressively shut down to maintain basic homeostatic functions. Very little insulin is secreted, and the body uses any remaining lipid stores to meet energy requirements and tissue protein to maintain gluconeogenesis. Intracellular ions, K^+, Ca^{2+}, Mg^{2+} and PO_4^{2-}, are depleted to maintain the extracellular concentrations.

Introducing calories too quickly, particularly refined carbohydrates, leads to a sudden increase in cellular metabolism. The intra-cellular pool of adenosine triphosphate is rapidly increased, requiring PO_4^{2-}, and K^+, Ca^{2+} and Mg^{2+} ions are taken up by cells resulting in a decrease in their concentration in the extracellular fluid and plasma. This destabilises many systems, but particularly the heart and central nervous system. Sudden death from arrhythmias, seizures and profound muscle weakness may occur (23).

To prevent refeeding syndrome the basic principles are:

- nutrition should be reintroduced slowly
- refeeding ions, Ca^{2+}, K^+, Mg^{2+} and PO_4^{2-}, should be monitored carefully
- micronutrients should be replaced proactively (23).

The controversies in EDs concern the initial levels of protein and calories, and how fast they should be increased.

In 2006, the National Institute for Health and Care Excellence (NICE) published detailed guidance on refeeding syndrome which was necessarily cautious because the evidence base was limited. Advice had to accommodate the needs of the sickest patients, particularly those undergoing artificial nutritional support in acute hospitals (24). Patients who are older or have trauma, burns and sepsis are more at risk of refeeding syndrome than younger patients with EDs without an active inter-current illness. Research in adolescents suggests that higher initial rates of refeeding of 1400 to 2000 kcals per day, increasing by 200 kcals daily, can be used safely in those who are at medium to low risk of refeeding syndrome, providing that they are subject to appropriate monitoring and supervision (25-28). The benefits of more rapid refeeding are faster stabilisation and recovery of weight and shorter times in the hospital. The evidence for refeeding in adults with ED is scarce, however, after a review of the available studies MEED recommended (11):

- Assess the risk for refeeding syndrome (Table 2)
- In patients not at high risk of refeeding syndrome, feeding can commence at 30–35 kcal/kg/day increasing by 200–300 kcal/day every two days, so that weight is starting to increase by the seventh day.
- Patients with other medical conditions such as infections, cardiac disease, liver disease, alcohol misuse or a BMI less than 13 kg/m^2 are at a high risk of refeeding syndrome and need a more cautious approach as outlined in the

NICE guideline (24). Typically, this would be 5–10 kcal/kg/day increased slowly to meet or exceed needs over 4 to 7 days, with frequent monitoring of the biochemical parameters.

- The initial intake should not be less than the patient was taking before admission.
- Food and a properly designed diet plan are the best approach to refeeding, but if the patient cannot manage a sufficient intake then nasogastric feeding may be required. The indications for nasogastric feeding are complex but are detailed in MEED and other references (9, 11).
- Refeeding should be supervised by a registered dietitian. An English coroner's report in 2021 stated that "a failure to follow the basic dietetic input" was a contributing factor in the death of a patient, whilst specifically highlighting that there had been, "no attempt to obtain any advice from a specialist eating disorder dietitian" (29). Obtaining appropriate dietetic advice and implementing it should, therefore, be a high priority.

Underfeeding syndrome

In underfeeding syndrome, the patient fails to achieve an adequate calorie intake and their nutritional status deteriorates. Two main factors lead to underfeeding.

1. An over-cautious approach to refeeding and failure to increase calorie intake. This can be linked to a lack of specialist dietetic input or a failure to follow a refeeding protocol.
2. Failure to control anorexic behaviours.

Patients with AN have an obsessional fear of weight gain and often go to extraordinary lengths to avoid doing so. It is important to understand that the person's disease drives their behaviour and that their attempts to resist treatment are predictable but can be life-threatening unless managed effectively (1).

Over-exercise

Overactivity and compulsive exercise are extremely common in AN but may also occur in BN. Often, the initial drive is to control body shape and weight. Patients with AN may have higher childhood activity levels and a greater than expected percentage of AN patients have previously been competitive athletes. The ability to exercise obsessively is often preserved, even in the presence of severe undernutrition, and exacerbates weight loss, can lead to severe hypoglycaemia and may make the correction of other complications, such as electrolyte disturbances, more difficult. The physical activity may be "overt", and is often solitary, rigid and obsessive. It may manifest as hours in the gym, running, cycling or swimming long distances. Frequently, however, it is covert, and the true extent is hidden. Even after admission to hospital, patients may use any opportunity to continue to exercise, including running errands for other patients, going up and down stairs and exercising in locked bathrooms. Staff need to be vigilant, particularly whenever patients are out of sight in places such as bathrooms, showers or single rooms. Micro-exercise and fidgeting are common. Patients may wiggle toes and hands, or sit down and stand up, often for hours at a time. It is important to recognise that these are anorexic behaviours, driven by the disease and that they must be controlled if treatment is to be successful. Specialist physiotherapy can be very helpful but may not always be available. Detailed advice is available (30).

Over-exercise may result in falls, which can cause disproportionate injuries because of the high prevalence of osteoporosis in men and women with AN.

Controlling behaviours on the medical ward

NPMTs often have difficulty managing behaviours and may need help and advice from clinicians with experience in EDs. Proactively developing links between acute medical units and SEDUs can be extremely helpful in improving the care of patients with EDs.

Table 2. Factors associated with a high risk of refeeding syndrome in patients with eating disorders, as outlined in MEED (11)

Clinical feature	High risk level	Management
Extremely low weight	%mBMI < 70% or BMI < 13 kg/m^2	Cautious refeeding
Prolonged low intake	Little or no intake for > 4 days	Cautious refeeding
Deranged baseline electrolytes	Low potassium, phosphorous, magnesium, calcium	Measure levels up to twice per day initially and supplement as needed
Low white blood cell count	< 3.8	Monitor
At risk for low thiamine (n.b., the precise requirement for thiamine is not known)	Low thiamine and other vitamins	Pabrinex, oral thiamine and multivitamins
Medical comorbidities and/or complications	Infection (e.g., pneumonia, cardiac disease, liver disease, alcohol misuse or other serious disease)	Should be discussed with an acute medical unit and high-dependency unit/intensive care unit considered if the patient has a serious comorbidity. Refeed cautiously

Useful strategies (1, 9) include the following.

- Develop a ward protocol for ED patients.
- Explain why the ward has adopted certain policies.
- Have established links with liaison psychiatry and with a SEDU.
- Ensure close observation of the patient, particularly at high-risk times such as immediately after meals.
- Avoid locked bathrooms and any area where patients cannot be observed. It may be safer to offer patients the use of a commode.
- Decide as a team what is going to be discussed on a ward round before reaching the patient.
- Have a clear, consistent policy involving all members of the team.
- Avoid splitting, which can be extremely destructive and ultimately endangers the patient's care.
- Limit unobserved time off the ward, such as trips to the hospital shop.
- Patients leaving the ward should be accompanied by an informed, responsible person.
- Patients should wear hospital night clothes because they are less likely to have weights sewn into them.
- Discuss the use of mobile phones and technology. Agree to limits and block harmful websites.
- Manage transitions to other units carefully, noting that these are high-risk points where the patient may be lost to follow-up (10).
- Seek permission to involve friends and family. Communicate with them and involve them in the patient's care if the patient gives permission (31).
- Be prepared to use mental health legislation if all the least-restrictive options have failed (32).
- Seek expert psychiatric advice.
- Document treatment and outcomes carefully.

Other problems

Hypoglycaemia

In the absence of diabetes mellitus, it is important to distinguish symptomatic hypoglycaemia from a slightly lower than normal blood glucose reading in an otherwise asymptomatic patient. The context of the finding is important.

A person who meets the high-risk criteria in MEED, who is of very low weight (BMI <13 kg/m^2) or is losing weight rapidly, or who is at a high risk of refeeding syndrome, is likely to have very low reserves of glycogen and may have difficulty maintaining their blood glucose. If they consume too large a calorie intake rapidly, particularly if it is a refined carbohydrate and easily absorbed, they may develop reactive hypoglycaemia in response to the rapid secretion of insulin. In extremely malnourished patients, there is a risk that sudden, severe hypoglycaemia may lead to sudden death.

Symptomatic hypoglycaemia should be treated with food, oral dextrose or, in extreme cases, with intravenous dextrose. This should be followed by more complex carbohydrates that will release glucose more slowly. The most important treatment is controlled refeeding, as described, to prevent refeeding syndrome.

Asymptomatic low-normal or near-normal plasma glucose readings in a patient gaining weight and adhering to a meal plan do not require treatment but may need to be monitored, particularly if the question of fitness to drive is raised.

The combination of type 1 (insulin-dependent) diabetes and EDs is complex and beyond the scope of this review, but detailed advice is available (MEED annex 3) (11).

Disorders of gut–brain interaction

Disorders of gut–brain interaction (DGBIs), previously and more commonly known as functional GI disorders, including functional dyspepsia and irritable bowel syndrome, define a spectrum of GI disorders associated with chronic or fluctuating GI symptoms, such as abdominal pain, diarrhoea, constipation, bloating and nausea, without harbouring an apparent organic structural or biochemical explanation for these symptoms (33).

DGBIs are common in patients with EDs, with some reviews suggesting that over 88% to 98% of patients with AN may have features of a least one DGBI and 35% to 49% will meet criteria for three or more (34). The commonest symptoms are post-prandial bloating and abdominal distension, but features of any functional disorder of the gut can occur. This may be due to ED patients having increased visceral awareness, but severe weight loss also leads to loss of muscle in the gut which may also contribute. The current and past use of laxatives and other drugs can also be relevant.

More detailed discussions of DGBIs are available (15, 34).

Coeliac disease, which affects over 1% of Western populations, may present with functional symptoms and should

be excluded with an IgA anti-tissue transglutaminase antibody test and total IgA. A normal faecal calprotectin and CRP do not completely exclude inflammatory bowel disease but are reassuring in the absence of a strong clinical suspicion. Invasive GI investigation should be undertaken with caution in very low weight patients (15, 34).

DGBIs are important, because symptoms often emerge during refeeding, creating discomfort and anxiety which can complicate management of weight gain. An expert gastroenterology opinion may be necessary.

Liver abnormalities

Abnormal liver function tests are common in AN and are usually mild increases in the transaminases AST and ALT, and do not generally indicate liver failure. Most will resolve over weeks or months as refeeding progresses (19). High transaminase levels, particularly if associated with deranged clotting tests, such as the standardised prothrombin time ratio or low plasma albumin, can be a sign of liver failure, which is more common in very low weight patients (15, 18) and requires an urgent hepatology opinion. Exclusion of other causes of liver disease is essential and patients may be best managed in a medical high-dependency unit.

Bone disease

Reduced bone mass, osteopenia and osteoporosis are common in AN, in both men and women. The causes are complex and centre on the effects of starvation on the hypothalamic-pituitary axis, with loss of pulsatile gonadotrophin-releasing hormone, reduced gonadotrophins, testosterone and growth hormone resistance. Thirty percent of cases may also have raised cortisol levels, whilst sick euthyroid syndrome may also occur (35).

The combination of factors leads to loss of bone mass and delayed bone growth, which is particularly serious during adolescence when maximum bone growth and mineralisation occur. The best test is dual x-ray absorptiometry scanning.

Restoration to normal weight is the safest and most effective treatment. Bisphosphonates should be used with caution in young women as they can have potential teratogenic effects and remain in the body for long periods. The use of hormone replacement therapy may have a role in some cases but is less effective in underweight people. Expert advice should be sought (36).

Conclusions

The medical consequences of EDs are multiple and reflect the complex psycho-pathophysiology of the diseases. NPMTs can find the care of patients with EDs very challenging. Care can be improved with a better understanding of the conditions, particularly the realisation that they are serious illnesses that drive the behaviour of the patient. Externalising the disorder, by moving the blame from the patient to the illness, can be a very helpful approach for both the patient and their family. Psychiatrists and specialist ED teams have a vital role to play in supporting medical teams by acting as sources of expert advice, including for legal issues, and by ensuring that patients go on to have their psychological problems addressed when they are physically stable.

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Avoidant restrictive food intake disorder (ARFID)

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Abstract

Avoidant/restrictive food intake disorder (ARFID) was introduced in DSM-5 and has more recently been included in ICD-11. It presents with restrictive eating patterns but the diagnosis hinges on the subsequent health problems and functional impairment, either physical or psychological, related to the restriction. Critically, the restricted eating is not associated with concerns about body image, weight or shape, in contrast to other restrictive eating disorders. This article provides an educational overview of ARFID, its presentation and subtypes, known comorbidities, and assessment and treatment options. ARFID-specific cognitive behavioural therapy and family therapy approaches have been developed but no randomised intervention studies have yet been undertaken. Case scenarios demonstrate how the diagnostic criteria may apply in clinical practice.

Keywords: ARFID, avoidant/restrictive food intake disorder, eating disorders, assessment, therapy

Introduction

Although it is a single diagnosis, avoidant/restrictive food intake disorder (ARFID) is an umbrella term for restrictive eating patterns that result in significant health problems, which may include weight loss, poor growth, nutritional deficits or poor emotional wellbeing. The restriction may relate to the quantity or range of foods consumed and the presentations of ARFID can be quite different. Those with ARFID are at risk of severe acute and chronic medical complications and, because of the heterogeneous presentations, may first present in a diverse range of physical or mental health settings. ARFID can affect children, adolescents and adults.

ARFID was introduced in DSM-5 and has more recently been included in ICD-11, replacing previous terms such as Feeding Disorder of Infancy and Early Childhood and Eating Disorder Not Otherwise Specified. While it shares restrictive eating patterns in common with other eating disorders such anorexia nervosa or bulimia nervosa, the key difference with ARFID is that the restrictive eating is not associated with concerns about body image, weight or shape.

The reported incidence and prevalence of ARFID differs according to country and type of study. In a German community sample of 8 to 13-year-olds, prevalence rates (the percentage of a particular population affected at a particular time) were 3.2% (1). However, this was based solely on child self-report, with no other sources of data such as parental reported information or clinical observations. In Australia, Hay et al. reported ARFID in 0.3% of older adolescents and adults, based on two screening questions (2). Among a large sample of 2,231 paediatric gastroenterology patients in the USA, in which high rates of restrictive eating might be expected, only 1.5% were classified as having ARFID and a further 2.4% had some features (3). Among young people presenting with clinically significant malnutrition, rates were higher. Two national surveillance studies of children and adolescents have been completed, with Canadian data showing the incidence of ARFID in those 5 to 18 years of age was 2.02 (95% confidence interval [CI], 1.76-2.31) per 100,000 patients (4), and data from the UK and Ireland showing an incidence of 3.09 (95% CI, 2.77–3.45) per 100,000 young people aged 5 to 17 years (5). There is far less in the way of robust data relating to adults with ARFID.

Diagnostic criteria

The DSM-5 diagnostic criteria for ARFID (6) are as follows.

- An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:
  - Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
  - Significant nutritional deficiency.
  - Dependence on enteral feeding or oral nutritional supplements.
  - Marked interference with psychosocial functioning.
- The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
- The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and

there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.

- The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

The DSM-5 criteria do not specify the threshold for "significant" weight loss or nutritional deficiency, or "marked" interference with psychosocial functioning, presenting additional challenges in subjective clinical assessment and consistency in research.

ARFID has, to date, been excluded from the scope of the NICE (National Institute for Health and Care Excellence) guidelines on eating disorders (7) for all ages, and therefore also from commissioning guidance. Community and inpatient services differ in whether they have chosen or been commissioned to include ARFID in referral criteria. Therefore, those with ARFID may receive starkly different levels of care depending on where they live.

How does ARFID present?

The DSM-5 diagnostic criteria (6) suggest three primary ARFID subtypes, including lack of interest in food, avoidance based on sensory characteristics of food, and concern about aversive consequences of eating.

Lack of interest

Those with a lack of interest in food typically present with low appetite, limited intake and prolonged mealtimes, or mealtimes which are only possible with distraction (e.g., television).

Sensory

Those with sensory sensitivity tend to present with a limited range of food intake, or avoidance of whole food groups (e.g., fruit, meat, vegetables), which may be based on sensitivities to temperature, texture or appearance. Avoidance of mixed textures or mixed foods may also be seen, along with gagging or retching at the smell or sight of particular foods. Those in this group tend to restrict themselves to a limited number of "safe" foods.

Fear

Concern about aversive consequences of eating tend to be associated with high anxiety levels, for example, fear of vomiting or choking. This may be based on a previous negative experience.

More recently, research has empirically derived and supported the validity of these three proposed subtypes, in addition to identifying a fourth "combined" subtype, which was the most common presentation in a large representative sample of children and adolescents with ARFID (8). This combined subtype includes a combination of symptoms from the sensory and "fear" subtypes.

What are the comorbidities and complications of ARFID?

Those with ARFID are at risk of similar physical health complications as those with other restrictive eating disorders and those who are underweight. Acute risks may include dehydration, cardiovascular instability, hypothermia and syncope, but with more longstanding symptoms, chronic complications relating to underweight or malnutrition, such as constipation, amenorrhoea, reduced fertility, low bone mineral density and greater risk of fractures may be seen, as well as complications relating to specific nutritional deficiencies (e.g., fatigue due to iron-deficiency anaemia or osteomalacia or rickets resulting from vitamin D deficiency), even in those who are not underweight. This may differ from nutritional deficiencies seen in the general population due to the severity of restriction of a range of foods in some cases of ARFID. In children and young people with restrictive eating disorders, impaired growth and delayed puberty can be long-term complications of being underweight (9).

ARFID is often associated with a comorbid mental health difficulty (anxiety disorders being most common [9.1–72% of clinical samples]), neurodevelopmental disorder (prevalence of autism spectrum disorder in children with ARFID was found to be up to 55% in a clinical sample of referrals to a tertiary care paediatric feeding clinic), and/or a physical health problems, particularly gastrointestinal symptoms or disorders, such as gastroesophageal reflux, constipation, abdominal pain or vomiting (10).

Picky eating (interchangeably described as fussy or selective eating) is commonly seen in young children and is regarded as a phase of typical development (11). It is also commonly associated with autism spectrum disorder (12), although it is important to differentiate ARFID from picky eating or the rigid eating patterns associated with autism spectrum disorder. Critically, the emphasis in ARFID is on the consequences of the eating patterns, such as a significant negative impact on physical or mental wellbeing or nutritional status, as per diagnostic criteria.

Assessment and treatment

A full assessment with multidisciplinary team input should take place and a biopsychosocial formulation produced.

Physical and mental health should be assessed and monitored, including a review of centiles on growth charts for young people. Clinical interviews, such as the semi-structured Pica, ARFID, and Rumination Disorder Interview, which has an internal consistency of ≥0.77 and moderate (κ = 0.75) inter-rater reliability for ARFID diagnosis, can be used to support assessment and diagnosis for all ages (13) as part of a wider clinical process. However, this assessment was based on a small sample size and further validation studies are in progress, in addition to the development of briefer screening tools (14).

Treatments for all feeding and eating disorders aim to address the specific thoughts, feelings and behaviours with which they present. Because in ARFID there is no anxiety about weight gain, in contrast to anorexia nervosa, and the psychopathology varies between subtypes, this alters the motivations of patients to engage in treatment. Consequently, ARFID must be managed with a patient-centred approach, with early identification and intervention to provide the most optimistic long-term outcomes. A holistic assessment will then determine the subtype and psychopathology of ARFID, which directs treatment options. For all those with ARFID, these may include the following.

- A review of physical health needs.
- A review of wider psychological needs (comorbidities may require concurrent treatment).
- Dietetic intervention and nutritional supplementation.
- Weight restoration, if appropriate.
- In severe cases, hospitalisation and alternative/additional methods of feeding, e.g., nasogastric or percutaneous endoscopic gastrostomy tube feeding.
- Behavioural interventions (e.g., graded exposure therapy/desensitisation/setting goals and expectations).
- "Tasting times" (offering new or less familiar foods outside of mealtimes to reduce pressure).
- Reward charts to increase motivation.
- Specific cognitive behavioural therapy for ARFID has been developed, incorporating psychoeducation, regular eating patterns and increasing food variety or quantity (15).
- For young people, family-based therapy (FBT) for ARFID is a manualised treatment based on FBT for adolescents with anorexia nervosa; it uses a similar approach, but specific targets depend on the maintaining mechanism, for example, those with the lack of interest subtype may have a goal of shortened mealtimes (15).

This is not an exhaustive list. For those with lack of interest in eating, clear mealtime structure and routine can be highly effective. There is emerging evidence to suggest that a variety of medications can be helpful, for example off-label use of cyproheptadine, an antihistamine, can stimulate appetite and result in weight gain, and is generally well-tolerated (16). The off-label use of the antidepressant mirtazapine may have similar beneficial effects (17). For those with sensory sensitivities contributing to restricted eating, food chaining (introducing new foods that are similar to those already eaten) may be effective. For those with an aversive/anxiety-driven presentation, typical anxiety management strategies such as graded exposure therapy and cognitive behavioural therapy can be effective. Anxiolytic medication may be indicated. For all presentations, there is often an important role of reassurance and psychoeducation in the assessment and management of ARFID.

In terms of treatment pathways and service provision, depending on the presentation and any complications or comorbidities, young people may be best suited to treatment by paediatrics, child and adolescent mental health services, feeding and eating disorder services or a combination of these. Adults may benefit from treatment by specialist eating disorder services, general mental health services, general physicians, specialist physicians or their general practitioner.

Conclusion

The diagnosis of ARFID represents a broad spectrum of presentations relating to restricted eating and associated negative physical or psychosocial consequences. People of all ages with ARFID may present in a range of physical or mental health settings, at all levels of care. A robust assessment will determine appropriate treatment options, the best location of care provision and the different disciplines required within a multidisciplinary team. All healthcare professionals have a role in identifying those with ARFID and raising awareness of this disorder.

Case scenarios

Case 1

Lucy is a 13-year-old female who had a severe choking incident on a piece of chicken 10 weeks ago. Since then, she has had high levels of anxiety about eating any food and is terrified of choking, even on small pieces of food. She has only been drinking water, juice and milkshakes. She has lost 5kg in weight since the onset of these anxieties. She has no concerns about her weight or shape and prior to the choking incident she was well and had no difficulties with eating. She is able to continue with education but her friendships have been affected as she does not want to go out with her friends to eat and is feeling isolated as a result.

Lucy has:

- fear of aversive consequences of eating (choking)
- significant weight loss
- interference with psychosocial functioning
- no lack of available food
- no culturally sanctioned practice
- no other known diagnosis.

She meets the diagnostic criteria for ARFID.

Key point: there is no specified time period for symptoms to be present for a diagnosis of ARFID to be made.

Case 2

Ajay is a 6-year-old male with autism spectrum disorder. He has always been a fussy eater and eats only crisps, bread, potatoes and chicken. He does not eat fruit or vegetables and becomes distressed when offered any other foods. He will only eat two brands of crisps and refuses potatoes if they are overcooked or undercooked. Ajay is able to eat with other people, in all settings, but has to take a packed lunch to school and whenever the family go away they have to take all his food with them, particularly if they cannot buy his preferred brand of crisps. He is tracking on weight and height centiles. He has no other medical problems. His blood tests show iron deficiency, so based on this result and his food intake, he is prescribed iron and calcium supplements.

Ajay has:

- a limited variety of food intake
- rigid eating behaviour
- nutritional deficiency
- interference with psychosocial functioning (distress about eating and need to take preferred foods when out of the home)
- no lack of available food
- no culturally sanctioned practice
- a diagnosis of autism spectrum disorder, but this does not fully explain his food restriction and his presentation requires additional clinical attention

He meets the diagnostic criteria for ARFID.

Key point: fussy or restrictive eating is commonly associated with younger children and with autism spectrum disorder. The key differentiator for a diagnosis of ARFID is the impact of the restrictive eating, and in this case, the severity of the eating restriction has impacted on his physical health and psychosocial wellbeing.

Funding and declarations of interest

The authors declare that they have no conflicts of interest.

DN is supported by the National Institute for Health Research (NIHR) Applied Research Collaboration Northwest London and NIHR Imperial Biomedical Research Collaboration. The views expressed are those of the author(s) and not necessarily those of the NIHR, the Department of Health and Social Care, NHS England and NHS Improvement. JC is supported by the Alicia Koplowitz Foundation, Spain.

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An update on prevalence rates of disordered eating behaviours in children and adolescents with overweight or obesity and the management of binge eating disorder

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Abstract

Background: A number of studies have been published in recent years examining disordered eating behaviours (DEBs) in children and young people (CYP).

Objective: To provide an up-to-date review of prevalence rates across a range of DEBs, including food addiction, in CYP living with overweight and obesity, across both community and clinical populations.

Methods: In January 2022, three separate databases were searched (PubMed, MEDLINE and PsycINFO) for papers published after April 2016. The search was updated in February 2024 using identical search terms across MEDLINE, Embase and OVID Journals. Data were extracted by the main author and prevalence rates of DEBs calculated from available data, if not already provided. Included studies were categorised as examining either binge or loss-of-control (LOC) eating only, food addiction and a range of DEBs.

Results: A total of 44 studies were included in this review. Of these, 37 were cross-sectional studies, three were cohort studies, two were prospective observational studies and two were case-control studies. The total number of participants across all included studies was 28,640. In studies focusing on binge or LOC eating alone, prevalence rates and methods of data collection varied widely. Amongst clinical samples, rates of binge eating pre-bariatric surgery were 37.7%, dropping to 18.5% at five years post-surgery. For young people living with obesity and concurrent attention deficit hyperactivity disorder (ADHD) and/or autism spectrum disorder (ASD), 65% reported binge eating symptoms. In community samples, rates of binge/LOC eating ranged from 8.8% to 52.8%. Within studies looking at food addiction in clinical populations, rates ranged from 9.9% to 30.8%; in community samples, this ranged from 16.2% to 23.8%. The Yale Food Addiction Scale (YFAS) and YFAS-Child version were used across all studies collecting data on food addiction, meaning greater consistency and generalisability of results when compared to studies assessing binge/LOC eating or a range of DEBs. Amongst studies assessing a range of DEBs, one found that there was presence of at least one DEB in 82.2% of a clinical population of adolescents living with obesity. Studies looking at a range of DEBs in community samples found prevalence rates ranging from 8.4% to 59.8% using a range of assessment tools.

Discussion: Heterogeneity between studies in terms of assessment tools used, methods of data collection and types of DEBs assessed limits conclusions about the true prevalence of disordered eating among CYP and how many might reach a diagnostic threshold for an eating disorder diagnosis. Further research is needed to help inform service delivery and effective referral and treatment pathways.

1. Introduction

Eating disorders continue to have the highest mortality rate of all psychiatric conditions based on physical consequences of starvation, purging and other eating disorder–related behaviours and suicide, respectively (1). Within child and adolescent populations, overweight is defined as BMI-for-age greater than one standard deviation above the growth reference median and obesity as over two standard deviations above the median (2). Overweight and obesity in children and young people (CYP; defined as age 0–18 years) is one of the most pressing public health issues of the 21st century, with almost 18% of all CYP aged between 5 and 19 years being classified as living with overweight or obesity, equivalent to 340 million CYP worldwide. This number continues to rise (3). Overweight and obesity have serious implications across a variety of biopsychosocial domains. Given that childhood and adolescence are characterised by important physical and psychological developments, living with overweight and obesity during this important period can have far-reaching consequences into adult life (4). There is well-established evidence to show that overweight and obesity in childhood is linked to reduced life expectancy, serious physical health risks in adulthood (including diabetes mellitus and cardiovascular disease) and significant socio-emotional consequences including isolation from peers, reduced self-esteem and poorer academic attainment (5).

Previous research has shown that within populations of adults living with overweight and obesity, rates of disordered eating are higher than in those of healthy weight (6). Less is known about the rates of disordered eating in CYP liv-

ing with overweight and obesity, although there is a growing evidence base on which this review will focus. A 2016 meta-analysis by He at al. (7) found that binge or loss-of-control eating occurred in nearly one-quarter of a sample of 9,818 CYP living with overweight and obesity. They noted the bidirectional influence of obesity and binge eating both being risk factors for one another. Another systematic review and meta-analysis by Yekininejad et al. (8) found that the rate of food addiction was 19% among CYP living with overweight and obesity.

The objective of this review was to provide updated prevalence rates for disordered eating in CYP living with overweight or obesity both in community and clinical samples. To avoid duplication of the meta-analysis by He et al., this systematic review included papers published after April 2016 and expanded the search criteria to include studies that examined a greater range of disordered eating behaviours (DEBs) amongst CYP living with overweight and obesity. There is debate within the field about whether food addiction can be conceptualised as a DEB or as a substance use issue (9). It has been included in this review as part of a broad investigation of disordered eating within a population of CYP living with obesity and because previous research has shown overlap between food addiction, obesity and disordered eating (10).

2. Methods

2.1 Sources and search strategy

The narrative review protocol was registered with PROSPERO. A separate search strategy was developed from the one used by He et al. Three health databases (PubMed, MEDLINE and PsycINFO) were searched on 5th January 2022 using the following search terms: "disordered eating" OR "binge eating" OR "binge eating disorder" OR BED OR binge OR "emotional eating" OR "loss of control eating" OR "food addiction" OR "eating addiction" AND child* OR adolescen* OR "young people" OR boy* OR girl* OR teen* OR youth OR paediatric* AND overweight OR obes* OR "excessive weight" or "raised BMI".

Restrictions placed on the search were as follows: 1. papers published prior to April 2016; 2. papers not published in the English language; 3. papers focusing solely on adult (over the age of 18 years) populations, or where there were a mix of adults and CYP (under the age of 18 years) but data were not separated.

The search was then repeated in February 2024. Due to changes in the available databases, MEDLINE, Embase and OVID Journals were used in the updated search.

The same search terms and restrictions were used for the updated search, apart from the stipulation that only papers published between January 2022 and February 2024 should be included. Duplicates were removed using the search engine followed by the main author (ETB) carrying out title, abstract and then full-paper screening against the inclusion and exclusion criteria according to the PRISMA checklist. See Figure 1 for the PRISMA flowchart.

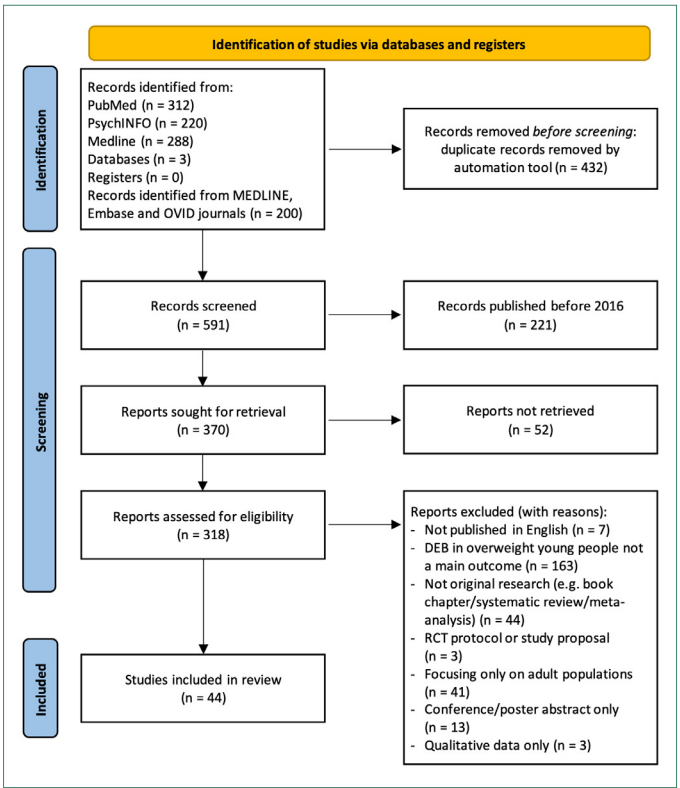

Figure 1. PRISMA flowchart

Abbreviations: DEB = disordered eating behaviour; RCT = randomised controlled trial

2.2 Selection criteria

The inclusion criteria were as follows: papers published in English; papers published in a peer-reviewed journal; and papers that reported on rates of DEBs in CYP (under the age of 18 years) living with overweight and obesity or provided enough information for rates to be calculated.

The exclusion criteria were as follows: papers not published in English; papers where rates of DEBs in CYP living with overweight and obesity were not main outcomes; papers that were not original research or reviews (e.g., book chapters/systematic reviews/meta-analyses); papers that were randomised controlled trial protocols or study proposals; and papers focusing only on adult populations.

2.3 Data extraction

Initial title screenings were followed by abstract and then full-paper screenings. Screening was carried out by the main author only. Once papers were identified for inclusion, the data were extracted. This was stored in a spreadsheet that included information on study title, main author, year of publication, country, type of study, number of participants, race, gender, age, BMI/weight status, treatment status, assessment tools, the

DEB assessed and main findings. Prevalence was assessed as the percentage of the studied population who experienced a symptom/disorder according to the assessment tool used.

2.4 Risk of bias and quality assessment

As the majority of included studies were cross-sectional, the Joanna Briggs Institute (JBI) tool for assessing analytical cross-sectional studies was used to assess methodological quality and to determine the extent to which a study had addressed the possibility of bias in its design, conduct and analysis (11). The JBI tool does not specify cut-off scores in terms of categorising studies as being of high, moderate, or low quality; however, for the purpose of this review, studies with scores of six or above were recorded as being of high quality, scores of four and five as moderate quality and below four as being low quality. Details of the different domains assessed with this tool are provided in Appendix 1.

3. Results

3.1 Summary of key features of included studies

Of the 44 included studies 15 were from Europe, 14 from North America, six from the Middle East, three from Asia, two from South America, two from Australia, one from Mexico and one from Africa.

The total numbers of CYP with overweight/obesity across the studies was 28,640.

Sixteen of the studies examined binge or loss-of-control eating (including objective binge episodes, subjective binge episodes and loss-of-control eating without specifying amount of food eaten); eight papers focused on food addiction; 18 looked at a range of DEBs (e.g., bingeing, purging, skipping meals); one study assessed emotional eating; and one included study looked at "secretive eating".

Of the 44 papers, 37 were cross-sectional studies, three were cohort studies, two were prospective observational studies and two were case-control studies. Thirteen were conducted in clinical (treatment-seeking) populations, 29 used community (non-treatment-seeking) samples and two studies looked at participants across clinical and community samples.

Thirty-six studies examined a mix of female and male participants while seven focused on female-only populations and one on a male-only population. The majority of papers examined populations across the weight spectrum and the gender divide specifically within the overweight/obese subset was often not available.

Only 14 studies included ethnicity information as part of the demographic data of their participants. This information was gathered during data extraction but is not included in the results of this review as information was not available for all included studies.

Using the JBI tool, 32 studies were deemed to be of high quality and 12 studies of moderate quality.

A wide range of assessment tools for disordered eating were used across the included papers. Eleven studies used the Eating Disorder Examination Questionnaire (EDE-Q) or its derivatives, seven used the 26-item Eating Attitudes Test or its derivatives, eight used the YFAS, two used the Eating Disorder Inventory or its derivatives, three used the SCOFF questionnaire, two used the Binge Eating Scale (BES) and one each for the following: the Kiddie Schedule for Affective Disorders and Schizophrenia, the Childhood Eating Behaviour Questionnaire, the Diabetes Eating Problem Survey-Revised, the Branched Eating Disorder Test, the Bulimic Investigatory Test Edinburgh (BITE), the Block Food Frequency Questionnaire, the EAT 2010 study survey and the Three-Factor Eating Questionnaire-R21. Eight used non-validated questionnaires/surveys made by researchers. One paper (Wentz et al. (16)) used both the EDI and the EDE-Q; one paper (Caran et al. (46)) used the EAT-26 and the BITE; one paper (Schulte et al. (32)) used the YFAS, the EDE-Q and the Block Food Frequency Questionnaire; and one paper (Järvholm et al. (13)) used the BES and the Three-Factor Eating Questionnaire-R21.

A brief summary of the assessment tools is included in Appendix 2.

Tables 1 to 7 provide summary information including main author, year of publication, assessment methods, JBI scores and the prevalence of DEBs.

3.2 Summary of results

This review highlights the wide range of rates of DEBs across community and clinical populations of overweight and obese CYP.

In studies focusing on binge or LOC eating alone, prevalence rates and methods of data collection varied widely. Amongst clinical samples, rates of binge eating pre-bariatric surgery were 37.7%, dropping to 18.5% at five-year follow-up post-surgery (13), while amongst a sample of CYP living with obesity with concurrent ADHD and/or ASD, 65% reported binge eating symptoms (16). In community samples, rates of binge/LOC eating ranged from 8.8% (25) to 53.8% (recurrent and non-recurrent binge episodes) (21). In one community sample, 4.7% met full diagnostic criteria for BED (24).

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Decker et al. 2022 (12)	USA	Clinical sample, all with severe obesity. Surgical group (those who underwent bariatric surgery) 79.9% female, n = 111; 20.1% male, n = 28. Mean age 16.9 ± 1.4 and non-surgical group (those attending for lifestyle modification programs) 81.9% (n = 68) female; 18.1% (n = 15) male; 16.1 ± 1.4.	Prospective observational study using EDE-Q - Bariatric Surgery version comparing group of CYP who underwent bariatric surgery with a non-surgical group who presented to nonsurgical lifestyle modification programmes. JBI score: 8	Surgical group: objective binge eating, 29.7% (n = 41) vs non-surgical group: 10.8% (n = 9); p = 0.02.
Järvholm et al. 2020 (13)	Sweden	Clinical sample. 81 participants post-bariatric surgery and 80 matched controls who underwent conventional treatment. Surgical group: 53 females, 28 males. Control group: 45 females, 35 males. Binge eating prevalence data were only available for surgical group. Surgical group mean age: 16.5 ± 1.2; control group mean age: 15.8 ± 1.2.	Non-randomised matched-control study measuring 5-year mental health and eating pattern outcomes in adolescents with obesity or morbid obesity following bariatric surgery. Disordered eating assessed using the BES and Three-Factor Eating Questionnaire. Other measures taken include the Rosenberg Self-Esteem Scale and the Mood Adjective Checklist. JBI score: 5	Surgical group: binge eating at baseline, 37.6% (n = 29). Binge eating at 5-year follow-up: 18.5% (n = 15).
Spettigue et al. 2020 (14)	Canada	Clinical sample. 182 participants with obesity (98 females, 84 males). Mean age: 15.47.	Cross-sectional study that included adolescents at point of assessment for a paediatric tertiary care weight-management program. Disordered eating was assessed through select questions on binge eating taken from the EDE-Q along with psychiatric and anthropometric data. JBI score: 5	Binge eating present in 49.5%.
Obeid et al. 2020 (15)	Canada	Clinical sample. 212 participants with obesity (109 females; 103 males). Mean age: 15.5 ± 1.22.	Cross-sectional study including obese CYP referred to a tertiary care weight-management program. Disordered eating was assessed using the EDE-Q along with data on depressive symptoms and suicidal ideation using the CDI. JBI score: 5	Binge eating present in 28.4%.
Wentz et al. 2019 (16)	Sweden	Clinical sample. 76 participants with obesity (37 females, 39 males). Mean age: 12.4 ± 3.0.	Cross-sectional study examining disordered eating and neurodevelopment disorders carried out at an obesity treatment centre within a children's hospital. Disordered eating was assessed using the EDI-C and EDE-Q. Participants had either a pre-existing diagnosis of ASD ± ADHD or met criteria for ADHD according to DAWBA. Anthropometric data were gathered. JBI score: 7	65% showed LOC eating; 10.5% met criteria for probable BED or BED-OSFED.
Pearlman et al. 2019 (17)	USA	Clinical sample. 29 participants with overweight and 99 participants with obesity. Mean age: 14.35 ± 1.55.	Cross-sectional study examining family weight-based teasing, psychosocial functioning and eating pathology in military dependent CYP. Sample taken from binge eating disorder and adult obesity prevention trial. Disordered eating was assessed using the EDE-Q. Other measures included the BDI-II. JBI score 6	47.7% reported LOC eating in last month.
Egbert et al. 2019 (18)	USA	Clinical sample. 385 CYP with overweight or obesity. Mean age: 10.89 ± 2.25.	Cross-sectional study investigating association between LOC eating and ADHD. Sample was selected from 6 different research institutions (enrolled in either non-intervention studies or weight loss programmes). Disordered eating over past 28 days was assessed using EDE along with anthropometric data. Other measure used was CBCL. JBI score: 8	32.5% reported at least one episode of disordered eating (OBE, SBE, OO). 72% of this group reported also experiencing LOC.
Fiechtner et al. 2018 (19)	USA	Clinical sample. 817 participants with obesity. Mean age: 9.7 ± 1.9.	Cross-sectional study investigating binge eating symptoms from a baseline survey for participants enrolled in the Study of Technology to Accelerate Research (STAR), a cluster-randomised obesity intervention. Binge eating was assessed with 3 parent-report questions. JBI score: 6	Sneaking, hiding or hoarding food: 33.1%; eating large amounts even when not hungry: 40.3%; inhibited/embarrassed eating in front of others: 8.2%.

Table 1. Binge or loss-of-control eating in clinical samples

Abbreviations: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BDI = Beck's Depression Inventory; BED = Binge eating disorder; BES = Binge Eating Scale; CBCL = Child Behaviour Checklist; CDI = Children's Depression Inventory; CYP = children and young people; DAWBA = Development and Well-being Assessment; DEB = disordered eating behaviour; EDE-Q = Eating Disorder Examination Questionnaire; EDI-C = Eating Disorder Inventory for Children; JBI = Joanna Briggs Institute; LOC = loss-of-control; OBE = objective binge eating; OO = objective overeating; OSFED = other specified feeding or eating disorder; SBE = subjective binge eating

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Rozzell-Voss et al. 2024 (20)	USA	Community school-based sample. Of sample with overweight: males, 52.7% (n = 1858); females, 47.3% (n = 1668). Age range: 9–10 years. No mean age provided.	Cross-sectional. Binge eating was assessed using KSADS-5 which relied on parental reports of their child's eating habits over the past 2 weeks. JBI score: 7	12.8% (n = 238) of males reported binge eating; 10.0% (n = 167) of females reported binge eating.
Byrne et al. 2023 (21)	USA	Community sample. All female participants. Mean age: 15.5 ± 1.5. With overweight: 52.9% (n = 18). With obesity: 47.1% (n = 16).	Cross-sectional study. LOC eating was assessed using the EDE-Q. Study used magnetoencephalography (MEG) to investigate attentional bias while evoking neural responses to angry or happy face cues and measured energy intake and macronutrient consumption patterns. JBI score: 8	LOC eating in 46.2% of overweight sample; 53.8% of obese sample.
Pace et al. 2022 (22)	Italy	Community sample. All female participants; n = 56. Mean age: 16.4 ± 1.3.	Cross-sectional study. Binge eating behaviours were assessed using the BES. BES score >17 indicated participants being at risk of BED. The relationship with binge eating behaviours and interview-assessed attachment representations was assessed. JBI score: 6	66.7% (n = 6) of overweight girls scored >17 on the BES.
Sepúlveda et al. 2022 (23)	Spain	Community sample. 37 males with overweight; 47 males with obesity; 42 females with overweight; 40 females with obesity. Age range, 8–12 years (mean age not given).	Cross-sectional study. Questions on LOC eating were derived from definition proposed by Tanofsky-Kraff. The relationship between LOC eating and socioeconomic disadvantage, emotional distress, disharmonious family environment and participant's psychological and emotional distress were investigated. JBI score: 7	24.1% overweight participants had LOC eating; 50% of obese participants had LOC eating; difference in LOC eating was significant compared to normal-weight participants ($p < 0.001$)
Olsen et al. 2021 (24)	Denmark	Community sample. 274 participants with overweight/obesity. Mean age: 16.5 ± 4.2.	16-year follow-up from the Danish Copenhagen Child Cohort (CCC2000). Participants completed a web-based questionnaire adapted from the McKnight Risk Factor Survey and the Avon Longitudinal Study of Parents and Children, including items approximating DSM-V criteria for BED. JBI score: 8	8.5% reported weekly overeating with LOC; 4.7% of the overweight/obese population met diagnostic criteria for BED.
West et al. 2019 (25)	USA	Community sample. 468 participants with overweight/obesity. Mean age: 14.9 ± 1.6.	Cross-sectional study investigating risk factors for binge eating by socioeconomic status. Sample derived from Project EAT (Eating and Activity in Teens and Young Adults), a 15-year longitudinal study of dietary behaviour, weight concerns and psychosocial functioning among a heterogeneous group of young people. Binge eating was investigated using adapted questions taken from the adult version of the Questionnaire on Eating and Weight Patterns-Revised, along with anthropometric and sociodemographic data. JBI score: 8	8.8% of overweight or obese participants reported binge eating (with LOC) in the past year.
Gall et al. 2016 (26)	Australia	Community sample. 59 participants with obesity. Females – non-obese: mean age, 15.49 ± 1.62; obese: mean age, 16.06 ± 1.29; Males – non-obese: mean age, 14.90 ± 1.70; obese: mean age, 15.03 ± 1.39.	Cross-sectional study recruiting CYP across 12 secondary schools. Loss-of-control eating was assessed using a sub scale of the EDE-Q. Other collected data included body dissatisfaction using a subscale of the EDE-Q, physical health status and emotional wellbeing using the K-10. Anthropometric data were also recorded. JBI score: 7	Loss-of-control eating: 48.49% in girls, 14.28% in boys; combined prevalence: 32.2%.
Schlüter et al. 2016 (27)	Germany	Community sample. 163 CYP with overweight/obesity. Mean age: 15.0 ± 2.8.	Cross-sectional study recruiting adolescents from 18 schools. Loss-of-control eating was assessed using a subscale of the EDE-Q. Recurrent LOC was set at >4 episodes of LOC eating in past 28 days and nonrecurrent LOC eating was <4 episodes over last 28 days. The Clinical Impairment Assessment was used to assess severity of psychosocial impairment due to eating pathology. JBI score: 7	Recurrent LOC eating in overweight sample: 21.3%. Recurrent LOC eating in obese sample: 29.3%. Non-recurrent LOC eating in overweight sample: 13.1%. Non-recurrent LOC eating in obese sample: 26.8.%. Overall prevalence of LOC eating (both recurrent and nonrecurrent) across overweight and obese sample: 52.8%.

Table 2. Binge or loss-of-control eating in community samples

Abbreviations: BED = Binge eating disorder; BES = Binge Eating Scale; CYP = children and young people; DEB = disordered eating behaviour; EDE-Q = Eating Disorder Examination Questionnaire; EDI-C = Eating Disorder Inventory for Children; JBI = Joanna Briggs Institute; KSADS = Kiddie Schedule for Affective Disorders and Schizophrenia; K-10 = Kessler Psychological Distress Scale; LOC = loss-of-control

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Koca et al. 2023 (28)	Türkiye	Clinical sample, from endocrinology clinic. Female: 48.3% (n = 87); male: 51.7% (n = 93). Mean age: 13.25 ± 2.76. Mean BMI: 31.32 ± 4.62.	Cross-sectional study. Food addiction symptoms assessed using YFAS-C. Internet addiction scores assessed using Parent-Child Internet Addiction Scale. JBI score: 5	Food addiction scores: 27.8 ± 15.6 ($p < 0.001$) and internet addiction scores: 32.2 ± 20.3 ($p = 0.008$), both significantly higher in obese group vs healthy group. No significant difference between gender in terms of food addiction score. Individuals with obesity had higher internet addiction scale scores and food addiction scores.
De Almeida et al. 2023 (29)	Brazil	Clinical sample, weight-loss treatment seeking. Female: 53.4% (n = 64); male: 46.7% (n = 56). Mean age: 9.6 years ± 0.7.	Prospective observational study. Food addiction symptoms assessed using YFAS-C over two time points 18 months apart. JBI score: 6	44 occurrences of food addiction – n = 29 in initial assessment, n = 15 in final assessment, n = 4 across both. 33.4% (n = 40) subjects in total exhibited food addiction in at least one assessment.
Cura-Esquivel et al. 2022 (30)	Mexico	Clinical sample attending a paediatric clinic for excess weight and obesity. 163 (56%) boys; 128 (44%) girls. Age range: 6–17 (median age: 15). Mean age not provided.	Cross-sectional study. YFAS-C used to assess symptoms of food addiction. JBI score: 5	Food addiction was present in 14.4% (n = 42) of total population, 13.6% (n = 23) of overweight group and 15.6% (n = 19) of obese group ($p = 0.638$). Proportion of subjects with FA diagnosis did not differ significantly by age between children and adolescents ($p = 0.918$) or gender ($p = 0.62$).
Naghashpour et al. 2018 (31)	Iran	Clinical sample. Sample included 48 participants with overweight, 49 participants with obesity and 20 participants with morbid obesity. Mean age: 9.6 ± 1.7.	Cross-sectional study looking into prevalence of food addiction among a sample of Iranian school students. YFAS-C was used along with collection of other sociodemographic and anthropometric measurements. JBI score: 7	19 of 117 overweight/obese participants reported features meeting diagnostic criteria for food addiction. Prevalence: 16.23% .
Schulte et al. 2018 (32)	USA	Clinical sample. 181 (122 females; 59 males) participants with obesity. Mean age: 13.75 ± 1.35	Secondary data analysis of baseline data taken from a sample of African American CYP enrolled in a 6-month weight loss intervention programme. Disordered eating was assessed using YFAS-C, Youth EDE-Q and Block Food Frequency Questionnaire alongside anthropometric and sociodemographic data. JBI score: 7	9.9% scored above cut-off on the YFAS-C.
Tompkins et al. 2017 (33)	USA	Clinical sample of 26 (14 females; 12 males) participants with obesity. Mean age: 14.0 ± 1.9.	Participants were evaluated before and following a 12-week, evidence-based, outpatient behavioural weight-management program from 2013 to 2015. Food addiction was assessed using the YFAS-C along with measures for health-related quality of life and appetite responsiveness. JBI score: 7	13/26 scored 3 or more on YFAS; 8/26 scored 3 or more and showed clinically significant impairment or distress (5 females and 3 males – this was not statistically significant). Prevalence: 30.8%.

Table 3. Food addiction in clinical samples

Abbreviations: CYP = children and young people; DEB = disordered eating behaviour; EDE-Q = Eating Disorder Examination Questionnaire; JBI = Joanna Briggs Institute; YFAS-C = Yale Food Addiction Scale for Children

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Tosun et al. 2023 (34)	Türkiye	Community sample. Mean age: 15.3 ± 1.6 years. Mix of male and female participants but proportion not specified. 33 participants with overweight; 7 participants with obesity.	Cross-sectional. Symptoms of food addiction were assessed using the YFAS-C. JBI score: 5	3% of overweight participants had food addiction; 14.3% of obese participants had food addiction. No significant difference in YFAS-C scores between males and females or between weight status.
Meseri et al. 2020 (35)	Türkiye	Community sample. 127 male participants with overweight and 60 male participants with obesity; 92 female participants with overweight and 46 female participants with obesity. Mean age not given. Age range: 15–19 years.	Cross-sectional study carried out in 3 high schools in Western Turkey. YFAS was administered through face-to-face interviews along with collection of sociodemographic and anthropometric details. JBI score: 8	Prevalence of food addiction was 25.6% (n = 56) in overweight participants and 29.2% (n = 31) in obese participants. Prevalence: 26.8%.

Table 4. Food addiction in community samples

Abbreviations: DEB = disordered eating behaviour; JBI = Joanna Briggs Institute; YFAS-C = Yale Food Addiction Scale for Children

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Daniel et al. 2023 (36)	Ethiopia	Clinical sample taken from diabetic clinic. Total sample of 91 children and adolescents with overweight. Female: 52.2%; male: 47.8%. Age range: 11–19 years (median age: 15). Mean age not provided.	Cross-sectional study. DEPS-R. Range – purging behaviour (self-induced vomiting, skipping insulin, not taking enough insulin); non-purging behaviour (skipping meals, alternating eating, eating more than usual, avoiding checking blood sugar). JBI score: 6	59.34% (n = 54) of overweight population had DEBs, which was significantly higher than non-overweight group ($p < 0.005$).
Fogh et al. 2020 (37)	Denmark	Clinical sample. 3621 participants with obesity (1967 female; 1654 male). Mean age: 11.4 ± 4.6.	Cohort study included CYP enrolled into the Danish Childhood Obesity Biobank collecting information about disordered eating using structured interview questions in 3 domains: cognitive restraint, emotional eating and uncontrolled eating, along with anthropometric data. JBI score: 6	DEBs present in 82.2% of the total sample.

Table 5. Range of disordered eating behaviour in clinical samples

Abbreviations: CYP = children and young people; DEB = disordered eating behaviour; DEPS-R = Diabetes Eating Problem Survey-Revised

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Alsheweir et al. 2024 (38)	Saudi Arabia	Community sample, all female participants. Age range: 12–19 years. Mean age: 14.56 ± 1.89. 65.0% (n = 102) with overweight; 35.0% (n = 55) with obesity.	Cross-sectional. DEBs were assessed using the EAT-26. Score of >20 on EAT-26 indicates high risk of eating disorder. JBI score: 6	EAT-26 >20: 28.4% (n = 29; p = 0.433; OR, 1.382; 95% CI, 0.616–3.103) in overweight population; 38.2% (n = 21; p = 0.080; OR, 2.194; 95% CI, 0.911–5.286) in obese population. BMI had a positive correlation with dieting scale ($p < 0.001$) and negative association with oral control ($p < 0.001$).
Rossi et al. 2023 (39)	Brazil	Community school-based sample. Female: 52.3% (n = 146); male: 47.7% (n = 133) with overweight/obesity. Age range: 11–14 years. Mean age not provided.	Cross-sectional study. DEBs assessed using a study-specific questionnaire asking about purgative behaviour and binge eating. JBI score: 6	6.3% of overweight/obese sample used laxatives vs 3.2% of normal weight; use of diuretics: 4.2% vs 3.9%; vomiting induction: 7.1% vs 5.6%; overeating: 49.7% vs 43.5%; no eating: 36.2% vs 20.1% – none reached significance.
López-Gil et al. 2023 (40)	Spain	Community school-based sample. 342 children and adolescents with excess weight; female: 56.2%; male: 43.8%. Mean age: 13.9 ± 1.5.	Cross-sectional study. DEBs assessed using SCOFF questionnaire. JBI score: 7	61.4% (n = 135) of overweight population had SCOFF scores ≥2.
Aagaard et al. 2023 (41)	Denmark	Community sample of children and adolescents attending a lifestyle camp in the Netherlands. 174 participants; 60.9% girls and 39.1% boys. Mean age: 11.8 ± 1.38. 16.1% (n = 28) with overweight; 83.1% (n = 146) with obesity.	Cross-sectional study. Emotional overeating was assessed using the CEBQ. Quality of life was assessed using the PedsQL version 4.0. JBI score: 5	74.1% had medium or high tendency to emotionally overeat. QoL was 6.5 points lower (95% CI, 1.3–11.7, $p < 0.01$) in children with medium emotional overeating score and 13.7 points lower (95% CI, 8.5–18.9, $p < 0.01$) in children with a high emotional overeating score.
El Shikieri et al. 2022 (42)	Saudi Arabia	Community school-based sample. All female participants. 39 with overweight; 10 with obesity. Mean age: 13.1 ± 2.7.	Cross-sectional study. DEBs assessed using EAT-26 among a population of girls in Saudi Arabia. Information on nutritional status was gathered. JBI score: 5	7.7% (n = 3) of overweight participants had EAT-26 scores > 20; 10.3% (n = 4) of obese participants had EAT-26 scores > 20.
Tsekoura et al. 2021 (43)	Greece	Community sample. 673 participants with overweight; 424 with obesity. Mean age: 12.8 ± 1.4	Cross-sectional epidemiological study carried out in Greek schools using EAT-13. Score of 12 or over indicated high risk for developing an eating disorder. JBI score: 4	EAT-13 score was pathological (>12) in 28.2% (n = 190) of overweight children and 33% (n = 140) of children with obesity. Prevalence: 30%.
Fatima et al. 2020 (44)	Saudi Arabia	Community sample. All female participants. 44 participants with overweight; 18 participants with obesity. Mean age: 17.03 ± 1.25.	Cross-sectional study carried out with female students across 4 high schools in north-west Saudi Arabia. Disordered eating was assessed using the EAT-26 along with sociodemographic and anthropometric data. JBI score: 8	43.2% (n = 19) overweight participants; 50% (n = 9) obese participants scored >20 on EAT-26. Total prevalence of disordered eating in overweight and obese participants: 45.2%.
Hughes et al. 2019 (45)	Australia	Community sample. 640 participants with overweight (324 females; 316 males); 234 participants with obesity (100 females; 134 males). Mean age: 14.4 ± 0.5.	Cross-sectional study using a sample of 14- and 15-year-olds taken from Longitudinal Study of Australian Children (LSAC). DEBs over past 3 months were assessed using the BET along with sociodemographic and anthropometric data. JBI score: 6	Estimated prevalence of regular binge eating in overweight and obese populations was 1.2% and 1.7%, respectively. Estimated prevalence of overvaluation of weight for sense of self in overweight and obese populations was 21.3% and 22.4%, respectively. Estimated prevalence of regular engagement in compensatory behaviours in overweight and obese populations was 7.0% and 4.4%, respectively.
Caran et al. 2018 (46)	Brazil	Community sample of 98 participants (36 males; 62 females) with overweight/obesity. Mean age: 16.9 ± 0.6.	Cross-sectional school-based study investigating associations between DEBs and energy and nutrient intake. EAT-26 and BITE were used to assess disordered eating symptoms with scores of 20 or over and 10 or over indicating abnormal/unusual food patterns, respectively. Anthropometric data were also collected. JBI score: 5	Across overweight/obese females, 15.6% had EAT-26 score >20; 51.4% had BITE score >10. Across overweight/obese males, EAT-26 score was not shown; 11.7% had BITE score >10.

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Sepúlveda et al. 2018 (47)	Spain	Community sample of 170 (86 males; 84 females) participants with overweight/obesity. Mean age: 10.03 ± 1.55.	Cross-sectional study investigating loss-of-control eating and childhood mental disorders in youth with overweight/obesity. DEBs were assessed using the ChEAT. Other mental disorders were assessed using K-SADS-PL, STAIC and CDI. Anthropometric data was also collected. JBI score: 7	15.6% had scores of ≥20 on ChEAT.
Almuhlafi et al. 2018 (48)	Saudi Arabia	Community sample of 65 female participants with overweight/obesity. Mean age: 16.8 ± 0.9.	Cross-sectional study examining early menarche, obesity and DEBs (binge eating, self-induced vomiting and use of laxatives). EAT-26 was used to assess DEBs. Anthropometric data were collected. JBI score: 8	19.4% of overweight/obese population showed DEBs.
Kim et al. 2018 (49)	South Korea	Community sample of 6953 participants with overweight and 3307 participants with obesity (total: 10,260). Mean age not provided.	Large cross-sectional study with participants taken from the 11th Korea Youth Risk Behavior Web-based Survey (KYRBS) giving a nationally representative sample of adolescents. DEBs over the past 30 days was assessed using the following questions: (a) "fasting (skipping meals for >24 hrs)"; (b) "eating only one type of food, such as grapes, eggs, or milk" (referred to as the one-food diet); (c) "vomiting"; (d) "using laxatives or diuretics"; and (e) "taking diet pills without a doctor's prescription". Anthropometric and sociodemographic data were obtained from self-reported measures. JBI score: 4	DWCB in obese sample: 11.6%; DWCB on overweight sample: 9.7%.
Bauer et al. 2017 (50)	USA	Community sample. 1162 participants with overweight, obesity or severe obesity. Mean age: 14.3 ± 1.9.	Cross-sectional study with participants taken from EAT 2010 study which recruited across 20 schools. EAT 2010 survey was used to investigate "extreme weight control behaviours" (use of diet pills, self-induced vomiting, use of laxatives or diuretics) and binge eating along with sociodemographic and anthropometric measurements. JBI score: 7	Extreme weight-control behaviours in overweight group: 8.4%; obese group: 13.5%; severely obese group: 13.2%. Binge eating in overweight group: 7.9%; obese group: 9.9%; severely obese group: 17.1%.
Rodgers et al. 2017 (51)	USA	Community sample. 886 participants with overweight/obese. Mean age: 14.6 ± 2.0.	Cross-sectional study with participants taken from the EAT 2010 study (as per Bauer et al. (50)). Disordered eating was assessed using study-specific questions which had been deemed to have adequate concurrent validity and test-retest reliability. Sociodemographic and anthropometric data were also gathered. JBI score: 6	Dieting: 59.3%; unhealthy weight-control behaviours: 59.8%; overeating: 18.2%.
Feng et al. 2017 (52)	China	Community sample. 77 participants with overweight/obesity. Mean age: 15.1 ± 1.7.	Cross-sectional study which recruited participants from a middle school. DEBs were assessed using the SCOFF questionnaire. Anthropometric data were taken from self-reports of height and weight. Body Part Dissatisfaction Scale, Positive and Negative Affect Schedule, Perceived Sociocultural Pressure Scale, media use and sociodemographic data were also collected. JBI score: 5	Prevalence of DEB: 42.9%.
Nurkkala et al. 2016 (53)	Finland	Community sample. 373 male-only participants with overweight/obesity. Mean age: 17.9 ± 0.7.	Cross-sectional study using participants from the MOPO study which recruited from all conscription-aged men at mandatory military call-ups. Disordered eating was assessed using 2 subscales from EDI-3 (drive for thinness and bulimic behaviour). Other gathered information included physical activity, sociodemographic and anthropometric data. JBI score: 8	Drive for thinness: 11.8%; bulimic behaviour: 3.2%; DEB overall: 12.6%.

Table 6. Range of disordered eating behaviour in community samples

Abbreviations: BET = Branched Eating Disorder Test; BITE = Bulimic Investigatory Test Edinburgh; BMI = body mass index; CDI = Children's Depression Inventory; CEBQ = Child Eating Behaviour Questionnaire; ChEAT = Children's Eating Attitudes Test; CI = confidence interval; CYP = children and young people; DEB = disordered eating behaviour; DEPS-R = Diabetes Eating Problem Survey-Revised; DWCB = disordered weight-control behaviours; EAT-26 = Eating Attitudes Test; K-SADS-PL = Kiddie Schedule for Affective Disorders and Schizophrenia Present and Lifetime Version; PedsQL = Paediatric Quality of Life Inventory Questionnaire; STAIC = State-Trait Anxiety Inventory for Children

Study author and year	Country	Sample	Assessment method and JBI score	Prevalence of DEB
Al Metsaka et al. 2023 (54)	UAE	Mixed school and clinical sample. Obese sample: female: 46% (n = 121); male: 54%; (n = 142). Age range: 5–16 years. Mean age not provided.	Case-control. DEBs assessed using SCOFF questionnaire. JBI score: 6	42% (110) of obese participants had positive SCOFF results (score ≥2) vs 7% of normal-weight participants.
Kass et al. 2017 (55)	USA	Mixed community and clinical sample. 577 participants with overweight or obesity. Mean age: 11.18 ± 2.45).	Cross-sectional study with participants taken from those presenting for research studies or presenting for treatment at 5 separate eating disorder or obesity treatment centres. Data was collected using EDE-Q or ChEDE. Other information on behaviour and mood was gathered using the CBCL and CDI along with sociodemographic and anthropometric data. JBI score: 6	Secretive eating: 19.2%. Loss-of-control episodes: 30.7%. Purging episodes: 2.8%.

Table 7. Range of disordered eating behaviours in mixed community and clinical samples

Abbreviations: CBCL = Child's Behaviour Checklist; CDI = Children's Depression Inventory; ChEDE = Child Eating Disorder Examination; DEB = disordered eating behaviour; EDE-Q = Eating Disorder Examination Questionnaire; JBI = Joanna Briggs Institute

Within studies looking at food addiction in clinical populations, rates ranged from 9.9% (32) to 33.4% (29). In community samples, this ranged from 3% (34) to 26.8% (35). Tompkins et al. (33) found that 30.8% of young people living with overweight or obesity within their clinical sample met "diagnostic criteria" for food addiction. Amongst these, there were statistically significant lower rates of attendance and higher rates of attrition from the weight-loss intervention programme, along with significantly lower psychosocial health-related quality of life scores. Data on food addiction were gathered using the YFAS across all studies, meaning greater consistency and generalisability of results.

Amongst studies assessing a range of DEBs, Fogh et al. (37) found at least one disordered eating behaviour in 82.2% of a clinical population of CYP living with obesity enrolled in a multidisciplinary obesity treatment programme. The remainder of studies looking at a range of DEBs were community samples which found prevalence rates ranging from 8.4% (50) to 61.4% (40), again with a wide range of assessment methods and ways of defining DEBs. López-Gil et al. (40) used a score of 2 or more on the SCOFF questionnaire to define the presence of DEBs. The SCOFF questionnaire was designed to detect anorexia nervosa and bulimia nervosa in adults and may have limited utility in overweight and obese CYP populations (56). Rodgers et al. (51) found presence of DEBs in 59.8% of participants using study-specific questions that categorised a broad range of DEBs, including smoking as a way to control weight and ever having changed the way the participant ate in order to lose weight.

Many of the papers showed increased rates of comorbid psychiatric disorders. Spettigue et al. (14) found that 37% of a population of CYP living with obesity reported symptoms of social anxiety, which was higher amongst CYP with obesity who engaged in binge eating when compared to CYP with obesity who did not binge eat. Another paper looked at associations between binge eating and ADHD and found that nearly three-quarters of a group with both overweight/obesity and ADHD experienced LOC eating (18). Negative affect was found to be significantly associated with DEBs (52).

Quality of life was also shown to be affected, with one study reporting that CYP with a high tendency to emotional overeating had significantly lower quality-of-life scores compared to those with a low tendency to emotional overeating (41).

Family and peer interactions were shown to be negatively impacted, with Pearlman et al. (17) finding that the presence of family weight-based teasing was significantly associated with greater eating concern, shape concern, weight concern and global eating pathology when using the EDE. Amuhlafi et al. (48) found that a group of obese CYP had significantly lower scores of self-perception of body image and higher scores of perceived peer pressure compared to non-obese participants. Attachment relationships were implicated in DEBs, with Pace et al. (22) highlighting that insecure attachment to caregivers acts as a risk factor for binge eating, through affecting emotional regulation leading to "emotional eating".

The study by Egbert et al. (18), which was the only study investigating the relationship across differing socioeconomic statuses and DEBs, found that belonging to a lower socioeconomic group was associated with binge eating.

4. Discussion

This review summarises the high rates of DEBs in CYP living with overweight and obesity across both clinical and community settings globally, and the far-ranging impacts that these behaviours can have on quality of life and wider mental health outcomes. Similar to findings from He et al. in their 2016 meta-analysis (7) looking into binge/LOC eating only, rates of DEBs varied widely between different studies and showed a high degree of heterogeneity. This review included studies assessing a broader range of DEBs. Heterogeneity of assessment methods and prevalence rates remained a feature of studies published after 2016. Future research into this area may benefit from the use of a standardised tool, such as the EDE-Q, to allow for more meaningful comparisons and generalisability of results. While not all CYP with disordered eating will go on to develop eating disorders, research has shown that DEBs predict future outcomes related to obesity and eating disorders (57).

CYP eating disorder services in the United Kingdom continue to see an increase in referrals since COVID-19 (58). This is reflected through NHS England's access and waiting time initiative which stipulates that "urgent" cases should be seen within one week of referral. In 2017/18, 78.9% of these cases were seen within this timeframe compared with just 59% of cases in 2021/22 (59), highlighting the increased pressure on services. Rates of obesity have also increased during the pandemic, likely due to changes in dietary patterns and reduced physical activity (60). Recognising that obesity itself is a risk factor for disordered eating, it can be postulated that rates of DEBs associated with overweight and obesity have also increased. Greater demand on eating disorders services and Complications from Excess Weight (CEW) clinics (61) has resulted in longer waiting times for assessment and treatment and may be acting as a barrier to CYP living with overweight and obesity accessing services appropriately and in a timely manner. Given that disordered eating behaviours and body dissatisfaction may reflect an eating disorder prodrome (62), identifying and targeting DEBs in CYP living with overweight and obesity with prevention and early intervention strategies could help to treat symptoms before they develop into eating disorders and improve health trajectories over the life course.

Development and targeting of prevention and early intervention strategies for DEBs in the context of overweight and obesity need to additionally consider potential weight stigma, including self-stigma, and how this might impact on help-seeking behaviours (63). Research shows that individuals at higher weight may delay or avoid accessing treatment due to self-stigma or past negative interactions with healthcare professionals (64). Once they have accessed treatment, weight stigma can be exhibited by clinicians working in eating disorder services, with some feeling uncomfortable treating patients with obesity (65). Patients presenting with symptoms meeting the diagnostic threshold for binge eating disorder (BED) are more likely to be overweight or obese (66) and therefore potentially more likely to be subject to weight stigma. Since BED was included as a standalone diagnosis within DSM-5, it has become an increased focus for research (please see Appendix 3 for DSM-5 diagnostic criteria for BED). A recent meta-analysis assessing the prevalence of BED in CYP showed that it occurs at similar rates to anorexia nervosa and bulimia nervosa (67); however, there are still discrepancies between available resources for these disorders despite the high burden on those suffering from BED (68). This is highlighted to an extent within current UK guidance for treatment of eating disorders with first-line treatment of anorexia nervosa and bulimia nervosa taking the form of 18 to 20 one-hour sessions of family therapy over the course of one year and six months, respectively (see other articles in this issue for more detail on treatment modalities for other eating disorders). In comparison, first-line treatment for BED recommends guided self-help which should take place over 16 weeks and include the following components: cognitive behavioural self-help materials, a focus on adherence to the self-help programme and four to nine brief supportive sessions with a clinician each lasting around 20 minutes to supplement the self-help programme. If it is not possible to deliver guided self-help or it has been ineffective after four weeks of treatment, then cognitive behavioural therapy for BED should be offered as second-line treatment (69). Some studies have reported the use of dialectical behaviour therapy (DBT) in effectively treating BED however, due to small sample sizes, larger randomised controlled trials are needed to further assess DBT as a treatment for BED in young people (70).

The lack of larger studies into effective treatments for BED may reflect its more recent addition into diagnostic classifications compared to anorexia nervosa and bulimia nervosa. Health outcomes in CYP with BED are likely to be improved with more research focused on treatment approaches and outcomes. Based on studies investigating weight stigma in adults, and weight stigma being recognised as also impacting young people (65), there appears to be a need for further research into how CYP living with overweight and obesity experience both preventative strategies targeting DEBs, how they experience treatment within specialist eating disorders services and how this may impact on outcomes.

Food addiction is not currently listed as a diagnosis within DSM-5; however, given the prevalence of high symptom scores according to YFAS within CYP with overweight or obesity highlighted by this review, this appears to be another area that would benefit from increased research. There should be careful consideration of the impact of including food addiction in discussions on the subject of DEBs and eating disorders. This is due to the conceptualisation and management of addictive behaviours differing widely from DEBs and eating disorders.

5. Strengths and limitations

Strengths of this review include the assessment of prevalence of a wide range of DEBs, including food addiction, across a large total sample of CYP in a range of settings.

The conclusions that can be drawn from this review in terms of binge and LOC eating and ranges of DEBs are limited by the degree of heterogeneity amongst studies in terms of methods of data collection and reporting. To be able to draw firmer conclusions about prevalence rates, the data would benefit from separate meta-analyses across the different domains assessed (i.e., binge eating/LOC eating and food addiction). Data on rates of food addiction appear to be more robust due to the use of a single measure. However, the concept of food addiction itself does not have universal consensus (71). Additional limitations for this study were the lack of a second reviewer of included papers and the lack of co-production in the generation of the review, which could have consulted those with lived experience of the subject matter.

6. Conclusions and implications

With high rates of CYP with overweight and obesity reporting DEBs, it is imperative that individuals can access appropriate care at an early stage to prevent poor health outcomes in the immediate-to-longer term. This involves routinely assessing DEBs in CYP with higher weight to ensure opportunities for early intervention are not missed.

More research is needed to investigate novel strategies for reducing DEBs within CYP living with overweight or obesity that take a holistic biopsychosocial approach, given the complex aetiology and comorbidity of these behaviours. More longitudinal studies in this area could improve understanding of how DEBs evolve and intersect with weight trajectories in CYP. Further research into this area could be used to help inform development and delivery of public health and primary preventative strategies aimed at reducing DEBs in CYP living with overweight and obesity, along with informing integrated care pathways that address both DEBs and overweight/obesity simultaneously. An additional focus of research could be to assess the effectiveness of current available treatments for BED in this age group.

Appendix 1

1. JBI checklist for assessing cross-sectional analytical studies uses the following eight domains.
2. Were the criteria for inclusion in the sample clearly defined?
3. Were the study subjects and the setting described in detail?
4. Was the exposure measured in a valid and reliable way?
5. Were objective, standard criteria used for measurement of the condition?
6. Were confounding factors identified?
7. Were strategies to deal with confounding factors stated?
8. Were the outcomes measured in a valid and reliable way?
9. Was appropriate statistical analysis used?

Appendix 2

Description of assessment tools used.

Eating Disorders Examination Questionnaire (EDE-Q): Self-report questionnaire which consists of 36 items and generates four subscales, "dietary restraint", "eating concern", "shape concern" and "weight concern". Items measuring binge eating, self-induced vomiting and loss-of-control eating are also incorporated in the scale, but not included in the total score.

Eating Attitudes Test (EAT)-26: Standardised self-report measure of symptoms and concerns characteristic of eating disorders. Score of >20 indicates high risk of an eating disorder.

Yale Food Addiction Score (YFAS): A 25-item self-report measure that has been developed to identify those who are most likely to be exhibiting markers of substance dependence with the consumption of high-fat/high-sugar foods. A food addiction symptom (e.g., tolerance, withdrawal, loss of control) count can be obtained, which is similar to the criteria for substance dependence of the DSM-IV-TR (72). Additionally, two items assess clinically significant impairment or distress from eating. Food addiction can be "diagnosed" when three symptoms and clinically significant impairment or distress are present.

Eating Disorder Inventory (EDI): Self-report questionnaire dealing with symptoms of eating disorders and related behaviour. The instrument consists of 91 items subdivided into 11 subscales. The first three subscales, "drive for thinness" (excessive concern with dieting), "bulimia" (uncontrolled overeating) and "body dissatisfaction" (discontent with body shape), are categorised as symptom subscales. The remaining eight are classified as psychological subscales and include "ineffectiveness" (worthlessness and lack of control over one's life), "perfectionism", "interpersonal distrust" (reluctance to have close relationships), "interoceptive awareness" (uncertainty in respect of emotional states related to hunger and satiety), "maturity fears", "asceticism" (seeking virtue in self-discipline), "impulsive regulation" and "social relationships" (insecurity in terms of social interplay). A total score can be calculated based on the sums of the 11 subscales.

SCOFF Questionnaire: Screening instrument for detecting eating disorders based on the following questions: "Do you make yourself sick because you feel uncomfortably full?"; "Do you worry you have lost control over how much you eat?"; "Have you recently lost more than one stone in a 3 month period?"; "Do you believe yourself to be fat when others say you are too thin?"; and "Would you say that food dominates your life?". One point is given for every "yes"; a score of ≥2 indicates a likely case of anorexia nervosa or bulimia nervosa.

Binge Eating Scale (BES): A questionnaire consisting of 16 items for assessing behaviours such as loss-of-control overeating and eating unusually large amounts of food. Total scores range from 0 (less binge eating) to 46 (more binge eating). The BES is a good indicator of binge eating in patients undergoing metabolic and bariatric surgery, and a BES score of 17 or lower is suggested as a cut-off for distinguishing patients with no binge eating from patients with binge eating (those with scores > 17).

Branched Eating Disorder Test (BET): Validated tool to assesses eating disorder symptoms over the past three months. The BET consists of nine stem items branching out to a maximum of 31 items. The items map closely onto symptoms of anorexia nervosa and bulimia nervosa as defined in the DSM. Minor revisions were made to the original BET (which had consisted of 10 stem items and a maximum of 27 items) to ensure consistency with the current DSM-5 anorexia nervosa and bulimia nervosa criteria and to clarify wording.

Bulimic Investigatory Test Edinburgh (BITE): A 33-item self-rating scale that consists of two subscales: the symptom scale (30 items), which measures the degree of symptoms, and the severity scale (3 items). Total score is the sum of the two subscale scores. A total score of > 25 indicates a possible case of binge eating.

Block Food Frequency Questionnaire: A 60-item questionnaire designed to measure an individual's relative nutrient intake as well as absolute nutrient values, to assess both nutrients and foods, and to assess diets of a variety of demographic groups

EAT 2010 Survey: A 96-item self-report about eating, physical activity and weight-related behaviours designed to be used as part of a research project with middle school and high school students.

The Three-Factor Eating Questionnaire-R21 (TFEQ-R21): A 21-item questionnaire that assesses three aspects of eating behaviour: emotional eating (eating as a response to negative emotions), uncontrolled eating (eating in response to food exposure or hunger) and cognitive restraint (trying consciously to restrict eating). Scale scores range from 0 to 100. A higher score indicates more of the respective eating behaviour. The TFEQ-R21 has been validated in adolescents.

Appendix 3

DSM-5 diagnostic criteria for binge eating disorder (73).

1. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following.
   A. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat in a similar period of time under similar circumstances.
   B. The sense of lack of control overeating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).
2. Binge eating episodes are associated with three (or more) of the following.
   A. Eating much more rapidly than normal.
   B. Eating until feeling uncomfortably full.
   C. Eating large amounts of food when not feeling physically hungry.
   D. Eating alone because of being embarrassed by how much one is eating.
   E. Feeling disgusted with oneself, depressed, or very guilty after overeating.
3. Marked distress regarding binge eating is present.
4. The binge eating occurs, on average, at least 1 day a week for 3 months
5. The binge eating is not associated with the regular use of inappropriate compensatory behavior (e.g., purging, fasting, excessive exercise) and does not occur exclusively during the course of anorexia nervosa or bulimia nervosa.

Severity grading:

Mild: 1 to 3 episodes per week

Moderate: 4 to 7 episodes per week

Severe: 8 to 13 episodes per week

Extreme: 14 or more episodes per week

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Purging disorder: considerations for clinical presentation, epidemiology, risk factors and interventions

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Abstract

Purging disorder (PD), a DSM-5 other specified feeding or eating disorder, involves purging in the absence of binge eating among individuals who are not underweight. Epidemiological studies indicate that PD is more common in women than men and affects 1.3% to 4.8% of girls. Clinical presentation includes elevated body image concerns, mood disturbance and perfectionism, similar to other eating disorders. However, PD is characterised by greater somatic complaints compared to other eating disorders, including greater postprandial gastrointestinal distress compared to bulimia nervosa (BN). Studies of biological factors support greater release of postprandial gut peptides that trigger satiation and satiety in PD compared to BN, and these biological factors are linked to the clinical presentation of PD. Prospective risk factors for PD onset differ from those for anorexia nervosa onset and include higher premorbid body mass index, body dissatisfaction and dieting. Relative to its prevalence in the general population, PD is rare in eating disorder treatment settings. Treatment dropout is high in PD, with more than a third of patients discontinuing treatment early. Less than half of those with PD are free from an eating disorder at the end of treatment and at one or more years of follow-up. Recommendations for tailoring cognitive behavioural therapy include applying techniques for mood intolerance to address emotional and gastrointestinal distress that maintains purging in the absence of binge eating. Such efforts may benefit patients with PD as well as those who purge across eating disorder diagnoses.

Keywords: purging disorder, epidemiology, biology, risk factors, intervention, treatment, outcome

Introduction

More than 10 years ago, the *Diagnostic and Statistical Manual for Mental Disorders, Fifth Edition (DSM-5)* included purging disorder (PD) as a named other specified feeding or eating disorder (OSFED), described by "Recurrent purging behavior to influence weight or shape (e.g., self-induced vomiting; misuse of laxatives, diuretics or other medications) in the absence of binge eating" (1). This review covers the topics of diagnosis, epidemiology, clinical presentation, biological factors, risk factors, interventions and outcomes for PD.

Diagnostic considerations

Like all OSFED, PD can only be diagnosed among those who have a clinically significant disorder that does not meet the full criteria for anorexia nervosa (AN), bulimia nervosa (BN) or binge eating disorder (BED). Consistent with the requirement of clinically significant distress or impairment, a systematic review found that PD was associated with impaired health-related quality of life in children and adolescents (2). There is partial symptom overlap between PD and both AN and BN because purging occurs in all three. However, the overlap is partial because only PD requires the presence of recurrent purging; only AN requires the presence of low weight; and only BN requires the presence of binge eating. Thus, successful differential diagnosis requires understanding how the DSM-5 defines purging, underweight and binge eating.

Purging includes a range of behaviours that evacuate matter from the body, such as self-induced vomiting and misuse of laxatives, diuretics or other medications. An example of other medication use includes insulin omission in type 1 diabetes because insufficient insulin contributes to hyperglycaemia and excess urination. The guidelines for underweight are an adult body mass index (BMI) <18.5 kg/m^2 or, for children and adolescents, a BMI <5th percentile for age and sex. Finally, a binge episode involves experiencing a loss of control while consuming a large amount of food (e.g., a package of cookies) within a limited period of time, and binge episodes are frequently associated with later feelings of guilt. Given significant variability across people and contexts in food consumption, determining whether an amount of food is definitely larger than what most people would eat can be challenging. As a rule of thumb, consumption of more than 1,000 kcal (4,184 kJ) within two hours at home and outside of special occasions is more than most people consume. Women with PD often endorse a loss of control over their eating but do not report consuming more than most people would eat under similar circumstances. In clinical interviews, women with PD reported eating approximately 500 kcal (2100 kJ), on average, when they lost control of their eating. In contrast, women with DSM-5 BN reported consuming an average of approximately 2,700 kcal (11,300 kJ) (3).

The International Classification of Diseases, 11th Revision (ICD-11) (4) does not require that binge episodes involve a large quantity of food, and the ICD-11 diagnosis of BN subsumes many cases of DSM-5 PD (5). However, cases of

DSM-5 PD in which purging does not compensate for food consumption, referred to as non-compensatory purging, would not be diagnosed as ICD-11 BN.

Beyond the boundaries set by formal diagnostic criteria for AN and BN, the DSM-5 provided no provisional diagnostic criteria for PD, and no approach was offered for differential diagnosis and diagnostic hierarchies among the OSFED examples. Consequently, characterisation of PD in research and clinical settings has varied.

Epidemiology

Point prevalence estimates for adolescent girls have ranged from 1.3% to 4.8%, depending on age group and how PD is defined (6-9), with lower prevalence in pre- and peri-pubertal girls. Like other eating disorders, PD is more common in girls than boys. However, across population-based samples, boys make up approximately 20% of children diagnosed with PD (7, 8). Mirroring gender differences in adolescents, PD affects approximately 2% of women and 0.5% of men (10-12). PD may be less common in non-Western contexts, with one study reporting a 0.2% point prevalence in women screened in Malaysia (13).

Compared to its prevalence in non-clinical samples, PD appears to be underrepresented relative to AN and BN in clinical settings (14-19). Among outpatients, AN outnumbered PD 7:1 (18, 20), BN outnumbered PD from almost 4:1 to 6:1 (18, 20) and BED outnumbered PD almost 6:1 (20). Among inpatients, the AN:PD ratio was almost 17:1 and BN:PD ratio was almost 10:1 (19). In a large sample of 1,711 PD patients (14), males accounted for only 2.2% of PD patients – far less than what has been observed in non-clinical samples, consistent with evidence that males are less likely to receive eating disorder treatment (21).

Several factors may contribute to underrepresentation of PD in treatment. Poor recognition of illness severity, stigma and shame, lack of encouragement to seek treatment and low motivation represent barriers to treatment seeking (22). Studies support that each barrier may play a role in underrepresentation of PD in clinical settings. Fatt et al. (23) found that self-identification of a body image problem was a significant predictor of treatment seeking and examined differences across DSM-5 eating disorders on this factor. Despite using purging to influence weight or shape, just over half of girls with PD and less than a third of boys with PD described themselves as having a body image problem, suggesting poor recognition of severity, particularly for boys. Poor recognition appeared to be more common in PD than BN, where >80% of girls and >67% of boys described themselves as having a body image problem. Like AN, PD may represent a more ego-syntonic condition in which the person views use of vomiting or purgatives as a harmless weight-management strategy. Those who do not match the stereotype for an eating disorder – which primarily depicts individuals as being underweight – may be less likely to recognise themselves, or be recognised by others, as having problems that cross the threshold into being a disorder (24). Higher purging frequency is associated with greater concerns about stigma (25) and is often hidden from others out of shame, reducing the likelihood of encouragement from friends of family to seek treatment. Higher purging frequency is also associated with greater treatment ambivalence (25).

Poor detection of eating disorders in health settings represents another major barrier to care; only 10% of individuals with PD were detected and referred to treatment versus approximately 50% of those with AN or BN (26). Universal screening for eating disorders is needed to improve detection, including asking everyone about use of purging to control weight or shape (27). Finally, PD may be misdiagnosed as another eating disorder given its partial symptom overlap with AN and BN, or PD may be identified as atypical AN due to an absence of guidelines for differential diagnosis when criteria are met for both. Folding cases of PD under the umbrella of another eating disorder diagnosis raises the risk of inadequate assessment and treatment. Once a diagnosis has been assigned, clinicians may be biased by heuristics in their clinical judgements which could negatively impact prognosis (28).

Clinical presentation and correlates

Patients with PD have an elevated drive for thinness, body dissatisfaction, problems with interoception, fears of adulthood, problems regulating impulses, social insecurity, interpersonal sensitivity, obsessive/compulsive features, depressive features and somatisation (16). Although characteristic of many eating disorders, these features were higher in patients with PD compared to those with AN, BED or atypical AN, suggesting that PD falls on the higher end of the severity spectrum (16). A recent meta-analysis supports the interpretation of PD as presenting with comparable severity to BN based on evidence of similar eating pathology, general psychopathology or physical health impairments (29). Yet, Krug and colleagues (16) found distinctions between PD and BN, suggesting that PD was different from BN without being less severe than BN. Compared to BN, Krug et al. (16) and others have found that those with PD have a later age of onset (6, 30), lower impulsivity (31, 32), higher emotional reactivity (20) and a lower frequency of vomiting (31) but use more methods of purging (33) and endorse greater somatic concerns (14). Use of multiple purging methods may reflect greater presence of non-compensatory purging in PD – that is, purging that occurs in the absence of any eating episode (34), and may be linked to elevated risk for alcohol and other substance use disorders in PD (35).

As described in Diagnostic considerations, above, women with PD often subjectively experience a loss of control while eating despite consuming an average of only 500 kcal (2100 kJ) prior to purging (36). Using an *ad lib* meal as a

Eating disorder	CCK	GLP-1	PYY	Insulin
Purging disorder	No difference from controls Higher than bulimia nervosa	No difference from controls Higher than bulimia nervosa	Higher than controls Higher than bulimia nervosa	No difference from controls Higher than bulimia nervosa
Anorexia nervosa	Inconclusive	Inconclusive	Mixed, but may be higher than controls	Lower than controls, but with higher sensitivity
Bulimia nervosa	Higher than controls Lower than purging disorder	Higher than controls Lower than purging disorder	No difference from controls Lower than purging disorder	No difference from controls, but with reduced sensitivity Lower than purging disorder
Binge eating disorder	Inconclusive	No difference from controls	Inconclusive	Higher than controls, but with reduced sensitivity

Table 1. Summary of altered biological factors in purging disorder and other eating disorders (adapted from Williams and Keel (58))

Abbreviations: CCK = cholecystokinin; GLP-1 = glucagon-like peptide 1; PYY = peptide tyrosine tyrosine

Note: "Inconclusive" reflects a pattern of mixed results in which studies have reported levels that are significantly higher, significantly lower and levels that do not differ significantly from controls.

behavioural measure of satiation, observed food intake was significantly correlated with self-reported food intake in a sample that included women with PD, BN and no eating disorder; women with BN consumed significantly more food compared to women with PD and controls to achieve the same subjective state of feeling full (36). After eating, both women with BN and women with PD experienced significant increases in nausea, stomach ache and desire to vomit, which was not observed in healthy women (36). Greater somatic concerns and gastrointestinal distress following intake of a normal amount of food in PD may reflect distinct disruptions in physiological responses to food intake that support distinguishing between PD and BN in the DSM-5 (37).

Biological correlates

PD has been linked to distinct physiological responses to food intake that correspond to both the absence of binge eating and presence of vomiting after normal amounts of food (see Table 1). Women with BN have demonstrated lower cholecystokinin (CCK) responses (38) and glucagon-like peptide 1 (GLP-1) levels (39) following a standardised liquid meal compared to women with PD and controls. Given the roles of CCK and GLP-1 in producing satiation (a signal to the brain to stop eating), these differences may explain the presence of objectively large binge episodes in BN and their absence in PD. Despite consuming the same amount of food in the standardised meal, women with PD reported significantly greater increases in nausea and stomach ache after eating compared to both women with BN and healthy women (3). These increases were predicted by postprandial increases in the gut satiety peptide, PYY. Women with PD demonstrated a significantly elevated postprandial PYY response compared to both controls and women with BN, who did not differ from each other (3). Finally, compared to women with BN, those with PD demonstrated a significantly greater insulin response to a fixed test meal, with controls demonstrating a response that did not differ significantly from either BN or PD (40). Combined with prior findings, these results suggest unique biological correlates for PD, in which women demonstrated intact CCK and GLP-1 responses and an elevated PYY response to food intake. In contrast, BN is characterised by blunted CCK and GLP-1 responses and an intact PYY response to food intake. The unique combination of intact satiation signals and excessive satiety signalling in PD may contribute to maintenance of purging after normal amounts of food.

Keel et al. (41) recently reported that delayed gastric emptying was associated with self-induced vomiting in both PD and BN and predicted increased gastrointestinal distress after food intake (41). A single dose of 10 mg of metoclopramide effectively increased the gastric emptying rate and eliminated group differences in gastric emptying. However, metoclopramide caused increased PYY release. As a consequence, all participants experienced an exacerbation of PYY response to the test meal and associated nausea and stomach ache. Although these results provided compelling evidence that PYY causes gastrointestinal distress, findings suggest the need for caution when attempting to isolate and correct a specific physiological process within a complex system. Importantly, biological correlates of PD do not necessarily reflect maintenance or aetiological factors as they may be consequences of eating disorder behaviours.

Prospective risk factors

A handful of studies have examined prospective risk factors for PD in community-based samples. The largest of these comes from a longitudinal study in which 14,541 pregnant women living in the Avon area of the UK were enrolled to provide data on themselves and allow data to be collected on their children, beginning at birth (42). In one paper using this sample, researchers examined BMI trajectory from birth to 12.5 years of age to examine the prospective risk of an eating disorder diagnosis at 14, 16 or 18 years of age in the children (43). PD contributed 133 of the 536 detected eating disorder cases (25%), with a 9:1 female: male ratio. Prior to PD onset, girls (by age 5) and boys (by age 6) demon-

strated a significant increase in BMI percentile compared to those who did not develop eating disorders. For children who went on to develop BN, BMI percentiles increased and diverged significantly from non-eating disorder controls as early as 2 years of age. In contrast, premorbid BMI trajectories were significantly lower for girls (by age 4) and boys (by age 2) who went on to develop AN compared to those who did not develop eating disorders (43). Findings support that factors driving differences in eating behaviours and weight at a young age set the stage for differences in the central features of the various eating disorders. It also suggests how a higher premorbid weight may buffer those with PD against becoming underweight when they purge without bingeing.

Stice et al. (30) collapsed data across three separate school-based prevention trials of high-risk adolescents and young adults, resulting in a sample of 1,272 female participants who endorsed body image concerns. Body dissatisfaction appeared to be a common risk factor across PD, BN and BED, but overeating emerged as a predictor of disorders characterised by large binge episodes and did not uniquely contribute to risk for onset of PD or AN (30). Instead, more frequent dieting predicted PD onset and emerged as the first risk factor in analyses determining unique pathways for developing PD (44). Findings indicated highest PD risk in girls who dieted more, held more positive thinness expectancies and experienced elevated but not extremely high negative affect (44). Similar to findings from children living in Avon, lower BMI was a unique branch for developing AN.

Children who go on to develop PD may not experience the same drive to consume large amounts of food that give rise to the very early elevations in BMI seen in BN and BED but may, nonetheless, gain more weight during childhood than their peers. In cultures that idealise thinness and stigmatise higher body weights, these children may turn to dieting with the belief that this will make both their bodies and lives better. When dieting does not produce the desired effects, feelings of ineffectiveness and negative mood may provide the nudge to try purging. Purging produces dehydration which, in the short run, creates the illusion of weight loss. In addition, findings from an ecological momentary study of PD indicated that purging alleviates negative affect (45). Thus, purging may be maintained as a strategy to control weight and mood.

Risk factors shared between PD and other eating disorders suggest that existing eating disorder interventions may be effective for PD. Risk factors that are specific to PD offer insights into how these interventions may be tailored to meet the specific needs of those with PD.

Interventions and outcomes

Limited information exists to guide the prevention and treatment of PD. However, most research suggests that targeting risk and maintenance factors shared across eating disorders provides a good starting point. A brief intervention to reduce internalisation of the thin ideal produced a statistically and clinically significant reduction (62%) in risk of PD onset in samples combined from three randomized controlled trials (RCTs) (46). The intervention also significantly reduced risk for subthreshold BN/BN onset, but not subthreshold/full threshold AN or BED over three-year follow-up. Such findings support a more central role for thin ideal internalisation in risk for PD and BN, compared to AN and BED.

Several other RCTs have included PD along with patients with BN or subthreshold BN (47-50) but did not include enough participants with PD to report their outcomes separately. Findings from larger case series of patients receiving cognitive behavioural therapy (CBT) suggest caution in generalising findings from BN to PD. Tasca et al. (17) reported outcomes for patients evaluated in a tertiary care centre, including 122 with PD and 415 with BN, among whom 25 with PD (20%) and 126 with BN (30%) were referred for CBT in their day program. In addition to a lower likelihood of referral for treatment, PD was associated with higher dropout compared to BN (37% vs. 20%) and lower likelihood of good outcome (48% vs. 57%). Similar patterns emerged for patients treated at a specialised eating disorders unit. Riesco et al. (51) described treatment outcomes in 57 patients with PD, and Fernández-Aranda et al. (52) described outcomes for 484 patients with BN over the same period from the same centre in an online supplement. Dropout was higher in PD compared to BN patients (37% vs. 28%) and full remission was lower in PD compared to BN patients (18% vs. 25%). Although direct comparisons between PD and BN were not presented, the pattern of differences points to less favourable outcomes for PD.

Preliminary findings indicate that more effort should be placed on tailoring treatments for the unique configuration of symptoms of PD, based on what we have learned thus far. Treatments should address weight history and that purging in the absence of binge eating may contribute to weight suppression – that is, maintenance of weight that is lower than the highest premorbid weight. In the context of CBT or enhanced CBT (CBT-E), prescription of a normal pattern of eating and abstinence from purging may produce rapid weight gain which could contribute to the increased dropout observed in PD. Greater emphasis on weight and shape concerns earlier in treatment using cognitive dissonance techniques may facilitate greater acceptance of treatment by prioritising physical and emotional health over weight. Treatments should acknowledge that individuals with PD experience a physiologically distinct response to eating that increases stomach ache, nausea and desire to vomit after eating amounts of foods that others find tolerable. Krug et al. (16) recommended the mood intolerance module of CBT-E to help PD patients accept and tolerate feelings of excess fullness and anxiety. Combined with exposure and response prevention techniques successfully employed in a case study using CBT-E for an adolescent with PD (53), adaption of mood intolerance to address intolerance of

gastrointestinal distress represents a novel strategy to tailor CBT to PD.

Keel (54) summarised outcomes from 11 follow-up studies that included data from a combined total of 943 individuals with PD with duration of follow-up ranging from just over two months to 10 years. Overall, 40% had no eating disorder at follow-up. Approximately 20% had PD, and another 20% continued to purge at a reduced frequency or to exercise excessively in the absence of binge eating, suggesting that 40% would fall within a broad phenotype for PD. Finally, 20% had BN and virtually no cases of AN or BED were found. Studies consistently supported a greater likelihood of persistence of PD versus crossover to BN or any other eating disorder, suggesting that PD is not a prodromal stage of BN in most cases.

Two studies included in Keel's (54) summary reported outcomes for patients with PD at five or more years following intake. At five-year follow-up of inpatients, Koch, Quadflieg, and Fichter (15, 55) reported that 5% of patients with PD had died compared to 3.7% of purging AN patients and 1.1% of purging BN patients, with significantly higher mortality in PD and AN compared to BN. The 5% crude mortality rate in PD reflected a standardised mortality ratio of 3.9 (95% confidence interval: 2.1–7.2) or a nearly four-fold increase in risk of premature death associated with PD. Where cause of death could be determined, medical complications from the eating disorder or suicide accounted for all but one (55). PD patients were significantly older and had a significantly longer duration of illness at admission compared to purging patients with AN or BN, suggesting that potential delays in recognition, referral or treatment may have contributed to worse outcome. At follow-up, approximately 40% had no eating disorder diagnosis (15).

Forney et al. (56, 57) reported long-term outcomes of PD in a sample of 84 women followed for approximately 10 years. No participants died during the follow-up period. Full recovery was achieved in 30% of the sample (56). Women were significantly more likely to continue to have PD than to cross over to BN (57). Greater concerns with weight or shape predicted illness maintenance, and quality of life was impaired in physical, psychological and social domains (56).

A notable feature of these two longer follow-up studies is that full remission ranged from 30% to 40%, closely matching the estimated 40% remission collapsed across all follow-up studies of PD, including those of much shorter duration. This suggests minimal improvement in outcomes over extended periods of time, highlighting the need for earlier and better interventions.

Conclusion

PD is a serious eating disorder characterised by the use of vomiting, laxatives or other medications to influence weight or shape in the absence of binge eating in individuals who are not underweight. The disorder affects a substantial number of people, most of whom do not receive treatment. Clinical presentation includes significant disturbances in mood, personality and interpersonal function, with PD falling on the more severe end of the spectrum of eating disorders, along with BN. Women with PD report unique problems with somatic symptoms, including increased gastrointestinal distress, and these features are linked to delayed gastric emptying and elevated release of gut peptides following food intake. This, combined with a premorbid history of elevated weight, may negatively impact acceptability of CBT in PD. Tailored treatment approaches could involve addressing overvaluation of weight and shape earlier in treatment, adapting modules for mood intolerance to address tolerance of gastrointestinal distress, and employing exposure and response prevention to help patients with PD consume normal amounts of food without purging. A minority of those with PD report eating disorder remission in follow-up studies. Eliminating barriers to treatment and adapting interventions for PD could improve outcomes. Finally, addressing purging as a primary symptom in treatment may benefit patients who purge in the context of other eating disorders, helping many patients for whom the gold standard of treatment does not work.

Funding and declarations of interest

The author receives royalties from Oxford University Press for the following titles: *Eating Disorders, Second Edition (2017); The Void Inside: Bringing Purging Disorder to Light (2020).*

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Current views on relative energy deficiency in sport (REDs)

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Abstract

Relative energy deficiency in sport (REDs) is a clinical syndrome which includes the adverse effects on health and performance caused by chronic low energy availability. This article explores the current view of REDs, highlighting the recent updates from the International Olympic Committee consensus statement issued in September 2023. Psychological factors and mental health are recognised as having a reciprocal relationship with both the aetiology and outcome of the chronic low energy availability that leads to REDs. This has important implications in terms of prevention and management for individuals experiencing REDs. Unintentional or intentional unbalanced behaviours around high levels of exercise and insufficient nutrition lead to a situation of low energy availability. Low energy availability is not synonymous with REDs; rather, cumulative and sustained low energy availability, particularly low carbohydrate availability, leads to the clinical syndrome of REDs comprising a constellation of adverse consequences on all aspects of health and performance. Furthermore, REDs is not synonymous with an eating disorder (ED), although some individuals may have disordered eating or an ED. REDs can potentially arise in both biological sexes, at all ages and all levels of exercise. This is of particular concern for the young aspiring athlete or dancer, where behaviours are being established and in terms of long-term consequences on mental and physical health. The mechanism of sustained low energy availability leading to these negative health outcomes is through the adaptive down-regulation of the endocrine networks. Therefore, raising awareness of the risk of REDs and implementing effective prevention and identification strategies is a high priority.

Keywords: low energy availability, relative energy deficiency in sport (REDs), hormone, psychology, nutrition, exercise

Introduction

Relative energy deficiency in sport (REDs) is a clinical syndrome which includes the adverse effects on health and performance caused by chronic low energy availability. REDs was first described in the International Olympic Committee (IOC) consensus statement published in the British Journal of Sports and Exercise Medicine in 2014 (1). Since then, there have been updates published in 2018 (2) and, most recently, in September 2023 (3).

Seminal studies of female collegiate runners in the 1980s found that those athletes with higher weekly training load but the same food intake as those with lower training load experienced menstrual disruption, including secondary amenorrhoea and poor bone health (4). This led to the description of the female athlete triad, which comprises a clinical spectrum of eating patterns, menstrual function and bone health. This ranges from optimal fuelling, good menstrual function and good bone health to eating disorders, amenorrhoea and osteoporosis.

However, as further evidence emerged, it became apparent that the impact of under-fuelling is not confined to menstrual and bone health. Rather, the consequences of under-fuelling are multisystemic and can also affect male athletes. This led to the initial description of REDs in 2014 as a syndrome comprised of the potential adverse effects on many systems in the body with both physical and mental health implications. Crucially, unlike the female athlete triad, REDs also included the potential negative sequelae on athletic performance. Ultimately, the goal for all athletes is to perform to their best, so REDs is not something of interest just in academic or clinical circles. REDs is highly relevant to both biological sexes and exercisers of all levels and ages.

What is energy availability?

The underlying aetiology of REDs is low energy availability. The life history theory describes how biological processes compete for energy resources (5). Energy requirement for movement is prioritised from an evolutionary point of view in order to take evasive action from predators. The residual energy from food intake is described as energy availability. This is roughly equivalent to resting metabolic rate for the individual. Simply lying in bed all day, staying alive, has a high level of energy demand for humans as homeotherms. The numerical value of energy availability is expressed in kcal/kg of fat-free mass. The energy availability requirement for health will vary between individuals depending on sex, age and body composition. Although energy availability is a very useful concept, in practice it is not actually measured outside of the research setting. Rather, objective surrogates indicating energy availability can be measured, such as triiodothyronine which is used as a primary indicator of low energy availability as outlined in the updated REDs Clinical Assessment Tool, which is described in further detail below (6).

An important highlight from the updated consensus statement on REDs is that it is specifically low carbohydrate avail-

ability that is most detrimental, especially for reproductive hormone networks. Comparing isocaloric intake, where there is a low proportion of energy from carbohydrate, this has the most marked negative consequence on both hormone health and performance. The mechanism of sustained low carbohydrate availability appears to involve the hormone leptin, an adipokine, which is secreted by adipose tissue. Low levels of leptin cause suppression of the reproductive axis via the hypothalamus-pituitary axis (7).

Aetiology of low energy availability

Low energy availability is a situation where, once energy demand from movement has been met, the available residual energy is insufficient to support the functioning of other biological life processes.

Low energy availability could arise unintentionally or intentionally (8). Unintentional low energy availability is where an exerciser does not appreciate the energy demands of exercise and other activities with an energy demand. For example, many athletes will not consider the energy required to "commute" to a training session on foot or by bike. Unintentional low energy availability could be due to practical issues; for example, a long cycle ride over several hours will require the cyclist to take nutritional sources in the pockets of clothing and/or plan in suitable stops where it is possible to obtain nutrition. Similarly, going to a training camp, especially at altitude, will greatly increase energy demand from exercise and this needs to be factored in. Finances could also be a limiting factor.

On the other hand, intentional low energy availability is where an exerciser intentionally restricts nutrition intake in the belief that this might confer a performance advantage in terms of body weight, composition or shape. Intentional food restriction covers a range of eating behaviours, from disordered eating to a clinically diagnosed eating disorder. This is particularly associated with any exercise against gravity such as running, road cycling and climbing; weight category sports like martial arts; aesthetic forms of sport (diving, gymnastics); and dance.

For individuals with intentional low energy availability, psychology and mental health can have a reciprocal interaction (9). Personality characteristics such as self-motivation and perfectionism can be very laudable traits in terms of dedication to exercise training to achieve success. However, when these characterises impact and support rigid behaviours around training and nutrition, this can become problematic (Figure 1). Those who are able to adapt to external pressures and have a flexible approach to training and nutrition are more likely to experience positive outcomes, whereas those who have a more rigid approach, which might include disordered eating, an eating disorder and/or exercise dependence, are more likely to experience negative outcomes. This reinforces self-doubt and culminates in a vicious circle of perpetuating rigid behaviours and negative outcomes in terms of both physical and mental health.

Evidence for this interaction between psychological factors and the risk of REDs was found in our study of dancers, referenced in the updated IOC consensus statement. A significant relationship was found between psychological factors such as anxiety around body shape/weight and missing training. These psychological factors had significant associations between physical manifestations of low energy availability (low body weight) and physiological outcomes (menstrual irregularity) (10). Similarly, in more of our published research papers referenced in the IOC consensus statement focusing on male athletes, a significant association was found between cognitive nutritional restraint and negative physiological and performance outcomes (11).

Acknowledging this reciprocal interaction between internal and external factors is a systems biology approach, highlighted in the recently updated IOC consensus statement. From a physiological point of view, the brain is a high-energy-demand organ, requiring a good supply of glucose. Low carbohydrate availability will restrict this cerebral energy supply, which can impair cognitive function and, ultimately, decision making. It is interesting to reflect that the neuroendocrine gatekeeper, the hypothalamus, monitors internal and external factors, not distinguishing between the source of stressors when initiating an adaptive response (7).

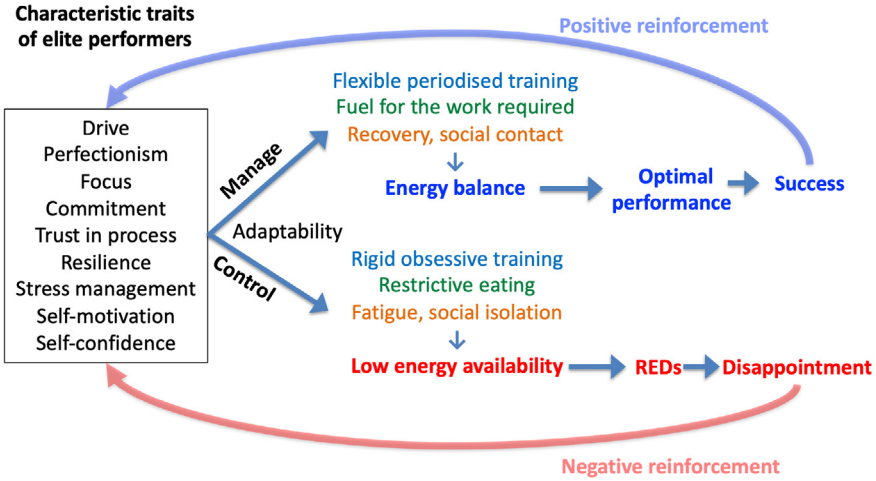

Figure 1: Psychological factors in REDs (reproduced with permission from nickykeayfitness.com)

Consequences of cumulative low energy availability

Low energy availability is not synonymous with REDs. Indeed, short-term low energy availability might initially help performance. Low energy availability can become problematic, depending on the time scale, which, in turn, determines the degree of adaptive response, described in the clinical physiological model of REDs (12). The first system to adapt to low energy availability is bone, as bone turnover moves in favour of resorption over formation. This is why bone stress responses, specifically bone stress fractures, can be an early warning sign of REDs and is designated a primary indicator in the updated IOC consensus statement. There will follow sequential down-regulation of metabolic rate, mediated via the thyroid axis, followed by the reproductive axis. In women, primary amenorrhoea or sustained functional hypothalamic amenorrhoea (FHA) lasting 6 months or more is a severe primary indicator of REDs. In men, low-range testosterone is a severe primary indicator. Ultimately, body composition will be adversely affected, with the only endocrine system to be up-regulated being that of the hypothalamic-pituitary-adrenal axis (13).

Health

Cumulative low energy availability causes the syndrome of REDs, which produces progressive adverse effects on all aspects of health and physical, mental and social wellbeing, as described in the REDs conceptual model. Poor sleep will compound these negative health effects (7).

Performance

Although there may be some initial good performances, chronic low energy availability will result in adverse performance consequences of REDs, described in the REDs performance conceptual model. In our referenced papers in the consensus statement, we found that in male athletes, short-term low energy availability negatively impacted performance (14). In another of our referenced studies, we showed that male cyclists in sustained low energy availability over 6 months not only experienced bone loss commensurate with that experienced by astronauts in space, but these cyclists also underperformed compared with their energy-replete fellow cyclists (15). On a positive note, explaining to athletes and dancers that improving energy availability will improve their performance can help in overcoming problematic behaviours.

Identification of those at risk

In view of the potential adverse health and performance effects of REDs, it is a priority to raise awareness of this risk to affect prevention. To this end the British Association of Sports and Exercise Medicine (BASEM) has produced a website, health4performance.basem.co.uk, dedicated to providing reliable information on REDs for athletes, parents, coaches and healthcare professionals, together with BASEM-endorsed online courses. Targeting and identifying those at increased risk is very important. Young athletes and dancers can be most severely affected as down-regulation of hormone function due to low energy availability can cause delays in growth and development. In particular, delayed puberty and menarche dampens the accrual of peak bone mass, with implications for bone health (16). Furthermore, there is evidence that these adverse effects on bone health might not be fully reversible (17).

From a psychological point of view, the young aspiring athlete and dancer is also at heightened risk. This was explored and viewed by many dancers in the BBC *Panorama* episode, "The Dark Side of Ballet Schools" (season 33, episode 28). Selection for specialised training will inevitably favour those who are self-motivated and dedicated. In a group of individuals sharing similar psychological traits this could act as a "breeding ground" for reinforcing these characteristics in ways that could lead to behaviours which are not conducive to positive outcomes, rather reinforcing the negative interpretation of external and internal factors, leading to a vicious circle of reinforcing attitudes and behaviours leading to REDs, as described in Figure 1.

Risk stratification

Early identification of those at risk of developing REDs is an important preventative strategy, especially for young aspiring athletes and dancers in whom behaviours around eating and exercise are being established and developed. A step-by-step approach to identify and risk-stratify individuals is provided in the second version of the Relative Energy Deficiency in sport Clinical Assessment Tool (REDsCat v2) (6). Initial low-cost screening questionnaires can be helpful, particularly if tailored to a specific sport/activity or dance, for example, the sports-specific energy availability questionnaire (18) and the dance energy availability energy questionnaire (10). These can be helpful in identifying those individuals for whom further investigation is clinically indicated. As REDs is a diagnosis of exclusion, targeted blood testing excludes medical conditions *per se* and provides objective quantification in the stratification of risk. Severe primary indicators of REDs are issues in the reproductive axis, namely a long duration of amenorrhoea in females and low-range testosterone in males.

From a combination of all these results, the individual can be placed in an appropriate risk category. The updated REDsCAT v2 includes a more fine-grained approach, with four categories of green, yellow, amber and red. This assessment also provides the background on which to base the appropriate level of support. For all, management will be directed at restoring energy availability and include modification of training schedules and nutritional intake. However, the details will vary according to the severity of REDs. Individuals with intentional REDs, especially when formally diag-

nosed with an eating disorder, will need more intensive input than a person with transient unintentional low energy availability.

Management

A nuanced approach is required for individual athletes, depending on their risk stratification and biopsychosocial factors. In all cases, some degree of psychological support will be helpful. Involvement of the extended multidisciplinary team is ideal, including the physician, dietitian, coach and parent (where appropriate), with the athlete/dancer at the centre.

Restoring energy availability will require careful discussion around nutrition in terms of the consistency of eating patterns and composition of food groups consumed. This starts with regular meals containing good portions of complex carbohydrate and protein. Studies show that inconsistent intake of carbohydrate (e.g., "backloading" eating to the evening) produces an unfavourable hormone profile. Fuelling around training is also a high priority for hormone health and driving positive adaptations to exercise. Pre-training consumption of carbohydrate, together with post-training refuelling with both complex carbohydrate and protein within 20 minutes of stopping, are important behaviours for favourable hormone response to exercise (7).

In terms of pharmacological intervention, National Institute for Health and Care Excellence (NICE) guidelines, updated in 2022, recommend body-identical hormone replacement therapy (HRT) over the combined oral contraceptive pill for bone protection in those with evidence of bone poor health due to FHA as a consequence of REDs (19). Poor bone health is defined as an age-matched Z score less than −1 of the lumbar spine (trabecular bone is particularly sensitive to low oestradiol) and/or two or more stress fractures at a site of concern (trabecular-rich bone). For male athletes/dancers, external testosterone is not appropriate, as this supresses internal hormone production. Furthermore, testosterone is on the World Anti-Doping Agency banned list and it is not possible to obtain a therapeutic use exemption as REDs is a functional condition, not a medical condition.

Prevention

Prevention is always the ultimate goal. In order to achieve this, a cultural shift in sport and dance is required. The emphasis should be on the fact that health is a prerequisite for performance. Pursuing a lighter body weight or leaner body composition will not automatically lead to improved performance. Each individual will have a personal "tipping point". As we are all different, there is no such thing as a generic "ideal" weight, shape or body composition.

In practical terms, prevention can be considered as primary, secondary and tertiary (20). Primary prevention consists of providing and disseminating reliable educational resources. Secondary prevention includes early identification of those at risk of developing REDs, together with prompt and correct diagnosis. For example, regardless of whether the individual is an athlete or dancer, amenorrhoea in a woman of reproductive age (apart from physiological amenorrhoea of pregnancy) is never "normal", whether blood tests are in range or not. The tertiary level of prevention encompasses evidence-based treatments. As mentioned above, NICE guidelines are now in line with those of the Endocrine Society and the IOC in advising HRT for bone protection in FHA, rather than the oral contraceptive which masks underlying hormone dysfunction and is not bone-protective. Similarly, thyroxine is not advised where there is down-regulation of this axis as a consequence of REDs. This is not the same as the medical condition of a primary underactive thyroid indicated by raised thyroid-stimulating hormone (7).

Conclusion

Ultimately, we all have a role to play in supporting exercisers, athletes and dancers in avoiding "the REDs card" (21). This involves the extended multidisciplinary team, starting with the individual exerciser, and extending to their family, friends and coaches, and then bringing in healthcare professionals from medicine, dietetics and physiotherapy.

Imbalances in behaviours around exercise and nutrition can have potential negative consequences on all aspects of health and performance. On a positive note, exercise, supported with appropriate nutrition, is an excellent way to achieve and maintain optimal physical, mental and social health, and support performance. This is applicable for exercisers of all ages and levels, from the recreational to the amateur to the elite athlete.

Funding and declarations of interest

No funding received.

The author declares that she has no conflicts of interest.

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Muscle dysmorphia in men: challenges in classification and recognition

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Abstract

Muscle dysmorphia (MD) is a condition marked by increased preoccupation with increasing muscle size and sculpting the body to achieve a very defined muscular look akin to a bodybuilder's physique. First described in the 1990s, MD is still a condition about which little is known and there exists an ongoing debate regarding its classification, manifestations and best ways to treat it. It is undeniably closely linked with conditions on the eating disorder spectrum and this proximity has invited many opinions to challenge its classification under the umbrella of body dysmorphic disorders. Further exacerbating the efforts to understand MD is the fact that, so far, little work has been done to understand the depth at which it is affecting our society and extent of its presence among individuals. More work is needed to understand the intricacies of this condition and to clarify its position among other body image-centric conditions; only then will we be able to address it fully and take tangible steps to alleviate its symptoms.

Introduction

In 1993, Pope, Katz and Hudson (1) carried out a study in which 8.3% of 108 male bodybuilders were described as exhibiting signs of a body image disorder characterised by the belief that they were "weaker and smaller" despite being "large and muscular". The term "reverse anorexia" was used to mark this condition due to its characteristic preoccupation with "bigness" as opposed to "thinness". This was one of the earliest descriptions of the condition we now know as muscle dysmorphia (MD). In the study, Pope et al. suggested a link between anorexia and reverse anorexia and a potential increased risk of developing reverse anorexia in male bodybuilders. They also reported an increased use of steroids in patients with reverse anorexia. The term "muscle dysmorphia" was coined in a 1997 study by Pope et al. (2) as a subtype of body dysmorphic disorder (BDD) that affected both men and women. In this study, the rising prevalence of the disorder was linked to an increased interest in weightlifting and body sculpting in society, and it was suggested that reversing the prevalent and fashionable bodybuilding trends could lead to a drop in the numbers of MD cases (2). Comorbidities such as steroid use and elevated stress levels were also highlighted. The diagnostic criteria developed in that study are still used to this day (Box 1). Box 2 shows, by comparison, the DSM-5 diagnostic criteria for MD under the umbrella of the obsessive-compulsive disorder branch of BDDs.

Box 1. Muscle dysmorphia diagnostic criteria as suggested by Pope et al. (2); individuals need to satisfy all the criteria in order to be diagnosed

1. The preoccupation with the idea that one's body is not as lean or as muscular as desired, coupled with prolonged weightlifting and strict dieting.
2. The preoccupation negatively impacting the individual's life in two out of the following four areas.
   A. Forgoing social, recreational and occupational activities to maintain their diet and workout regimen.
   B. The avoidance of situations that would call upon exposing their body and only indulging with marked signs of distress and discomfort.
   C. The presence of clinically significant levels of distress in social, recreational and occupational functioning due to the preoccupation with body size.
   D. The continual partaking in dieting, exercising and substance abuse despite knowing their adverse physical and psychological effects.
3. The preoccupation is primarily linked with the idea of being too small and not being muscular enough.

Precipitating factors

In 2000, the first controlled MD study was conducted by Olivardia, Pope and Hudson (4), in which they canvassed and screened individuals from several gymnasiums. Participants were separated into a MD group consisting of 24 men and a second group consisting of 30 men with "normal" weightlifting habits. They found that the men in the MD group exhibited higher degrees of body dissatisfaction, disordered eating habits, prevalence of anabolic steroid use and lifetime prevalence of DSM-IV mood, anxiety and eating disorders. The media, along with peer pressure, has been suggested as one of the main reasons behind the increased risk of developing MD (5). In their work, Thornborrow et al. established that samples from both Western, educated, industrialised, rich and democratic (WEIRD) and non-WEIRD societies exhibited pressure to seek muscularity and suggested that media dissemination between cultures helps in delivering westernised body ideals to cultures that might not have been as inclined to seek a muscular body ideal (5). A study of 593 "celebrity worshippers" in China examined the role that parasocial attachments to celebrities has on

Box 2. DSM-5 diagnostic criteria for body dysmorphic disorders (3)

Disorder class: obsessive-compulsive and related disorders

A. Preoccupation with one or more perceived defects or flaws in physical appearance that are not observable or appear slight to others.

B. At some point during the course of the disorder, the individual has performed repetitive behaviours (e.g., mirror checking, excessive grooming, skin picking, reassurance seeking) or mental acts (e.g., comparing his or her appearance with that of others) in response to the appearance concerns.

C. The preoccupation causes clinically significant distress or impairment in social, occupational or other areas of functioning.

D. The appearance preoccupation is not better explained by concerns with body fat or weight in an individual whose symptoms meet diagnostic criteria for an eating disorder.

Specify if:

- With muscle dysmorphia, the individual is preoccupied with the idea that his or her body build is too small or insufficiently muscular. This specifier is used even if the individual is preoccupied with other body areas, which is often the case.

Specify if:

Indicate degree of insight regarding body dysmorphic disorder beliefs (e.g., "I look ugly" or "I look deformed").

- With good or fair insight: the individual recognises that the body dysmorphic disorder beliefs are definitely or probably not true or that they may or may not be true.
- With poor insight: the individual thinks that the body dysmorphic beliefs are probably true.
- With absent insight/delusional beliefs: the individual is completely convinced that the body dysmorphic beliefs are true.

the degree of body dissatisfaction and found a significant association between muscularity-oriented body dissatisfaction and celebrity worship in men (6). Even action figures traditionally marketed towards young boys have become leaner and more masculine. In their 1999 study, Pope et al. (7) collected an assortment of popular action figures and carried out waist and chest measurements; they found that the more recently produced toys were markedly more muscular. They suggested that their findings provided the male analogue to research on toys such as Barbie and their effect on female body image, and how the normalisation of a certain body type through these toys sets a standard to be achieved from a young age (7). Perhaps no other male toy embodies this focus on "outlandish physique" as much as G.I. Joe, an action figure that was first introduced in 1964, according to a New York times article entitled "Drugs, Sports, Body Image and G.I Joe" (8). Furthermore, the advent of online dating has played a part in creating pressure to conform to a certain ideal in order to be viewed as desirable. A study examining the relationship between dating apps and body dissatisfaction among sexual minority men (bisexual, gay and men who sleep with men) using the Male Body Attitude Scale (MBAS) (9) found that dating app users reported significantly higher degrees of body dissatisfaction compared to the participants who were not on those apps (10).

Manifestations and links to eating disorders

MD is a condition that manifests itself in extreme dieting and exercise regimes, social and professional dysfunction, anxiety, supplement abuse leading to possible physical harm, depression and suicidality (11). MD has been linked to eating disorders since it was first described as "reverse anorexia nervosa" by Pope et al. in their seminal paper in 1993 (1). Of note, however, is the fact that in their study, Pope et al. concluded that two out of the three individuals with anorexia nervosa (AN) also suffered from "reverse anorexia nervosa". This degree of overlap was noted by the authors as worth investigating, commenting that the similar nature of the two conditions.

It justified the name "reverse anorexia nervosa" since the disorder seemed to present much like AN but in reverse (1). In fact, there exists a significant degree of similarity between the diagnostic criteria for MD, AN and bulimia nervosa (BN) (12). According to the DSM-5, AN and BN are characterised by a degree of self-evaluation based on body shape and weight (3). This self-evaluation is also present in MD patients (2). People suffering from these conditions are in pursuit of different versions of the "ideal body" to which they attach their own self-worth. Similarly, in a 2004 study by Olivardia et al. (13) that examined the link between male body dissatisfaction and various other associated factors, including eating pathologies, the authors found a positive relationship between male body dissatisfaction and measures of eating pathologies.

Diagnostic tools

There are several diagnostic tools for MD based on the current diagnostic criteria. The Muscle Dysmorphia Inventory (MDI) (14) is a self-reporting tool which includes 40 items and six sub-scales: body size–symmetry, physique protection, exercise dependence, supplement use, dietary behaviour and pharmacological use (14, 15).

The Muscle Dysmorphia Disorder Inventory (MDDI) (16) was derived from the MDI to incorporate better the functional impairment associated with MD (15). The original MDDI consisted of 21 self-report items scored on a five-point Likert scale across three subscales: drive for size, appearance intolerance and functional impairment (16). A more recent version of the MDDI consists of 13 items across the same three subscales (17). Other assessment tools include the

Adonis Complex Questionnaire (18), the Muscle Dysmorphia Symptoms Questionnaire (4) and the Muscle Appearance Satisfaction Scale (19).

Classification

MD is categorised as a BDD within the somatoform disorders (3). However, there is ongoing debate about how MD is conceptualised and classified, with detractors of the current classification highlighting the similarities between MD, AN and other eating disorders, as mentioned earlier. One major area of contention centres around the argument that, unlike other BDDs, MD exhibits an obsessive-compulsive preoccupation with exercise and diet which is similar to AN (20). Contrary to previously held beliefs, meticulous and strict dieting is not a secondary feature, but a primary and fixed feature in developing and maintaining MD (21); individuals with MD report a heightened sense of anxiety with regard to diet disturbances (2). This strict adherence to dieting further links MD to the eating disorder spectrum in a way that is not matched by any other BDD. Similarly, the role of exercise has been shown to be central to the development of AN, especially amongst males (22), thus indicating that both excessive exercise and strict diets are integral in the development of both MD and AN. Moreover, it is argued that, unlike most BDDs, MD shows a skewed gender ratio, with males more likely to be affected than females, and AN also has a skewed – if reversed – gender distribution (23, 24). It has been argued that eating disorder assessment tools are often directed towards traditional feminine body concerns, such as hip and buttock measurements, while neglecting body concerns that could pertain more closely to the male population, rendering the entire diagnostic process skewed (25). These factors seem to drive the conclusion that MD needs to be reconceptualised as an eating disorder rather than a BDD. Alternatively, Chung et al. (20) argue that both MD and AN are marked by the presence of certain obsessive-compulsive tendencies with regard to body shape, weight, exercise and dietary practices, and therefore it would potentially be beneficial to include MD as an obsessive-compulsive disorder better to address these aspects of disordered behaviour, rather than focusing on the body dissatisfaction elements. However, if both AN and MD exhibit obsessive-compulsive tendencies, the question then is, should they be both classified as obsessive-compulsive disorders, or should they be conceptualised as eating disorders with obsessive-compulsive tendencies?

It is evident that the classification of MD remains open to debate. Two separate systematic reviews, conducted in 2012 (26) and 2020 (27), concluded that research in MD still needs to cover multiple areas to achieve a better understanding of the true nature of the illness. Recommendations have ranged from keeping MD on the BDD spectrum, reclassifying MD as an ED, reclassifying MD as an obsessive-compulsive disorder or categorising MD as a distinct disorder under the "Feeding and Eating Disorders" category (26, 27). A study by Foster et al. (28) suggested reclassifying MD as an "addiction to body image", based on the notions that individuals maintain long-lasting harmful practices due to their addictive tendencies towards attaining and sustaining a "perfect body type". The lack of detailed research is a limitation to progress in the classification debate. It is important for more studies to look at the true nature of MD among people who are suffering from the condition in order to provide an accurate depiction of the lived experiences of these individuals. It is possible that many critical nuances of this disorder are yet to be identified. This detailed, accurate understanding of the manifestations of the disorder on an intimate level should help to inform those designing comprehensive large-scale studies to define the parameters of MD more clearly and place it where it belongs categorically.

Recognition and challenges

Following this early work, MD and the preoccupation with muscle size has become a hot topic of research, especially in the last 10 years (29), leading to the addition of MD to the DSM-5 (3), where it is characterised as a subset of BDD. Similarly, MD is mentioned in the ICD-11 under the umbrella of BDD (30). Despite the uptake in research, there is an ongoing uncertainty about how to classify the disorder. In 2016, dos Santos Filho et al. (31) conducted a systematic search of the literature dedicated to the study of MD and concluded that not enough work had been done to ensure the "validity, clinical utility, nosological classification and inclusion of MD as a new disorder in classificatory systems of mental disorders". Another issue is that while clinicians are encountering more patients with this disorder, little work has been done with individuals who have been clinically diagnosed with MD in order to glean from them their experiences (32). To date, only one study we could find had been conducted to examine the diagnostic criteria established by Pope et al. in 1997 (2) (shown in Box 1). Hitzeroth et al. (33) used structured diagnostic interviews and examined a sample of 28 amateur bodybuilders in Western Cape in South Africa to determine whether they satisfied the proposed diagnostic criteria. They found a prevalence of 53.6% for MD and a 33% prevalence of comorbid BDD. More work is needed to establish the extent to which MD is affecting society. Prevalence rates have been shown to vary from 1% to 54%, depending on the study. This discrepancy is often attributed to the lack of a standardised method of diagnosing MD. However, it has been suggested that up to 1 in 10 gym-going men in the UK could be suffering from MD (34). It is unclear what percentage of gym memberships are held by men; however, it is estimated that the split is 46% and 54% for males and females, respectively (35). Coupled with the fact that more than 16% of the UK's population (10.7 million) held an active gym membership in 2024 (36), this implies that 490,000 men in the UK (1.48% of the male population) could be suffering from MD and all of its potentially life-threatening consequences. This number is close to the estimated 427,000 males suffering from MD in the UK that was posited by Tod et al. in their 2016 review (29). In

comparison, it is estimated that 266,300 and 443,800 people suffer from AN and BN, respectively (37). This suggests that MD could be as pervasive as these conditions. However, it remains misunderstood and misdiagnosed, and treatment options remain vague and unfocused. More attention needs to be paid to this condition.

Conclusion and future questions

MD is a condition marked by excessive preoccupation with muscular size and features. It can appear in both sexes but seems predominately to affect men. The rationale to explain this gender polarity relates to societal expectations of muscularity among men. MD manifests in a variety of behaviours, with the main three being an unhealthy association with exercising in order to gain muscle, very rigid and strict dieting and use of steroids/other androgenic substances. MD classification as a subtype of the BDD spectrum has long been a topic of debate, with sceptics arguing that MD has much more in common with other eating disorders such as AN, with both conditions being characterised by unhealthy dieting and exercise. However, much of the research has focused on a categorical approach to define MD and not much has been undertaken to look into MD as an independent condition with features transcending the different categories. The issue of classification remains unresolved. Should MD be classified within the category of one of the other disorders or should it be viewed as a separate condition comprising features of eating disorders, body dysmorphia and obsessive-compulsive disorder? However, the more important questions are how MD, an apparently widely prevalent condition, should be recognised, and how it should be managed satisfactorily to minimise the potentially serious comorbidities. These questions will be best addressed by conducting more studies to look at the lived experiences of the individuals who have suffered from MD. It is only through the deep understanding of such stories that future research could be shaped to best address the unique manifestations of MD across different individuals. Furthermore, future studies need to examine the sociocultural differences amongst people suffering from MD and how these affect the ways the condition manifests. Different sexualities and ethnicities infer different life experiences and therefore potentially different areas of concentration when it comes to one's relation to one's body. An example of this was manifested in a study on MD among transgender men (38). This study found that, despite similar scores in the drive for size category, transgender men were more likely to show anxieties and body avoidance behaviour compared to cisgender men. These differences are potentially fuelled by different life experiences that warrant further investigation in order to gain additional understanding of MD that reaches beyond the two dimensional "muscular versus skinny" approach.

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Eating disorders during the perinatal period

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Abstract

Eating disorders (ED) are severe psychiatric disorders that affect women in reproductive age. Although ED features tend to reduce during pregnancy, remission may only be temporary, with features typically resurfacing during the postpartum period. There is evidence that women with ED may have increased risk of adverse pregnancy and birth outcomes and be more vulnerable to psychiatric comorbidities such as depression and anxiety. Maternal ED may also have implications for child psychological, cognitive and eating behaviours. Pregnancy and motherhood, particularly in the early stages, is an opportune time in a woman's life for health professionals to engage with affected women and initiate appropriate treatment and support to promote the best possible maternal and infant outcomes.

Keywords: eating disorder, pregnancy, postnatal, mothers, intergenerational transmission

Introduction

Eating disorders (ED) are a heterogenous group of mental illnesses that are associated with significant health and psychosocial functional impairments and often comorbid with other mental illnesses. There are several types of ED, some of which have received more attention in the perinatal literature than others and, as such, are the focus of this article, including anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and other specified feeding and eating disorders (OSFED) (1).

Menstrual dysfunction and infertility

The association between AN and menstrual dysfunction has been well cited in the ED literature (2, 3). Indeed, amenorrhea (i.e., the absence of menstruation for at least three consecutive months) was, until recently, a core diagnostic criterion of AN before its removal in DSM-5 (1). This change was in response to the mounting evidence suggesting it better reflects weight and nutritional status and can be a marker of clinical severity relevant for all ED subtypes, rather than providing diagnostic value (4).

Findings from a comprehensive review indicate that up to 84% and 11% of women with AN reportedly experience amenorrhea and oligomenorrhea (i.e., infrequent menstruation), respectively, and disturbances do not resolve in all cases following weight restoration (5). While menstrual disturbances are more frequently reported by women with AN, women with BN and BED similarly experience menstrual dysfunction at high rates, though more commonly oligomenorrhea (5). Studies have demonstrated strong associations between amenorrhea and low weight, calorie restriction and high levels of exercise, whereas oligomenorrhea has been linked to binge eating, vomiting and use of appetite suppressants (5). It is hypothesised that these different associations relate to different hormonal and metabolic changes; for instance, heightened stress, calorie restriction and high levels of exercise, often common but not exclusive to AN, can lead to a deficiency in gonadotropin-releasing hormone (GnRH) which contributes to ovulatory dysfunction, known as functional hypogonadotropic hypogonadism (6).

Given the common occurrence of menstrual disturbance in women with ED, some studies suggest women with ED may also be more likely to experience infertility. A recent systematic review of 10 studies of women seeking fertility treatment reported prevalence rates ranging between 0.5% and 16.7% for active ED and between 1.4% and 27.5% for a history of ED (7). The prevalence rates of AN, BN and BED in women seeking fertility treatment were up to 1.7%, 10.3% and 18.5%, respectively. One of the studies included in the review reported that the majority of women receiving GnRH treatment had a history of an ED, most commonly AN (8). The substantial variations in prevalence are likely attributable to the review including both women with ED and those with disordered eating behaviours, as well as the use of different tools to measure eating pathology. Contrastingly, findings from two large population-based cohort studies did not identify differences in pregnancy rates between women with and without AN (9, 10). Easter et al. (9) reported that women with AN more frequently sought fertility advice but it was women with history of both AN and BN who took longer to conceive and more often conceived via fertility treatment. No significant difference was found in mean age between cases and controls. The authors noted that women with AN and BN had the highest prevalence of lifetime purging and lowest pre-conception body mass index (BMI), suggesting that the severity of the ED might explain the higher risk of fertility-related problems in this group. Other findings indicate higher rates of unplanned

pregnancies among women with both AN and BN, which may relate to menstrual disturbances and misconceptions among women regarding their ability to conceive in the absence of menstruation (9-11).

Prevalence of eating disorders

Few studies have investigated the prevalence of ED in antenatal samples. Of those available, prevalence rates for active ED during pregnancy range between 1.5% and 7.6% (12-15). These wide discrepancies are largely due to variations in diagnostic tools and the definitions employed, in the absence of validated screening tools and consensus around operationalised definitions for antenatal populations (16, 17). There is some evidence to suggest pregnancy may also represent a risk for the development of a new ED (12, 13). Although less common than the exacerbation of pre-existing ED, the significant physical, hormonal and psychological changes associated with pregnancy may also contribute to the onset of new cases, most commonly BED (12). The estimated lifetime prevalence – which is the proportion of the population who have experienced an ED at any point in their life – in pregnant women is considerably higher than the rate of active ED, at around 15.4%, the majority of whom will have lifetime AN or OSFED (15). It is therefore important to screen for both current and past ED during antenatal visits to identify people actively experiencing features and recognise those who are at risk of deterioration and may benefit from enhanced support throughout the antenatal and postnatal periods.

Features and experience during pregnancy

Several quantitative studies have examined changes in ED and comorbid mental health (including anxiety and depression) symptomatology over the pregnancy period. Using data from a prospective observational cohort study, Easter et al. (18) reported that women diagnosed with active and past ED had significantly higher levels of psychopathology during pregnancy compared to healthy controls. However, while overall ED features decreased during pregnancy in women with a current ED, those with a history of an ED experienced a steady increase in features (18). Findings from a small clinical sample in remission from AN and BN conducted in an outpatient setting similarly indicated that two-thirds of women in remission prior to pregnancy experienced a resurgence of ED features during pregnancy (19). Overall reductions in features are likely largely to be driven by reductions in certain behavioural (i.e., self-induced vomiting or excessive exercise) factors rather than in cognitive features, which are thought typically to persist throughout the perinatal period (12, 20-22).

Other studies have explored changes in features of disordered eating in population-based samples, rather than focusing on women with a diagnosed ED. Baskin et al. (23, 24) reported that features decreased during pregnancy and that psychosocial factors, negative attitudes to pregnancy and motherhood predicted an increase in features, whereas self-compassion, social support and relationship satisfaction predicted a decrease (23, 24). Other studies have identified positive associations between perfectionism, dissatisfaction with body image and symptoms of pre-traumatic stress (25, 26).

Findings from a recent meta-ethnographic study substantiate the findings from quantitative investigations. Fogarty et al. (27) reported that the early pregnancy period can be particularly challenging for women with current and past AN and BN as they experience changes in appetite, body weight and shape that conflict with their eating-disordered cognitions and motivation to protect their unborn infant from potentially harmful behaviours. Most women report feeling more adjusted as their pregnancy progresses, though this is not always the case, and some women may still engage in compensatory behaviours, which can lead to feelings of shame and guilt (27). Taborelli and colleagues (28) conducted a qualitative study exploring the experience of transition from pregnancy to motherhood in a sample of postnatal women with severe ED. The authors found that women who gave birth to a healthy infant were less motivated and less likely to discontinue engaging in compensatory behaviours in a subsequent pregnancy as they were less concerned about the potential harm, having felt reassured by their previous pregnancy (28).

Pregnancy and birth outcomes

Women with ED may have heightened risks of adverse pregnancy and birth outcomes, with evidence suggesting that associations are mediated by a culmination of factors, including clinical severity and pre-conception, pregnancy weight and nutrition status, and largely independent of other psychopathology (29). A large population-based birth cohort study reported that women with lifetime BN have an increased risk of miscarriage (30). Women with BED may also have a greater risk of miscarriage (31), possibly related to the higher risk of obesity which is similarly linked to risk of miscarriage (32). Earlier studies suggest hyperemesis gravidarum is more common among purging types of ED (33), whereas, more recently, Mantel et al. (29) demonstrated an increased risk of hyperemesis gravidarum for all ED subtypes. Findings also suggest that women with current AN, lifetime BN and eating disorder not otherwise specified (EDNOS) may be more likely to experience anaemia during pregnancy, which is likely to be related to nutritional deficiencies that are common to ED (29, 34); however, data are limited.

The most consistent findings pertain to AN with regard to elevated risks of intrauterine growth restriction, small for gestational age and lower birth length and weight (29, 30, 35-39). A population-based cohort study of a large sample of women who had been hospitalised for AN before or during pregnancy found that risks remained regardless of

when hospitalisation occurred, although the risks were greater for women with a recent hospitalisation and those with comorbid mental health conditions (39). Lifetime BED has been linked to an increased risk of delivering an infant that is large for gestational age (34, 37). Few studies have examined birth outcomes in association with OSFED, although there is some evidence that sub-threshold ED similarly reflect a heightened risk of adverse birth outcomes (37, 38). Findings from Mantel et al. (29) indicate a slightly decreased risk of assisted birth for women with AN and sub-threshold ED compared to women without an ED. The same authors found a 60% increased risk of preterm birth in women with AN compared to controls, while women with BN and EDNOS had a slightly lower, but still significant increased risk. Medically induced preterm birth presented a higher risk than spontaneous preterm birth, with an 80% increased risk for women with AN, 60% for BN and 70% for EDNOS. Additionally, women with AN faced a two-fold increased risk of having a neonate with microcephaly, while the risk increased by 60% for women with BN and 40% for those with OSFED. Other risks associated with maternal ED include suspected foetal distress, stillbirth, rapid and prolonged labour, caesarean section, induced delivery and low Apgar scores (29, 34, 37-41).

Postnatal mental health

The postpartum period is a high-risk time for relapse and exacerbation of ED symptomatology (24, 42, 43). Following the delivery of a baby, dissatisfaction with body weight and shape is common, even in mothers without a history of ED. In the first month post-delivery, 75% of women report being preoccupied about their weight, with 70% of women attempting to lose weight by four months post-delivery (44). Indeed, the proportion of women with an ED nearly triples from pregnancy to the postpartum period (45). Although during pregnancy, women with ED seem to be more accepting of their body changes due to understanding that their body is serving the function of growing their child (27), worries about body and shape are likely to resurface during the postpartum period. In the first year postpartum, return to baseline ED psychopathology levels is a common course, with some research suggesting that relapse rates may be as high as 50%, depending on the population (19, 20, 46), but the desire to lose weight can itself be a trigger for the development of a new ED (47, 48). Factors known to increase the risk of relapse in disordered eating features are negative attitudes to pregnancy and motherhood, while self-compassion, social support and relationship satisfaction are associated with a decrease in risk (24, 43). The demands of caring for a newborn, along with sleep deprivation and emotional strain, can increase vulnerability to relapse (49).

Furthermore, women with ED may also be prone to anxiety and depressive symptoms in the postpartum period (18, 50). Studies suggest the prevalence of depressive symptoms is around 30% in women with an ED (20, 51, 52). In a recent nationwide US cohort study of 1,166,577 pregnant women from 2003 to 2016, it was found that all psychiatric diagnoses, including ED, increased the risk of postnatal depression irrespective of a previous history of depression (53). Likewise, findings by Makino et al. demonstrated that 50% of women in an outpatient clinical sample who developed postnatal depression had a previous ED history (19). This may not be unsurprising, given the high level of comorbidity of ED with depression (54). However, the small sample size, absence of a control group and recruitment from a private outpatient clinic limit the generalisability of these findings.

Breastfeeding practices and child feeding interactions

The effect of maternal ED on infant and child feeding has received considerable attention in the literature. Infant feeding is one of the crucial, although sometimes challenging, tasks of parenting, but is also one of the key means of communication between the mother and the child. Mothers with ED might experience difficulties in feeding behaviours with their children, starting with breastfeeding (55, 56). There is evidence to suggest that feeding difficulties starting early in life, may persist and have implications for other aspects of future child and adolescent development (57, 58).

Breastfeeding patterns have been widely explored in women with ED, yet findings are inconsistent, probably due to variations in study designs, populations and infant feeding practices more broadly (59, 60). A large population-based study found a longer breastfeeding duration in mothers with ED, especially in mothers with BN (59). Breastfeeding may increase the rate of weight loss after birth so some women, including women with ED, may engage in both prolonged breastfeeding and excessive pumping of breastmilk as a maladaptive weight-control behaviour (61). While Torgersen and colleagues found similar rates of initial breastfeeding rates between ED mothers and healthy controls, they noted earlier cessation among women with ED (62). Conversely, in a study carried out by Nguyen and colleagues, mothers with a history of ED were less likely to initiate breastfeeding, although this finding was not statistically significant after adjustment for confounding factors, including socio-demographics, BMI and maternal psychopathology (63).

Feeding difficulties are relatively common in infants, broadly speaking, with some evidence to suggest that mothers with ED may report greater difficulties. Population-based cohort studies have found that women with AN report slow feeding, poorly established routines and exhaustion during feeding (59, 60), while infants of mothers with BN reportedly exhibited higher levels of refusal to take solids compared to healthy controls (59).

Mothers with ED may express greater concerns about their infant being or becoming overweight (64), which may lead to heightened monitoring of eating practices compared to controls (65). In severe cases, this may lead to decreased caloric intake in the child and validation of dieting behaviours (66, 67). Children of mothers with ED may be more ex-

posed to critical attitudes toward weight and shape and mealtimes and eating patterns that deviate from the norm, and this may have implications for the development of ED later in life (68).

Parenting and the parent–child relationship

Maternal ED may also have implications for other aspects of parenting beyond the domains of food and eating (69). ED may be very time consuming, and an extreme preoccupation with weight and shape and the compensatory behaviours may impact on a mother's ability to respond sensitively to her infant's needs and, in turn, on the parent–infant bonding (48, 70). Furthermore, women with ED might be more vulnerable to anxiety and depression, which might also affect the mother's availability for the infant (71). Maternal ED is a risk factor for the development of an ED in the offspring (72, 73) due to its impact on parenting styles, and this goes beyond a genetic contribution (74-78). Indeed, family and twin studies estimate that genetic heritability significantly contributes to the development of ED, with genetic factors accounting for 58% to 74% in AN, 59% to 83% in BN and 41% to 57% in BED (79), though further research is needed.

Koubaa and colleagues examined maternal adjustment and attitudes in mothers with three-month-old infants, finding that those with a history of an ED before pregnancy showed significantly more negative attitudes toward motherhood and less favourable maternal adjustment compared to healthy controls (80). Research also demonstrates that mothers with ED are more vulnerable to anxiety and depressive symptoms in the early postnatal period (18, 53). Mothers with a lifetime ED are more likely to report difficulties in parenting their 18-month-old daughters and, in mothers with lifetime BN, difficulties in looking after their sons, compared to healthy controls (81).

In a small study of videotaped mother–infant play interactions, mothers with ED were rated as less sensitive, more controlling and more hostile toward their children compared to controls (82). Offspring of mothers with ED were rated as less involved and less responsive to their mothers (82). Maternal perceptions of the child's psychological problems were correlated with decreased emotional availability in mother–child interactions in mothers with ED (83). Social factors, such as relationship difficulties and marital conflicts, might also hinder the parenting ability and impact on overall child development (84). However, it is important to note the evidence on parenting ability and child development must be treated with caution, given the methodological limitations of such studies, including small and heterogeneous samples and a lack of consideration for other important factors such as sociodemographic issues.

Child cognitive, motor and language development

Research on neuropsychological profiles of offspring of mothers with ED has focused on understanding both the impact of maternal ED on children and the intermediate endophenotypes of ED (i.e., markers of disorder that might lie on the pathways between genetic or biological risk and actual phenotypical manifestations (85)).

Literature has shown that specific cognitive and neuropsychological differences might be present in the offspring of mothers with ED (81, 86, 87). In a population-based study carried out by Kothari et al. on children aged 8 to 10 years, children of mothers with lifetime BN displayed poorer visual-spatial functioning while children of mothers with lifetime AN had higher full-scale and performance IQ, increased working memory capacity, better visuospatial functioning and decreased attentional control (86). Investigating the early cognitive development (at 18 months and 4 years) in a sub-set of these children, the same authors indicated that the offspring of mothers with AN displayed greater difficulty with social understanding and poorer motor skills, planning and abstract reasoning (88). In a smaller longitudinal study, it was found that the infants of mothers with ED exhibited poorer language and motor development compared to those of control mothers. When examining outcomes based on active versus past ED, it was noted that child cognitive difficulties were linked to both maternal active and past ED (89). Ultimately, in a small longitudinal cohort study, Koubaa and colleagues found that children of mothers with AN or BN scored higher on measures of neurocognitive development than controls, reflecting difficulties in language and social skills (90). Overall, these findings highlight possible early developmental difficulties in motor and cognitive development in children of mothers with ED which warrants further exploration.

In the Danish Birth Cohort Study, boys aged 18 months who were exposed to maternal lifetime AN were less likely to have delays in cognitive and language development than healthy controls. No differences were found in cognitive and language development between exposed and unexposed girls or in motor development for either of the sexes (89).

To our knowledge, only one study to date has examined social cognition among children born to women with ED in mid-childhood and early adolescence, with some evidence of differences between at-risk (maternal ED exposure) and low-risk children (born to mothers with no ED). Specifically, maternal lifetime BED and maternal lifetime binging and purging were found to be associated with poorer social communication in children, while maternal binging and purging was also associated with differential facial emotion processing and poorer recognition of fear from social motion cues (87). These highly preliminary findings indicate a possible link between social communication difficulties and bulimic/binge eating–type phenotypes; however, replication is essential. A potential explanation for the differences in cognitive, motor and language development in children of mothers with ED, as compared to healthy controls, is that

infants of mothers with AN may be at greater risk of underfeeding, which could hinder development. The scarcity of research on motor development within this population limits the ability to draw firm conclusions. Additionally, there may be a complex interplay between environmental risks and protective factors shaping cognitive development, given the shared genetic links between AN and higher levels of educational attainment (91, 92). This might explain why the difference is diminished in most children by the end of primary school.

An important recent population-based study utilising the Swedish Medical Birth Registry found that maternal ED, across all subtypes, was associated with a higher risk of autism spectrum disorder and attention deficit hyperactivity disorder in children compared to those born to mothers without an ED. Additionally, the study observed a trend suggesting an even greater risk for children whose mothers had an active ED, especially in cases of maternal AN (93). This finding underlines the need to consider whether at least some of the above cognitive relationships are related to whether the mothers with ED were or were not autistic.

Identification and management during and following pregnancy

As outlined above, the evidence of persistent features and heightened risks for mother and infant highlights the importance of identifying women who are at risk and providing appropriate treatment and support during pregnancy and throughout the postpartum period to help reduce the risk of adverse outcomes (56).

Preferably, women with ED would be identified and receive appropriate treatment and support before pregnancy so that they are in a better state of health for when they do try to conceive. However, this may not always be practicable given that it is dependent on women having had prior access to services, which is often low in ED for a variety of reasons (94), and also on women actively planning for a pregnancy. The early stages of a first pregnancy can present a key opportunity for engaging with women, as they are likely to be highly motivated to address their ED (28).

Pregnant and postnatal women with ED may understandably be apprehensive about discussing their ED with health professionals due to feelings of shame and fear of being unfairly judged or stigmatised, particularly those who actively experience symptoms or are vulnerable to weight stigma (95, 96). To encourage a disclosure about an ED, health professionals should routinely enquire about current and history of mental illness with all women at their first routine contact in pregnancy and postpartum (97). It is imperative that these discussions are conducted in a sensitive, non-judgemental and empowering manner, and that disclosures are followed up with a comprehensive assessment of current health and needs (96).

In accordance with clinical guidance and best-practice recommendations, pregnant and postnatal women with a recognised ED should be allocated a dedicated health professional (e.g., a general practitioner or midwife) who can provide continuity of care as part of a wider multidisciplinary approach that includes all clinicians involved in their care. Effective communication and coordinated efforts among the various services involved (including general practice, maternity, health visiting, mental health and social care) is key to provide appropriate treatment and follow-up care. They should be offered a referral to an ED or to a perinatal mental health service, if the former is unavailable. The threshold for specialist services should be low during the perinatal period. Available ED treatments will need to be adapted for pregnant and postnatal women (i.e., interventions may need to continue throughout pregnancy and for a year postpartum and should consider several factors, including the perinatal stage, foetal or infant health, and maternal physical and mental health needs). Women should be provided with additional monitoring to identify any changes in mental and physical condition and foetal growth scans, where appropriate. They should also be engaged in sensitive and tailored discussions about the importance of healthy nutrition and infant feeding and weaning and signposted to voluntary organisations for online (e.g., Beat, the UK's leading ED charity) and local face-to-face peer support (e.g., local breastfeeding and new mum groups) (56, 97-99).

Conclusion

ED are common in women of reproductive age. Symptomatology tends to improve during pregnancy, with resurgence in the postpartum period. Postnatal changes in body shape, compounded by sleep deprivation and emotional stress, can heighten susceptibility to relapse of ED. Women with ED may be at increased risk of adverse pregnancy and birth outcomes, and recent evidence indicates that this applies to any ED subtype and women with current or past ED. Furthermore, women with ED may be more prone to developing psychiatric comorbidities such as depression and anxiety during the perinatal period. Research has mainly focused on AN and BN. Further research is needed to explore the impact of the broader spectrum of ED, particularly subthreshold ED, OSFED, pica, rumination disorder and ARFID, on pregnancy and the postpartum period and to improve identification of ED in the perinatal period. It is also important to note that the majority of studies included were conducted in Westernised countries and, where demographic details were available, participants were predominantly from White ethnic backgrounds and of higher socio-education status. Given that ED presentations may differ across ethnic groups and cultures (e.g., relating to parenting practice and cultural norms) (100), further research with more representative and diverse patient and community populations is essential to determine the applicability of the findings in this review to the wider population.

Early identification and response to maternal ED and comorbid risk factors are important to mitigate adverse mater-

nal and infant outcomes. It is important that health professionals feel equipped with the necessary knowledge and skills to provide women with appropriate treatment and support throughout the perinatal period to help reduce the impact on maternal and infant outcomes.

Declaration of interests

The authors declare they have no conflicts of interest.

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The NICE guideline for the recognition and treatment of eating disorders

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Abstract

The National Institute for Health and Care Excellence (NICE) guidelines are evidence-based recommendations intended to inform clinical decisions on the prevention and management of specific health conditions in the national health services of England and Wales. Recommendations made in the guidelines are based on evidence from systematic reviews of the published literature and expert opinion and are developed by the National Guideline Alliance. The NICE guideline for the recognition and treatment of eating disorders (NG69) was published in 2017, replacing the previous 2004 guideline (CG9) and reflects a substantial increase in the evidence base in the intervening period. The guideline covers assessment, diagnosis, treatment, monitoring and inpatient care for children, young people and adults with eating disorders, specifically anorexia nervosa, binge eating disorder, bulimia nervosa and other specified feeding and eating disorder. Avoidant/restrictive food intake disorder, pica and rumination disorder are not covered. The guideline emphasises the importance of early intervention and treatment by specialist, community-based eating disorder services and the involvement of family and carers in supporting recovery. Psychological treatments, which might be eating disorder–focused cognitive behavioural therapy, eating disorder–focused family therapy or guided self-help, depending on the specific diagnosis, are recommended as the primary intervention for all eating disorders covered by the guideline. Medication is not recommended as the sole treatment for eating disorders but can be used as an adjunct. The guideline suggests collaboration with other specialist healthcare services to manage physical and mental health comorbidities, for example diabetes, and to manage the treatment of eating disorders in individuals who may be at particular risk of adverse outcomes, for example pregnant women, children and young people. Inpatient or day-patient care is recommended for those with severely compromised physical health. The guideline also provides guidance on the delivery of compulsory treatment under the Mental Health Act for individuals whose physical health is at serious risk.

1. Introduction

The National Institute for Health and Care Excellence (NICE) guideline for the recognition and treatment of eating disorders (NG69) (1) was published in May 2017 and replaces the previous clinical guideline (CG9) published in 2004. NG69 outlines recommendations for the assessment, treatment, monitoring and inpatient care of children, young people and adults with eating disorders and is intended to provide guidance for healthcare professionals, healthcare commissioners and providers, and other professionals involved in the provision of eating disorder services, as well as individuals suspected of having, or diagnosed with, an eating disorder, and their families and carers. The limited number of recommendations with evidence graded either "A" or "B" (see Table 1) in the previous (2004) guideline reflected the general lack of high-quality data at the time of its development, in particular for the treatment of anorexia nervosa and atypical eating disorders. The new guideline incorporates more recently published evidence both for treatment outcomes and problems related to the delivery of eating disorder therapies. Studies of treatments for bulimia nervosa and binge eating disorder, comparative studies of psychological and biological treatments for anorexia nervosa, and studies on the efficacy of treatments for atypical eating disorders (other specified feeding and eating disorders, OSFED) were considered for the updated guidance. The guideline does not include recommendations for the treatment of avoidant/restrictive food intake disorder due to the low level of available evidence, or for obesity (in the absence of an eating disorder), which is the focus of a separate clinical guideline (CG189).

2. Methodology

NICE guidelines are developed by the NICE guideline committee with reference to the standard methodology outlined in the NICE Guideline Manual. Recommendations are based on a systematic review of the available evidence with consideration of the clinical and cost effectiveness of the included interventions and services. Where evidence is lacking or inconclusive, recommendations are based on the consensus view of the guideline committee.

3. Recommendations

3.1 General principles of care

In addition to a general commitment to equal access to treatment, the guideline emphasises awareness among cli-

Grade		Level of evidence	
A	At least one meta-analysis, systematic review or randomised controlled trial (RCT) classified as 1++ and directly applicable to the target population of the guidelines; or a systematic review or body of evidence consisting principally of studies rated as 1+, directly applicable to the target population and demonstrating overall consistency of results; or evidence drawn from a NICE technology appraisal.	1++	High-quality meta-analyses, systematic reviews of RCTs or RCTs with very low risk of bias.
		1+	Well-conducted meta-analyses, systematic reviews of RCTs or RCTs with a low risk of bias.
B	A body of evidence including studies rated as 2++, directly applicable to the target population of the guidelines and demonstrating overall consistency of results; or evidence extrapolated from studies rated as 1++ or 1+.	2++	High-quality systematic reviews of case–control or cohort studies. High-quality case–control or cohort studies with a very low risk of bias and a high probability that the relationship is causal.
C	A body of evidence including studies rates as 2+, directly applicable to the target population of the guidelines, and demonstrating overall consistency of results; or evidence extrapolated from studies rated as 2++.	2+	Well-conducted case–control cohort studies with a low risk of bias and a moderate probability that the relationship is causal.
D	Evidence level 3 or 4; or evidence extrapolated from studies rated as 2+; or formal consensus.	3	Non-analytical studies such as case reports and case series.
		4	Expert opinion or formal consensus.

Table 1. Recommendation grades and corresponding levels of evidence

nicians of the distress individuals with eating disorders may feel in discussing their condition, their possible feelings of stigma and shame and the need for information and interventions specific to their age and level of development.

Eating disorders should be assessed in the context of each individual's home, educational, work and wider social environment, including the influence of the internet and social media.

Family members, carers, teachers and peers are encouraged to play a role in supporting individuals during treatment but may also require support for their own health. Confidentiality should be maintained, within the limits imposed by the requirements of working within a multidisciplinary team. The guidance suggests that consent for assessments and treatments for children under the age of 16 years should be sought on the basis of Gillick competence, that is, a clinical determination that the child is competent to give consent to medical treatment in the same way as an autonomous adult (2, 3). The adequacy and appropriateness of this approach in a broader medical context has been questioned, however (4-6), and the full NICE guideline emphasises that there should be no assumption of capacity for individuals under the age of 16 years. The Care Quality Commission guidance on the treatment of anorexia nervosa under the Mental Health Act 1983 (7), cited in the full guideline, also imposes caveats on the assumption of capacity in individuals over the age of 16 years up to the age of 18 years. Additionally, safeguards established in law by the Protection of Children Act 1999 (8) apply to all those under the age of 18 years.

3.2 Identification and assessment

The general guidance regarding assessment and treatment states that these should be carried out at the earliest opportunity, and priority given to those at risk of severe emaciation. While "severe emaciation" is not defined by NICE, emaciation has been defined elsewhere as being below 10% of the standard weight of the normal population, and significant body weight loss as weight loss of more than 20% (9). Results from assessments with screening tools such as the SCOFF (Sick Control One Fat Food) questionnaire (10) are not recommended as the sole means of determining an eating disorder diagnosis, and clinicians should also consider key factors including unusually low or high body mass index (BMI) or body weight for age, rapid weight loss, dieting or restrictive eating practices and changes in eating behaviour reported by family or carers (see Box 1). In children and adolescents, attention should be paid to signs of faltering growth, delayed puberty or stunted height.

Assessment of individuals with a suspected eating disorder should include an examination of physical health, including signs of malnutrition and compensatory behaviours (for example, self-induced vomiting, misuse of laxatives or diet pills, or excessive exercise), assessment of neurodevelopmental disorders and mental health problems commonly associated with eating disorders (for example autism spectrum disorder, depression, anxiety, self-harm and obsessive-compulsive disorder), and evidence of alcohol or substance misuse. Where compensatory behaviour is suspected, assessment of fluid and electrolyte balance should be conducted. The need for electrocardiogram (ECG) monitoring should be assessed in those who might be at risk of cardiac irregularities, for example due to rapid weight loss, excessive exercise or severe purging behaviours. The need for emergency care in those with compromised physical health or who may be at risk of suicide should also be considered.

Decisions on whether to offer treatment should not be based on a single measure, such as BMI or duration of illness.

Based on the initial assessment, individuals with a suspected eating disorder should be referred immediately to a community-based, age-appropriate eating disorder service for further assessment and treatment.

Box 1. Factors to consider when assessing for an eating disorder or when deciding to refer people for assessment

1. An unusually low or high body mass index (BMI) or body weight for age.
2. Rapid weight loss.
3. Dieting or restrictive eating practices (such as dieting when they are underweight) that are worrying the individual, their family members or carers, or professionals.
4. Family members or carers report a change in eating behaviour.
5. Social withdrawal, particularly from situations that involve food.
6. Other mental health problems.
7. A disproportionate concern about their weight or shape (e.g., concerns about weight gain as a side effect of contraceptive medication).
8. Problems managing a chronic illness that affects diet, such as diabetes or coeliac disease.
9. Menstrual or other endocrine disturbances or unexplained gastrointestinal symptoms.
10. Physical signs of:
    - Malnutrition, including poor circulation, dizziness, palpitations, fainting or pallor.
    - Compensatory behaviours, including laxative or diet pill misuse, vomiting or excessive exercise.
11. Abdominal pain that is associated with vomiting or restrictions in diet that cannot be fully explained by a medical condition.
12. Unexplained electrolyte imbalance or hypoglycaemia.
13. Atypical dental wear (such as erosion).
14. Whether the individual takes part in activities associated with a high risk of eating disorders (e.g. professional sport, fashion, dance or modelling).

3.3 Recommendations for treatment

3.3.1 Common recommendations for treatment

Psychological treatments are recommended as the first-choice interventions for adults, children and young people with anorexia nervosa, binge eating disorder, bulimia nervosa or OSFED. The recommendations encompass a broad range of psychotherapeutic strategies, some of which are specific to a particular eating disorder (for example, the Maudsley Anorexia Nervosa Treatment for Adults), reflecting both the diversity and disparity of approaches to treatment, and a recognition of the importance of considering individual needs and preferences (see Tables 2–5 for a comparison of the recommendations).

Medication should not be offered as the sole treatment for an eating disorder. It was considered by the guideline committee that physical therapy, including transcranial magnetic stimulation, acupuncture, weight training, yoga and warming therapy, should not be offered as any part of treatment due to the general lack of evidence for the efficacy of these approaches, specifically with regard to remission, and the low quality of the evidence that is available.

Acute medical care should be provided for individuals in whom severe electrolyte imbalance, severe malnutrition, severe dehydration or incipient organ failure are detected.

3.3.2 Treating anorexia nervosa

All individuals with anorexia nervosa should be provided with multidisciplinary support including psychoeducation about the disorder, monitoring of weight, mental and physical health, and risk factors. Dietary counselling should also be offered, although the form that this should take is not specified in the guideline.

The guideline emphasises the goal of helping the person with anorexia nervosa to reach a healthy body weight or BMI for their age.

If treatment for anorexia nervosa is declined or ineffective, individuals without severe or complex problems should be discharged to primary care and advised that they can seek referral for treatment again at any time. A review of physical and mental health, including assessment of weight or BMI, blood pressure and ECG monitoring where necessary, should be offered at least annually to individuals with anorexia nervosa who are not receiving ongoing treatment. Children and young people who have not completed puberty should also be monitored for growth and development.

Bone density scans should be considered after 1 year of underweight in children and young people and after 2 years of underweight in adults (earlier in the event of bone pain or recurrent fractures). Treatment with transdermal 17-β-oestradiol (with cyclic progesterone) should be considered in young women (aged 13 to 17 years) with long-term low body weight and low bone mineral density with a bone age over 15 years, and treatment with physiological doses of oestrogen in those additionally exhibiting delayed puberty. However, routine treatment with oral or transdermal oestrogen to treat low bone mineral density in children and young people is not recommended. Oestradiol fuses bone growth plates so it is important to ensure that growth is complete before giving therapeutic oestradiol. It should also be considered that recent growth spurts could temporarily result in low bone mineral density of the lumbar spine. Specialist paediatric or endocrinological advice should be sought before starting any hormonal treatment

for low bone mineral density, and treatment should be coordinated with the eating disorder team. Treatment with biphosphates should be considered for women over 18 years of age. Combined oral contraceptives are not recommended for bone protection. Clinicians should refer to the NICE guideline on assessing the risk of fragility fractures in osteoporosis (CG146) for further guidance.

Amenorrhea is no longer included among the diagnostic criteria for anorexia nervosa in females. However, assessment of menstrual function, determination of amenorrhea and separation of primary and secondary amenorrhea/functional hypothalamic amenorrhea (FHA) due to disordered or restrictive eating should still be performed. Where secondary amenorrhea is present and associated with low bone mineral density for age (based on bone mineral density z-score if under 40 years), then hormone replacement therapy (HRT) is indicated. Where subclinical ovulatory disturbance, rather than "full" FHA, is detected and HRT is initiated to maintain bone health, an attempt should be made to synchronise sequential HRT with the menstrual cycle.

3.3.2.1 Adults with anorexia nervosa

For adults with anorexia nervosa, psychological treatment should be offered in the form of individual eating disorder–focused cognitive behavioural therapy (CBT-ED), the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA) or specialist supportive clinical management (SSCM). If CBT-ED, MANTRA or SSCM is unacceptable, contraindicated or ineffective, the guideline recommends offering one of the other options from this group that has not already been tried or, alternatively, offering eating disorder–focused focal psychodynamic therapy (FPT). See Table 2 for a comparison of these interventions.

3.3.2.2 Children and young people with anorexia nervosa

The guideline recommends considering anorexia nervosa–focused family therapy (FT-AN) for children and young people with anorexia nervosa, either in the form of single-family therapy or combined single-family and multi-family therapy. Children and young people should be offered the option to attend some sessions separately from their family and carers. If FT-AN is unacceptable, contraindicated or ineffective, individuals should be offered individual CBT-ED or adolescent-focused psychotherapy for anorexia nervosa (AFP-AN). See Table 3 for a comparison of these interventions.

3.3.3 Treating binge eating disorder

Psychological treatments for binge eating disorder are not aimed at weight loss. Where obesity is a concern in individuals with binge eating disorder, further reference should be made to the NICE guideline on obesity identification, assessment and management (CG189).

3.3.3.1 Adults, children and young people with binge eating disorder

The guideline suggests all individuals with binge eating disorder should be offered a binge eating disorder–focused guided self-help programme. If this is unacceptable, contraindicated or ineffective, group or individual CBT-ED should be offered. See Table 4 for a comparison of these approaches.

3.3.4 Treating bulimia nervosa

Individuals with bulimia nervosa should be advised that psychological interventions have a limited effect on body weight.

3.3.4.1 Adults with bulimia nervosa

Adults should be offered a bulimia nervosa–focused guided self-help programme incorporating cognitive behavioural self-help materials for eating disorders. Guided self-help should be supplemented by a series of brief support sessions. The guideline suggests 4 to 9 sessions of 20 minutes each over 16 weeks, initially on a weekly basis.

If guided self-help is unacceptable, contraindicated or ineffective after 4 weeks, adults with bulimia nervosa should be offered individual CBT-ED (see Table 5).

3.3.4.2 Children and young people with bulimia nervosa

Children and young people should be offered bulimia nervosa–focused family therapy (FT-BN). As part of this approach, the young person and their parents should be encouraged to develop a collaborative approach to establishing healthy eating behaviours. Support should also be considered for family members not involved in the family therapy sessions. If FT-BN is unacceptable, contraindicated or ineffective, CBT-ED should be considered (see Table 5).

3.3.5 Treating other specified feeding and eating disorders

There are no specific recommendations for the treatment of OSFED. Instead, the guideline suggests that the most appropriate treatment be selected based on consideration of the eating disorder it most closely resembles.

4. Physical and mental health comorbidities

Eating disorder specialists and other healthcare teams should collaborate to monitor the effectiveness of the treatments for the eating disorder and comorbid conditions using appropriate outcome measures and assess the potential impact of each treatment on the others.

4.1 Diabetes

The guideline specifies collaboration between eating disorder and diabetes teams to monitor and manage physical and mental health. Additional recommendations for the treatment of eating disorders in people with comorbid diabetes include close monitoring of blood glucose and blood ketones and addressing the possibility of insulin misuse. People with bulimia nervosa and diabetes should also be considered for monitoring for glucose toxicity (hyperglycaemia-induced inhibition of insulin secretion and glucose metabolism (11, 12)), insulin resistance, ketoacidosis and oedema. Clinicians are advised to refer to the NICE guideline on type I and type II diabetes in children and young people (NG18), type I diabetes in adults (NG17) and type II diabetes in adults (NG28) for further guidance.

4.2 Comorbid mental health problems

Decisions on whether to treat comorbid mental health problems in parallel with the eating disorder or separately and in sequence should be taken with consideration of the relative severity and complexity of the eating disorder and the mental health problem, the individual's level of functioning and the preferences of the individual as well as those of their family or carers, where appropriate. Clinicians are advised to refer to the NICE guidelines for the specific mental health problem for further guidance.

4.3 Medication risk management

Where medication is prescribed to treat a comorbid mental or physical health condition, consideration should be given to the possible effects of malnutrition and compensatory behaviours on effectiveness and side effects, and the possible effect of the eating disorder on medication adherence, for example, where medication might affect body weight. Pre-existing medical complications should be considered and ECG monitoring offered to individuals taking medication that might affect cardiac function.

4.4 Substance or medication misuse

Substance misuse should not preclude treatment for eating disorders unless it interferes with treatment. If substance misuse does interfere with treatment, a multidisciplinary approach involving substance misuse services is proposed.

4.5 Growth and development

The guideline suggests that concerns about delayed physical development or faltering growth in children and young people with an eating disorder should be referred to a specialist paediatrician or endocrinologist.

5. Conception and pregnancy

Treatment for eating disorders during the perinatal period should follow the standard treatment guidelines for the appropriate eating disorder. More intensive prenatal care for women with current or remitted anorexia nervosa should be considered to ensure adequate prenatal nutrition. Education and advice should be offered to all women with an eating disorder who plan to conceive, in order to increase the chances of conception and to reduce the risk of miscarriage. A dedicated professional (e.g., GP or midwife) should be responsible for supporting and monitoring women during pregnancy and the postnatal period to reduce possible risks to the health of the mother and child, with reference to the NICE guideline on antenatal and postnatal mental health (CG192). Guidance on providing advice to pregnant women about healthy eating and feeding their baby is available in the NICE public health guideline on maternal and child nutrition (PH11).

6. Inpatient and day-patient treatment

Previously, inpatient care was central to the management of eating disorders. More recently, community-based care has been preferred, and inpatient hospital admissions are generally limited to those with severe medical risk or who have failed to respond to outpatient care.

If physical health is severely compromised, individuals should be admitted to a medical inpatient or day-patient service for medical stabilisation and refeeding, if this is not possible in an outpatient setting. The decision on whether to admit to inpatient or day-patient care should not be based on absolute weight or BMI. Inpatient care is recommended in cases of rapid weight loss (e.g., more than 1 kg per week), or when medical risk parameters (e.g., blood tests, physical observations and ECG) have values or rates of change in the concern or alert ranges requiring active monitoring. Other factors that might influence the decision to admit to inpatient care include a significant decline in physical health and whether parents or carers of children and young people have the ability to support them and avoid significant harm under day-patient care. Clinicians are advised to consult the Royal College of Psychiatrists' resource on Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) or the junior MARSIPAN report. Since 2022,

these guidelines have been superseded by the Medical Emergencies in Eating Disorders (MEED) guidance (13).

A care plan should be developed in collaboration with individuals admitted to inpatient care, their families or carers, and the community-based eating disorder service. This should include the objectives and outcomes for the admission, planning for discharge and transition back to community-based care.

Inpatient care should not be used solely to provide psychological treatment for eating disorders. In individuals considered to be at acute mental health risk (e.g., significant suicide risk), psychiatric crisis care or psychiatric inpatient care should be considered. Inpatient care for children and young people should be provided in age-appropriate settings and be located near the individual's home.

Refeeding should take place under the direction of staff trained to recognise the symptoms of refeeding syndrome and how it should be managed.

Inpatient care should be reviewed within 1 month of admission. The decision to discharge an individual from inpatient care should not be made solely on the basis of an achieved healthy weight.

7. Compulsory treatment and the Mental Health Act

Where it is determined that a person's physical health is at serious risk due to an eating disorder, they do not consent to treatment and it is considered that they can only be treated safely in an inpatient setting, the guideline recommends following the legal framework for compulsory treatment set out in the Mental Health Act 1983. Where this situation applies to a child or young person, their parents or carers should be asked to provide consent on their behalf, if necessary, under the terms of a legal framework for compulsory treatment, for example, those set out in the Mental Health Act 1983/2007 (14) or the Children Act 1989 (15).

8. Comment

8.1 Quality of evidence

Despite forming the basis for the treatment recommendations made in the guideline, the quality of the evidence supporting the use of psychological interventions for eating disorders was, in most cases, considered low or very low according to GRADE (Grading of Recommendations Assessment, Development and Evaluation) criteria. Evidence was frequently downgraded due to indirectness, imprecision and risk of bias. A further limitation was the general lack of data for the efficacy of treatments in males. Evidence for pharmacological and nutritional interventions (e.g., nutritional counselling and dietary supplements) were graded low or very low, leading to the recommendation that they should not be used as sole treatments for eating disorders. Evidence for physical interventions (e.g., physiotherapy, yoga, physical exercise and acupuncture) was, in most cases, considered to be very low quality.

8.2 Recommendations for future research

The guideline makes several recommendations for further research to address limitations of the current evidence. These include:

- Comparison of the clinical and cost effectiveness of individual CBT-ED, group CBT-ED and guided self-help for adults with binge eating disorders.
- Investigation of the effectiveness of reduced duration and intensity of psychological treatments for eating disorders compared with standard treatment.
- Investigation of the clinical biochemical markers that best predict acute physical risk for people with eating disorders.
- Investigation of the impact of comorbidities on treatment outcomes for eating disorders and effective approaches to the management of comorbidities.
- Investigation of factors associated with continued benefit after successful treatment for anorexia nervosa.

9. Challenges to implementation

In their summary of current treatment provision for eating disorders in the NHS, the guideline committee highlighted a number of disparities in the care offered in both paediatric and adult services, often reflecting regional inequalities in funding and referral criteria. These inconsistencies apply to all aspects of eating disorder care provision, including recognition, assessment, treatment, including access to specialist eating disorder services, and transition between services, and are reflected in a high degree of variability in basic treatment strategies and settings. For example, the lack of specialist eating disorder services in some regions has meant that children and young people with eating disorders may be treated by generic Child and Adolescent Mental Health Services teams. The age thresholds for access to specialist services and transitioning to adult services also vary. In an attempt to standardise access to care pathways for children and young people, a commissioning guide, the Access and Waiting Times initiative, was published in 2015. However, this only applies to individuals under the age of 18. Access to specialist care for adults is highly dependent on funding allocation, with some regions offering referrals only to those who meet strict criteria, for example, based

on BMI thresholds, despite attempts to gain parity for eating disorders across the lifespan.

Primary care practitioners are often the first point of contact for individuals with eating disorders, but experience, skill and confidence in making a preliminary assessment and diagnosis are highly variable. Clinicians also have varying degrees of knowledge of and experience in delivering specific interventions.

With regard to inpatient care, there are no internationally recognised criteria for admission. In practice, the availability and form of inpatient care depend on the extent of local facilities and the acute care they are able to provide. In the UK, the MARSIPAN protocol, recently superseded by the MEED guidance, outlines the care pathway for admission to inpatient care for those at extreme medical risk and highlights the responsibilities of healthcare professionals at every level of care provision.

It remains highly desirable to avoid inpatient admissions, not least due to the potential stigma involved, in particular that associated with compulsory admissions. This may have a negative effect on both self-image and the quality of life of the individual. In the last two decades, practice in England and Wales has moved away from an emphasis on in-patient treatment and the focus is now on limiting the duration of hospitalisation and minimising compulsion, which is in line with the NHS Long Term Plan (16). Although not mentioned in the NICE guidance, this situation is exemplified by recent changes in the protocol for nasogastric tube feeding which can now be delivered, in most cases, in an intensive outpatient setting without the need for extended inpatient admission (see the article on nasogastric tube feeding under physical restraint elsewhere in this issue).

Conflicts of interest

The authors declare that they have no conflicts of interest.

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	CBT-ED	MANTRA	SSCM	FPT
Duration	Typically 40 sessions over 40 weeks. Twice-weekly sessions in the first 2 or 3 weeks.	Typically 20 sessions. Weekly sessions for the first 10 weeks and a flexible schedule for the remainder of the sessions. Up to 10 extra sessions for people with complex problems.	Typically 20 or more weekly sessions (depending on severity).	Typically up to 40 sessions over 40 weeks.
Approach	Aim to reduce the risk to physical health and any other symptoms of the eating disorder. Encourage healthy eating and reaching a healthy body weight. Create a personalised treatment plan based on processes that appear to be maintaining the eating problem. Enhance self-efficacy. Include self-monitoring of dietary intake and associated thoughts and feelings. Include homework to help the person practice in their daily life what they have learned.	1. Getting started and finding motivation for recovery 2. Working with support, including family and others 3. Improving nutritional health 4. Understanding anorexia 5. Developing treatment goals 6. Understanding and relating to emotions helpfully 7. Exploring thinking styles, and challenging styles that are rigid, perfectionist, attention to detail 8. Developing identity outside of the eating disorder 9. Relapse prevention Motivate the person and encourage them to work with the practitioner. Be flexible in how the modules of MANTRA are delivered and emphasised. Encourage the person to develop a "non-anorexic identity". Involve family members or carers to help the person: - Understand their condition and the problems it causes and the link to the wider social context. - Change their behaviour.	Assess, identify and regularly review key problems. Aim to develop a positive relationship between the person and the practitioner. Aim to help people recognise the link between their symptoms and their abnormal eating behaviour. Aim to restore weight. Include physical health monitoring. Establish a weight range goal. Encourage reaching a healthy body weight and healthy eating.	Patient-centred focal hypothesis specific to the individual that addresses: - What the symptoms mean to the person. - How the symptoms affect the person. - How the symptoms influence the person's relationships with others and with the therapist. First phase Focus on developing therapeutic alliance between therapist and person with AN. Address pro-anorexic behaviour and ego-syntonic beliefs and build self-esteem. Second phase Focus on relevant relationships with other people and how these affect eating behaviour. Final phase Focus on transferring therapy experiences to situations in everyday life and address concerns about what will happen when treatment ends.
Components	Nutrition, cognitive restructuring, mood regulation, social skills, body-image concerns, self-esteem and relapse prevention. Explain the risks of malnutrition and being underweight.	When the person is ready, cover nutrition, symptom management and behaviour change.	Provide psychoeducation and nutritional education and advice. Allow the person to decide what else should be included as part of their therapy.	

Table 2. Comparison of recommended psychological treatments for anorexia nervosa in adults (Abbreviations used in Tables 2 - 5 are expanded at the bottom of Table 5)

	FT-AN	CBT-ED	AFP-AN
Duration	Typically 18 to 20 sessions over 1 year. Review needs of the child or young person 4 weeks after starting treatment and then every 3 months to establish regularity of sessions and duration of treatment.	Typically up to 40 sessions over 40 weeks. Twice-weekly sessions in the first 2 or 3 weeks. 8 to 12 additional brief family sessions with the person and their parents or carers (as appropriate).	Typically 32 to 40 individual sessions over 12 to 18 months. More regular sessions early on to help the child or young person build a relationship with the practitioner and motivate them to change their behaviour. 8 to 12 additional family sessions with the child or young person and their parents or carers (as appropriate). Review needs of the child or young person 4 weeks after starting treatment and then every 3 months to establish regularity of sessions and duration of treatment.
Approach	Emphasise the role of the family in helping person to recover. Avoid blaming the child or young person or their family members or carers. Include psychoeducation about nutrition and the effects of malnutrition. Early in treatment, support parents or carers to take a central role in helping child or young person manage their eating. Emphasise that this is a temporary role. First phase Aim to establish a good therapeutic alliance between the child or young person, their parents or carers and other family members. Second phase Support the child or young person (with help from their parents or carers) to establish a level of independence appropriate for their level of development. Final phase Focus on plans for when treatment ends (including any concerns the child or young person and their family have) and on relapse prevention. Address how the child or young person can get support if treatment is stopped.	In family sessions and in individual sessions, include psychoeducation about nutrition and the effects of malnutrition. In family sessions: - Identify anything in the child or young person's home life that could make it difficult for them to change their behaviour and find ways to address this. - Discuss meal plans. Aim to reduce the risk to physical health and any other symptoms of the eating disorder. Encourage reaching a healthy body weight and healthy eating. Create a personalised treatment plan based on the processes that appear to be maintaining the eating problem. Take into account the child or young person's specific development needs. Enhance self-efficacy. Include self-monitoring of dietary intake and associated thoughts and feelings. Include homework to help the child or young person practice what they have learned in their daily life. Address how the child or young person can get support if treatment is stopped.	In family sessions and in individual sessions, include psychoeducation about nutrition and the effects of malnutrition. Focus on the child or young person's self-image, emotions and interpersonal processes and how these affect their eating disorder. Develop a formulation of the child or young person's psychological issues and how they use anorexic behaviour as a coping strategy. Address fears about weight gain and emphasise that weight gain and healthy eating is a critical part of therapy. Find alternative strategies for the person to manage stress. In later stages of treatment, explore issues of identity and build independence. Towards end of treatment, focus on transferring the therapy experience to situations in everyday life. In family sessions, help parents or carers support the child or young person to change their behaviour. Address how the child or young person can get support if treatment is stopped.
Components		Nutrition, relapse prevention, cognitive restructuring, mood regulation, social skills, body-image concerns and self-esteem. Explain the risks of malnutrition and being underweight.	

Table 3. Comparison of recommended psychological treatments for anorexia nervosa in children and young people

	BED-focused guided self-help	Group CBT-ED	Individual CBT-ED
Duration		Typically 16 weekly group sessions of 90 minutes each over 4 months.	Typically 16 to 20 sessions.
Approach	Use cognitive behavioural self-help materials for eating disorders. Focus on adherence to the self-help programme. Supplement with brief supportive sessions (e.g., 4 to 9 sessions of 20 minutes each over 16 weeks, on an initial weekly basis).	Focus on education, self-monitoring of eating behaviour and help in analysing individual problems and goals. Development of daily food intake plan and identification of binge eating cues. Body exposure training and help in identifying and correcting individual negative beliefs about their body. Help with avoiding relapse and current and future risks and triggers.	Develop a formulation of individual psychological issues to determine how dietary and emotional factors contribute to the binge eating. Advise to eat regular meals and snacks to avoid feeling hungry. Address emotional triggers for binge eating using cognitive restructuring, behavioural experiments and exposure. Include weekly monitoring of binge eating behaviours, dietary intake and weight. Weight records to be shared with individual. Address body-image issues if present. Advise against attempt at losing weight (e.g., by dieting) during treatment as this might trigger binge eating.

Table 4. Comparison of recommended psychological treatments for binge eating disorder in adults, children and young people

	Adults		Children and young people	
	BN-focused guided self-help	Individual CBT-ED	FT-BN	Individual CBT-ED
Duration		Typically up to 20 sessions over 20 weeks. Consider twice-weekly sessions in first phase.	Typically 18 to 20 sessions over 6 months.	Typically 18 sessions over 6 months. More frequent sessions early in treatment. Include up to 4 additional sessions with parents or carers.
Approach	Use cognitive behavioural self-help materials for eating disorders. Supplement with brief supportive sessions (e.g., 4 to 9 sessions of 20 minutes each over 16 weeks, on an initial weekly basis).	Initially focus on: - Engagement and education. - Establishing pattern of regular eating and providing encouragement and support. Address eating disorder psychopathology (e.g., extreme dietary restraint, body shape and weight concerns, tendency to binge eat in response to difficult thoughts and feelings). Towards end of treatment focus on maintaining positive changes and minimising risk of relapse. If appropriate, involve significant others to help with one-to-one treatment.	Establish a good therapeutic relationship with child or young person and their family members or carers. Support and encourage family members to assist in recovery. Avoid attributing blame to child or young person, their family members or carers. Use a collaborative approach between parents and child or young person to establish regular eating patterns and minimise compensatory behaviours. Include regular meetings with child or young person on their own. Include self-monitoring of bulimic behaviours and discussions with family members or carers. In later phases, support child or young person and their family members or carers to establish level of independence appropriate to their level of development. In final phase, focus on treatment plans for when treatment ends and on relapse prevention.	Initially focus on role of bulimia nervosa in child or young person's life and on building motivation to change. Provide psychoeducation about eating disorders and how symptoms are maintained. Encourage child or young person gradually to establish regular eating habits. Develop case formulation with child or young person. Teach the child or young person to monitor their thoughts, feelings and behaviours. Set goals and encourage the child or young person to address problematic thoughts, beliefs and behaviours with problem solving. Use relapse prevention strategies to prepare for and mitigate potential future setbacks. In sessions with parents and carers: - Provide education about eating disorders. - Identify family factors that stop child or young person from changing behaviour. - Discuss how family can support recovery.
Components			Include information about: - Regulating body weight. - Dieting. - Adverse effects of attempts at weight control by self-induced vomiting, laxatives or other compensatory behaviours.	

Table 5. Comparison of recommended psychological treatments for bulimia nervosa

Abbreviations: AFP-AN = adolescent-focused psychotherapy for anorexia nervosa; AN = anorexia nervosa; BED = binge eating disorder; CBT-ED = eating disorder-focused cognitive behavioural therapy; FPT = focal psychodynamic therapy; FT-AN = anorexia nervosa-focused family therapy; FT-BN = bulimia nervosa-focused family therapy; MANTRA = Maudsley Anorexia Nervosa Treatment for Adults; SSCM = specialist supportive clinical management

Assessment of the individual with an eating disorder and their family

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Abstract

This article highlights the critical importance of assessing eating disorders, addressing both physical and mental health impacts. The proposed framework combines medical history, physical assessment and family influences. The emphasis is on achieving early recognition and effective intervention using a multidimensional approach.

Keywords: mental health, physical health, eating disorders, anorexia nervosa, assessment, family dynamics

1. Introduction

Eating disorders are intricate mental health conditions with profound impacts on both physical and psychological wellbeing (1, 2). This paper covers the assessment process for these disorders, focusing on the interplay of medical, psychiatric and sociocultural factors that influence their development and persistence (3, 4).

The International Classification of Diseases, 11th Revision (ICD-11), categorises conditions such as anorexia nervosa, bulimia nervosa and binge eating disorder as severe mental health issues that disrupt eating behaviours, body weight and shape. Understanding these classifications is important for developing effective, tailored interventions (5, 6). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), reinforces the importance of precise assessment in diagnosing these disorders.

Effective treatment hinges on a comprehensive assessment encompassing medical, psychiatric and sociocultural dimensions (7, 8). The evolution of eating disorder assessment methodologies reflects a shift toward multidimensional and integrative approaches, with a growing emphasis on the critical interplay of medical, psychiatric and sociocultural dimensions. Mitchell and Peterson (9) laid the groundwork by emphasising standardised diagnostic tools, such as the Eating Disorder Examination (EDE), to evaluate disordered eating behaviours and associated psychological conditions, noting the importance of assessing patient readiness for change. Building on this, Rienecke, Nance and Wallis (10) expanded the scope by advocating for developmental, cultural and familial considerations, emphasising the use of validated instruments to assess symptom severity and functional impairment. More recently, Mehler and Andersen (7) reinforced the necessity of thorough assessments that include rigorous medical evaluations to identify complications such as electrolyte imbalances and cardiovascular issues, which are common in this population. These reviews collectively highlight that effective treatment depends on holistic assessments that address the severe physical, psychological and sociocultural risks, including heightened suicide rates, associated with eating disorders (1, 8, 11, 12). This integrated approach enhances diagnostic precision and informs tailored interventions, emphasising the urgency of timely and detailed care.

The evolution from the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) guidelines to the Medical Emergencies in Eating Disorders (MEED) framework signified a significant advance in assessment protocols. While MARSIPAN focused on immediate medical stabilisation, MEED integrates comprehensive medical and psychological evaluations, emphasising the interconnectedness of physical and mental health (13-18). Timely evaluations are essential for detecting changes in eating habits and ensuring effective intervention.

The assessment of eating disorders differs between adolescents and adults. For adolescents, family dynamics, school pressures and developmental changes are typically key factors (17, 19, 20). In contrast, adult assessments address broader psychosocial factors and long-term health consequences, including chronic medical conditions and entrenched behavioural patterns (21-23).

Assessing eating disorders is particularly challenging due to factors such as patient denial or minimisation of symptoms, which can obstruct accurate diagnosis and treatment. This difficulty is compounded for under-recognised groups, including males, older adults, ethnic minorities and those of average weight (24-26). Stigma and the complex interplay of physical, psychological and social factors often hinder effective communication (27, 28), while patients may downplay their symptoms due to embarrassment or lack of insight, further complicating diagnosis (29). While structured questionnaires can provide valuable data, they may overlook individual nuances; in contrast, clinical interviews allow for deeper insights but rely heavily on patient disclosure. The broad spectrum of eating disorder sub-

types, including those at normal weight, and the dynamic nature of these conditions necessitate comprehensive and adaptable assessments (6, 20, 23). For adolescents, developmental factors add complexity to the assessment process, making corroborating information from caregivers essential, especially when comorbidities such as anxiety or depression are involved (21, 22, 30).

2. Assessment of eating disorders

A comprehensive eating disorder assessment by a multidisciplinary team (MDT) – including a psychiatrist, dietician and therapist – is essential for diagnosis, severity evaluation and treatment planning. This approach integrates history, clinical assessment, diagnostic tools and family dynamics within a biopsychosocial framework.

3. Biopsychosocial formulation

Eating disorders are complex conditions influenced by biological, psychological and social factors, including predisposing, precipitating, perpetuating and protective elements.

Biologically, genetic predispositions contribute significantly, with heritability estimates for anorexia and bulimia ranging from 50% to 80% (31). Neurobiological factors like serotonin and dopamine imbalances, and hormones such as leptin and ghrelin, increase vulnerability (32). Autism spectrum disorder (ASD) also influences eating disorder development, particularly anorexia, emphasising the need for tailored treatments addressing ASD-related behaviours (33).

Psychologically, predisposing factors include perfectionism and negative self-evaluation, which can lead to rigid dietary rules and compulsive behaviours (34). Precipitating factors, such as trauma or weight-related teasing, often trigger disordered eating (35). Maladaptive cognitions and societal pressures perpetuate the disorder through persistent negative beliefs and internalisation of thin ideals (36).

Jacobi et al. (35) highlight the critical roles of social, familial and cultural factors in perpetuating eating disorders. Socially, individuals often face isolation and stigma, fostering shame and reinforcing disordered behaviours. Within families, dynamics such as overinvolvement, criticism or lack of emotional support exacerbate the disorder, alongside parental modelling of dieting or imposing unrealistic expectations. Culturally, the glorification of thinness, particularly in Western societies, perpetuates body dissatisfaction and restrictive eating, as individuals strive to meet unattainable ideals. These interconnected influences create a complex backdrop that sustains eating disorders and emphasises the need for holistic, context-aware interventions.

4. Mental health assessment

4.1 History

Good history-taking is essential in eating disorder assessments; it can offer vital insights into the individual's experiences and the onset and progression of the disorder.

Onset and duration

Understanding the progression of an eating disorder involves examining changes in eating habits over time to discern patterns and trajectories. Exploring personal history may reveal links between stressful or traumatic events and the individual's relationship with food, facilitating comprehensive interventions aimed at addressing underlying factors contributing to the disorder.

4.2 Psychological assessment

Eating habits

During assessment, exploring changes in eating patterns and recent habits is essential. Questions on specific dietary preferences or restrictions, such as vegetarianism, must be asked. Exploring family eating patterns provides insight into familial influences on dietary choices. These inquiries gather information about nutritional habits and family dynamics, facilitating a holistic understanding of eating patterns.

Eating attitude

During assessment, it is essential to ask individuals about their preoccupation with thoughts about food, eating or body image, including the intensity and frequency of these concerns. Inquiries should cover feelings of guilt after meals, changes in mood, anxiety levels, or concentration, fears related to body fat or weight gain and preferences for food textures or sensory aspects.

Eating behaviours

Individuals are asked about any binge eating episodes and prompted to detail the circumstances. Enquiries should also explore behaviours like separating or smearing food to reveal the underlying emotions and thoughts linked to these actions.

Weight-controlling strategies

As part of the assessment, individuals are asked to detail their weight control strategies, including restrictive eating, exercise frequency and methods such as laxatives, purging or self-induced vomiting. They are also questioned about any episodes of diarrhoea related to their eating habits.

Body image and shape

Individuals are prompted to share changes in their perception of body shape over time. Additionally, questions are posed regarding behaviours such as body checking or measuring. By sensitively exploring these aspects, clinicians gain deeper insights into body image concerns and potential preoccupations.

4.3 Psychiatric history

Evaluating past treatments and their outcomes is essential in assessing individuals with eating disorders. Reviewing previous interventions helps clinicians to understand their effectiveness and to identify areas for adjustment. Additionally, examining coexisting mental health conditions is important, as these can influence and aggravate the eating disorder.

4.4 Risk assessment for self-harm and suicide

Individuals with eating disorders face a significantly higher risk of self-harm and suicide compared to the general population. Research, such as the meta-analysis by Preti et al. (12), shows a 27.2% rate of suicide attempts among those with eating disorders, highlighting the need for thorough risk assessment and appropriate intervention. This evaluation should consider current and historical factors contributing to vulnerability, including access to harmful online content and substance use.

4.5 Insight and motivation

Assessing insight and motivation, particularly gaining an understanding of the factors influencing the patient's perception of their condition, can provide valuable information for effective treatment. Patients often minimise or deny their symptoms (37). Understanding their perception of the condition and factors influencing their motivation provides critical insights into their readiness and commitment to recovery.

4.6 Temperament and personality

In the assessment process, individuals are asked to describe their temperament and overall personality traits. It is essential to ask about tendencies toward perfectionism in various aspects of their lives, including attitudes towards food and body image. By exploring these aspects sensitively, clinicians can gain deeper insight into the individual's psychological makeup and potential contributing factors to their eating disorder.

4.7 Social and environmental factors

The influence of support systems from friends, family and others, as well as societal and cultural factors, is important in the development and management of eating disorders. Individuals are asked to describe the support they receive from friends, family or others in managing their overall wellbeing. Additionally, consideration is given to societal or cultural factors that may contribute to the eating disorder.

5. Medical assessment

A key aspect of eating disorder assessments is a detailed evaluation of medical history and current physical health, given the extensive impact that eating disorders can have on organ systems, the risk of potentially life-threatening complications and the necessity to exclude organic causes of weight loss (13).

5.1 Medical history

Inquiry should be made about potential physical health issues associated with eating habits, including dizziness, chest pain or fatigue. The history-taking should also explore whether the individual has pre-existing medical conditions or takes medications that might impact their condition. Any history suggestive of organic causes of weight loss must be elicited. This should include identifying any pre-existing conditions that could influence or be affected by the eating disorder, such as diabetes, metabolic disorders, gastrointestinal issues, psychiatric conditions, autoimmune disorders or thyroid problems.

Recent or recurrent illnesses should be recorded, particularly those that have led to significant weight loss or nutritional deficiencies. Additionally, past hospitalisations related to physical or psychiatric conditions, including complications linked to the eating disorder, should be noted. The use of weight-loss aids, such as laxatives, diuretics, appetite suppressants or other supplements, should also be documented, detailing their duration, frequency and effects. It is important to document all medications the patient takes, including prescriptions, over-the-counter drugs and supplements, focusing on those that impact appetite, weight, metabolism or mental health.

5.2 Weight history and weight change

Individuals are asked to provide a detailed history of their weight throughout adolescence and adulthood, including their highest and lowest weights, current weight and any notable trends. Enquiries are made regarding the frequency of self-weighing and how this practice impacts their emotions or behaviours.

5.3 Pubertal development

Assessing the onset of puberty and related physical changes is essential for understanding the developmental stage of adolescents who may have an eating disorder. Inquiring about the onset of menstruation in females offers vital insights into their reproductive health. It can help identify any potential issues related to menstrual irregularities or conditions such as amenorrhea. For males, exploring the development of secondary sexual characteristics, such as increased muscle mass, voice changes and body hair, can provide important information about pubertal progression and overall hormonal health. These assessments can not only identify any concerns about normal development but can also assist in the early detection of potential health concerns related to malnutrition, allowing for timely interventions to support optimal growth and wellbeing during this critical period.

5.4 Anthropometry

Height

Sequential height measurement, conducted using a calibrated, wall-mounted stadiometer, is a good indicator of nutritional status and overall health. It is recommended that height be measured every three months, except in post-menarche patients with minimal potential for further growth. Regular height assessments are essential for identifying complications such as growth stunting or osteoporosis, and informing targeted management strategies tailored to the patient's needs.

Weight

Accurate weight assessment is essential in evaluating eating disorders. Standard protocols are followed, including voiding before measurement and wearing minimal clothing to prevent inflated readings. Calibrated digital or balance-beam scales are used to ensure reliable weight tracking. Body mass index (BMI) is the primary metric for adults, calculated by dividing weight in kilograms by height in meters squared. BMI categories are underweight (<18.5 kg/m^2), normal weight (18.5–24.9 kg/m^2) and obese (>30 kg/m^2) (38).

Growth and development changes must be considered for children and adolescents. The percentage of median BMI (%mBMI) compares an adolescent's BMI to sex-specific medians, offering a more accurate reflection of nutritional status. Adult BMI criteria are unsuitable for adolescents, and %mBMI does not apply to adults due to differences in growth patterns. In children, weight-for-height percentiles between the 5th and 95th percentiles are normal.

BMI should be interpreted cautiously because it can be affected by factors such as muscle mass, pregnancy and fluid retention. Accurate assessment and treatment of eating disorders require nuanced clinical judgment, with values individualised to reflect unique physiological factors, for example, post-menarche changes in women.

5.5 Physical health examination

A thorough physical examination is essential for evaluating suspected eating disorders. It can distinguish between organic and eating-disorder-related features, detect physical complications and guide tailored treatment plans, enabling early intervention and comprehensive care (39).

Skin

The skin can reveal physiological and nutritional imbalances in individuals with eating disorders. Pale or yellowish skin may indicate anaemia due to iron or vitamin B12 deficiency, or liver dysfunction from malnutrition. Russell's sign, calluses on the back of the hand, may result from self-induced vomiting. Bruising and petechiae suggest increased skin fragility or impaired blood clotting. Lanugo, fine hair covering the body, is an adaptive response to conserve heat during malnutrition. Dehydration manifests as dry skin, sunken eyes and poor skin turgor. Poor wound healing often indicates inadequate protein or vitamin C intake; further signs of vitamin C deficiency include petechiae or ecchymosis. Brittle nails may result from insufficient biotin, zinc or magnesium. Self-harm lesions reflect emotional distress and body image concerns, often present in eating disorders. Vitamin B deficiency can manifest as seborrheic dermatitis, angular stomatitis and glossitis; it can also lead to skin redness, scaling and inflammation.

Ear, nose and throat

Repeated vomiting can cause dental erosion, gingivitis and periodontal disease due to prolonged stomach acid exposure; chronic irritation may lead to parotid enlargement and pharyngeal redness from throat irritation. Dry, brittle hair or hair loss indicates poor nutrient intake, reflecting the body's prioritisation of essential nutrients during malnutrition. Swollen lymph nodes (lymphadenopathy) may arise from infections or inflammation linked to a compromised immune system. Thyroid gland examination can assess the impact of hypo/hyperthyroidism on weight loss, a

common issue in eating disorders. Facial puffiness, resulting from fluid imbalance, may be seen in severe malnutrition. Halitosis (bad breath) can be caused by reduced saliva from dehydration. Restrictive eating habits can also cause an acetone smell, signalling ketosis.

Cardiovascular system

Bradycardia, defined as a pulse below 60 bpm, often indicates reduced metabolic rate due to low energy intake and electrolyte disturbances, including deficient potassium levels. If accompanied by dizziness, fainting or chest pain, it requires urgent medical attention, especially if the pulse falls below 50 bpm. Hypotension, often resulting from dehydration caused by purging behaviours, leads to low blood pressure and decreased blood volume. Monitoring blood pressure while lying and standing helps to assess orthostatic changes that indicate dehydration or electrolyte imbalance. Orthostatic hypotension, a drop in blood pressure upon standing, reflects low blood volume. Oedema, caused by fluid imbalances and nutrient deficiencies, increases cardiovascular strain. Cyanosis, a bluish tint in the skin, particularly in the extremities, may indicate severe malnutrition and poor oxygenation. Mitral valve regurgitation, caused by cardiac muscle thinning due to starvation, highlights structural changes in the heart. Cardiac arrhythmias, often due to electrolyte imbalances such as low potassium, interfere with the heart's electrical conduction and pose additional cardiovascular risks. Cardiomegaly, an enlarged heart, resulting from chronic malnutrition and loss of cardiac muscle mass, can further compromise cardiac function.

Musculoskeletal system

Inadequate nutrition can cause reduced bone density and compromise bone health, making individuals more susceptible to fractures and stress fractures. Additionally, proximal muscle atrophy or wasting, resulting primarily from insufficient protein intake, can manifest as muscle weakness and loss of muscle mass.

Gastrointestinal system

Abdominal discomfort and the presence of a mass may stem from inadequate fibre intake and dehydration, exacerbating constipation, a common gastrointestinal complaint in this population. Delayed bowel sounds, reflecting disrupted gastrointestinal motility, may be observed due to irregular eating patterns characteristic of eating disorders. Additionally, gastroparesis, a condition where the stomach empties slowly, may further complicate gastrointestinal motility and contribute to symptoms such as bloating, nausea and early satiety. Ascites, characterised by abdominal swelling from abnormal fluid collection, may indicate severe malnutrition or liver dysfunction.

Neurological system

Diminished deep tendon reflexes may be observed due to malnutrition and electrolyte imbalances disrupting nerve function. Peripheral neuropathy, stemming from malnutrition-related vitamin deficiencies, can cause symptoms like numbness and tingling in the extremities. Malnutrition can impair cognitive function, leading to difficulties in concentration, memory and thinking ability. Additionally, individuals with eating disorders may exhibit symptoms of specific neurological conditions related to nutritional deficiencies, such as beriberi or Wernicke's encephalopathy, which may present with various neurological manifestations, including peripheral neuropathy; in the case of beriberi, cardiac abnormalities, and in Wernicke's encephalopathy, confusion, ataxia and ophthalmoplegia can occur.

Endocrine system

Hypothermia, characterised by a body temperature below 35.5°C can result from decreased metabolic activity and loss of subcutaneous fat due to inadequate calorie intake.

Pubertal assessment

Pubertal assessment using Tanner stages is typically deferred to a later stage or if there are concerns about delayed puberty. This evaluation enables developmental progress and abnormalities in sexual maturation to be tracked.

6. Medical investigations

6.1 Blood tests

Blood tests in eating disorder assessment can help to distinguish between eating disorders and organic causes of symptoms, assess consequences of malnutrition, evaluate weight-controlling strategies and identify the risk of refeeding syndrome.

Blood tests to rule out organic causes of symptoms

Blood tests are essential for ruling out organic causes of symptoms. A full blood count identifies anaemia, infections or bone marrow issues. Thyroid function tests diagnose thyroid disorders affecting weight regulation, including euthyroid syndrome, where results are abnormal despite normal thyroid function. HbA1c tests help detect diabetes, alongside baseline blood glucose measurements to assess hypoglycaemia concerns. Liver function tests assess liver health, which can be affected by malnutrition, while renal function tests evaluate kidney function, particularly if acute

kidney injury or dehydration is suspected. Anti-tTG antibodies are used for coeliac disease screening. Urinary pregnancy testing and measuring luteinising hormone, follicle-stimulating hormone and oestradiol may be relevant for amenorrhoeic girls.

Blood tests to assess the consequences of malnutrition

The comprehensive metabolic panel evaluates electrolyte imbalances, bone profiles and magnesium levels. Iron studies assess anaemia and iron deficiency resulting from inadequate nutrient intake. Vitamin D, folate and B12 levels are often compromised. The levels of these vitamins should be determined; they are important for both bone and neurological health. Lipid profiles offer insights into cardiovascular risk, particularly in cases of extreme weight loss. Zinc levels should not be routinely assessed via blood tests due to inaccuracies; instead, hair specimens provide more reliable results. A micronutrient assessment by a dietitian, coupled with clinical evaluation, may be a more suitable approach.

Other blood tests to consider in specific scenarios

There are various other circumstances in which blood tests may be considered, including those in which there is known or suspected self-induced vomiting, laxative overuse or over-exercise. Blood tests should be used as part of the assessment of refeeding syndrome. These are discussed in the following sections.

Self-induced vomiting

This practice can result in significant electrolyte changes, including low potassium, chloride and magnesium levels. The loss of hydrochloric acid during vomiting disrupts the acid-base balance and affects renal tubules, leading to potassium loss. Self-induced vomiting can induce metabolic alkalosis, characterised by elevated serum bicarbonate levels due to the loss of hydrogen ions, resulting in an increased blood pH.

Laxative misuse

Laxative misuse can result in electrolyte imbalance, dehydration, metabolic alkalosis and impaired kidney function, as evidenced by blood test abnormalities, including low potassium, elevated BUN (blood urea nitrogen) and creatinine, metabolic alkalosis and hypomagnesemia. These complications can lead to cardiac arrhythmias, muscle weakness, seizures and kidney problems. Monitoring electrolyte levels, kidney function and markers of organ damage through blood tests is essential for comprehensive care and early intervention. Additionally, vigilance for complications such as anaemia and bone changes is paramount in managing the consequences of laxative misuse.

Over-exercise

Elevated creatine kinase and lactate dehydrogenase levels indicate muscle damage, suggesting potential strain or injury incurred during physical exertion. Electrolyte disturbance, such as hypokalaemia, hyponatraemia and hypochloraemia, can result from prolonged physical activity accompanied by excessive sweating, disrupting the body's delicate balance of essential ions. Elevated BUN and creatinine levels are indicators of dehydration induced by significant fluid loss through sweat, highlighting the physiological toll of extended periods of strenuous exercise.

Blood tests to identify the risk of refeeding syndrome

Refeeding syndrome, a potential complication in nutritional rehabilitation, arises from electrolyte imbalance. Rapid carbohydrate reintroduction prompts insulin release, causing low phosphorus levels and possible hypophosphataemia. Decreased potassium and magnesium levels can occur, posing risks to cardiac, respiratory and neuromuscular function. A complete set of urea and electrolyte tests, including additional magnesium, calcium and phosphate, is required.

6.2 Electrocardiography (ECG)

ECG findings in severe malnutrition reveal cardiac abnormalities linked to conduction issues, electrolyte imbalance or structural changes. Key markers include QTc prolongation (corrected QT interval over 460 ms in males and 470 ms in females), T-wave abnormalities (flattening or inversion) and heart rate irregularities such as sinus bradycardia (below 60 bpm) and sinus tachycardia (above 100 bpm). Other signs include atrial fibrillation (irregular rhythm without discernible P waves) and ventricular arrhythmias, such as premature ventricular contractions or ventricular tachycardia. These ECG findings are important for assessing cardiac health in individuals with severe malnutrition and guiding appropriate management strategies.

6.3 Dual-energy x-ray absorptiometry (DEXA) scan

The DEXA scan is valuable for assessing bone health, especially in those with anorexia nervosa, who often have low bone mineral density (BMD). It provides baseline BMD measurements and assists in monitoring the impact of malnutrition on bone health. This is particularly important for females with persistent amenorrhea, as they are at an increased risk of osteoporosis and fractures due to hormonal imbalance affecting bone density. According to NICE guidelines, children and young people should have a DEXA scan after one year of being underweight, or sooner if bone pain or fractures occur. Adults should undergo a scan after two years of being malnourished or earlier. DEXA

scans should not be repeated more than once per year, unless bone pain or fractures develop, to limit unnecessary radiation exposure while ensuring effective monitoring.

7. Risk assessment of comorbid physical and mental health conditions

Research shows that 20% of cases involve additional mental health risks (1), while 80% present medical risks (40). The UK MEED guidance provides a structured approach to evaluate the risks comprehensively. For details, see Table 1.

Checklist of "Lightbulb" signs

The MEED guidance includes a Checklist of "Lightbulb" signs to identify indicators of increased severity in eating disorders.

Realm of inquiry	Finding	Notes
History	Rapid weight loss	>1 kg per week for two weeks
	Acute food refusal	>24 hours seek advice
	Frequent vomiting	Risk of hypokalaemic alkalosis
	Faints, chest pain	Cardiorespiratory malfunction
	Little urine output	Renal shutdown
	Intractable constipation	Colonic atony
	Suicidal thoughts	Suicidal behaviour
Examination	BMI <13	Depends on rate of weight loss
	Pulse <40 bpm, postural hypotension with recurrent syncope	Red on risk assessment
	Core temperature 35.5°C	Red on risk assessment
	Muscle weakness (SUSS)	SUSS score 0-1, red on risk assessment
Investigations	Any significant ECG abnormality	Red on risk assessment
	Hypokalaemia	<2.5 mmol/L red on risk assessment
	Hyponatraemia	Water loading
	Low phosphate	From being refed or recent binge
	Raised transaminases	Usually due to malnutrition
	Urine SG <1.010	Water loading
	Hypoglycaemia, glucose <3 mmol/L	Can occur in extreme starvation, often with ketosis
	HbA1C > 10%	The patient has type 1 diabetes and an eating disorder

Table 1. MEED (reproduced with permission from the Royal College of Psychiatrists)
Abbreviations: ECG = electrocardiogram; SG = specific gravity; SUSS = Sit up, Squat, Stand Test

8. Family assessment

Understanding family dynamics is important for treating eating disorders and ensuring long-term recovery (40, 41). While an initial overview of the family system provides a foundation, a thorough assessment is essential at the beginning of therapy. This assessment includes gathering detailed information about family composition, such as each member's name, age and role. It also involves reviewing the medical and psychiatric history of family members, particularly any previous occurrences of eating disorders or mental health conditions. Understanding the family's attitudes toward food, dietary practices, restrictions and cultural influences is essential.

Additionally, the assessment explores family dynamics, including communication patterns and support systems. Evaluating how family roles and relationships affect the individual with an eating disorder helps identify sources of conflict and support (42, 43).

Recognising the impact of the eating disorder on the family's psychosocial context is vital for developing a targeted treatment plan. By addressing these dynamics through family therapy, clinicians can facilitate realignment and support sustained recovery, ensuring that the family's specific needs and challenges are effectively discussed (40, 41).

9. Differential diagnosis

A comprehensive differential diagnosis requires evaluation of a range of medical and psychiatric conditions that may present with symptoms or signs similar to those of eating disorders. This includes assessing gastrointestinal, endocrine, neurological and autoimmune disorders and malnutrition-related complications, as well as psychiatric conditions such as major depressive disorder, anxiety disorders, neurodiversity, personality disorders and obsessive-compulsive disorder.

10. Collateral history

Gathering collateral history from family or close contacts is essential in eating disorder assessments, as patients may under-report or minimise symptoms. External perspectives can uncover hidden behaviours and provide insight into early triggers, family dynamics and overall functioning. This additional information helps clinicians to make accurate diagnoses and tailor individual interventions appropriately.

11. Diagnostic tools and screening

Screening and assessment tools

Screening tools identify potential eating disorders, but they differ from comprehensive clinical assessments, which are essential for accurate diagnosis and personalised treatment planning. Brief screening tools like the SCOFF questionnaire are helpful for initial identification of individuals in primary care or school settings who are likely to require specialist referral. In contrast, detailed diagnostic questionnaires, like the EDE, are more suitable in specialised clinical settings as they facilitate thorough evaluations and tailored treatment strategies.

Screening tools

SCOFF questionnaire: according to Morgan, Reid and Lacey (44), this is used in clinical settings and comprises five questions assessing eating disorder risk factors. A score of two or more suggests a likely diagnosis, prompting further evaluation for eating disorders in individuals aged 13 and older. This test has a sensitivity of 81.5% and a specificity of 89.0% (44).

S – Do you make yourself **S**ick because you feel uncomfortably full?

C – Do you worry you have lost **C**ontrol over how much you eat?

O – Have you recently lost more than **O**ne stone (6.35 kg) in three months?

F – Do you believe yourself to be **F**at when others say you are too thin?

F – Would you say **F**ood dominates your life?

The **Eating Disorder Examination for Adolescents (EDE-A)** is an assessment tool specifically designed to evaluate eating disorder symptoms and behaviours in adolescents aged 12 to 18. It is adapted from the original EDE to suit adolescents' developmental and psychological characteristics (45).

Eating Disorder Examination Questionnaire (EDE-Q): adapted from the EDE interview, a self-reported instrument assessing eating disorder psychopathology. It is tailored for age groups including adults 18 years and older (46). It has a sensitivity of 84% and a specificity of 79% (47).

The **Eating Attitudes Test (EAT-26)** is a widely employed self-report questionnaire for individuals aged 13 years and older. It evaluates attitudes and behaviours concerning eating habits and body image through 26 items, effectively identifying those at risk of developing eating disorders. (48). A score of 20 or higher indicates a high level of concern about dieting, body weight or problematic eating behaviours.

The **Binge Eating Scale (BES)** is a self-reported questionnaire suitable for adolescents and adults. It explores behaviours and emotions linked to binge eating to provide valuable insights into the presence and severity of binge eating behaviours (49). This test has a sensitivity of 81.8% and a specificity of 97.8% (50).

The **Nine Item Avoidant/Restrictive Food Intake Disorder (NIAS)** is a brief assessment tool designed to identify individuals exhibiting symptoms of avoidant/restrictive food intake disorder (ARFID) quickly, prompting further evaluation and intervention by healthcare professionals (51).

Clinically useful questionnaires

The **PARDI-AR-Q** is a self-report measure of the symptoms of ARFID, based on the Pica, ARFID and Rumination Disorder Interview (52).

The **Body Shape Questionnaire (BSQ)** is a self-report tool used in clinical and research contexts to assess concerns and preoccupations regarding body shape. It evaluates body dissatisfaction and weight-and-shape-related distress to provide insights into body-image-related distress (53).

The **Dutch Overeating Questionnaire (DEBQ)** is a self-report tool designed to assess different aspects of eating behaviour. Focused on emotional eating, external eating and restrained eating, it helps identify patterns related to overeating in response to emotions, external cues and conscious control efforts (54). It is typically used for individuals aged 18 years and older.

Diagnostic tools

The **Eating Disorder Examination for Children (ChEDE)** is a structured interview designed to assess eating disor-

ders in youth. It evaluates eating behaviours, body image concerns and related psychological issues, offering essential insights for diagnosis and treatment (55, 56).

The **Eating Disorder Examination (EDE)** is a structured clinical interview widely considered the gold standard for assessing adult (>18 years) eating disorders (57). It has four subscales: restraint, eating concern, shape concern and weight concern.

The **Pica, ARFID and Rumination Disorder Interview** (PARDI) is a semi-structured, multi-informant clinical assessment designed to assess and diagnose pica, ARFID and rumination disorder according to DSM-5 criteria.

Assessment of clinical impact tools

The Clinical Impairment Assessment (CIA) evaluates the effects of eating disorders on diverse life domains, including relationships, work and overall wellbeing, offering clinicians valuable insights into the broader consequences of these disorders (58). The CIA is typically used for individuals aged 14 years and older. This test carries a sensitivity of 76% and a specificity of 86% (58).

12. Diagnosis

Table 2 provides a comparative overview of the diagnostic criteria for various eating disorders defined by the ICD-11 and DSM-5-TR. It highlights similarities and critical differences between the two diagnostic systems, illustrating each system's unique approach to categorising and defining eating disorders based on symptomatology, severity, duration and contextual factors.

13. Conclusion

Evaluating eating disorders transcends mere diagnosis; it is a critical blueprint for bespoke treatment and comprehensive recovery. By taking into account medical history, clinical evaluation and family dynamics within the biopsychosocial model, it can facilitate early detection and effective therapy. Thorough assessment can clarify severity and guide personalised interventions, with the aim of achieving effective recovery and enduring health.

Funding

No funding or grants were received for this work.

Declaration of interest

The authors declare that they have no conflicts of interest.

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ED diagnosis	ICD-11	DSM-5-TR	Key differences
Pica	Pica is characterised by regular consumption of non-nutritive substances or raw food ingredients. Substances may include non-food objects like clay, soil, chalk, or raw food ingredients such as salt or corn flour. The behaviour is persistent or severe enough to require clinical attention. Typically occurs in individuals who have reached a developmental age of approximately two years. Consumption of non-food items causes damage to health, impairment in functioning, or significant risk due to the frequency, amount, or nature of ingested substances.	A. Persistent eating of nonnutritive, non-food substances over at least one month. B. Eating nonnutritive, non-food substances is inappropriate for the individual's developmental level. C. The eating behaviour is not part of a culturally supported or socially normative practice. D. If the eating behaviour occurs in the context of another mental disorder (e.g., intellectual developmental disorder [intellectual disability], autism spectrum disorder, schizophrenia) or medical condition (including pregnancy), it is sufficiently severe to warrant additional clinical attention.	ICD-11 comprehensively describes substances consumed and behaviour severity, emphasising developmental aspects. In contrast, DSM-5-TR considers cultural and social norms alongside the presence of other mental disorders or medical conditions and requires a minimum duration of one month.
Rumination-regurgitation disorder/rumination disorder	Characterised by intentional and repeated regurgitation of previously swallowed food. Regurgitation may involve re-chewing, re-swallowing, or deliberately spitting out. Behaviour occurs frequently (several times per week) over several weeks. Not fully explained by other medical conditions causing regurgitation or nausea/vomiting. Diagnosis limited to individuals at least two years old.	A. Repeated regurgitation of food over at least one month. Regurgitated food may be re-chewed, re-swallowed, or spat. B. The repeated regurgitation is not attributable to an associated gastrointestinal or other medical condition (e.g., gastroesophageal reflux, pyloric stenosis). C. The eating disturbance does not occur exclusively during anorexia nervosa, bulimia nervosa, binge eating disorder, or avoidant/restrictive food intake disorder. D. If the symptoms occur in the context of another mental disorder (e.g., intellectual developmental disorder [intellectual disability] or another neurodevelopmental disorder), they are sufficiently severe to warrant additional clinical attention.	ICD-11 criteria provide comprehensive descriptions of behaviour and specify frequency/duration requirements for diagnosis, emphasising minimum age for diagnosis. In contrast, DSM-5-TR criteria consider comorbid medical conditions and exclude diagnosis if the eating disturbance occurs exclusively within other specified eating disorders.
Avoidant/restrictive food intake disorder (ARFID)	ARFID characterised by: Insufficient quantity or variety of food intake results in weight loss, nutritional deficiencies, or adverse physical health effects. Significant impairment in various areas of functioning. Eating behaviour not driven by a preoccupation with body weight or shape. Not due to food unavailability, other medical conditions, mental disorders, or substance/medication effects.	A. An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) associated with one (or more) of the following: 1. Significant weight loss (or failure to achieve expected weight gain or faltering growth in children). 2. Significant nutritional deficiency. 3. Dependence on enteral feeding or oral nutritional supplements. 4. Marked interference with psychosocial functioning. B. The disturbance is not better explained by a lack of available food or by an associated culturally sanctioned practice. C. The eating disturbance does not occur exclusively during anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced. D. The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.	ICD-11 highlights the physical health impact of food restriction, while DSM-5-TR also considers psychosocial functioning. DSM-5-TR includes exclusion criteria for cultural practices and other disorders, offering a comprehensive framework. It also assesses the severity of eating disturbances relative to concurrent medical or mental conditions, prompting additional clinical attention if needed.
Anorexia nervosa	Anorexia Nervosa characterised by: Significantly low body weight for height, age, and developmental stage. Commonly defined by BMI less than 18.5 kg/m^2 in adults or BMI-for-age under 5th percentile in children/adolescents. Rapid weight loss (>20% of total body weight within six months) may replace low body weight guidelines if other criteria are met. Children/adolescents may fail to gain weight as expected. Persistent behaviours to prevent weight restoration include restricted eating, purging, and excessive exercise. Central role of low body weight or shape in self-evaluation.	A. Restricting energy intake relative to requirements leads to a significantly low body weight regarding age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than usual or, for children and adolescents, less than minimally expected. B. Intense fear of gaining weight or becoming fat or persistent behaviour that interferes with weight gain, even at a significantly low weight. C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.	ICD-11 focuses on specific BMI thresholds to define low body weight, while DSM-5-TR emphasises weight relative to developmental trajectory and physical health without specifying BMI. Additionally, DSM-5-TR incorporates criteria concerning fear of weight gain and disturbance in body weight or shape perception, aspects not explicitly outlined in the ICD-11 criteria. Notably, ICD-11 allows for rapid weight loss as an alternative diagnostic criterion, while DSM-5-TR does not expressly mention this criterion.

ED diagnosis	ICD-11	DSM-5-TR	Key differences
Bulimia nervosa	Bulimia Nervosa is characterised by: Frequent, recurrent binge eating episodes (once a week or more over at least one month). Binge eating involves subjective loss of control, eating significantly more or differently than usual. Compensatory behaviours like self-induced vomiting, laxative misuse, or excessive exercise. Preoccupation with body shape or weight influencing self-evaluation. Marked by distress or impairment in various areas of functioning. Does not meet diagnostic requirements of Anorexia Nervosa.	A. Recurrent episodes of binge eating. Both of the following characterise an episode of binge eating: 1. Eating, in a discrete period (e.g., within any 2 hours), an amount of food that is larger than what most individuals would eat in a similar period under similar circumstances. 2. A lack of control of overeating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). B. Recurrent inappropriate compensatory behaviours to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise. C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months. D. Self-evaluation is unduly influenced by body shape and weight. E. The disturbance does not occur exclusively during episodes of anorexia nervosa.	ICD-11 defines binge eating episodes as occurring at least once weekly over one month, while DSM-5-TR requires this frequency for three months. ICD-11 emphasises impairment in various areas of functioning, whereas DSM-5-TR focuses on body shape and weight influence on self-evaluation. ICD-11 excludes individuals meeting anorexia nervosa criteria, while DSM-5-TR does not specify this criterion.
Binge eating disorder	Binge eating disorder is characterised by: Frequent, recurrent episodes of binge eating (once a week or more over several months). Binge eating episodes involve subjective loss of control, eating significantly more or differently than usual. Accompanied by distressing emotions like guilt or disgust. They are not followed by inappropriate compensatory behaviours seen in Bulimia Nervosa. Marked by distress or impairment in various areas of functioning.	A. Recurrent episodes of binge eating. Both of the following characterise an episode of binge eating: 1. Eating, in a discrete period (e.g., within any 2-hour period), an amount of food that is larger than what most people would eat in a similar period under similar circumstances. 2. A lack of control overeating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). B. The binge eating episodes are associated with three (or more) of the following: 1. Eating much more rapidly than usual. 2. Eating until feeling uncomfortably full. 3. Eating large amounts of food when not feeling physically hungry. 4. Eating alone because of feeling embarrassed by how much one is eating. 5. Feeling disgusted with oneself, depressed, or very guilty afterwards. C. Marked distress regarding binge eating is present. D. Binge eating occurs, on average, at least once a week for three months. E. Binge eating is not associated with the recurrent use of inappropriate compensatory behaviour as in bulimia nervosa and does not occur exclusively during bulimia nervosa or anorexia nervosa.	The ICD-11 emphasises the absence of compensatory behaviours post-binge eating, while the DSM-5-TR excludes their presence and includes additional associated features. Both criteria highlight marked distress or impairment related to binge eating behaviour. The ICD-11 specifies the absence of binge eating during episodes of bulimia nervosa or anorexia nervosa, while the DSM-5-TR adds this criterion and specifies the absence of associated compensatory behaviours.
Other specified feeding or eating disorder	Involve atypical or subthreshold presentations of feeding or eating disorders, which may include variations in the frequency, duration, or severity of symptoms or the presence of symptoms that do not fully meet the criteria for a specific disorder.	This category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. Sub-classes include atypical anorexia nervosa/purge disorder.	ICD-11 acknowledges variations in symptomatology that deviate from established criteria, while DSM-5-TR categorises presentations causing distress but not meeting full disorder criteria. DSM-5-TR introduces sub-classes like atypical anorexia nervosa/purging disorder for specificity.
Feeding or eating disorders unspecified/unspecified feeding or eating disorder	This is a broad category used when the symptoms do not fit into specific diagnostic criteria or when there is insufficient information available for a more specific diagnosis.	The unspecified feeding or eating disorder category is used when the clinician chooses not to specify why the criteria are not met for a specific feeding or eating disorder. It also includes presentations with insufficient information to make a more specific diagnosis.	ICD-11 employs a "broader category" for cases not fitting specific diagnostic criteria or lacking sufficient information without specifying reasons. In contrast, DSM-5-TR introduces an "unspecified feeding or eating disorder category", explicitly addressing situations where criteria are not met for a specific disorder, including insufficient information. Furthermore, DSM-5-TR offers detailed guidance on clinician discretion in specifying reasons for not meeting criteria.

Table 2. Comparison of diagnostic criteria for eating disorders between the ICD-11 and DSM-5-TR

A summary of risk factors and protective factors in eating disorders

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Abstract

Given the increasing prevalence of eating disorders, a greater awareness of risk factors among clinicians is essential. This should enable appropriate screening for at-risk groups, reducing the risk of developing eating disorders and prompting individualised treatment programmes.

The risk factors for eating disorders are multifactorial, and we will discuss factors under the following domains: demographic, biological and developmental, personal, psychological and sociocultural. Protective factors will also be discussed.

Introduction

A recent meta-analysis showed that the prevalence of eating disorders in the UK is higher than previously estimated, with a lifetime mean of 8.4% for women and 2.2% for men (1). Furthermore, there is evidence to suggest that prevalence rates have increased significantly between the periods of 2000 to 2006 and 2013 to 2018 (1). An increasing prevalence has led to an increasing demand on specialist eating disorder services, resulting in longer waiting times and a comparatively higher "illness threshold" for patients to gain access to specialist treatment (2).

Patients with eating disorders are therefore increasingly being managed by non-specialist services, including child and adolescent/general adult mental health teams, general medical teams and general practitioners. If prevalence and illness thresholds continue to rise, the severity of eating disorder illness that is expected to be managed by non-specialist services is also likely to rise.

The 2017 parliamentary ombudsman report on the avoidable deaths of three patients with eating disorders (3) highlighted how harm can be prevented with prompt and effective intervention. The subsequent call for a review of junior doctor training in eating disorders revealed that the average medical school graduate receives less than two hours of teaching on eating disorders throughout their entire undergraduate medical degree (4). Medical education has not kept up with increasing clinical demands. This is a particularly pressing issue given that eating disorders are associated with high levels of physical and psychiatric comorbidity and a high mortality rate (5). Non-specialists may be asked to manage complex and risky patients in a community setting with minimal training, in a very specialised area of psychiatry. This includes general adult psychiatrists and GPs. GPs are frequently the first point of contact with health services for those with eating disorders, and early detection from GPs may contribute to better outcomes (6). The inverse is also true – lack of detection or poor care from GPs may cause overall worse outcomes (7). Early detection of an eating disorder (8) and subsequent early intervention (9) have been demonstrated to have a significant impact on recovery, symptom burden and mortality. In primary care, the focus must be on early detection and care planning, which should include discussion with more specialist services but may place a large burden of the responsibility for delivery of care on the general practitioner.

A key element of early detection and care planning is health professionals' knowledge of the risk and protective factors associated with eating disorders, especially during early contacts with health services in, for example, primary care (6). In this review, we will discuss risk factors and protective factors around eating disorders, specifically focussing on anorexia nervosa, bulimia nervosa and binge eating disorder, although many of these risk factors will also be applicable to eating disorder not otherwise specified and avoidant/restrictive food intake disorder diagnoses.

Risk factors

Identification of groups at risk of developing eating disorders allows for focused monitoring, targeted prevention strategies and earlier intervention, all of which contribute to more favourable outcomes. However, in order for risk factors to be clinically useful, they need to be both sensitive and specific. In this section, we will focus on risk factors that are both sensitive and specific to eating disorders in demographic, biological and developmental, personal, psychological and sociocultural domains.

Demographic risk factors

Age and gender are well-known risk factors for eating disorders. Women develop eating disorders at rates significantly higher than men (10). The reported differences between men and women are variable depending on the source; some studies show that women have a lifetime risk almost four times higher than men (1). In addition, rates of eating disorders in women and men have changed substantially in the past decades; males comprised only 10% of patients diagnosed with eating disorders in the 1960s (11), compared to up to 25% in 2020 (1). Evidence suggests that men are historically less likely to receive an eating disorder diagnosis and cases of men with an eating disorder were considered vanishingly rare (12). It is only in the past two to three decades that diagnoses of eating disorders, and particularly anorexia nervosa, in men have become more widely accepted. This is attributed to greater understanding of eating disorders amongst professionals and an overall increasing prevalence of eating disorders. The impact of changing gender roles in society is difficult to measure but may also play a role in the changes in male-to-female risk ratios in eating disorders (13).

Academic and societal concepts of gender and sexual identity are changing and rates of eating disorders among LGBTQI groups are significantly higher than those in the general population; some studies suggest that over 50% of LGBT adolescents have received an eating disorder diagnosis, whilst over 60% have engaged in at least one disordered eating behaviour (14), compared to 13% and 22% in general population, respectively (14, 15). Our current understanding of the impact of gender on eating disorders is limited, with the complex intersectionality between gender, sexual identity and eating disorders remaining unexplored (16).

This is further complicated by adolescence being the peak period of eating disorders risk (10), with the risk highest between the ages of 15 and 19 (17). Those with earlier age of puberty onset are also at increased risk (18). Factors such as bodily changes, identity formation and transition to adulthood have all been implicated in this risk period (18). A growing body of research has highlighted the role of oestrogen, and oestrogen receptor genes, in the development of eating disorders – this may contribute to the increased risk both around puberty in females (18), and also around menopause (19).

Studies on the impact of ethnicity and ethnic minority status on the risk of developing an eating disorder are far from conclusive; some studies suggest no differences in risk based on ethnicity (19) whilst others report that being mixed race may increase risk and being from black/Hispanic backgrounds may reduce risk (20). Higher parental socioeconomic status has been associated with increased risk of developing an eating disorder, especially anorexia nervosa (21), in contrast to other major mental illnesses; however, the validity of these findings is now being questioned, with the suggestion that increased risk may in fact be better explained by other factors, such as higher educational attainment, which is linked to anorexia nervosa (22).

Biological and developmental risk factors

Genetic factors are thought to play a significant role in the development of eating disorders, with heritability estimates from twin studies in the range of 48% to 74% for anorexia nervosa, 55% to 62% for bulimia nervosa and 39 to 45% for binge eating disorder (23).

In addition, genome-wide association studies have revealed extensive genetic overlap between anorexia nervosa, psychiatric disorders and related traits, such as bipolar disorder and neuroticism (24).

The interplay between genetic factors and eating disorders is further complicated by intergenerational association. Studies have reported that an individual with a parent who has a history of an eating disorder is twice as likely to develop an eating disorder than those with parents who have no history of eating disorders (25). In addition, family history of any affective disorder has been shown to increase the risk of developing an eating disorder (26), and the closer the relative, the higher the risk conferred. It is likely that there is a degree of overlap between genetic risk and environmental/social factors when a relative is in very close proximity to the patient, such as a parent or sibling. Our comprehension of the impact of these genetic and environmental factors on the risks of developing an eating disorder remains limited at present. It is likely that there is an epigenetic contribution to the development of eating disorders, given the apparent interaction between genetic risk factors and environmental stressors; however, the evidence remains limited at present (27).

Regarding biological risk factors, satiety and ovarian hormones have been linked to the core symptoms of eating disorders (28). Imbalances in glutamatergic and dopaminergic mesolimbic reward pathways have also been implicated, showing abnormalities similar to those seen in drug addiction in patients with binge eating disorder (29). Glucocorticoids, stress response and dysregulation in these axes have been linked to modulation of appetite; however, further study is required to establish direct links (30).

Childhood obesity has been linked to subsequent development of bulimia nervosa or binge eating disorder (31), whereas low childhood body mass index has been associated with anorexia nervosa (32). Together with evidence indicating an association between childhood energy balance disorder and later development of eating disorders (33), these vulnerabilities suggest a metabolic causative factor for eating disorders (32).

Certain long-term physical illnesses, such as coeliac disease (34), type 1 diabetes mellitus (35) or serious childhood illnesses requiring hospital admission (36) have also been associated with the development of disordered eating behaviours. Inflammatory bowel diseases, namely Crohn disease and ulcerative colitis, show a complex bidirectional relationship with eating disorders (37). There is evidence of bidirectional diagnostic overshadowing; an increased fear of food-related symptoms in those with IBD may induce disordered eating behaviours.

Research has suggested that the prevalence of eating disorders among people with type 1 diabetes is 7% (38), the association being strongest with bulimia nervosa (39). The latter is sometimes referred to as "diabulimia" and involves the misuse of insulin to prevent weight gain. It is possible that the biological and psychological implications of having type 1 diabetes increase the risks of subsequent eating disorders (40).

Neurotransmitter imbalances are linked to the perpetuation of anorexia nervosa and bulimia nervosa, particularly serotonin (41). This imbalance can heighten anxiety and perpetuate the obsessive thoughts around food and body image in eating disorders. Compared with findings in anorexia nervosa, serotonergic changes in binge eating disorder appear to be inconsistently skewed toward reduction of serotonin activity (41). In addition, dysregulation of appetite-related hormones has been shown to contribute to the perpetuation of binge eating disorder, though the mechanism remains unclear (42).

Neurodevelopmental disorders such as attention deficit hyperactivity disorder (ADHD) (43) and autism (44) both show high levels of co-occurrence with eating disorders. It is not clear whether these should be considered risk factors; however, it is important to be aware that someone with, for example, ADHD is more likely to meet the diagnostic criteria for an eating disorder (45). It is also important to be aware that presentations may vary with the presence of a concomitant neurodevelopmental disorder (46).

Finally, gut microbiota is an emerging area of interest, with some evidence suggesting patients with anorexia nervosa have a very different gut microbiome profile from those of the general population (47). It is unclear if the difference observed reflects a predisposing factor for anorexia nervosa or the effects of starvation. In addition, differences/changes in microbiome profile have been observed in factors reported earlier, such as anxiety and depression symptomology (48), immune system defence mechanisms and the metabolism of insulin (47).

Psychological risk factors

Certain personality traits, such as perfectionism (49, 50), body dissatisfaction and negative emotionality (51), have all been linked with the development of eating disorders in the context of a social setting that idealises thinness. In the context of an eating disorder, perfectionist traits are mostly associated with restriction as they can drive individuals to maintain rigid eating patterns, reinforcing their perceived control (52). Other traits implicated in the development of eating disorders include low self-esteem, negative body image and feelings of inadequacy (53). Impulsivity and difficulties with emotional regulation are more closely associated with bingeing/purging behaviours (54).

Diagnoses of affective disorders such as anxiety or depression are common in those diagnosed with eating disorders (55). Low self-esteem has been shown to be a universal risk factor for eating disorders (37); it has even been hypothesised that low self-esteem directly causes eating disorders (56), and it has been robustly demonstrated that self-esteem and risk of developing an eating disorder follow a reciprocal relationship, that is, the lower the self-esteem, the higher the risk.

Some individuals with eating disorders struggle with emotional regulation and may use food intake or food restriction as a coping mechanism to alleviate distress (57). For example, in binge eating disorder, emotional regulation through binge eating plays a significant role in the perpetuation of the illness; individuals use food as a coping mechanism to alleviate stress, anxiety or depression (58). The negative reinforcement of emotional relief maintains the pattern of compulsive eating, as the emotional relief is frequently only short-lived and is replaced with more negative feelings resulting directly from the binge (59).

Difficulties in emotional regulation may also play a key role in maintaining the symptoms of eating disorders (60). Chronic starvation in anorexia nervosa can lead to anhedonia and worsen existing comorbidities which can, in turn, lead to emotional distress which acts to perpetuate the illness; thus, difficulties in the regulation of emotions act as both a predisposing and a perpetuating factor (61, 62).

Individuals with eating disorders may feel compelled to maintain the secrecy of their behaviours. Strong feelings of shame or guilt are associated with symptoms of disordered eating (62), and this can lead to social withdrawal and isolation which can perpetuate their illness (63). For example, social isolation has been shown to contribute to the perpetuation of anorexia nervosa, as individuals with anorexia withdraw from social activities and relationships, limiting their opportunities for external influence and support (64). Social isolation has also been shown to play a role in the perpetuation of binge eating disorder, as the individual's withdrawal from others combined with the cycle of overeating followed by negative emotions appears to increase the intensity of symptoms, which further reinforces the illness and the social isolation (65).

Motivation to recover or to change disordered eating behaviours is a difficult-to-quantify risk factor for both the per-

petuation and precipitation of an eating disorder. It is variable across a patient's lifetime, appearing to increase with age (66) and being influenced by a range of lifestyle and social factors (67).

Personal risk factors

A personal history of mental illness has been shown to increase risk of developing an eating disorder (68); in fact, many patients with eating disorders have been shown to meet diagnostic criteria for anxiety disorders prior to developing symptoms of disordered eating (69).

A personal history of trauma seems to compound all other risk factors as well as conferring increased risk itself (69). Traumatic experiences or adverse life events may act as triggers for the development of an eating disorder, pushing individuals toward restrictive eating as a method of regaining a sense of control. These can include experiences such as childhood maltreatment (70), insecure attachment (71), teasing, bullying or social exclusion (72), or childhood sexual abuse (73). Studies have shown that when patients diagnosed with eating disorders are compared with a control group, significantly more patients with eating disorders than community controls have experienced either a severe life event or a period of marked difficulties during the year before onset of their illness (64). The most common serious life stressors before onset involved close relationships with family and friends (interpersonal events) (64). Of all those diagnosed with eating disorders who had experienced either a severe life event or period of marked difficulties during the year before the onset of their illness, those with bulimia nervosa had most commonly experienced a serious life stressor, whereas difficulties with sexuality seem to be specifically related to the onset of anorexia nervosa (64). Social stressors and problems affecting interpersonal relationships can result in the formation of a vicious cycle, as problems with interpersonal relationships are secondary consequences of an eating disorder and have been shown to contribute to the perpetuation and perseverance of the illness (52).

We have previously mentioned that the highest-risk age group is those between 15 and 19 years of age; two factors that appear to be closely linked to this age group and act as major contributing factors are the impact of dieting behaviours and the impact of academic stress (i.e., the pressure to succeed academically). It was noted that female adolescents who severely dieted were 18 times more likely to develop an eating disorder than those who did not (74). Literature on the impact of academic stress on eating disorders is lacking but it has been implicated in contributing to stress in the years prior to diagnosis (75), and also implicated as an exacerbating factor in those already diagnosed, causing emotional distress which is manifested as symptoms of disordered eating (76). Transitioning to higher education has been reliably shown to increase risk – this appears to be as a result of a combination of factors including age group, academic pressure, peer influence and the impact of social media (77).

The relationship between eating disorders and recreational activities, such as sport, is complex. However, it seems that, in general, sports that involve a subjective judgement of performance (e.g., ballet, gymnastics), as well as sports that are weight category–dependent or in which weight has a significant impact upon performance (78), confer higher risks of eating disorders, whilst sports that involve more objective judgement of performance by final score (e.g., football, netball) and are not weight category–dependent may in fact confer protection against the development of eating disorders (79, 80). Among professional sports, the risk is higher (81), and specific links to situations like being weighed in public or attempts to reduce weight in order to "make weight" for a competition or event have been identified as risk factors (78).

The home environment is closely linked to development of eating disorders, with family dysfunction and particularly negative food-related experiences involving the family being closely associated with increased disordered eating (82). In particular, childhood undereating and fussy eating have been linked to the development of anorexia nervosa, whilst childhood overeating has been linked to the development of binge eating disorder (83).

Sociocultural risk factors

Idealisation of thinness is a strongly contributing predisposing factor, both in general terms as societal beauty standards have shifted over the 20th and 21st centuries (84) and specifically within families and social groups where the phenomenon of "fat talk" (topics of conversation around eating and body image, specifically disparaging or negative comments about size and body shape in relation to eating) has been shown to be strongly correlated with the presence of symptoms of disordered eating (85). Sociocultural influences, such as the idealisation of thinness (including media exposure, pressures for thinness, thinness expectancies) contribute to body dissatisfaction and may prompt maladaptive eating patterns (86).

In addition to the increasing prevalence of unrealistic/unachievable beauty standards, there has also been an increasing normalisation of diet culture and this, combined with the idealisation and pursuit of thinness, exerts a great deal of social pressure on vulnerable individuals and contributes to a distorted body image (87). Distorted body image is implicated in the genesis of all eating disorders, but in binge eating disorder the dieting and restriction, often in response to societal pressures, can escalate into episodes of compulsive overeating (88). Dieting alone puts an adolescent at significantly increased risk of developing an eating disorder (74).

Peer pressure and societal ideals have also been shown to contribute to the perpetuation of bulimia nervosa (89).

Reflections from patients who have recovered from bulimia nervosa have cited the desire to conform to societal expectations regarding body image as a strong factor in the propagation of the cycle of binge eating and purging, and this is likely to be applicable to symptoms of disordered eating in general.

Social media have been well documented to contribute both to the development of disordered eating but also to relapse risk in those in recovery, through the mechanisms of social comparison, thin ideal internalisation and self-objectification, as well as driving body dissatisfaction (90). This is especially true in highly visual social media (91) and appears to be related to exposure to idealised standards of thinness/leanness/muscularity; however, social media literacy and positive self-image appear to protect against these risks (90).

Protective factors

Definitions of "protective factors" vary across the literature. However, for the purposes of most research on eating disorders (and for the purposes of this paper), the following well-established summary is sufficient. A psychosocial protective factor is that which modulates or in some other way reduces the impact of a risk factor or risk factors on a person's development, contributing to an overall positive outcome and (of particular relevance in eating disorders) promoting the "establishment and maintenance of self-esteem and self-efficacy" (92). Many of the protective factors we think about in the prevention and treatment of eating disorders are not solely specific to disordered eating but will apply to a wide range of mental health difficulties or diagnoses (93). In a similar vein, protective factors do not necessarily apply universally, and it has been demonstrated robustly in the literature that demographic factors such as socioeconomic status, gender and ethnicity (among others) will influence the impact of protective factors (94). The significance of specific protective factors varies across the research, but it is relevant to note that many of these protective factors (e.g., social and emotional support, family environments) are also modifiable.

Beginning with the home environment during development, and beginning with perhaps the broadest and least specific protective factor, it has been shown that feeling satisfied with one's family life between the ages of 10 and 12 years is linked to a reduction in levels of disordered eating in early adolescence and, thus, a (non-specific) feeling of satisfaction in one's family life might be protective against the development of eating disorders (95). In a similar vein, higher levels of familial "connectedness" (96) also appears to convey protection against developing disordered eating behaviours. This may link to the fact that the structure and cohesiveness of the family unit has also been shown to play an important role, as having a higher number of full siblings has been associated with a lower risk of developing an eating disorder (whilst having a higher number of half siblings appears to be associated with a higher risk of developing an eating disorder) (97). There is strong evidence to show that living in a two-parent family reduces the risk of disordered eating, even in the presence of other risk factors (98).

A more specific measure of the effect of the home environment is attitudes towards weight and eating within the family home. Evidence suggests that conversations around healthy eating in the home convey protection against disordered eating behaviours (99), whilst conversations focused solely on weight (100) or critical comments about weight are associated with an increase in disordered eating behaviours (101) – linking to earlier discussions around "fat talk". A high frequency of meals eaten as a family has been shown to be protective against disordered eating behaviours (102) and this appears to show a stronger association when also combined with a positive atmosphere at the dinner table (100), although other data indicates that frequency alone is insufficient to have a protective effect, and that only when frequency is combined with a positive atmosphere is the protective impact present (96).

The importance of family support should not be underestimated, both as a protective factor and as a positive influence on treatment outcomes. Adolescents who reported higher levels of unconditional parental support also had lower rates of developing eating disorders, and a higher level of unconditional parental support has been shown to be protective against the impact of negative life events (103). Symptom burden has also been shown to be lower in those with high levels of family support, for example, purging behaviours (104).

Personality traits are often cited in the development of eating disorders, particularly in anorexia. When examining protective factors, a higher level of personal resilience is associated with better outcomes (improved psychological health and a reduction in symptom burden) (105). Positive self-esteem/self-image is also demonstrated to be both protective against development of eating disorders and associated with better outcomes (106). In the same way that lack of emotional regulation is associated with the development of, for example, binge eating disorder (107), strong emotional regulation (differentiated from emotional suppression) is shown to be protective against developing an eating disorder (108).

Personal resilience is also protective, and levels of family support and care experienced during adolescence are directly correlated with levels of personal resilience (109). Research therefore supports both early family involvement in care, as well as care planning that looks at the patient not just as an individual but as a member of the family unit (94) and examines the relationships and dynamics present within the home.

Relevance to treatment

Eating disorders are serious psychiatric illnesses with high burdens of morbidity and mortality. Early intervention has

been shown to be beneficial in improving treatment outcomes and reducing the impacts of symptom and illness burden, such as developmental disruption. One model of early intervention that has demonstrated promising results is the First Episode Rapid Early intervention for Eating Disorders (FREED) program which aims to address "barriers to early, effective eating disorder treatment in emerging adults aged 16 to 25 years" (110). The program targets those at the onset of their illness and works to address the risk factors around the patient, in addition to treating the patient themselves. The results show a significant increase in body mass index compared to those receiving treatment as usual, as well as a reduction in intensity of service usage (111). Furthermore, those treated under the FREED program also experience a reduction in symptom burden and an increase in self-acceptance. They also reported being able to build a support network and focus on life outside their eating disorder (112). Other studies have reported the effect of eating disorder prevention programmes on university campuses on the risk of students developing an eating disorder (113). More research is needed to design and evaluate preventive eating disorder interventions, with the potential of scalability to population level.

Summary and clinical implications

As inferred from the range of risk factors discussed here, the development of an eating disorder is a multifactorial process. The range of risk factors discussed here are summarised in Figure 1 and it is helpful in clinical practice to conceive of these as "vulnerability factors" that can be accrued and put someone at lesser or greater risk. The quote "genetics loads the gun but the environment pulls the trigger" (114) is a useful way to conceptualise this, and also to understand why two seemingly very similar patients may present very differently.

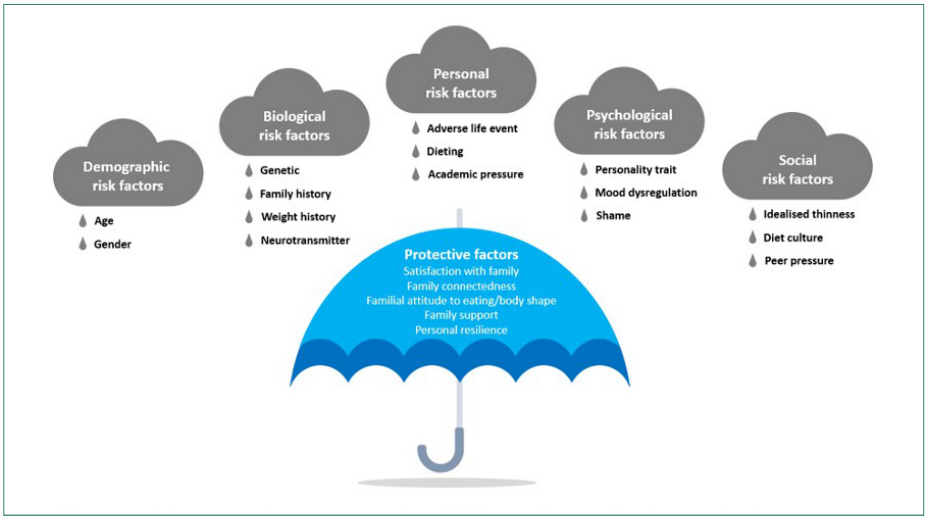

Figure 1: Diagrammatic representation of risks and protective factors in the development of eating disorders

The key clinical implications and messages from this discussion should be that eating disorders, whilst serious, are also treatable and, to some extent, preventable. The prognosis is drastically improved by early intervention, and early identification is vital for interventions to be provided in a timely manner. Eating difficulties cannot be viewed in isolation but must be viewed in the context of their own individual situation; risk and protective factors should be reviewed to form a working care plan alongside the patient and their support network. With knowledge of these factors, clinicians will be more able to provide effective early care for patients, reducing the disease burden for individuals, their loved ones and for society. Furthermore, with these aims in mind whilst care planning, clinical teams should be more able to take a truly patient-centred approach to holistic care planning.

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Risk assessment in eating disorders: using MEED to reduce mortality

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Abstract

Eating disorders (EDs) are potentially fatal illnesses. Sadly, over the years, we have become aware of several deaths where detailed review suggests that they could have been avoided. This was the motivation to write what is now known as MEED, Medical Emergencies in Eating Disorders, published in 2022.

MEED is the most developed guidance on treating severely medically ill patients with EDs and should be used by all clinicians having contact with ED patients. This article documents the physical risks that EDs present, and the preventable deaths, particularly of the most unwell patients. It introduces MEED as a system which has the potential to avoid some of those deaths and improve management. A new website is introduced, meed.org.uk, which may make MEED more accessible to frontline staff and improve its uptake.

Staff are encouraged to be trained to use MEED and to familiarise themselves with the Risk Assessment Framework it contains. Each group of clinical staff as well as patients and carers will find summary sheets and specific advice in MEED. In this article, we have provided links to each problem area we anticipate will be encountered and links to the summary sheets for clinicians, patients and carers. We also provide two clinical vignettes, one a child and one a young adult, to demonstrate how MEED can be used in real-life situations with substantial clinical risk.

We strongly advocate for training to be made mandatory for any staff likely to be assessing or treating a patient with an ED so that the avoidable deaths, mostly in adults, which continue to be reported by coroners, can be eliminated.

Refeeding of severely malnourished patients often takes place in medical or paediatric settings, and previous guidance has led to overcautious refeeding, resulting in "underfeeding syndrome". MEED provides clear, up-to-date, evidence-based guidance which allows essential treatment of low weight by safe refeeding, thereby avoiding refeeding syndrome while avoiding underfeeding syndrome, which has resulted in several documented deaths.

Keywords: eating disorders, risk management, anorexia nervosa, bulimia nervosa, guidance, MEED

Introduction

Eating disorders (EDs), namely anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder, avoidant/restrictive food intake disorder and their atypical forms are common conditions that affect those of all ages and can lead to serious, sometimes fatal, health outcomes. The most lethal is AN, with a standardised mortality ratio (SMR) (corrected for age and sex) of 5.86, followed by BN and atypical EDs, with SMRs of about 2 (1). Some of the deaths occurring in patients with EDs appear to be avoidable, as was reported extensively by the Health Ombudsman for England in a review of three cases (2) in which it was suggested that improvements in clinical management could perhaps have avoided the deaths. At the time of the ombudsman's report, the issue had already been identified (3) and a guidance document (Management of Really Sick Patients with Anorexia Nervosa, MARSIPAN) published in 2010. Hence, there was evidence in these cases that available guidance was not being followed. Indeed, the Manchester Senior Coroner wrote in 2021 in relation to the death of a patient with AN that she was investigating: "This is not a question of lack of familiarity by professionals, it reflects a complete absence of any understanding that MARSIPAN exists and indeed how to implement it in respect of the emergency treatment of an anorexic patient" (4).

There are therefore at least two issues to consider.

1. Preventable deaths are occurring in patients with EDs.
2. The guidance that has been available since 2010 has not been implemented by all clinicians providing care for patients with EDs.

Physical problems encountered when assessing and treating EDs

The types of physical problems, apart from low BMI, encountered in EDs were studied by Mehler et al. (5) who documented them in a series of 1026 adults hospitalised for treatment of an ED. Some of their results are given in Table 1.

Some comments on the list in Table 1 seem appropriate.

1. Low potassium (hypokalaemia) is possibly the most significant and dangerous physical problem in EDs. It can affect patients with both AN and BN. Low potassium is a complication of frequent purging (intentional vomiting

and/or laxative use). It can cause abnormal heart rhythms and can be life-threatening (6).

2. Metabolic alkalosis is often associated with low potassium. This is because vomiting causes loss of acid (hydrogen ions, H^+) from the stomach and this leads to metabolic alkalosis. The body tries to correct this by exchanging H^+ for potassium (K^+) in the kidney. This works for a while because there is a lot of potassium stored in cells, but eventually the body becomes so depleted of potassium that the blood level falls and at that point cardiac arrest can occur.
3. Low sodium (Na^+) is often caused by the patient drinking too much water, usually in order to appear to increase their BMI. Water intoxication occurs in compulsive water drinking and can be fatal (7).
4. Hypoglycaemia or low glucose can occur during starvation in AN, and as a result of taking insulin in a diabetic patient. Glucose in the blood is maintained via the chemical glycogen which is stored in the liver and the muscles. During complete starvation, glycogen stores are used up in about 24 hours (8). After that time, fat is broken down and ketones released from that process to allow essential organs to function, even when the blood glucose is very low. However, this form of metabolism is limited and depends on fat cells being present. In patients with AN, the level of fat can fall to very low levels. In the study by Kerruish et al. (9), the lowest level observed in a group of adolescents was 4.2% (compared to a normal minimum of 15.6%), and when this gets used up the patient can die. Thus, although little or no food intake is not usually associated with hypoglycaemia because the body's response adjusts to the poor intake, hypoglycaemic coma has been reported in AN (10).
5. Prealbumin, also known as transthyretin, is a protein that, if low, indicates possible malnutrition.
6. Low white blood cells (WBC). Over one-third of the patients with restricting AN had low WBCs. This is significant for two reasons. First, it may render the patient more susceptible to infection because of reduced immunity. Second, low WBCs have been associated in adolescents with a possibly increased risk of refeeding syndrome (RFS) (11).
7. Osteoporosis is a well-recognised long-term complication of AN (12) and leads to increased fracture risk. The cause is not clear, although hormonal changes, nutritional deficiency, including reduced levels of calcium and vitamin D (also noted in Table 1), and chronic low weight leading to reduced stress on the skeleton are all possible factors. It seems to be at least partly reversible by weight gain (12). Adolescents with AN are at much greater risk of developing osteoporosis than adult patients, as their bones are still developing and peak bone mineral density is not reached until early in the third decade (13).

Measure	AN restricting	AN purging	BN
Low prealbumin	51.4%		
Low white cells	36.1%		
Osteoporosis	34.3%	21.0%	
Vitamin D deficiency	30.0%		
Metabolic alkalosis	16.8%	33.3%	23.4%
Low sodium	16.0%		
Low potassium	14.2%	42.4%	26.2%
Low glucose	7.1%		

Table 1. Abnormal investigations reported in adults with eating disorders. Mehler et al. (5)

The development of MEED

In 2008, a case history was presented at the British Association for Parenteral and Enteral Nutrition conference. She was a young woman with AN, admitted very underweight to a gastroenterology ward. Attempts were made to feed her but, due to her illness, they did not succeed. The family was desperate to support her, but she continued to lose weight and died.

Following this tragic story, one of the current authors (PHR) met with the consultant physician and they invited a group of physicians and psychiatrists to discuss what could be done. Their meetings were almost all online and they eventually agreed for the Royal College of Psychiatrists to publish a document called MARSIPAN (Management of Really Sick Patients with Anorexia Nervosa) in 2010. This document was endorsed by the Royal Colleges of Physicians and Pathologists.

In 2012, an equivalent guidance for under 18s, Junior MARSIPAN, was produced. A revision of the first document appeared in 2014 and in 2019, a new group was set up with the collaboration of the National Collaborating Centre for Mental Health (NCCMH) which led to the publication in May 2022 of Medical Emergencies in Eating Disorders (MEED) (14).

MEED aimed to be more inclusive than MARSIPAN, providing guidance in one document for all EDs across the whole lifespan.

The MEED development group included a project group with nine members from NCCMH and clinicians, a 13-member Expert Reference Group with experts by experience, both patients and a carer, adult and child and adolescent eating disorders psychiatry, liaison psychiatry, gastroenterology, paediatrics, dietetics and emergency medicine. A

third group of 38 contributors were mostly nominated by organisations including BEAT (beateatingdisorders.org.uk), various Royal Colleges and clinical services and 30 stakeholder groups registered to provide advice. The evidence used in writing MEED was a mixture of published studies and expert consensus. While MEED was written for the UK health service, studies and guidance documents from different countries were read and their results incorporated if appropriate. MEED was endorsed by the Academy of Royal Colleges. There has been, until now, no formal audit or evaluation of the uptake of MEED or of its value in assessing risk or predicting the outcome of EDs. Figures from death certificates have shown no significant change in UK mortality from EDs between 2001 and 2018 (15). MARSIPAN was published in 2010. While there is no completed formal audit of MEED, the results of a survey on the MEED website (meed.org.uk) of 186 healthcare workers (HCWs) requesting copies of a patient's risk assessment, dated 21 November 2024, showed the following specialisms:

Specialist ED service: N = 53 (28.5%)	Gastroenterology: N = 9 (4.8%)
Paediatrics: N = 46 (24.7%)	Child and adolescent mental health: N = 5 (2.7%)
General adult medicine: N = 29 (15.6%)	Emergency medicine: N = 3 (1.6%)
General adult psychiatry: N = 28 (15.1%)	General practice: N = 3 (1.6%)
Parent or carer: N = 10 (5.4%)	

These results are encouraging and show that 22% of website users were medical HCWs treating adults. It is of interest that MEED is also being used by carers. Overall, 79% of respondents were doctors.

What are the main causes of death in eating disorders?

There are two ways to examine this important question: first, by referring to studies in the literature and second, by relating events arising from clinical experience.

Mehler et al. (16) acknowledged that evidence from studies of medical causes of death was inadequate. They postulated a number of plausible mechanisms but acknowledged they are not all proven. These include the following.

1. Cardiac structural changes associated with weight loss.
2. Refeeding syndrome.
3. The effects of electrolyte changes such as hypokalaemia due to purging.
4. ECG changes including QTc prolongation, exacerbated by the effects of drugs, such as neuroleptics, on QTc.
5. Hypoglycaemia.
6. Bradycardia leading to cardiac arrest.

Fichter et al. (17) reported cause of death in 65 patients with EDs and cited the following causes.

1. Circulatory collapse.
2. Cachexia.
3. (Multiple) organ failure.
4. Infection (pneumonia).
5. Kidney failure.
6. Suicide in 23% of deaths.

The most common diagnosis in each cause of death was AN, apart from suicide which was distributed equally between AN and BN.

In the MEED development group, a number of case histories were collected in which the patient had died and the death might have been preventable. A list of these cases follows:

1. Failure to use the Mental Health Act (or equivalent). This was reported several times. In one case, the patient, whose ED compelled her to oppose weight gain, lost weight until she died with no consultation with mental health services. In another, a female aged 19 years, mental health services were involved and the patient was detained under the English Mental Health Act, but the physician refused to agree to any treatment being imposed.
2. Failure to treat extreme hypoglycaemia. This was documented by the Health Services Ombudsman (2). A 19-year-old female patient with severe AN was found to have a low serum glucose. This was not treated appropriately and the patient died.
3. Failure to recognise and treat RFS. An 18-year-old female patient was admitted to a medical ward with severe AN. She was refed and developed major electrolyte disturbance. This was not recognised as RFS and she died from multi-organ failure. This is a situation in which blood tests recommended by MEED (serum phosphate, potassium) can indicate the presence of RFS and guide management.

4. Provision of no or almost no calories in an apparent attempt to avoid RFS. This has been termed underfeeding syndrome and we are aware of a number of fatal cases, although the overall prevalence is unknown. For example, a 20-year-old female patient with severe AN was transferred from an ED ward to the emergency department for assessment of chest pain. No cause was found but mildly raised liver function tests were discovered, probably due to malnutrition. She was admitted for liver investigations and not her malnutrition, which was not addressed. She died after a week on around zero calories.
5. Inability of nurses to prevent exercise leading to fatal outcome. A 19-year-old female patient with severe AN was being watched by two "special" mental health nurses who had received no training or experience in managing AN. The patient engaged in "micro-exercising", where she would stand at all times, not sleeping or eating for three days, and would move her feet and hands constantly while she stood. The nurses were not able to intervene and after three days the patient collapsed in coma associated with hypoglycaemia and died.
6. Inappropriately providing palliative care to a patient with AN. A 20-year-old female Dutch patient with AN was transferred from a clinic in the Netherlands to one in Portugal. She received therapy but continued to lose weight and died. The account of her illness and death was documented in a video recording online, Emma Wants to Live (18). It appears that the patient received palliative care and was not treated under mental health legislation against her will. The UK NICE recommendations for EDs (19) state: "1.12.1 If a person's physical health is at serious risk due to their eating disorder, they do not consent to treatment, and they can only be treated safely in an inpatient setting, follow the legal framework for compulsory treatment in the Mental Health Act 1983." We agree with that advice, while acknowledging that there is a legitimate discussion to be had concerning palliative care in EDs (20). Nevertheless, the attempt to define "terminal anorexia" has been strongly criticised (21).
7. Not feeding the patient while pursuing possible causes of raised liver function tests. Several cases came to the attention of the MEED development group in which obvious undernutrition had not been treated while other possible medical diagnoses were investigated. In two cases, the patient was severely underweight and was found to have abnormalities of liver enzymes. They were investigated for these but subsequently deteriorated and died, probably from undernutrition. The lessons to be learnt here are, first, that raised liver enzymes are frequently seen in severely underweight patients with AN (22) and second, that undernutrition must be treated urgently, according to MEED guidance, while other necessary investigations proceed.

Managing high-risk eating disorders in different contexts

EDs can present in many different places. The task of the clinician is always as follows.

1. To establish whether or not an ED is present.
2. To assess the level of risk that it may pose.
3. To act appropriately to reduce that risk.

The response to risk can be seen as a stairway or stepped process. For low risk, continue managing at home. This is not only for HCWs such as GPs but also for family members. As the risk rises, and the MEED Risk Assessment Framework is a good guide to this, the place of care becomes more complex. This process is illustrated in Figure 1. At the lowest level of risk, the patient and family may be primarily responsible for managing risk and their role might be to ensure the family member with the ED is encouraged to eat. At the primary care level, monitoring of weight, electrolytes and mental state are appropriate at low or moderate levels of risk, while specialist services, whether eating disorders day care, inpatient medical care or specialist eating disorder unit care, would normally be involved at the higher levels of risk.

Where do patients with eating disorders present for care?

The places where patients with EDs present are diverse (23). Below is a provisional list of clinical services likely to be faced with a patient with an ED and hence required to make a risk assessment.

Primary care. Patients with different EDs may present to the GP with symptoms of the ED, such as weight loss, bingeing, vomiting or laxative abuse. Sometimes, however, because of shame or unwillingness to accept treatment for the ED, a patient may come with a physical problem, such as amenorrhoea or infertility related to low weight, or be found to have unexpected low potassium in a blood test, or a psychological difficulty such as depression, self-harm or anxiety. All of these problems, as well as many others, can signify an ED.

Secondary care, including the emergency department (low weight, weakness, cardiac arrhythmia due to hypokalaemia), any medical outpatients (weight loss, gastrointestinal problems), paediatric outpatients (failure to grow, picky eating, mood changes, abdominal pain), gynaecology (amenorrhoea), infertility (due to weight loss), postnatal care (difficulties with lactation, recurrent ED symptoms postpartum, depression), dietetics (weight loss, vitamin deficiency), medical inpatients (need for refeeding, rejection of help to gain weight) orthopaedic care (unexpected fractures, unexplained loss of height) and dental care (dental erosion due to excessive vomiting). This list is not exhaustive.

In all of these contexts, it can be helpful to ask some screening questions, such as: "Is eating an issue for you?", "You

are a little underweight, what would you say to putting on a couple of kilos?" and "Are you happy with your weight and shape?" The answers can point the clinician in the direction of an ED.

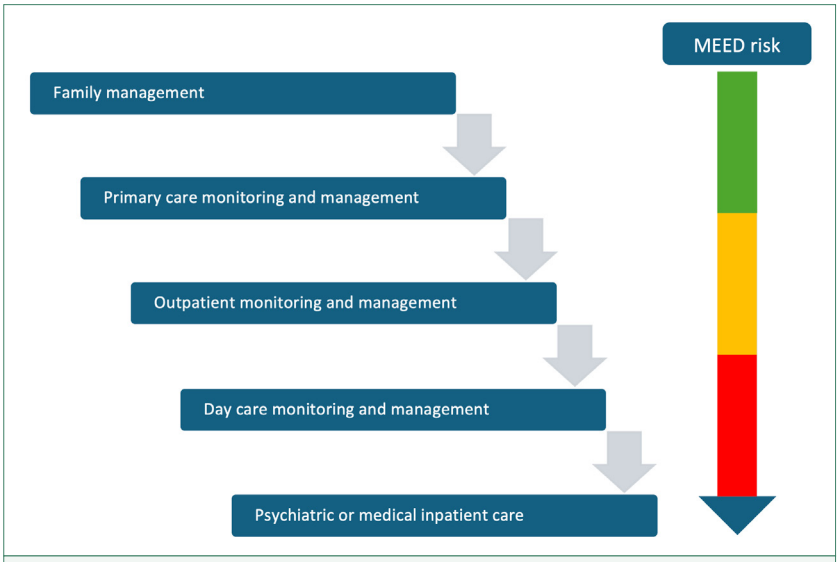

Figure 1. How increasing risk level (illustrated by the green-amber-red arrow on the right) is associated, on average, with increasing complexity of care.

How does MEED address the different risk areas for adults and for children and adolescents?

MEED contains a number of resources of use to clinicians. Figure 2 depicts a flow chart indicating how it can be used. By locating the issue you are facing on the left, the link on the right will take the reader to the relevant part of the MEED document. Alternatively, the link to the relevant document will be found on the MEED website. Table 2 lists various roles in healthcare (also not exhaustive) that can be involved in the care of people with EDs, as well the patients themselves and their carers. In the MEED website, clicking on "Summary sheets for each professional and supporter" leads to a list of sheets from which to choose.

The MEED checklist

The checklist approach, pioneered by surgeon Atul Gawande (24), identifies key issues that cause clinical problems and provides brief, unambiguous advice on how to address them. In writing the MEED (and MARSIPAN) guidance, we included a postcard-sized checklist to address some of the most important issues that clinicians face when seeing a severely ill patient with an ED, perhaps for the first time in their career. It is reproduced in Figure 3.

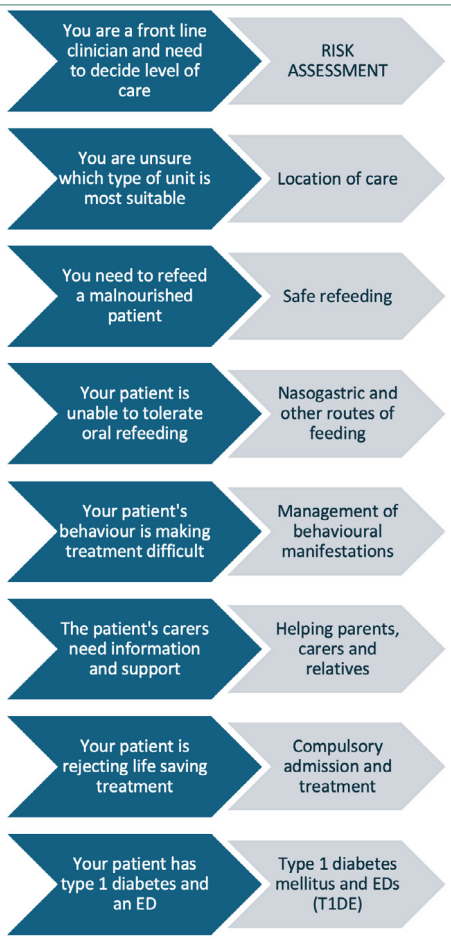

Figure 2. Accessing resources in MEED (see the MEED website: meed.org.uk)

The checklist is divided into three columns: assessing, refeeding and managing. The "assessing" column asks three basic questions: "Does the patient have an eating disorder?", "Is the patient medically compromised?" and "Is the patient consenting to treatment?". This allows the clinician (for example, a GP or emergency department physician) to refer a high-risk ED patient for urgent eating disorders care and, if necessary, obtain an urgent opinion on the need for compulsory care.

The "refeeding" column assumes that the patient is in medical or psychiatric care and that refeeding is being attempted. The checklist allows the clinician to assess the risk of RFS and to initiate refeeding at a level appropriate to the RFS risk, while monitoring necessary physical tests.

The "managing" column deals with the important issues of collaboration between professionals, a frequent source of problems, training of nurses and behaviours to be aware of that could impair response to treatment.

We believe that use of the checklist by frontline staff in all healthcare settings could result in reduced mortality and morbidity in patients with severe EDs, as they seem to do in surgical patients (25).

Be concerned and alert but don't panic!

Yes, EDs can be dangerous and can even lead to death. Moreover, if you are found to have neglected a patient's risk factors, you (and your employer) may be criticised in an investigation. However, the majority of patients do not suffer these catastrophic outcomes and as well as being alert to the possibility of a serious health issue, we should equally not panic whenever a patient is found to be vomiting, self-harming or losing weight. There are a few golden rules that a HCW might wish to keep in mind.

Role
Psychiatrist
Liaison psychiatrist
Physician
Dietitian
GP
Managers and commissioners
Nurse
Psychologists and therapists
Relatives and carers
Generic psychiatry teams
People with eating disorders
Emergency department staff, on-call medical and paediatric staff
Paediatrician
Physiotherapist

Table 2. How to find your summary sheet in MEED. Click on the role or use meed.org.uk to find the summary sheet.

1. Do a MEED risk assessment on all patients referred.
2. If there are significant risks (amber or red), the HCW should ask him or herself, "Is the risk high enough to recommend a change in management?" (e.g., more frequent monitoring, day care or inpatient admission).
3. If the answer to the above question is "I'm not sure", then the HCW should ask someone more senior and experienced or, if the HCW is that senior person, he or she should discuss the case with a peer.
4. The HCW should never ignore significant risks.
5. Once the HCW has done all of the above he or she should assure him or herself that the risk is being managed as well as possible and attend to other responsibilities.

There is a danger in providing care for patients with EDs that the HCW may become overanxious, and this can affect their own mental health and capacity to function in their role. If they think this is happening, we would suggest discussing it with a colleague(s), consider taking some time off, seek help from friends, relatives or perhaps their GP, and consider raising these concerns with their line manager.

Some clinicians faced with a patient with a severe ED find it hard to make an overall assessment and get drawn into investigating an abnormal blood result (such as nutritionally caused abnormal liver function or thyroid function), which can lead to them unintentionally neglecting to treat the obvious and much more dangerous malnutrition. This can be more common with male patients, where EDs may be less likely to be suspected and can lead to delays in treatment (26). If the HCW suspects that this may be happening, MEED should be consulted, the case should be discussed with someone experienced in the medical management of EDs and the HCW should arrange to attend a course in ED risk assessment.

Two clinical vignettes

A 13-year-old boy has stopped eating entirely following the birth of a baby sister. He is brought to you, his GP, by his father. He has lost 3 kg in weight over four weeks and is very distressed. He thinks he looks better because, he says, a teacher at school had previously referred to him as "chubby". You check his weight (31.1 kg) and height (1.55 m) and find his m%BMI is 72%. The boy talks vaguely about feeling that he should disappear so his family can care for the new baby, and his parents have found some paracetamol tablets in his school bag. He does not wish you to share information with his parents because "They'll be too worried".

Risk assessment

First, diagnosis is required. An ED, probably AN, is likely, but other causes of weight loss should be excluded. Using the MEED Risk Assessment Framework, a number of risk areas appear. He has lost 3 kg over four weeks, which is an average rate of weight loss of 0.75 kg per week. That rates as amber. The quoted m%BMI is referring to the percentage median BMI from the formula, BMI/(50th percentile BMI for the same age and sex) x 100. So, if the child's weight is 31.1kg and his height is 1.55m, his BMI is 12.96. For a boy of 13 years, the 50th percentile for BMI is 18.20, so the patient's percent median BMI is (12.96/18) x 100 = 72%. This also rates amber on MEED.

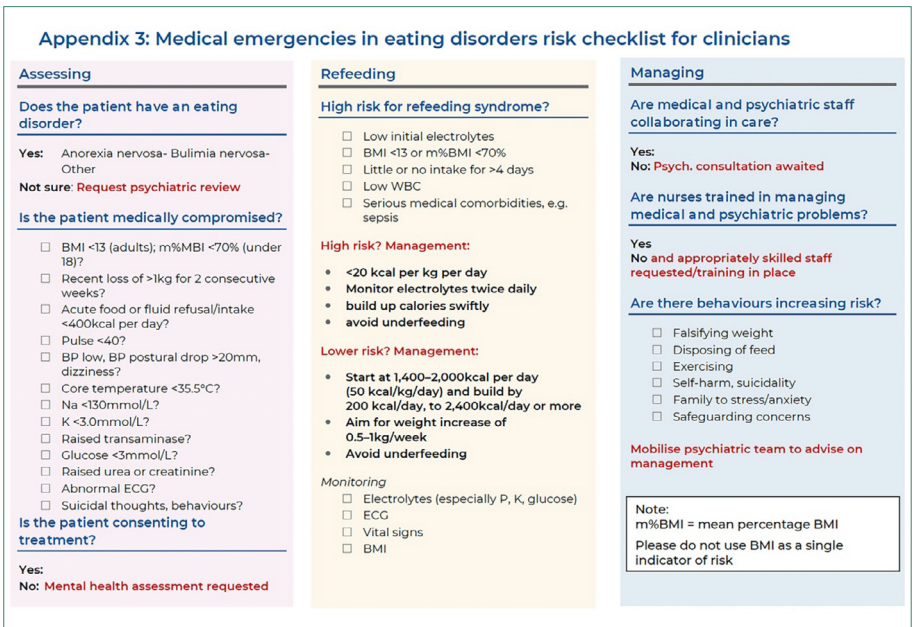

Figure 3. The MEED checklist (reproduced with permission from the Royal College of Psychiatrists)

Lastly, he is expressing vague suicidal thoughts which would need investigation but would also probably be rated amber on MEED. He is therefore rated amber on at least three MEED measures and should be assessed on all other risk factors (electrolytes, ECG etc.) so that a full risk assessment can be made.

A 19-year-old young woman attends university near your clinic. She has a two-year history of AN and was admitted to hospital for nine months, being discharged at a BMI of 17.2 (46.3 kg; height, 1.65 m) in March in the year that she moved to university from home. Her medical monitoring, including weekly weight and bloods, is being managed by her GP, requested by the ED doctor. When seen in your clinic, she has lost weight following her discharge six months earlier and has a BMI of 15. She attends therapy and appears to be using it appropriately. Four weeks later, you try to find her medical monitoring results and discover that she has not been attending her GP, so she has effectively not been monitored. There are medical members of your multidisciplinary team, but they are located over 60 miles away in another town. She attends for her therapy session and looks significantly thinner than the last time you saw her. Her BMI is 14. You assign her urgently for outpatient medical review, but she fails to attend. Two weeks later she is found by her cleaner on the floor of her room, unable to stand and is taken to the emergency department of the nearest hospital.

Risk assessment

Using MEED, this patient also has a number of risk areas. When seen initially, she had lost 6 kg in six months, a rate of 0.25 kg per week (MEED risk, green). Then, in four weeks, she lost 2.6 kg, a rate of 0.65 kg per week (MEED risk, amber). Her BMI fell to 14 (MEED risk, amber). Not attending her GP for monitoring is not specified as a risk on MEED but could be considered equivalent to poor "engagement with management plan" and rated as amber or, possibly, red.

This is an example in which several amber ratings should alert the clinician that the risk is climbing and a medical review is essential. This did not occur and she was found collapsed in a very poor state.

Cautionary notes

While we believe that MEED can be very helpful as a risk assessment tool, a few factors need to be borne in mind in order to optimise its use.

1. MEED does not provide a quantitative measure of risk, that is, a patient with four reds on MEED is not necessarily at a greater level of risk than a patient with three.
2. Sometimes patients who have been chronically underweight may be more medically stable, despite lower weights and heart rates etc., than others who might still be at a relatively normal weight but have lost weight rapidly.
3. Management decisions need to be made on a case-by-case basis: for example, decisions to admit or discharge to ED units or medical/paediatric wards cannot be made reliably using protocols or algorithms created solely using MEED scores or physical measurements.

Perhaps these caveats could be best summarised with the aphorism, "always look at the patient and not just their MEED scores"!

Implementing MEED in health facilities

A guidance document is only any use if it is used. MARSIPAN and Junior MARSIPAN, the predecessors to MEED, were popular and anecdotally appeared to be implemented in the UK and Ireland. However, following a number of deaths occurring in health facilities the coroner, Sean Horstead, wrote in 2021, "The evidence of hospital staff revealed, at best, inconsistent implementation of the Royal College of Psychiatrists MARSIPAN guidance for the emergency treatment of AN patients and, at worst, a failure to implement the Guidance at all" (27).

Since the publication of MEED in 2022, the guidance has been cited many times in the UK and Ireland. A Google search in April 2024 using the terms "MEED anorexia" revealed articles and posts by the Royal Colleges of Psychiatrists, Emergency Medicine, Intensive Care Medicine and Paediatrics and Child Health; by primary care, nursing and medical education organisations; and by acute and mental health trusts and private psychiatric services. Concerns expressed by the coroner cited above and others (e.g., concerning the death of Nichola Lomax (4)) might lead to improvements in practice but that seems unlikely without changes in the education of HCWs. The campaign by BEAT (28), the UK EDs charity, "Worth more than 2 hours" identified that only 16 out of 41 UK medical schools were providing satisfactory ED teaching. Training for all clinicians who may provide care to a patient with an ED is urgently required in order to improve knowledge about EDs.

It is our view that education is one of the best keys to ending unnecessary deaths from EDs and that this should be taken up by medical, nursing and dietetic schools as well as by postgraduate training organisations for general and emergency medicine, primary care, gastroenterology, intensive care medicine, paediatrics and other relevant specialities. Furthermore, we would suggest that EDs competency should be required in specialist training in these and other relevant fields.

Healthcare providers also have a role in spreading the word. We recommend that MEED training should be mandatory (as, for example, are resuscitation and infection prevention in medical units) for all staff who might provide a clinical

service to a patient with an ED in any clinical setting including mental health, acute healthcare, primary care and any other relevant setting. This training should be provided and monitored by healthcare management.

We believe that only through widespread comprehensive, regular and updated training will acute healthcare for patients with EDs improve and further unnecessary deaths be prevented.

1.	Eating disorders, especially anorexia nervosa, have an increased mortality
2.	Symptoms associated with particular risk include low and falling weight, vomiting, laxative abuse, electrolyte disturbance and suicidality
3.	The combination of physical and mental problems can pose challenges to a team without specialised knowledge
4.	MEED provides a risk assessment framework which is straightforward to use and available at meed.org.uk
5.	Patients with red or amber risk factors should have a full evaluation of their physical and mental states
6.	When an eating disorder patient with significant risks is under the care of a team that does not specialise in eating disorder management, there should always be liaison with at least one eating disorder specialist
7.	When refeeding eating disorder patients with weight loss, there is a risk of both refeeding and underfeeding syndromes
8.	Education of all healthcare workers who might provide care to an eating disorder patient should be part of basic training and if that has not occurred, the healthcare worker should receive training as soon as possible
	For eating disorders, please use **MEED**

Table 3. Key learning points about MEED

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Early intervention for eating disorders

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Abstract

Currently, one in five people with an eating disorder may develop a longstanding illness and there are delays of up to a decade in people accessing evidence-based eating disorder informed treatment. Such delays contribute to the high personal and community burden of eating disorders. The present paper reports known actions that are likely to overcome barriers to and enable early prevention in eating disorders across four themes within public health and primary care interventions. These are as follows: (1) public health programs to increase health literacy and reduce stigma, for example, Mental Health First Aid; (2) increased screening and early identification in primary care, for example, upskilling family doctors; (3) wide dissemination of accessible online and similar treatments, for example guided self-help cognitive behavioural therapy; and (4) whole of health service and similar developments to facilitate early eating disorder informed care, for example, the First Episode and Rapid Early intervention for Eating Disorders (FREED) program. Whilst there is robust evidence for many interventions, in particular guided self-help (including family therapy) and virtual forms of cognitive behavioural therapy, as well as general practitioner education, major gaps in knowledge are identified. These include the research base for healthcare first responder training in eating disorders, more recently defined disorders, particularly avoidant/restrictive food intake disorder, and the translation of effective screening instruments into regular and more widespread use. The future is however optimistic, given the growing evidence base, widening recognition and use of effective interventions and contemporary contributions of people with lived experience.

Introduction

Eating disorders are common and contribute significantly to worldwide mental health burden (1). The Global Burden of Disease study reported that the number of previously unrepresented global eating disorder cases in 2019 was almost 42 million and this comprised around 17 million people with binge eating disorder and 25 million people with other specified feeding and eating disorders (OSFED). Together, binge eating disorder and OSFED were responsible for 3.7 million disability-adjusted life years (DALYs) globally. The total eating disorder DALYs was 6.6 million (2). This latter figure includes the other two main eating disorders, anorexia nervosa and bulimia nervosa, but is yet an underestimate as research is lacking for the main other recognised feeding and eating disorder, avoidant/restrictive food intake disorder (ARFID) (3) or proposed disorders yet to be included in international classifications, such as orthorexia nervosa (4). In addition to high levels of mortality and community burden, people with eating disorders experience poor quality of life (1). One in five people with anorexia nervosa also have longstanding illness with particularly high levels of comorbid mental health and physical health conditions, significant social isolation and financial poverty, and the highest mortality rate of all mental health disorders at 20% after 20 years (5). Further, there are often lengthy delays of many years in people accessing evidence-based care (for example, (6)) These outcomes highlight the importance of early prevention and underscore calls for action and the translation of evidence into practice and providing services that are engaging and meet the needs of people living with an eating disorder (7).

Early intervention falls into the areas of primary indicated prevention, whereby people with early symptoms are targeted in intervention, and secondary prevention, which is providing treatment early after illness onset (8). In eating disorders, primary indicated prevention programs may focus on, for example, young people with high levels of body image concerns. Early prevention is most often used in primary care environments but can also be in the community, for example, in schools that have a program for screening or early identification of people with disordered eating/eating disorders. Notwithstanding the focus of the present paper, it should be acknowledged that universal and, in particular, selective primary prevention programs have been tested and found not only to prevent the onset of symptoms but also to prevent the full-spectrum disorder (9). These include studies that have evaluated media literacy, cognitive dissonance programmes and programmes that target or reduce the impact of eating disorder risk factors such as weight disorder, trauma and abuse or other comorbidities. This paper focuses, however, on the research and outcomes for those that do have early symptoms and/or a disorder where early prevention is critical to reduce the long-term personal, family and carer and societal impacts of eating disorders.

There is general agreement that early prevention can be effective. A systematic review has highlighted the importance of reducing the period of untreated illness to improve outcomes (10). For example, a multi-centre audit of outpatient care for adults with anorexia nervosa supported the contention that there are better outcomes with early

treatment (11). This study investigated symptom trajectory and service use, and compared early-stage versus severe and enduring classifications of people with eating disorders. Participants in the study were offered National Institute for Health and Care Excellence (12) recommended psychological therapies augmented by short digital treatment. They were grouped into two categories: early-stage illness of less than three years (n = 60) and a severe and enduring anorexia nervosa (SEAN) group (n = 41), defined by levels of high distress with a Depression, Anxiety and Stress Scale score of more than 60 and an illness duration of at least seven years (13). As expected, baseline comparisons between the groups indicated poorer work and social adjustment and higher levels of eating disorder symptoms amongst those with severe and enduring anorexia nervosa. After 12 months, there were higher rates of improvement and work and social adjustment amongst the early-stage participants compared to the SEAN group. The latter also had higher rates of accessing high levels of care (inpatient or day patient services) than did those with early-stage illness.

Unfortunately, early prevention is too often not achieved. As noted above, people with eating disorders usually live with their problems for a very long time before accessing care. In a study from Finland, up to 50% of people in the community with anorexia nervosa were unknown to healthcare services (14). The proportion of unrecognised illness is even higher for those with other eating disorders (15, 16). On the other hand, many people with an eating disorder are "hidden" in primary care (17) and general mental health settings (18). Whilst many may develop longstanding illness even with the best of care, it is known that recovery is yet possible and continues for up to 20 years, particularly for people with anorexia nervosa (19). Treatment approaches need to be rethought for this group (20). For early intervention to be effective, thereby reducing the numbers with enduring disorder, it must be acceptable and feasible, otherwise people will understandably not engage.

This paper will present the current status of actions that are likely to enhance early prevention in eating disorders. Four themes (summarised in Box 1) encompass public heath interventions and primary care interventions, all of which aim to reduce barriers to eating disorder–informed treatments and enable early intervention.

Box 1. Areas of early intervention for eating disorders

1. Public health programs to increase health literacy and reduce stigma
2. Increased screening and early identification in primary care
3. Wide dissemination of accessible online and similar treatments
4. Whole of health service and similar developments to facilitate early eating disorder-informed care

Early intervention and treatments – what works?

There is widespread agreement in international guidelines (for example, (12, 21)) that the majority of people with eating disorders are treated effectively with specific psychological therapies supplemented, as needed, with pharmacological agents. For people with early-stage illness, brief and relatively inexpensive guided self-help and pure self-help approaches have been developed, initially in the form of books and more recently as online moderated care. For example, the book by Peter Cooper, *Overcoming Bulimia Nervosa and Binge Eating*, first published in 1995 is now in its third edition (22). It and similar manuals of guided self-help cognitive behavioural therapy (CBT) have a body of randomised controlled trials supporting their efficacy such that the NICE guidelines (12) recommend them as first-line treatment in the care of binge eating disorder. In this regard, it is important to note that self-help manuals have been largely developed in a transdiagnostic format for disorders of recurrent binge eating, or for either binge eating disorder or bulimia nervosa. Further, and in contrast to guided self-help, the efficacy of pure self-help has been demonstrated mostly in people with binge eating disorder and it appears to be less efficacious for bulimia nervosa. These manuals have a large section (for example, up to half a book) of psychoeducational material and then a step-by-step manual for people to follow with their healthcare practitioner or under other guidance. They can be delivered effectively by non-specialists and, for example, general practitioners can certainly provide high-quality care (23). They can also be used without guidance, as pure self-help. However, the body of evidence supports guided self-help as being superior to pure unguided self-help for most eating disorders, particularly with regard to engagement and adherence (24). Similar to clinician-guided self-help CBT, brief forms of CBT have also been developed. An example is the 10-session manual of Waller et al. (25), which has had some support in non-randomised and randomised controlled trials (for example, (26, 27)).

In the digital age, psychological therapies, and particularly guided self-help, have been successfully translated into online versions (34, 35). Exemplars include iBED (internet-based cognitive behavioural therapy for binge eating disorder) (31), everyBody Plus (32), the Binge Eating eTherapy (BEeT) (33, 36) and the online translation of the widely used CBT-Enhanced for eating disorders (37), Digital CBT-E (29). These are particularly suitable for people with early-stage illness, or whilst waiting for an in-person assessment and care. Caveats include high attrition rates in some research studies (for example, (38)). Notably, feedback from people with lived experience from qualitative studies has highlighted considerations such as the quality of guidance and preference for personalised care (for example, (32, 39)). Digital CBT-E makes the point that it sets out to provide an individually tailored program that is responsive and makes adaptations according to the user's progress. The use of the internet to deliver guided self-help (or other care) also presents opportunities to capture properties such as the ability to incorporate game elements (for example, rewards)

Intervention	Eating disorder	Examples and programs
Pure self-help	BED	Overcoming Binge Eating (28, 29)
		Overcoming Bulimia Nervosa and Binge Eating (22)
Guided self-help	BED, BN, AN (families)	Overcoming Binge Eating (28)
		Overcoming Bulimia Nervosa and Binge Eating (22)
		GSH-Family-Based Treatment (30)
Virtual therapy	BED, BN, not-underweight ED	iBED (31)
		everyBody Plus (32)
		Binge Eating eTherapy (33)
		Digital CBT-E (29)
Brief therapy	BED, BN, other not-underweight ED	Brief cognitive behavioural therapy for non-underweight patients (25)

Table 1. Evidence-based early prevention treatment interventions

Abbreviations: AN = anorexia nervosa; BED = binge eating disorder: BN = bulimia nervosa; CBT-E = enhanced cognitive behavioural therapy; ED = eating disorder; GSH = guided self-help; iBED = internet-based cognitive behavioural therapy for binge eating disorder

beyond merely improving access (24). Research has also found that the use of a range of media formats (for example, animations as well as images and other graphics) may enhance outcomes (36). Furthermore, CBT for bulimia nervosa has been tested in formats such as an online chat group and been found to be effective, albeit with a slower rate of change compared to in-person CBT (40). This was similar to the findings in the INTERBED trial of online guided self-help where an end-of-treatment advantage for in-person care was no longer present at 18 months follow-up (41).

Adding to the armamentarium of these scalable versions of CBT, other evidence-based treatments for eating disorders have been presented in self-help manuals. For, example a self-help manual of dialectical behaviour therapy (DBT) for eating disorders (42) has been tested in a randomised controlled trial for people with binge eating disorder where guided self-help DBT had better outcomes than unguided self-help or a control self-help self-esteem manual, although the differences were not significant. In this study, the guidance was provided online using telemedicine (43).

There have been concerns about using self-help and similar interventions for people with anorexia nervosa where the medical risks are higher and the indication for multidisciplinary care stronger (24). However, for children and adolescents with anorexia nervosa who would otherwise require more complex and multidisciplinary care, an online (with teleconferencing) guided self-help version of family-based treatment (FBT; parental-guided self-help FBT or GSH-FBT) has been developed and trialled (30, 44). This is a brief (3–6 months) form of FBT with short sessions (around 30 minutes) involving parents only, and all meals and weight monitoring are out of session. The authors acknowledge it is unclear where within the continuum of service provision GSH-FBT will be found most effective. However, for those on a lengthy waiting list and/or in early-stage disorder it offers an alternative to no or delayed treatment.

An interesting further development of self-help is its use in addressing maintaining or predisposing problems for people with eating disorders such as low self-esteem and clinical perfectionism, for example, the manuals of Fennell (45) and Shafran, Egan and Wade (46). These can be used to support the additional modules in the enhanced form of the classic Fairburn manual for CBT (37). Self-help manuals may also be used to reduce the risk of full-syndrome disorder by addressing risk factors for disordered eating and body image problems, such as low self-esteem and perfectionism in young people (for example, (47-49)).

Enabling and overcoming barriers to early intervention

The barriers and facilitators of low identification and low treatment seeking amongst people with eating disorders are diverse and multiple strategies are needed to address them. They can be grouped into areas of broader public health concern (for example, stigma and costs) and primary care (for example, health literacy and screening).

Repeated studies have found that important barriers for people accessing help are stigma, shame and gaps in health literacy (50). The first goes beyond the stigma of having an eating disorder to include that of having a mental health problem in general and the stigma around weight-seeking behaviours. There are also practical barriers, for example, high costs of care in some jurisdictions. Health literacy in the general community is a major factor, and this includes failure to perceive the severity of illness as well as ambivalence about change due to societal endorsement of weight loss behaviours and the sense of personal validation for being in control of one's weight and eating behaviour (51). There is often a lack of knowledge about what help is available and effective for eating disorders, and confusion about what is an eating disorder. This is not helped by current conceptualisations whereby many diagnostic eating disorder features overlap and people may often transition between the major disorders of anorexia nervosa, bulimia nervosa and binge eating disorder (52). In problems where there is often high ambivalence about treatment, it is especially important to listen to people's preferences and offer choices, not least as this is a key factor in better outcomes generally in psychiatry (53, 54).

Health literacy extends to healthcare professionals. Bullivant et al. (51) conducted a scoping review and found, despite moderate understanding of eating disorder treatment, that there were low levels of empathy and negative attitudes towards people with eating disorders amongst some general practitioners, which impeded enabling care. Thus, when treatment is sought, people may encounter further barriers and providers may not prioritise disorders that are perceived as less severe. Too often still heard is the refrain that someone is not thin enough to require attention or that the eating disorders are simply not perceived as being as important as other disorders. This is despite the recognition of anorexia nervosa in people of adequate weight as a type of OSFED (atypical anorexia nervosa) and that there is no upper limit of body mass index (kg/m^2) in the diagnostic criteria for anorexia nervosa (3). In fact, Eisler at al. (55) have reported on the need for large-scale system changes in service delivery that reflect the evidence that early access to eating disorder–informed care reduces the longer-term burden on jurisdictions and care providers.

A highly successful intervention in addressing these barriers to care is Mental Health First Aid (MHFA) and MHFA for Eating Disorders (56). This started in Australia but is now worldwide and includes guidance, training and support for all people living, working or in any other contact with someone with an eating disorder. This includes people in the community who are not healthcare professionals, such as schoolteachers and care workers. MHFA informs an understanding of the nature of eating disorders, how someone can help a person with early signs of an eating disorder and what to look for in regard to behavioural warning signs. Risks associated with eating disorders, links to other relevant resources and strategies regarding how to approach someone who may have an eating disorder with very practical advice are presented. The current MHFA guidance is to accept that ambivalence about seeking help is common, counsel in how to discuss the specific circumstances when involuntary treatment may be considered and address the distress experienced in navigating these issues and maintaining relationships with the experiencing person. There is very practical advice about how to support a loved one in this situation which resonates with the principles of recovery-oriented practice, engagement of the community more broadly in care and supporting the person in the assessment of their choices and risk (57).

MHFA is part of a much wider network of community resources and programs which actively seek to improve people's early access to care, including in the UK, and there is ongoing investment in general and healthcare-specific programmes to close the treatment gap and reduce delays for people in their first episode of an eating disorder, an exemplar being First Episode and Rapid Early intervention for Eating Disorders (58). The website of this programme provides information for anybody who is worried about eating, weight or shape or similar, the best way forward, how to get help and support early, and also information for healthcare professionals with a treatment approach to help young people in the early stages of their eating disorder. Other organisations providing such advice and easily accessible resources (usually without monetary cost), as well as links to locate eating disorder–informed healthcare practitioners include Beat Eating Disorders in the UK (59) and the National Eating Disorders Collaboration (60), which is an initiative of the Australian Government Department of Health and Aged Care. These endeavours are also notable for a high level of incorporation of lived experience expertise.

In contrast to barriers, facilitators of help-seeking include experiencing other mental health problems or emotional distress and being concerned in general about one's health (50). In this regard, a general population study of reported healthcare use found that people with bulimia nervosa or binge eating disorder were more likely to have accessed mental health services if they had been asked about their mental health by their family doctor (17). Whilst it has been difficult to demonstrate the clinical impacts of screening in primary care it is likely that this does improve help-seeking (61) and there are several well-validated screening instruments that should be routinely used in this context (62, 63). The five-item SCOFF questionnaire (64) is the best known and is in widespread use and similar to the more recently developed transdiagnostic Screen for Eating Disorders (62). However, no tool is perfect; NICE guidelines recommend against over-reliance on any single questionnaire and advise practitioners to think about and ask about eating disorders, particularly in those with an increased risk, such as young people with general mental health problems, weight/shape body image concerns and common medical comorbidities such as diabetes (12).

Notably, programs have also been developed that have demonstrated efficacy in improving understanding and identification of eating disorders in primary care (for example, (65)). People living with an eating disorder can also be empowered to access more appropriate care. For example, Wade et al. (66) have co-designed and developed a consumer checklist to aid people when they are seeking evidence-based treatment. The efficacy of such aids is, however, yet to be tested. Such research is an important reminder that across all endeavours discussed in this paper, expertise from people with lived experience is essential to success.

Gaps in early intervention research and practice

Programs such as FREED (58) are setting a standard for research and evaluation. This is critical as recent reviews (67, 68) have pointed to the insufficiency of evidence for such programs on outcomes, such as change in behaviour of those trained or in improving mental and wellbeing more generally. Evidence is similarly needed for such outcomes in specific areas such as disordered eating and eating disorders.

The empirical testing in randomised controlled trials of guided self-help, and similar interventions in the online space,

has been largely for disorders of recurrent binge eating and their expansion into other eating disorders is just beginning. A major gap lies in the understanding of early intervention for other disorders such as ARFID; their treatment in general is under-researched, as is the testing of interventions suited to early-stage disorder (69). However, trials are underway (for example, (70)) and a self-help manual has been published (71).

Translating effective screening instruments into regular and more widespread use in primary care remains challenging, although there are promising developments, for example, with the embedding of eating disorder information in programs such as Health Pathways (72). How to reach parents and others living with a loved one with an emerging or full-syndrome eating disorder and what advice is best to give them is also complex. For example, whilst it is known that parent-to-child comments about weight, shape and eating increase risk for eating disorder symptoms, these differ for parent-child gender dyads (73). Simply, what to say and how to say it is not straightforward and research is needed to evaluate programs that may, for example, aim to improve parent-child conversations about these issues.

Finally, but of most importance, eating disorder research severely lags in the recognition that eating disorders are relevant to all (74), and notably to individuals from communities such as the gender diverse (75). Whilst scalable interventions such as online guided self-help should close gaps in reaching people, these can only do this if they are presented and delivered in ways that engage the socially disadvantaged and vulnerable. Research needs to measure actively the success of prevention programs in their impact on reducing inequalities in accessing and experiencing care.

Conclusion

In conclusion, there is an urgent need to reduce the burden of eating disorders in the community and close the treatment gap. The increasing evidence of effective approaches at multiple levels include indicative and secondary targeted programmes for people with early-stage disorder. In this paper, enhancing early intervention can be summarised in the context of four actions that build on each other, namely (1) public health programs to increase health literacy and reduce stigma, for example, Mental Health First Aid; (2) increased screening and early identification in primary care, for example, upskilling family doctors; (3) wide dissemination of accessible online and similar treatments, for example, guided self-help cognitive behavioural therapy; and (4) whole of health service and similar developments facilitating early eating disorder informed care, for example, the FREED program. Box 2 highlights key actions for healthcare providers. For all these, engagement of the expertise of people with lived experience is critical. The future is hopeful.

Box 2. Practice points to facilitate eating disorder early intervention

1. Include eating disorders in training of community healthcare first responders
2. Embed an eating disorder screening questionnaire in primary care resources
3. Include access to guided self-help and online delivery in service provision
4. Refer early from primary care to specialist eating disorder informed care

Conflicts of interest

Phillipa Hay receives/has received sessional fees and lecture fees from the Australian Medical Council, Therapeutic Guidelines publication and HETI (New South Wales and the former NSW Institute of Psychiatry), and royalties/honoraria from Hogrefe and Huber, McGraw Hill Education, Blackwell Scientific Publications, Biomed Central and PlosMedicine, and she has received research grants from the NHMRC and ARC. She is Chair of the National Eating Disorders Collaboration Steering Committee in Australia (2019-) and was Member of the ICD-11 Working Group for Eating Disorders. She has prepared a report under contract for Takeda (formerly Shire) Pharmaceuticals in regard to binge eating disorder (July 2017) and has been a consultant to and sponsored speaker at Takeda Pharmaceuticals events. All views in this paper are her own.

Funding information

There was no funding for this article.

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Development of the eating disorders psychoeducational, prevention and early intervention website, Be Body Positive: a narrative report

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Abstract

Be Body Positive (BBP) is a psychoeducational website offering information and prevention strategies to children and young people (CYP), parents/carers and professionals across three modules: (1) body image and healthy eating, (2) selective eating versus avoidant/restrictive food intake disorder and (3) disordered eating versus eating disorders. The platform allows for easy access to evidence-based prevention/early intervention strategies created by clinicians with feedback from CYP and parents/carers. It is the product of a partnership between East London NHS Foundation Trust, North East London NHS Foundation Trust, Barnardo's and the East London Business Alliance, with funding by the NHS Transformation Directorate.

Since its launch in May 2023, BBP has reached an audience of over 21,000 users, of which 18,000 are in the UK (as of 23 September 2024). Over 90% (n = 411) of professionals attending two national webinars indicated they are likely to use BBP to support CYP.

Introduction

The COVID-19 pandemic intensified pressure on eating disorder services due to the increased number of referrals and severity (1). In response to this pressure, most services tiered their capacity based on severity, with the result that fewer resources were available for prevention and early intervention in eating disorders during this time, despite these aspects usually being included in commissioning expectations.

In response to this service gap, clinicians and healthcare managers across East London NHS Foundation Trust (ELFT) and North East London NHS Foundation Trust (NELFT) worked together to scope out a digital technology that could provide early intervention and help prevent eating disorders among young people. Early intervention and prevention of eating disorders are vital to avoid severe complications, such as malnutrition, cardiovascular issues, bone density loss and mental health conditions, such as anxiety and depression (2, 3). Addressing eating disorders earlier ensures a young person can lead a more fulfilling life, allowing them to remain engaged in social activities, work and education, improves recovery outcomes as the body is less likely to have experienced damage and alleviates pressures on healthcare systems (3, 4).

Development process

A systematic review (5) highlighted that online psychoeducation combined with internet cognitive behavioural therapy (iCBT) effectively reduces eating psychopathology and improves eating disorder–related behaviours, such as body concerns, depression and overall global eating disorder symptoms. Be Body Positive (BBP) integrates CBT and other therapeutic modalities within its three modules.

In October 2021, a partnership formed between ELFT, NELFT, Barnardo's and the East London Business Alliance (ELBA). The partnership successfully won an NHS Transformation Directorate bid for a Digital Partnership Award of £500,000, with the objective of co-producing a nationally accessible digital psychoeducation tool for children and young people (CYP) aged 11 to 19 years, their parents/carers and professionals, that is freely available via the internet. The project aimed to enhance public awareness of body image concerns, foster media literacy, promote comprehension of a balanced and healthy diet, differentiate between behaviours associated with eating disorders and the disorders themselves, and further disseminate preventative and early intervention strategies.

ELFT and NELFT provided the clinical expertise and clinical leadership. ELBA brought a community element with a particular focus on linking into seldom-heard populations, ensuring that BBP was inclusive for populations who have been less likely to have had their voices heard, accessed services or engaged with systems due to various barriers

and disadvantages. Barnardo's has a national lens and provided specific voluntary, community and social enterprise mental health service delivery expertise. Fifty-three CYP, parents/carers and professionals were involved in the co-production of BBP.

The modules cover body image and healthy eating, selective eating versus avoidant/restrictive food intake disorder (ARFID) and disordered eating. The modules have each been designed in three versions: one for CYP, another for parents and a third for professionals who work with CYP. As well as the modules, BBP also has lived experience stories, resources and facilities for signposting to other services and support. Further details on the module content can be found in the section below.

Content

BBP has three evidence-based modules. Each of the three modules have different versions depending on if the user is a young person, a parent or carer or a professional.

Body image and healthy eating module

This module covers body image and healthy eating, addressing comfort in your body, media literacy, breaking free from diet culture and intuitive and balanced eating.

It was reconfigured from an existing "Body Image and Normal Eating" group that is delivered by the East London Community Eating Disorder Service for CYP. It is a CBT-informed psychoeducation module, based on manuals from the Hampshire Community Eating Disorders Service and published works such as "Cognitive Behaviour Therapy and Eating Disorders" (6) and "Banish Your Body Image Thief" (7).

Selective eating versus avoidant/restrictive food intake disorder module

Managing ARFID presents unique challenges, distinct from anorexia nervosa or bulimia nervosa. A dedicated module was developed to deepen understanding of ARFID and differentiate it from "fussy", "picky" or "selective" eating. This module includes psychoeducational content on diagnostic criteria and describes different treatment approaches, utilising CBT for ARFID (CBT-AR) and the sequential oral sensory interventions.

The parent/carer module explains the difference between selective eating and ARFID, the role of anxiety, the importance of preferred foods, unhelpful practices to avoid, supportive strategies, managing expectations, defining success and engaging in self-care.

The clinician's module explores the developmental trajectories of ARFID from childhood into adulthood, addressing psychological and environmental factors. It includes outcome measures and treatment interventions to help clinicians tailor their approaches.

Disordered eating versus eating disorders module

This module was created in response to rising referrals to eating disorder services, often with comorbid conditions and emotional dysregulation. It offers guidance on recognising and managing disordered eating in CYP who do not meet the diagnostic criteria for eating disorder services.

To enhance understanding of disordered eating in CYP, this module includes practical and emotional support for those affected. It explains what disordered eating is, how it differs from eating disorders and how to identify it. It also aims to correct common misconceptions about disordered eating.

Designed to be interactive, the module encourages users to reflect on their own disordered eating challenges and their main drivers. It features content from emotion-focused family therapy to support the high levels of emotional dysregulation seen in people with disordered eating and to help parents and carers support individuals with disordered eating, as well as CBT approaches.

Launch and recognition

The BBP website launched on 8 March 2023, with new clinically approved resources being added regularly. In an effort to tackle digital inequalities, the partner organisations have worked with mental health support teams in the UK to develop school-based workshops allowing professionals to deliver the BBP modules in face-to-face educational settings. Additionally, ELBA partnered with corporate organisations who have donated digital devices to enable wider access to the website.

Since the launch of the website, a poster describing the development of the BBP resources has been presented at the European Society of Child and Adolescent Psychiatry Congress and the Child and Adolescent Mental Health Services National Summit (8). During Eating Disorder Awareness Week in 2024, the project was recognised at national level by Wera Hobhouse, the Liberal Democrat Member of Parliament for Bath, during a speech in the House of Commons on 29 February.

Impact to date

Since its launch in May 2023, BBP has reached an audience of 21,027 users, of which 18,000 are in the UK (as of 23 September 2024). Over 90% (n = 411) of professionals combined across two national webinars stated they would be likely to use BBP to support the CYP they work with. The three most popular pages visited are the landing page (10,934 views), session one of the selective eating versus ARFID module for young people (3,751 views) and session one of the body image and healthy eating module for young people (2,871 views). BBP has continued to post on social media with engagement on these platforms rising continuously at a rate of 8% per month.

Figure 1 highlights the journey of developing, designing and launching BBP and the roles each organisation played in the process.

Box 1. Comments from attendees of the BBP launch event

"Media today is not what it was a long time ago with a lot quicker access … so having so many demands and perspectives on what body image is … I think this particular website does it quite brilliantly."

- Parent/carer

"I think the website has been done brilliantly. Looking at the colours and the way things move etc.; it is so friendly and so warm that I don't think about where I've come from to be able to click on something … it just finds me."

- Child/young person

"Be Body Positive is an excellent toolkit for anyone working with young people as it breaks down expert knowledge into engaging content and resources."

- Professional

Future development of BBP

An app version of BBP has been developed and is currently being tested. This was initiated in response to requests from young people, who say that they use phones more than computers. Additionally, this should help with digital inclusivity as CYP from lower income households are more likely to have a smartphone than their own laptop.

A formal usability study of BBP has recently been completed and is underway for publication. To evidence the clinical impact of BBP, an evaluation of the clinical foundation of the website will be carried out before proceeding to a pilot clinical impact research study.

Conclusion

BBP is a digital platform, comprising a webpage and upcoming app, designed for CYP, parents/carers and professionals. It addresses body image, dieting, fussy eating, disordered eating and eating disorders, providing users with fundamental skills.

BBP serves as a preventative and early intervention tool, helping CYP develop healthy eating habits and reducing the risk of developing eating disorders. It supports mental health and wellbeing while easing the burden on existing services by minimising the need for additional professional intervention.

The ultimate goal is to conduct a study to evaluate the clinical impact and effectiveness of this transformative tool.

Editorial comment

For those who have an eating disorder, those who think that they might have an eating disorder, parents, professionals and those who are just interested: please look at the Be Body Positive website, and share it as you consider it appropriate. It is a lively and up-to-date resource, providing essential information in a very positive way.

Declaration of interest

LD holds a partnership role in the Be Body Positive programme in kind through Barnardo's and was commissioned to support co-production work and to obtain informal feedback on the Be Body Positive tool. NB received paid contributions via East London NHS Foundation Trust for time and contributions to the programme. PB, EL, PF, EC, SS and KQ contributed NHS clinical time allocated in kind to the development and launch of Be Body Positive. AG conducted her MSc dissertation on a topic relating to this website. IP holds a partnership role in the Be Body Positive programme in kind and was commissioned to support the co-production work. RN received paid contributions via National Health Services for time and contributions to the Mental Health Services. SW received paid contributions via East London NHS Foundation Trust for time and contributions to the programme.

Acknowledgements

Children and young people, parents, carers and professionals involved in the evaluation and who have given feedback, support and guidance throughout the development and launch of BBP.

NHSX for funding the initial project.

East London NHS Foundation Trust.

North East London NHS Foundation Trust.

East London Business Alliance.

Barnardo's.

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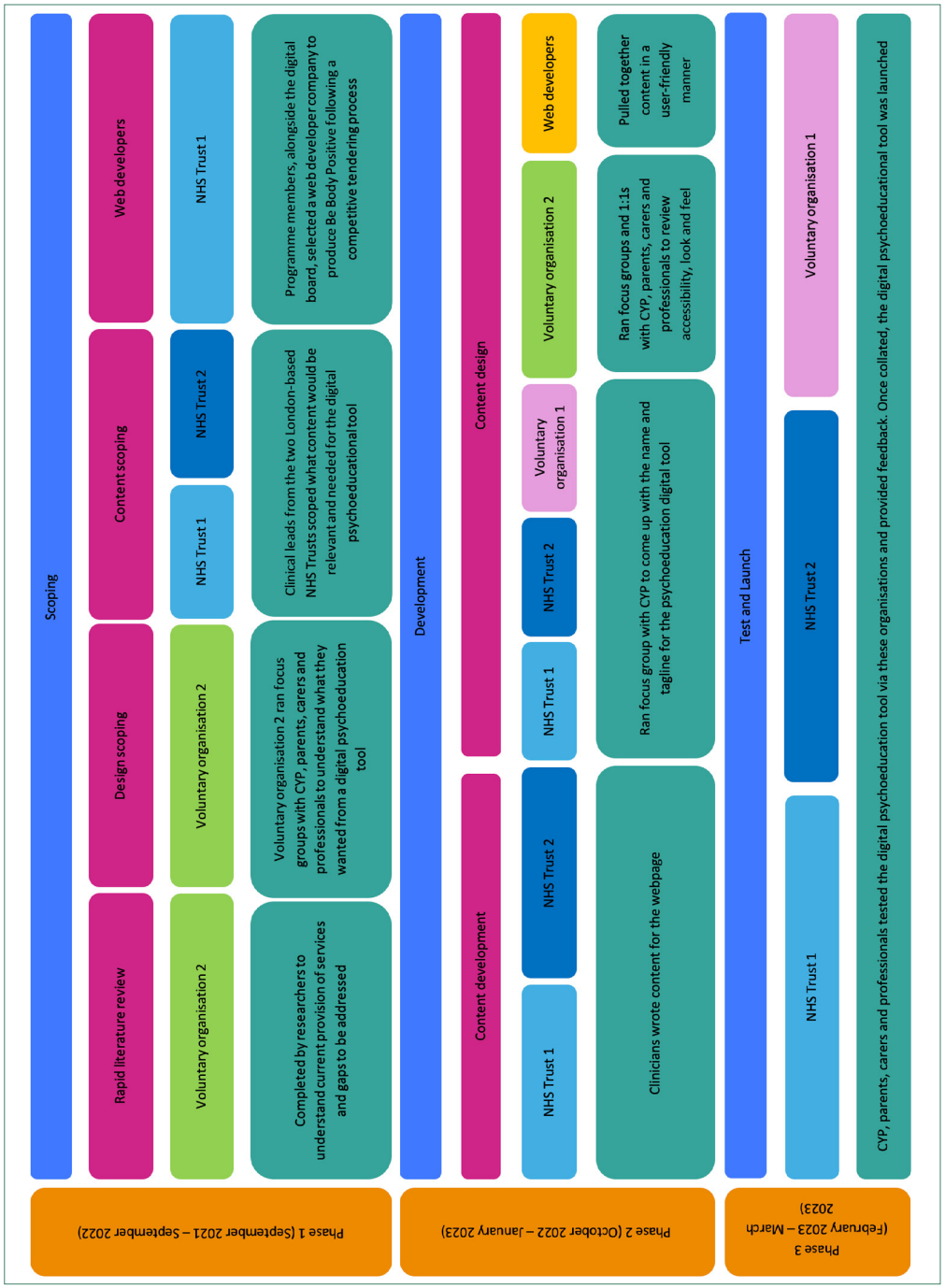

Figure 1. Design, development and launch process for the Be Body Positive website

The role of social and family support in the management of eating disorders

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Abstract

This paper aims to consider the role of informal social support in contributing to the welfare of people with eating disorders (EDs). Anorexia nervosa usually emerges between the ages of 16 and 17 years for females and at 12 years for males, followed by other common forms of EDs, such as bulimia nervosa and binge eating disorder. Families can play a key role in the outcome of an ED by recognising the problem and accessing early support. Unfortunately, the provision of services does not match the current need. Carers have been involved in co-designing and co-delivering information and support that can fill some service gaps. This involves learning how to manage the traps that are easily triggered and lead to unhelpful interactions driven by expressed emotion, such as overprotection, accommodating the ED behaviours by ignoring and/or using hostile confrontation and criticism. Families provide a great amount of practical support and are important partners during treatment. They can prevent the individual from becoming isolated and trapped within the ED identity.

Keywords: eating disorders, families, expressed emotion, early support, treatment

Introduction

Eating disorders (EDs) are serious conditions that negatively impact both the person with the disorder and their family members. Clinical guidelines emphasise the importance of involving and supporting family members in the care of their loved one (1, 2). Family members are impacted in many ways, including financial strain, social isolation, physical health (3) and emotional and psychological stress (3, 4). By addressing these challenges faced by family members, we can improve both their wellbeing and the treatment outcomes for their loved one (3, 4). Families often shoulder guilt and distress as they assume that they have contributed to the illness. As in most forms of illness, there may be a genetic element; however, the aetiology is not fully known and probably involves several interacting factors, possibly activated by puberty.

In Figure 1, we outline how three broad factors, including those related to the illness itself, the societal response to the illness or the parental/carer response to the illness can impact the functioning and wellbeing of carers and interfere with their ability to provide effective care and support. In this paper, we consider the level of difficulties that carers face, respect the key roles they provide and discuss ways in which health professionals can work productively with carers.

Illness factors

First, there is often a large mismatch between what close others recognise as problematic and the experiences of the individual. There are a variety of ways in which the ED may become valued for the individual. For example, living by the rules of the ED facilitates a focus on the goal of being "good enough", which is a key maxim for those at risk of developing an ED. EDs flourish alongside temperamental traits of anxiety, social comparison, sensitivity to reward and/or punishment, perfectionism and compulsivity or impulsivity. This alignment between values, personality features and the ED leads to ambivalence and resistance to the need to change. In contrast, the disruption to core features of family functioning,

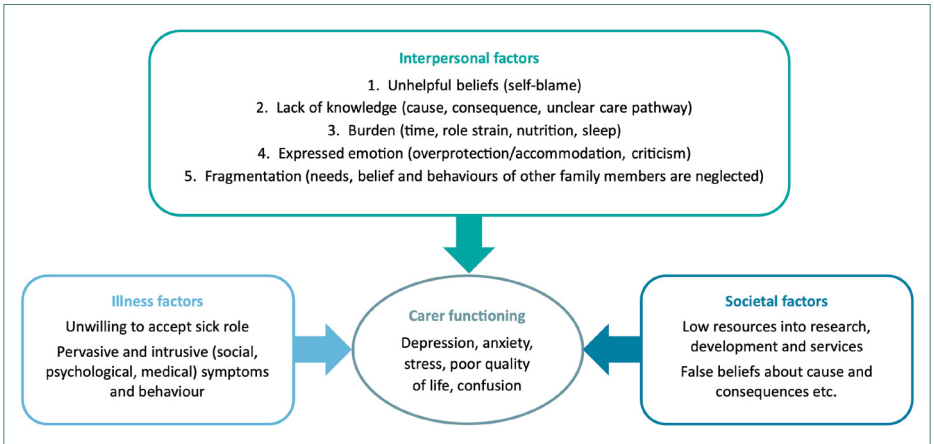

Figure 1. Factors that affect carer function

such as the provision of nutrition and a healthy environment, has a large impact on the family and the wider social network. This disparity between the stages of change of the individual and the family makes planning for change difficult. There is good evidence to suggest that the demands of the ED on the family unit, coupled with the constant worrying and unpredictability of the illness, bring multi-layered changes reflected by a "new normal", where life becomes centred around the ED (5).

Societal factors

Society and the media have contributed to the causes of EDs by fostering idealised and unrealistic body image standards and the opportunity for social comparison by normalising symptoms that may entrap the individual. Previous studies have explored the role of social media on body dissatisfaction and negative body image (6). However, there is a lack of evidence about individual differences and how social media, body images and pro-ED societal influences affect distinctively heterogeneous and under-represented groups.

Recent research has discredited harmful established stereotypes that have shaped public understanding of and research on EDs for decades (7). This research highlighted that many aspects of disadvantage increase the risk of developing an ED, including socioeconomic disadvantage, food insecurity and weight stigma, challenging the view that EDs only affect those who are affluent. The myth that EDs only afflict privileged, White, middle-class females may have contributed to the paucity of resources that have been allocated to increase knowledge about the causes and consequences of EDs and what constitutes an effective care pathway for these problems. However, carers and individuals themselves have been diligent in bringing to the attention of the government the deficiency in resources allocated to EDs (8). There is now an ombudsman overseeing this area and more attention and resources have been given to research, training and services.

Family factors

Recognition and access to care

In the absence of reliable evidence and understanding, many carers jump to the conclusion that they are responsible for the development of the ED. The consequent guilt and distress add to the burden arising from the high levels of practical support that carers provide (9, 10).

Parental responsibility for causing the illness is one of the many myths associated with EDs which can hinder recovery. One of the truths associated with an ED is that carers can facilitate early intervention by recognising the early signs and taking steps to access help, which can lead to an improved outcome. Carers, including family members, teachers, coaches and those in primary care, have a key role in early recognition and access to care.

Nevertheless, the first step is fraught with difficulties because of the ambivalence and secrecy about the illness. Also, accessing the correct form of help can be difficult. Often, the signs and symptoms of an ED are dismissed as a teenage "phase" or conceptualised as part of a physical problem. A multicentre European study found that, on average, two intermediary health professionals and a period of over two years elapsed before specialised services were accessed (11). Indeed, a systematic review reported that the average duration of untreated EDs was 29.9 months for anorexia nervosa (AN), whereas perhaps because the symptoms and signs of binge-spectrum disorders are less visible, the delays in accessing treatment were longer, 53.0 months for bulimia nervosa (BN) and 67.4 months for binge eating disorder (BED) (12). A recent systematic review concluded that patients' shame, guilt and stigma, coupled with a lack of knowledge among health professionals, were the main barriers to seeking early help (13).

The diverse nature of EDs and the uncertainty about how they are best supported, combined with the exhaustion that arises from the high burden of care, impact different family members in a variety of ways. This complexity makes it challenging to develop a coherent and collaborative approach. For example, as discussed above, some family members blame themselves, possibly because a thread of EDs or other forms of mental illness exists within their family of origin. Others may be bewildered by how the illness defies the common-sense understanding that eating is essential to sustain health. Thus, the emotional reactions of the family can oscillate between a tendency towards overprotection and/or accommodation towards the behaviours, through to irritation, criticism and hostility. These common reactions occur both within and across individuals and both accommodation and criticism can have adverse impacts on the treatment outcome (14).

A meta-synthesis of the qualitative literature relating to the lived experience of caring (mainly from a parental perspective) for a range of EDs (for example, AN, BN or EDs not otherwise specified) found nine core themes (15). Amongst the themes were changes in their behaviour, for example, adapting to the illness by accommodating and enabling symptoms and tolerating and ignoring behaviours. Carer guilt was prominent across and within themes. Overall, caring for people with an ED placed a significant strain on interpersonal and family relationships with conflict, particularly around mealtimes.

The idea of "overprotection" and accommodation is complicated because it varies across cultures and changes as people grow. Different ways of measuring these behaviours can mean slightly different things. For example, parents might try to ease their child's fear of eating by giving lots of reassurance, preparing special foods and following spe-

cific mealtime routines (16). However, these "safety" behaviours can interfere with treatments meant to help the child overcome their eating fears (17, 18). They can also make ED behaviours take over family life, especially if the child has traits of autism or obsessive-compulsive disorder. To address this, families might need to make gradual, reasonable changes to reduce these behaviours.

A network analysis examining the connections between carers and the individual with the ED found that depression and accommodation impacted the outcome of the illness (19). These variations in emotional reactions can easily lead to fragmentation within the family. Time and attention for other family members need to be ring-fenced away from the huge burden of care absorbed by the ED. The heavy burden of care usually falls on mothers, which means that it is easy to overlook the needs and opinions held by other family members, such as fathers and siblings.

Fathers

Many of the studies that consider the parental burden and reaction to the development of an ED mainly examine the impact on the primary caregiver, who is usually the mother. However, the experience of both parents attending a skills-sharing intervention (SUCCEAT) was obtained from two clinics in Austria (n = 92) (20). Fathers had lower baseline levels of general distress, emotional overinvolvement and burden (for example, only 15% had >4 hours of contact compared to 46% of mothers). Both parents had similar levels of adherence and engagement with the skills-sharing workshops (fathers, 5.9/8 sessions and mothers, 6.5/8 sessions) and the majority reported satisfaction with the workshop and additional materials. Following the intervention, caregiver skills were increased and the ED burden and emotional overinvolvement were decreased. This highlights the important role that fathers can play by counterbalancing the tendency for mothers to become overly emotionally involved and protective. The inclusion of fathers can reduce the tendency for the family to use polarised approaches and become fragmented, which may lead to better outcomes.

Siblings

The sibling relationship varies according to age, gender, culture, stage of development and living arrangements. The small amount of research from siblings' perspectives suggests that the challenges they face are like those experienced by their parents (21). Siblings experience significant distress related to the ED symptoms and the physical state of their sibling (22), accounting for difficult and divergent emotions (23). The ED may build on the tendency for comparison and competition between siblings and increase family fragmentation. For example, this may lead to the size of a meal or the intensity of exercise being calibrated in competitive behaviours between siblings. On the other hand, siblings may help sustain peer relationships and protect against isolation. However, there needs to be a greater consideration of the impact that EDs have on siblings, who have unique needs that differ from those of other family members, such as parents (24). Yet, siblings often feel overlooked by healthcare services and have limited resources and support, with one study finding that the majority of experiences reported by siblings did not meet the published guidance for supporting carers (24).

A systematic review of the qualitative, quantitative and mixed-methods literature on siblings' experiences of having a brother or sister with an ED found that EDs have negative inter- and intrapersonal impacts on siblings, including fragmentation in family relationships, parentification and competition and jealousy (25). This research underscores the importance of considering the broader family context in the treatment of EDs and providing comprehensive support to all family members.

Peers

Individuals with EDs highlight the importance of relationships with significant others, such as friends and peers, in the recovery process. One of the key tasks of adolescent development is to seek group affiliation and develop a clear identity (26). However, EDs directly or indirectly limit social interactions. Also, secondary effects on social cognition can impact the quality of intimate relationships (27), contributing to loneliness and alienation, which are core experiences of the illness (28, 29). This social disruption can allow the ED identity to become more firmly embedded. On the other hand, those individuals who can share their thoughts, feelings and fears with close others, including siblings and family members, have better outcomes (30).

However, peers can also play a role in the development and maintenance of EDs and poor-quality relationships with peers are linked to greater ED symptoms (31). This is also relevant in inpatient settings, where peer relationships are often complex. While these relationships can reduce feelings of isolation and help normalise and validate individuals' experiences, they can also have harmful effects when individuals engage in psychological and behavioural comparisons.

Some individuals described this as a contagion effect, where they become more aware of the detrimental behaviours of others and are more likely to adopt them (32). The role of peers in the context of EDs is complex and multifaceted, so it should be considered on the basis of individual cases and what works best for the individual with the ED.

Partners and spouses

There is evidence to suggest that adults with EDs have similar chances of forming romantic relationships as their healthy peers. Yet, there is very limited knowledge about the experiences of partners/spouses caring for their loved ones. Partners of individuals with EDs have reported on the impact of caring responsibilities and the changes in psychosocial functioning related to the illness (5). Partners often describe that they feel isolated and lonely in the process of treatment due to the high level of care associated with the illness. They often experience rejection as a result of the primacy associated with the ED. Perceived stigma encourages secretive behaviours and a lack of sharing with close or extended social networks, which further increases the burden on partners.

The involvement of the family in treatment

One of the core principles of family-based treatment (FBT) is that the approach is agnostic about aetiology, focusing not on the causes of the illness but rather on engaging the family to provoke behaviour change (33). However, uncertainty about causal factors is both frustrating and debilitating for family members, who tend to blame themselves (34). The focus of FBT on particular aspects of recovery, such as refeeding, can be confusing to parents as they seemingly ignore the psychological symptoms of EDs; as such, it is imperative to have effective communication and sharing of appropriate information between the family and professionals (5). Thus, people with lived experience, such as patients and carers, have linked with professionals to produce materials that guide a collaborative approach. Charities such as Beat, FEAST, Bodywhys and First Steps have set up support groups. The New Maudsley Carers website offers access for both clinicians and families to the worksheets, videos and podcasts around the New Maudsley Carer Skills Workshops, and the Charlie Waller Trust is now one of the most active providers of carer skills workshops. Individuals have written books that share basic information (35) or specific skills, such as motivational interviewing (36) and the Maudsley Model of Collaborative Care (37).

The involvement of family members in clinician-led treatments

Family members play a critical role in the recovery process of EDs and a recent meta-analysis found that family-based interventions are effective for adolescents with EDs, leading to better recovery rates and reduced chronicity, compared to other interventions (38). A recent umbrella review concluded that treatments involving family members showed the most benefit for patients with AN (39). These highlight that strong family support systems and a supportive family environment are associated with positive treatment outcomes. By providing emotional support, participating in therapy and being involved in treatment planning, family members can significantly contribute to the recovery process.

A systematic review and meta-synthesis of 25 studies highlights the role of clinicians in acknowledging parental challenges, which can facilitate the process of recovery for adolescent AN patients by building stronger therapeutic relationships (40). For example, expressed emotion and psychological distress in carers have been identified as risk factors for relapse. Promoting collaboration between parents/carers and health professionals can improve outcomes and empower young people, carers and clinicians. Parents are encouraged to have high levels of involvement in meal support in the form of family therapy for younger patients. This is less often the case for adults unless there is a high level of risk which needs to be carefully managed. The Medical Emergencies in Eating Disorders guidelines offer materials that can be shared with carers to manage risk across the life span (41).

FBT views the family as a resource for the recovery of their loved one with an ED (42) and is considered best practice for the treatment of AN in children and adolescents by the National Institute for Health and Care Excellence (NICE) guidelines (2). FBT tasks parents with meal management, whereas siblings are tasked with emotional support.

Family skills-sharing

Carers, including siblings, fathers and partners, are invited, either together or occasionally separately, to skills training workshops which may be linked to services of independent charities, such as FEAST, Beat and the Charlie Waller Trust, among others. Figure 2 demonstrates the types of support available for EDs. These are a form of task-sharing and provide supporters with information and skills which have been found to reduce their caregiving burden and distress; they also show patient benefits, such as improving mood and reducing ED symptoms (16, 43). In a UK-wide multicentre study, we found that providing supporters of adult inpatients with AN access to the elements of the New Maudsley Approach within the Experienced Carers Helping Others (ECHO) study not only reduced carer burden but also impacted on the need for further support, in that it reduced the length of admission and the relapse rate (44, 45). Also, carers of adolescents with AN given access to these materials found caregiving less burdensome and it reduced service use (46). The materials have been translated into German and found to reduce carers' distress and improve caregiving skills in face-to-face and virtual workshops (47). Fathers engage well and actively share emotional reactions and skills in all-male groups (20).

Multifamily approaches

A variety of multifamily approaches in which several families (including patients) attend workshops designed to support change have been introduced. These were initially developed in adolescents and a randomised controlled trial was undertaken (48). A recent intervention, ECHOMANTRA, which included a form of the multifamily approach, found

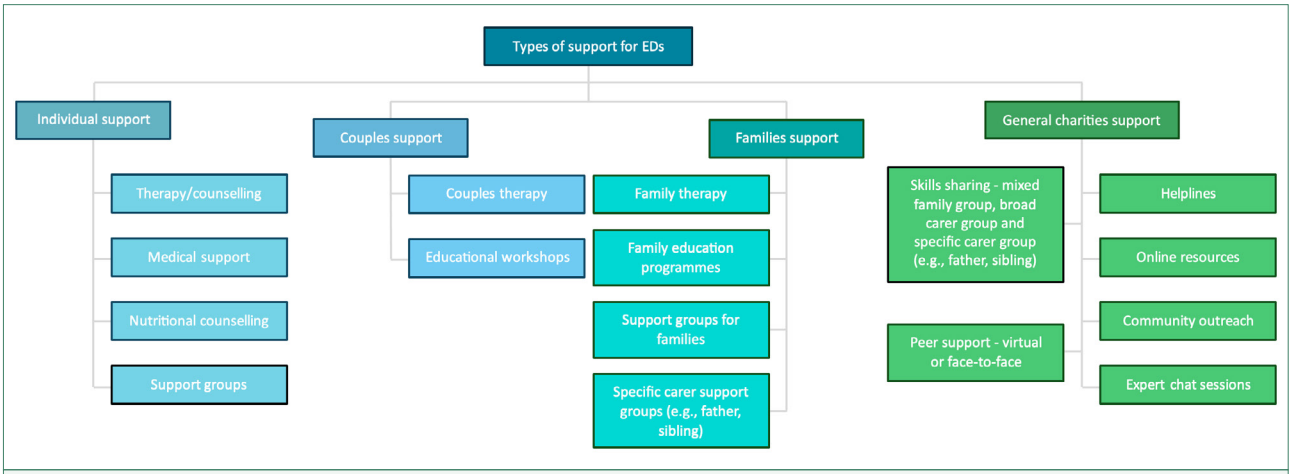

Figure 2. Types of support for eating disorders

that this element of the approach was highly rated by participants (17). This approach can include targeted support for siblings, partners and fathers or peer-delivered support for siblings (5).

Conclusion

Families or close others often play a key role in noticing and taking the steps needed to access early help for an ED, which can be a difficult step because the individual themselves does not recognise that there is a problem. The involvement of families or key elements of the social network participating in various ways to provide support is of particular relevance for people whose ED-related behaviours threaten their health or development. Families provide a large amount of invaluable unpaid care and frequently they are the first to recognise the initial ED symptoms. Therefore, increasing support and information channels for this group throughout all stages of the ED journey can positively impact treatment outcomes (10). People with lived experience reflect that isolation is a core part of the illness (28) and this is something that carers can target within their role. The development of a well-functioning adult identity benefits from support both within and outside the family and so a collaborative approach to care is needed.

Declaration of interest

The authors declare that they have no conflicts of interest.

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Advances in community treatment of eating disorders: home treatment for child and adolescent anorexia nervosa†

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Abstract

Over recent decades, for young patients with anorexia nervosa (AN), efforts have been made to develop alternative treatments at home to reduce long hospital stays or to avoid admissions altogether. This article explores the motivation for developing home treatment for this specific patient group as an advance in community treatment. Two main routes of home treatment have been developed: home treatment as an "add-on" to outpatient treatment and "stepped-care" home treatment after short inpatient treatment. Both treatment approaches are discussed in this article. Pilot studies with small sample sizes have provided evidence for the safety, feasibility and success of both home-treatment approaches for AN in children and adolescents with the help of their families. Home treatment is emerging as a promising strategy for avoiding hospital admissions and reducing the duration of hospital stays. However, even though the existing research so far is promising, further validation through rigorous multi-centre, randomised, controlled trials with larger sample sizes and comprehensive follow-up assessments is warranted.

Keywords: anorexia nervosa, eating disorder, child and adolescent, parental involvement, home treatment, community-based treatment

Abbreviations: AN = anorexia nervosa; ED = eating disorder; FBT = family-based therapy; IPT = inpatient treatment; RCT = randomised controlled trial; OPT = outpatient treatment; DPT = day-patient treatment

1. Background

Home treatment is a comprehensive approach to treating individuals with mental disorders by providing direct support within a patient's home environment. Emerging in response to the need for a reduction in the cost and burden associated with expensive and often prolonged inpatient treatment (IPT), home treatment has gained enormous popularity within recent decades (1-3). Moreover, the development of psychiatric home treatment aimed at mitigating the adverse effects of extended hospital stays has been particularly pronounced among children and adolescents (4). Home treatment involves regular and frequent visits to a patient's home, realised by a multidisciplinary team, with active engagement of family members, typically spanning a duration of three to six months and ensuring 24/7 availability for potential crises (for example, (1, 5)).

Home treatment programmes specifically for child and adolescent psychiatric disorders have been developed since the 1980s (for example, (6)). These programmes aim to care for patients in acute psychological crises with the objective of averting IPT (for example, (2, 7-10)) or, alternatively, as a stepped-care approach subsequent to hospital stays to transition from IPT to outpatient treatment (OPT) to shorten inpatient stays and stabilise progress (for example, (11, 12)). Both methods of home treatment, acute OPT to prevent IPT and a stepped-care intervention to shorten IPT, have demonstrated success for emotional and behavioural disorders (for example, (13)). Additionally, home treatment is associated with greater cost-effectiveness, increased patient satisfaction and a decline in admissions or reduction in the length of IPT (2, 5, 11, 14).

Data regarding eating disorders (EDs) are limited. In addition to the small number of individuals with anorexia nervosa (AN) included in a broader randomised controlled trial (RCT) investigating various child and adolescent psychiatric disorders (11), to our knowledge, only a few single case and pilot studies of adolescents with AN have investigated the effectiveness of home treatment for patients with from EDs (8, 12, 15, 16). Consequently, despite the promising results from these first reports and the apparent safety of this treatment strategy, home treatment for EDs remains an experimental approach that has not yet been integrated into any national ED guideline. Furthermore, to our knowledge, this technique has thus far been applied only within the treatment of children and adolescents with AN, with limited application to individuals with other EDs or adults. Given the scarcity of reports on home treatment programmes for a broader spectrum of individuals with EDs, this article concentrates on summarising the existing results and depicting the initial experiences of implementing home treatment for children and adolescents specifically dealing with AN.

† This topic and the results of the pilot studies have been extensively described in the following chapter: Zielinski-Gussen I, Dahmen B, Herpertz-Dahlmann B. Home Treatment for Eating Disorders. *In:* Robinson P, Wade T, Herpertz-Dahlmann B, Fernandez-Aranda F, Treasure J, Wonderlich S (eds.) *Eating Disorders An International Comprehensive View*. Springer. London, UK (2022).

2. Motivation for developing a home treatment programme for child and adolescent AN patients

For children and adolescents with AN, OPT is the preferred approach in numerous healthcare systems. Nevertheless, over the last decade, a notable rise in the number of child and adolescent patients with AN admitted to hospital has been observed in various European countries, including the UK (17), with a further escalation during the COVID-19 pandemic (18-21). In the USA, the demand for residential treatment for AN patients has significantly increased, partly because IPT in the USA typically focuses on short-term medical stabilisation (22).

Despite IPT still being considered the gold standard in many European countries for severe AN (23, 24), young patients often perceive hospitalization as coercive, leading to potential delays or even refusals of hospital admissions (25). Additionally, even though IPT is often effective at stabilising weight, it frequently fails to successfully modify specific ED behaviours, such as the "drive for thinness" (26). A considerable number of adolescents with AN face IPT readmission within one year of their previous hospital treatment (27, 28). Furthermore, prolonged IPT contributes to severe social impairments in patients with AN by separating them from their family and peer groups (29).

Recently, efforts have been made to create alternatives to (long) IPT. Therapeutic approaches from the USA and the UK have shown that involving parents in treatment significantly improves therapeutic success when treating children and adolescents with EDs. The best evidence of a successful outcome with this approach is from so-called family-based therapy (FBT), which was primarily developed as an outpatient approach for young patients suffering from AN (30). FBT is based on the idea that the caregivers of patients take on crucial co-therapeutic functions and take the lead in refeeding their children. Controlled studies have demonstrated that in the short term, compared to individual OPT, FBT is more effective in achieving weight gain (31), although its greater effectiveness in long-term outcomes is less evident (32). Furthermore, a recent pilot study demonstrated that outpatient FBT seems to be a safe and feasible treatment alternative for two-thirds of adolescent AN patients eligible for IPT (33). The success of involving parents, as demonstrated by FBT, has had a significant impact on the development and establishment of new therapeutic approaches.

In addition to improving OPT to prevent IPT, stepped-care approaches have been implemented for patients with severe AN to shorten IPT stays, using a gradual transition to less intensive treatment settings such as day-patient treatment (DPT) settings (34, 35). In an RCT with adolescent patients, following a short IPT stay for somatic stabilisation, the treatment effects of DPT were comparable to continued IPT (34). A year after the start of DPT, a similar increase in weight and mental development was observed compared to that observed after IPT (34). A follow-up study revealed even more positive outcomes after 2.5 years: DPT patients had significantly greater weights and lower rates of rehospitalisation than IPT patients (36). Furthermore, DPT has been indicated to be more cost-effective and superior to IPT for specific outcomes, such as psychosexual development and mental health (34, 37). Factors such as more intensive and earlier involvement of the family, along with active practice in the patients' familiar environments, were identified as crucial for achieving a more favourable outcome (38). However, despite the lower rehospitalisation rate than that following IPT, the rehospitalisation rate of DPT is still considered high, with approximately 30% of patients experiencing rehospitalisation within 2.5 years (39). Despite the early involvement of the family being considered a successful element of the treatment, parents as well as patients communicated challenges in the "difficult" transition from the hospital to the home environment. This aspect is of particular interest as it is generally known that factors responsible for the sustainment of specific AN behaviours are entrenched within everyday habits in patients' home environments (40). Thus, changes can be best achieved within the patients' community and family environments. Given the promising effects of more intense and early involvement of the family for children and adolescents with AN and active promotion of healthy eating within the direct patient environment, the necessity of developing specific home treatment programmes has been emphasised multiple times for this patient population (34, 41).

3. Home treatment programmes for children and adolescents with AN

3.1. Integrating home treatment as an "add-on" to outpatient FBT

The Department of Child and Adolescent Psychiatry at the University of Zurich, Switzerland, as well as independently the Department of Psychiatry of the University of Pittsburgh, United States, have directed their efforts towards enhancing existing OPTs to prevent IPT (8, 15, 16). This work suggests that home treatment could serve as a supportive "add-on" to outpatient FBT. In this approach, additional home treatment sessions are delivered to adolescent patients who undergo manualised FBT for AN (42). This treatment programme starts immediately after referral and lasts 10 to 16 weeks, incorporating, depending on the program, one to four individual home treatment sessions per week alongside regular FBT sessions (8, 16). Each session lasts approximately 60 minutes, with the frequency of home appointments tailored to the individual needs of the patients and their families. Active participation of at least one significant person from the patient's environment (for example, a parent or sibling) is required during each session (8).

As well as the certified FBT supervisor, who offers monthly supervision, the home treatment team contains a trained nurse and an FBT therapist (8). Within the work of the Department of Child and Adolescent Psychiatry at the University of Zurich, the home treatment sessions are exclusively conducted by a trained home treatment healthcare nurse who participates in at least one FBT session in which the goals for the home treatment are established (for example,

support in meal preparation or meal supervision). Home treatment nurses undergo specific training in FBT for adolescents with AN (42) and receive specialised training in home treatment strategies, encompassing general communication and mealtime support strategies (8, 15). In addition to their initial participation in the FBT session, the home treatment nurse regularly communicates with the FBT therapist throughout the treatment period, either in person or by phone or email.

At the onset of the home treatment intervention, ED-maintaining factors at both the family interaction level (for example, parental criticism) and the individual patient level (for example, frequent self-weighing) are evaluated by the FBT therapist (8, 15). Following this assessment, the precise goals for the home treatment programme (for example, complete caregiver responsibility for meal preparation) are determined through a collaborative process involving the caregivers, the patient, the FBT therapist and the home treatment nurse. Subsequently, the supervised home treatment nurse provides the home treatment intervention, addresses crucial issues (for example, disregarding agreements related to meal supervision), participates in family meals and provides guidance to the patient and their caregivers on overcoming specific interaction challenges (for example, family communication during mealtimes, food preparation).

The primary goal of these home sessions, which are conducted in addition to outpatient FBT, is to offer practical support to caregivers, strengthening their ability to refeed their child. Additionally, they aim to enhance both the family's and the patient's resilience factors and support resources, such as assisting patients to be reintegrated in their social lives (for example, engaging in hobbies, socialising and eating with friends).

3.1.1. Pilot results

To assess the feasibility and efficacy of the proposed supplementary home treatment in conjunction with FBT for adolescents with AN, a pilot study with a waitlist control design was conducted (8). The study included all adolescents with AN that were referred to the involved outpatient clinic between 2017 and 2019. Among the participants, 45 patients underwent FBT combined with home treatment and 22 patients exclusively received FBT while awaiting additional home treatment.

The results showed that both treatment cohorts exhibited noteworthy weight gain after the three-month intervention. Moreover, the number of patients who met the diagnostic criteria for AN and exhibited ED psychopathology decreased in both groups after three months of treatment. However, the group receiving home treatment combined with FBT demonstrated a greater body mass index increase. Additionally, the menstrual cycle resumed in a greater percentage of the female patients receiving home treatment, which is a significant measure of recovery in AN. Remarkably, none of the individuals in the combined treatment group required transfer to IPT, whereas three patients in the control group (13.6%) required hospital admission within the three-month period.

The findings suggest that incorporating home treatment as an adjunct to FBT is a feasible and effective approach for treating AN in adolescents, augmenting the impact of FBT. However, a follow-up study is essential to explore long-term effects and the results should be validated through an RCT, which is currently ongoing (43).

Moreover, the Department of Psychiatry of the University of Pittsburgh has also initiated a pilot study adding home treatment to FBT (16, 44).

3.2. Home treatment with a stepped-care approach following IPT

The research team at the Department of Child and Adolescent Psychiatry of the University of Aachen, Germany, devised a stepped-care home treatment approach for adolescents with severe AN admitted for IPT (12). In this stepped-care strategy, patients undergo an initial inpatient stabilisation period lasting five to eight weeks for somatic and psychological stabilisation, followed by 12 to 16 weeks of home treatment. Persistent severe ED behaviour (for example, inability to eat independently or daily purging), inadequate weight gain during the inpatient stabilisation phase or the presence of ongoing serious psychiatric or somatic comorbidities (for example, severe self-injurious behaviour or suicidality) at the intended discharge time preclude the initiation of home treatment; in such cases, IPT is continued. A distinctive feature of home treatment is that the same therapists who care for the patient during the inpatient stay continue the treatment at home. This significantly facilitates the introduction of treatment, as the therapeutic team is already familiar to the patient and family, making it easier for many families to "open the door" to the therapists.

The inpatient stabilisation phase is considered the first step within this stepped-care approach. This phase entails optimal preparation for patients and their caregivers to manage their EDs at home. Alongside participating in a dedicated psychoeducational group, caregivers actively participate in their child's treatment. While the children are still in the hospital, parents or primary caregivers engage in joint family meals and shared psychotherapeutic sessions. During family meals, a nutritional therapist or nurse assists parents in supporting their children during subsequent meals at home. Unlike FBT, joint family meals are practised multiple times until caregivers (and the patient) have gained sufficient experience. As patients achieve medical stability, they gradually spend more time at home. Caregivers supervise and support the patients in adhering to meal plans and refraining from weight-reducing practices (for example, excessive exercising). Towards the end of the inpatient stabilisation period, the practical implementation of

home treatment and the individual goals of this therapy are discussed with the patients and their families. By the time of discharge, patients must independently consume all meals with support from their then trained caregivers, and the target weight should be determined and communicated.

The second step of this treatment approach is initiated by the home treatment phase (12–16 weeks). Given that the risk of relapse is typically highest in the period immediately after discharge (45), the implementation of home treatment follows a diminishing pattern. In the initial phase (weeks 1–8 post-discharge), the multidisciplinary team conducts three to four weekly visits to the patient's family home. The multidisciplinary team includes an individual therapist (child and adolescent psychiatrist or psychotherapist), an experienced nurse, a nutritional therapist and other specialists (for example, social workers, occupational therapists, physiotherapists). Weekly supervision by an experienced child and adolescent psychiatrist ensures team cohesion. Each professional has a specific therapeutic role within the home treatment programme, tailored to the family's needs, whether through nutritional advice or assistance because of family conflicts. To meet specific needs, the different professionals (for example, nutritional therapists for severe eating problems, social workers for severe problems in structuring a day with age-appropriate activities) visit the families. The psychotherapist attends every week for continued psychotherapy (enhanced cognitive behavioural therapy, CBT-E). One session per week must be planned with both the patient and family together. During these initial two months, the focus is on promoting weight gain by addressing ED symptoms and aiding parents in managing food intake.

The subsequent phase (weeks 9–16 post-discharge) primarily aims to support the patients and their caregivers in rebuilding social connections (for example, engaging in activities with friends, participating in age-appropriate events and gradually attending school), fostering patient autonomy and, if needed, initiating additional support through community services (for example, youth welfare services). Initially (weeks 9–12), therapists typically maintain two home appointments per week, reducing to one visit per week in the final phase of home treatment (weeks 13–16). In addition to regular home visits, patients participate in weekly group therapy sessions. As well as addressing AN-specific concerns, these sessions delve into the practical challenges of everyday life with AN (for example, engaging in social activities with friends). The programme also offers a 24/7 hotline for medical or crisis intervention.

In summary, this home-based stepped-care treatment approach aims to provide direct and increased support for patients and caregivers in their home environments, facilitating their reintegration into age-appropriate activities. The ultimate goal is to restore normal participation in adolescent as well as family social lives, along with normalising nutrition, weight, cognitions, self-esteem and (eating) behaviour.

3.2.1. Pilot results

Between 2017 and 2019, a pilot study was conducted to examine the trajectory and one-year follow-up of this stepped-care approach for patients with severe AN (12). The inclusion criteria comprised patients with AN admitted for IPT for the first or second time (with the majority having undergone unsuccessful OPT), patients residing with at least one parent and within a one-hour commute from the hospital, patients lacking severe mental or physical comorbidities, and patients possessing an IQ of at least 80.

The sample consisted of 22 adolescent patients, all of whom exhibited significant weight gain from admission to the initiation of the home treatment programme. In one patient, home treatment was prematurely terminated due to persistent severe ED symptoms and IPT was successfully continued. The remaining 21 patients showed a continued weight increase during the home treatment phase which was sustained from the end of home treatment to the one-year follow-up. Importantly, no serious adverse events were reported, underscoring the safety of this approach. Evaluation further revealed a marked improvement in ED behaviour and general psychopathology as well as high treatment satisfaction (12). The reduction in ED psychopathology paralleled improvements observed in a stepped-care DPT approach for adolescents with AN (34). Additionally, patients' motivation for change significantly increased during treatment and remained stable up to the one-year follow-up (46). Furthermore, parents demonstrated enhanced skills in managing their child's ED throughout treatment, coupled with a decrease in perceived burden and depressive symptoms (12, 47).

It was concluded that this stepped-care approach, which involves home treatment following brief IPT, appears to be a safe and promising strategy for shortening IPT stays and potentially enhancing longer-term outcomes in adolescent AN patients. However, these findings need confirmation through a RCT with a more extensive sample size. Currently, a large multicentre RCT with more than 150 patients is being conducted (funded by the Federal Joint Committee, Germany [G-BA innovation fund], grant number 01VSF20006).

4. Conclusion

In the realm of treating adolescents with AN, home treatment has emerged as a promising strategy for averting hospital admissions and reducing the duration of hospital stays. Nevertheless, the existing body of related research remains limited, necessitating further validation of the aforementioned outcomes through larger controlled investigations. Rigorous RCTs with substantial sample sizes and comprehensive follow-up assessments are imperative to corroborate

these pilot findings, extending beyond AN to encompass the broader spectrum of EDs.

Furthermore, specific questions regarding the application of the different home treatment programmes still need to be explored in depth. One example is the question of whether specific patients or families might profit more from home treatment programmes, while others might not. Another interesting research question concerns the impact of this treatment setting on other family members. Next to the primary caregiver burden of, and skills in, handling the child's ED, the impact on the siblings should be assessed. Also, the satisfaction and workload of the members of the multidisciplinary home treatment teams should be assessed in detail to determine the feasibility of this alternative treatment setting.

The goal of establishing these new and tailored home treatment settings for child and adolescent AN as a progress in community treatment should be to further improve the prognosis for this debilitating disorder. More children and adolescents should be considered cured before entering adulthood and, if possible, no longer have any effects of ED symptoms in later life.

Declarations of interest

The authors declare that they have no conflicts of interest.

Funding

Part of the work of all the authors was funded by the Federal Joint Committee, Germany (G-BA innovation Fond), under grant number 01VSF20006.

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Cognitive behavioural therapy for eating disorders: past, present and future

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Abstract

Cognitive behavioural therapy (CBT) is a first-line treatment for eating disorders, including anorexia nervosa, bulimia nervosa and binge eating disorder, as approved by the National Institute for Health and Care Excellence (NICE). CBT addresses the cognitive and behavioural factors that maintain eating disorders. It offers patients tools to overcome difficulties. It is flexible to accommodate different presentations and complex comorbidities. CBT has a well-documented efficacy in treating eating disorders; research has shown that it significantly reduces symptoms and improves maintenance of long-term remission. The history and development of CBT for eating disorders began with Christopher Fairburn's interest in the application of CBT for eating disorders, followed by his development of evidence-based psychological treatments and the creation of enhanced CBT (CBT-E), which is appropriate for all types of eating disorders. CBT-E has four major goals: to engage patients in the treatment, to remove eating disorder psychopathology and behaviours, to correct the mechanisms maintaining eating disorder psychopathology and to ensure lasting change. CBT-E is a structured, patient-centred therapy suitable for a variety of settings, including outpatient and inpatient care, making it a flexible option for treating eating disorders in adults and adolescents. This paper summarises current applications of CBT for eating disorders and recent developments in the field.

Keywords: cognitive behavioural therapy, eating disorders, anorexia nervosa, bulimia nervosa, binge eating disorder, self-help, inpatient, outpatient treatment

Introduction

General practitioners (GPs) play a critical role in the early identification, initial management and referral of patients with eating disorders. This guide aims to equip GPs with essential knowledge of cognitive behavioural therapy (CBT) for eating disorders (CBT-ED), enabling them to support patients effectively throughout the treatment process. CBT-ED is approved by the National Institute for Health and Care Excellence (NICE) as the first-line treatment for eating disorders across the diagnostic spectrum, including anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED).

Eating disorders are complex health conditions characterised by abnormal eating behaviours and related psychological distress. They often co-occur with other mental disorders such as anxiety, depression and obsessive-compulsive disorder, as well as with physical comorbidities or complications, highlighting the need for comprehensive treatment approaches. CBT-ED addresses the cognitive and behavioural factors that maintain eating disorders and offers patients tools to overcome difficulties. It is also flexible, to accommodate complex comorbidities (1). It has well-documented efficacy in treating eating disorders; research has shown that CBT significantly reduces symptoms and improves long-term remission (2).

This paper outlines the historical development and fundamental principles of CBT-ED and highlights its theoretical foundations, key therapeutic strategies and practical considerations for GPs, including evidence-based self-help materials for patients and their families.

The history and development of CBT-ED

Christopher Fairburn became interested in the application of CBT-ED when he was a junior psychiatrist in Edinburgh, following a chance encounter with a patient who, despite having cognitions typical of AN, also binged and purged but maintained a healthy body weight. A few years later, in 1979, Gerald Russell named this presentation "bulimia nervosa", describing it as a rare condition with poor prognosis (3). After seeing several such patients in his clinic, who responded to a CBT approach, Fairburn launched a public campaign via Cosmopolitan magazine to estimate the prevalence of BN. The overwhelming response demonstrated its widespread prevalence and the urgent need for effective treatment (4).

After finishing his clinical training, Fairburn devoted his career to the development of evidence-based psychological treatment for eating disorders, working in the Department of Psychiatry in Oxford and supported by the Wellcome Trust. He led some of the first randomised controlled trials of psychological treatments in the world (5, 6). He further developed the model for BN in collaboration with patients and colleagues, creating CBT-BN, a groundbreaking model that revolutionised treatment and was approved by NICE in 2004. His subsequent work resulted in the development of enhanced cognitive behavioural therapy (CBT-E), a transdiagnostic model (2, 7, 8) which is appropriate for all types

of eating disorders. He also pioneered the integration of digital technologies to increase global access to training and delivering effective psychological treatments.

Fairburn's groundbreaking contributions have transformed the psychological treatment landscape for eating disorders; they have been recognised with an OBE in 2021 and the Distinguished Scientific Application of Psychology Award from the American Psychological Association in 2022 (9). His research and commitment to disseminating effective therapies have influenced clinical practices worldwide, providing hope and better outcomes for people with eating disorders.

In the last 30 years, the application of CBT has been further developed for different patient groups and treatment settings (Table 1). NICE refers to "CBT for eating disorders" to encompass these recent variations. Nevertheless, Fairburn's team's development of CBT-E remains empirically the most robust intervention to help people across the diagnostic spectrum of eating disorders (10). While there is no current treatment model that can achieve 100% remission, the 65% response rate of CBT-E has transformed outcomes for adults with eating disorders, both for non-underweight outpatients (11) and for patients with severe AN, requiring hospitalisation across the age range (12-17). Comparative studies of outpatient models for AN suggest that CBT demonstrates efficacy equivalent to other NICE-approved treatments (18, 19). However, systematic reviews indicate lower response rates in real-world studies, with approximately 50% response for BED and 40% to 45% for BN (20, 21). Notably, Solmi et al. (22) reported recovery rates improving over time, reaching 67% at 10 years with consistent use of evidence-based treatments.

CBT-E has four major goals:

1. To engage patients in the treatment and actively involve them in the process of change.
2. To remove eating disorder psychopathology and behaviours – that is, dietary restraint and restriction (and low weight if present), extreme weight-control behaviours and preoccupation with shape, weight and eating.
3. To correct the mechanisms maintaining eating disorder psychopathology.
4. To ensure lasting change.

There are several treatment manuals, a self-help book and online training and handouts for clinicians available (23-26).

Table 1 summarises the versatility and adaptability of CBT for different patient groups. This includes online self-help interventions for subthreshold eating disorders, guided self-help sessions with face-to-face or email support and short-form individual or group CBT sessions for BED and BN. For more severe cases, CBT-E is tailored to meet the needs of patients with AN, including adolescent adaptation that incorporates parental involvement. Additionally, intensive outpatient and inpatient CBT-E options offer improved outcomes for patients with severe and complex illnesses (1). These varied approaches underscore the flexibility of CBT-E, making it a robust treatment option that is adaptable to different clinical environments and patient needs.

General principles of CBT-E

CBT-E focuses on the specific psychological processes and behaviours that maintain an individual's eating disorder. This approach empowers patients to take control of their recovery and to participate actively in treatment decisions. To prevent patient resistance, CBT-E avoids prescriptive strategies, fostering a joint understanding of the psychological processes that drive disordered eating behaviours.

CBT-E is a structured, patient-centred therapy suitable for a variety of settings, including outpatient and inpatient care, making it a flexible option for treating eating disorders in adults and adolescents. CBT-E is delivered in stages, starting with early behavioural changes to reduce preoccupation with body shape, weight and eating habits (Figure 1).

The first stage focuses on understanding the patient's eating problems and helping them change and stabilise their eating patterns. Personalised education and addressing weight-related concerns are emphasised. The initial sessions should take place twice a week, to help with both engagement and focus on treatment.

The second stage involves reviewing progress and planning for the main treatment.

The third stage consists of weekly sessions addressing the mechanisms maintaining the eating disorder, including concerns about shape and eating, managing day-to-day events and moods and addressing dietary restraint. The patient and therapist can choose between focused and broad versions of CBT-E. Research suggests that the focused version is effective, even when the patient has additional problems (23, 43).

In the fourth stage, the focus shifts to maintaining progress and dealing with setbacks. A review session is held several months after treatment ends to assess progress and address any new issues.

For underweight patients, treatment usually requires 40 sessions over 40 weeks, incorporating weight regain into therapy. Early sessions involve considering the pros and cons of weight regain, aiming for patients to decide on

Setting		Study	Description	Patient group	Duration
	Online self-help	Toro et al. (27)	Online intervention for subthreshold EDs	Subthreshold ED	10 sessions
Outpatient CBT	Guided self-help	Jenkins et al. (28) Thiels et al. (29) Schmidt et al. (30) Grilo et al. (31) Melisse et al. (32)	Face-to-face vs. email/CD-ROM support in guided self-help sessions	BED, BN	10 - 16 sessions
	CBT-T	Tatham et al. (33) Wade et al. (34)	Short-form individual CBT sessions	BED, BN	10 weeks
	CBT groups	Moore and Waller (35)	Short-form group CBT sessions	BED, BN	10 weeks
	CBT-E	Fairburn et al. (5, 6) Mitchell et al. (36)	CBT-E for non-underweight EDs	BED, BN	Varies: BED 16 weeks, BN 20 weeks
	Broad or focused CBT-E	Fairburn et al. (7, 37) Frostad (38)	Treatment approach adapted for AN	AN (mild to moderate severity)	40 weeks
	Adolescent adaptation CBT-E	Dalle Grave et al. (14, 39, 40)	Incorporates physical health considerations and parental involvement, adjusted for faster weight restoration in adolescents	Adolescents	30 weeks
Intensive CBT-E	Multi-step or integrated CBT-E	Dalle Grave et al. (26) Ibrahim et al. (17)	Multi-step CBT tailored to the patient's progress	Severe AN or BN	Up to 20 weeks
	Intensive outpatient CBT-E	Dalle Grave et al. (26) MacDonald et al. (41)	Designed for patients needing more support than standard outpatient care but not severe enough for hospitalisation	Severe AN or BN	Up to 12 weeks, flexible
	Inpatient CBT-E	Dalle Grave et al. (26) Ibrahim et al. (17) Calugi et al. (42)	For patients not responding to less intensive treatments or needing close medical supervision	Severe AN or BN with comorbidities	13 weeks as an inpatient plus 7 weeks as a day patient
	Post-inpatient outpatient CBT-E	Dalle Grave et al. (26) Ibrahim et al. (17)	Supports the transition from hospital to home and reduces relapse rates		20 sessions over 20 weeks

Table 1. Overview of CBT for eating disorders in different treatment settings

Abbreviations: AN = anorexia nervosa; BD = bulimia nervosa; BED = binge eating disorder; CBT = cognitive behavioural therapy; CBT-E = enhanced cognitive behavioural therapy; CBT-T = 10-session cognitive behavioural therapy; ED = eating disorder

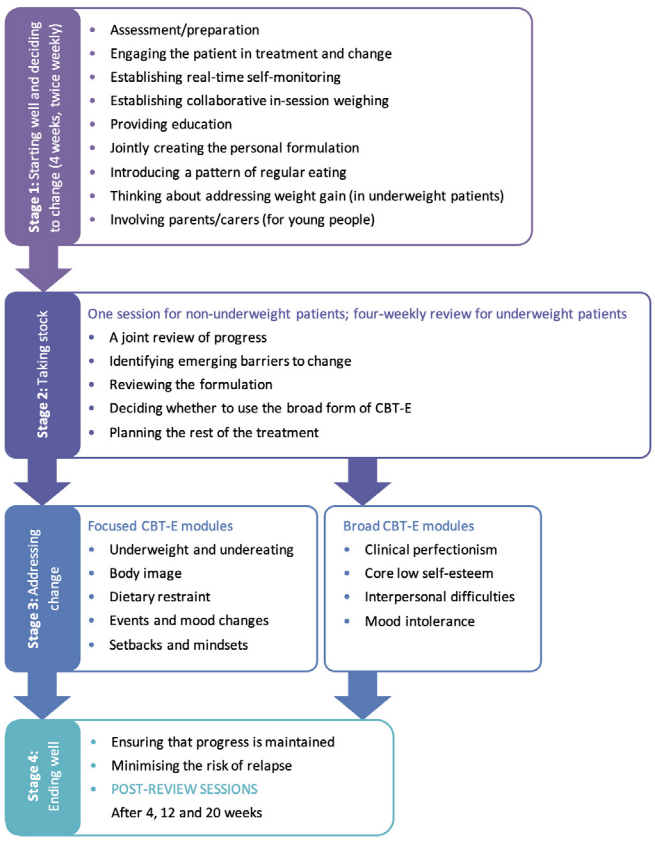

Figure 1. CBT-E process diagram (40)

weight regain themselves. In the final stage, the patient learns to maintain a healthy body weight.

CBT-E is an effective treatment for a range of eating disorders, including AN, BN and BED. Recent adaptations for avoidant/restrictive food intake disorder have been developed. Originally a one-to-one individual outpatient treatment for adults, CBT-E now includes intensive versions for day patients, inpatients and younger patients, with detailed treatment manuals (26).

CBT-E is highly individualised, with therapists tailoring the therapy to each patient's specific difficulties. A key technique of CBT-E is to create a personalised formulation of the patient's eating disorder. This formulation addresses specific processes, adapts to emerging issues, and actively educates and engages the patient. Figure 2 shows a schematic illustration of the structure of the formulation, which is adapted for the individual. Treatment involves a variety of adaptable cognitive and behavioural interventions with a focus on simplicity and effectiveness. This includes recording targeted thoughts and feelings as part of self-monitoring to address body image concerns. The treatment is flexible to include patients with different types of eating disorders and has no exclusion criteria.

CBT-E is time-limited. It typically consists of an initial assessment consultation followed by weekly 50-minute therapy sessions for 20 weeks or 40 weeks for people who are underweight.

Treatment for underweight patients

For underweight patients, the treatment extends to approximately 40 sessions over 40 weeks, reflecting the additional complexity and challenges associated with achieving and maintaining healthy weight. This extended treatment is structured into three steps.

1. **Step one** focuses on the decision-making process regarding weight gain. Given that underweight individuals often do not perceive their weight as a problem, this step emphasises the importance of collaboratively assessing the implications of change and fostering a sense of agency and ownership over the decision to pursue weight regain.
2. **Step two** is dedicated to the practical aspects of regaining a healthy weight. It involves personalised strategies and support to facilitate weight restoration in a manner that respects patient readiness and pace.
3. **Step three** centres on weight maintenance and relapse prevention. It aims to equip patients with the skills and confidence needed

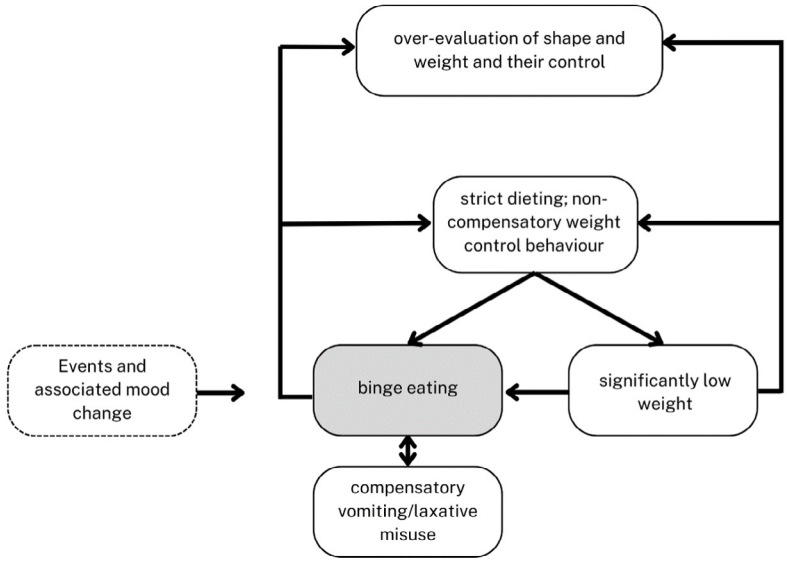

Figure 2. The transdiagnostic CBT-E formulation overview (44)

to sustain their healthier weight and proactively manage challenges.

This phased approach in CBT-E, particularly for underweight patients, is crucial for patient empowerment and collaboration. It ensures that individuals are not merely passive recipients of care but active participants in their journey towards recovery, making decisions that align with their values and goals.

The distinct stages and steps of CBT-E, tailored to meet the specific needs of non-underweight and underweight patients, reflect a structured, yet flexible framework that facilitates a comprehensive, focused and empathetic therapeutic process, offering a pathway for sustained remission and wellbeing.

Application of CBT for specific patient groups in different treatment settings

Self-help: Books and online resources for self-help CBT are available and further resources are being developed by the Oxford team. GPs can direct patients and carers with new presentations to these resources, providing accessible support for the initial management of eating disorders. The cbte.co website is an excellent resource both for the general public and clinicians (44).

Guided self-help: Patients receive structured support through face-to-face or digital sessions which guide them in applying CBT principles independently. There is robust evidence that guided self-help is effective in a significant proportion of patients with BEDs and less severe BN. Guided self-help is provided not only by secondary services but also by charities, such as Beat, or in some areas in the country, by Improving Access to Psychological Therapies. Online delivery has been shown to be cost-effective for BED (45).

CBT-T: This is a short-form individual CBT designed for non-underweight eating disorders, providing cheaper therapy with promising results for mild cases.

CBT groups: Group sessions offer peer support and collective learning, addressing common issues related to BEDs.

Outpatient CBT-E: This is the preferred treatment option for most adults with moderate eating disorders with a time-limited structure. Non-underweight patients typically undergo treatment for approximately 20 weeks, whereas underweight patients may require up to 40 weeks. Although some may worry that a fixed duration might compromise the personalised nature of CBT-E, having a set timeframe offers significant advantages. It enhances therapeutic focus and motivation, creates a sense of urgency for change, ensures that treatment progresses towards a formal conclusion and addresses critical future-oriented topics essential for long-term remission.

Adjustments to treatment duration are sometimes necessary. Patients with BEDs who show rapid improvement may have shorter treatment periods. Conversely, patients experiencing significant disruptions (such as clinical depression or interpersonal crises) or those who relapse shortly after completing treatment may require extended therapy. Treatment can be extended for several months in such cases, and regular four-week reviews should be conducted to assess the need for continued therapy.

Intensive outpatient CBT-E

Intensive outpatient and inpatient CBT-E are tailored to meet the needs of patients with more severe eating disorders. Each level of care incorporates specialised strategies to address specific challenges and promote progress and recovery.

This level of treatment is suited for individuals who require more support than traditional outpatient care offers but do not require hospitalisation. Intensive outpatient CBT-E maintains the core principles and strategies of its outpatient counterpart while introducing the following additional components.

- **Duration:** It is designed to last up to 12 weeks with flexibility based on the patient's progress, in areas such as weight regain or reducing binge eating episodes.
- **Daily structure:** Patients typically spend weekdays at the treatment facility, with the programme potentially including supervised meals, biweekly individual CBT-E sessions, dietary planning with a dietitian trained in CBT-E and regular medical reviews.
- **Transition to outpatient care:** As patients improve, they are gradually encouraged to eat meals outside the unit, transitioning towards conventional outpatient CBT-E.

This approach allows for more intensive treatment, with the goal of addressing specific difficulties more effectively than standard outpatient care.

Adaptation for adolescents

Dalle Grave's adaptation of CBT-E for adolescents acknowledges the unique challenges and needs of this demographic, particularly the potential long-term health implications of eating disorders and the critical role of parental involvement. Adolescents with eating disorders are at a heightened risk of developing severe medical complications such as osteopenia and osteoporosis, making the integration of regular medical assessments and a more cautious approach to hospital admissions crucial components of the treatment plan.

Duration of treatment for adolescents

For adolescents, CBT-E duration is tailored to their specific needs and recovery pace. While non-underweight patients undergo a 20-week programme similar to that of adults, underweight adolescents typically engage in a slightly longer treatment duration of approximately 30 weeks. This adjustment reflects the observation that adolescents often regain healthy body weight more quickly than adults do. However, the shortened timeframe does not compromise the treatment's effectiveness or thoroughness; it is designed to match the developmental and physiological responsiveness of adolescents.

Parental involvement

Parental involvement is a pivotal aspect of CBT-E for adolescents. Recognising the importance of a supportive home environment in the recovery process, the treatment model mandates significant parental participation. Initially, parents are engaged in a dedicated 90-minute session without the adolescent during the first week of treatment. This session aims to inform parents about the nature of the disorder, the treatment process and how they can support their teenager's recovery journey.

Subsequent treatment phases include joint sessions with the adolescent and their parents. These sessions, occurring in weeks 4 to 6 for non-underweight patients and weeks 8 to 10 for underweight patients, are designed to facilitate open communication, address familial dynamics that may impact eating disorders and develop a unified approach to recovery. These joint sessions, held immediately after the patient's individual session for approximately 15 to 20 minutes, are critical for ensuring that parents are equipped to provide appropriate support at home, reinforcing the principles and practices of the treatment.

Core elements of adolescent CBT-E

The core elements of the adolescent version of CBT-E, especially for underweight patients, are meticulously structured to address the multifaceted nature of eating disorders within this age group. This approach includes the following.

- **Educational components** are tailored to the adolescents and their parents, emphasising the importance of nutritional balance, risks of disordered eating behaviours and physical and psychological consequences of eating disorders.
- **Behavioural strategies** focus on normalising eating patterns, addressing body image concerns and developing healthy coping mechanisms for stress and emotions.
- **Cognitive interventions** aim to challenge and modify distorted beliefs and thoughts related to body image, self-worth and food.
- **Parental guidance and support** include providing parents with strategies to encourage healthy eating habits, improve communication and foster a positive and supportive home environment conducive to recovery.

By adapting CBT-E to the specific needs of adolescents and involving parents in the treatment process, this approach offers a comprehensive framework that not only addresses the immediate challenges of eating disorders but also promotes long-term recovery and wellbeing.

Complex comorbidities

All eating disorders have a high rate of comorbidities and complications. Common psychiatric comorbidities include affective and anxiety disorders, neurodevelopmental disorders and suicidality across the diagnostic spectrum. Chronic malnutrition in AN leads to progressive multiorgan damage, which is reversible with weight restoration. Gastrointestinal and endocrine complications are also common. CBT-E has been adapted for managing comorbidities and a manual is available for clinicians (1).

Dalle Grave recommends that some conditions, such as alcohol or substance dependence, need to be treated first, while others, such as diabetes and coeliac disease, require integrated treatment. His recently published guide for clinicians on the treatment of common comorbidities offers a rich overview for practitioners (1).

Inpatient treatment and integrated care

The number of patients requiring hospital treatment for severe eating disorders is increasing (16, 46, 47). However, hospitalisation is controversial owing to poor long-term outcomes and high costs. Inpatient treatment should be available for those who do not respond to outpatient treatment, but the threshold for admission, as well as the length and model of treatment, varies greatly depending on local historical arrangements (48).

UK inpatient treatment models

Inpatient programmes in the United Kingdom typically adhere to the NHS England Standard Contract for Specialised Eating Disorder Services and NICE guidelines, which are mandatory for both NHS and independently commissioned providers. The contract defines three types of admissions:

1. Unplanned or emergency admissions aiming to restore modest weight.
2. Short-term admissions for medical stabilisation.
3. Admissions focused on symptom recovery, such as achieving a weight that allows for less intensive future weight maintenance as well as improved eating behaviours and psychological understanding.

In practice, these admission categories frequently overlap. The eclectic multidisciplinary interventions were originally designed for outpatient settings and have not been thoroughly tested in inpatient settings. This can result in mixed messages and high disengagement rates, with up to 60% of patients self-discharging before achieving a healthy weight. Studies show that most adult patients are discharged at suboptimal weights after lengthy stays (49, 50).

Dalle Grave's team in Garda, Italy, has developed an inpatient and multistep programme based on CBT-E that improves patient experience and outcomes by prioritising individualised patient formulations and promoting autonomy (12, 26). This approach ensures consistency across the multidisciplinary treatment team, all of whom are trained in CBT-E, allowing the patient to overcome their disorder rather than coercing change. The programme includes an initial 13-week inpatient stay followed by 7 weeks of intensive day treatment and ongoing outpatient care. Treatment begins prior to admission and consists of 40 continuous sessions to ensure that care is uninterrupted (Figure 3).

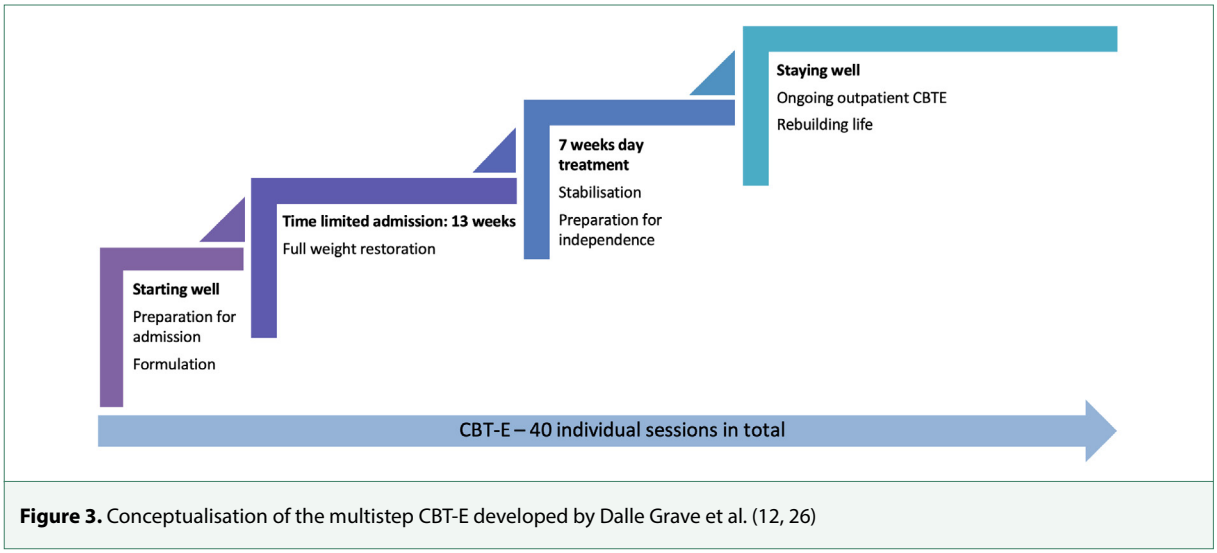

Figure 3. Conceptualisation of the multistep CBT-E developed by Dalle Grave et al. (12, 26)

Dalle Grave's manual (26) and papers on the method and outcomes show superior outcomes and completion rates compared to traditional eclectic models (14).

The model has been implemented in Oxford and demonstrated much improved outcomes compared with other approaches, including treatment as usual (TAU) and crisis admission (17). The differences between TAU and integrated CBT-E include:

- Integrated CBT-E across the care pathway without any interruption
- Time-limited and planned admission
- Full weight restoration, 1.5 kg/week
- Recovery focus
- 7 weeks of intensive support for weight maintenance
- Ongoing outpatient CBT-E without interruption

Inpatient CBT-E builds on traditional specialist eating disorder units by integrating psychological treatment within the multidisciplinary team and the care pathway

Inpatient CBT-E is reserved for those who have either not benefited from less intensive treatments or require immediate, intensive medical supervision.

- **Multidisciplinary team:** Treatment is delivered by a team of professionals, including physicians, psychologists, dietitians and nurses, all trained in CBT-E, ensuring a comprehensive and unified approach.
- **Assistance with eating:** Initial support is provided to overcome eating challenges in real time, helping patients adjust to healthier eating behaviours.
- **Relapse prevention:** Features aimed at reducing relapse include maintaining an open unit to allow exposure to external triggers while offering support, preparing for environmental challenges post-discharge, and involving significant others in creating a supportive home environment.

These additional elements of inpatient CBT-E focus on providing a safe and structured environment for intensive treatment while also preparing patients for a successful transition back into their daily lives, aiming to sustain the progress made during treatment and minimise the risk of relapse.

Both intensive outpatient and inpatient CBT-E represent critical components of a comprehensive care continuum for eating disorders, designed to provide an appropriate level of support and intervention based on individual patient needs. Through these tailored approaches, CBT-E seeks to facilitate recovery, encourage healthy behaviours and support the long-term maintenance of eating disorder remission.

Admission preparation

Inpatient CBT-E requires admission preparation, including appropriate preparation for physically compromised patients. Patients with AN are often fearful and ambivalent about treatment and recovery. Diet, weight and shape control are central to psychopathology; therefore, premature discharge is a risk unless the patient is fully committed to treatment. If possible, patients should start psychological treatment before admission or have a care coordinator to coordinate inpatient and outpatient treatments. The patient and carers should be able to visit the unit and meet the team to learn about the treatment. This helps to manage anxiety and engagement. Admission preparation may require more than one visit, but it is time well spent.

Refeeding

Extremely malnourished patients require safe refeeding. Underfeeding is as dangerous as refeeding syndrome, which tends to occur in patients with significant comorbidities. This has been highlighted in the MEED guidelines (51). Usually, patients tolerate an introductory 30–40 kcal/kg/day diet and gradually increasing amounts, depending on weight gain. According to NICE guidelines, the expected rate of weight gain in a hospital setting is approximately 0.5–1 kg per week. Slower weight restoration lengthens the hospital stay and is associated with poorer outcomes. Faster weight restoration (approximately 1.5 kg/week) is biologically safe and has been recommended by Dalle Grave (26). Most refeeding complications can be safely managed by expert medical and dietary support. The safety of higher calorie refeeding has also been established in adolescents (52, 53).

Patients with AN who have insulin-dependent diabetes require joint working between the diabetic and inpatient teams.

Mealtime support

Dietary restriction is a major maintaining factor in eating disorders. Therefore, introducing regular meals is an essential component of treatment, both for physical health and for addressing psychopathology. Regular eating is one of the most important CBT-E interventions and inpatient units can assist patients in regaining their normal eating patterns. Most specialist units in the United Kingdom provide intensive nursing support and supervision during mealtimes. Anxiety management is a critical component of this and requires a collaborative team effort (54). Smaller, but more frequent, meals are easier to digest for severely malnourished people at the beginning of weight restoration, and eating every few hours helps maintain energy levels; hence, most units have three main meals and three snacks, but later on having three larger main meals and one snack is usually satisfactory and easier to maintain after discharge (26). Dalle Grave recommends live self-monitoring and using distraction strategies to manage intrusive thoughts during mealtimes. These can also be incorporated into NHS settings, instead of nursing supervision.

In preparation for discharge, it is essential to include a variety of foods that reflect family traditions and lifestyles, and to practice eating outside of the hospital.

Psychological treatment follows CBT-E principles but is delivered by an entire team instead of one-to-one sessions only. This includes CBT-E group therapy and carer support.

Compulsory treatment

Most countries have legal frameworks that allow for compulsory treatment of people with severe mental illnesses. The Care Quality Commission issued a guidance note on the treatment of AN under the Mental Health Act 1983 in England and Wales to assist clinicians with treatment decisions when a high-risk patient refuses treatment. In this document, the patient's physical risk is prioritised. AN has a high suicide rate, so risks to oneself or others (e.g., while driving) also need to be considered. Treatment needs to be as collaborative as possible, both for the outpatient and for the detained patient (55, 56).

However, compulsory treatments have rarely been studied. Long-term outcomes studies do not support the presumption that compulsive treatment is inherently harmful, but additional research is required for this population of patients who are at extremely high risk (57).

The inpatient CBT-E programme can be motivating for patients who receive compulsory treatment. As explained above, CBT-E is highly collaborative and all efforts should be made to engage the patient informally. However, there are circumstances (usually late presentations) in which this is not possible. Nevertheless, an integrated psychological

approach using the multidisciplinary team can be highly effective in engaging initially non-consenting patients. This requires further study.

Transition and prevention of relapse

The risk of relapse after discharge is highest in the first year, particularly within the first 60 to 90 days (58). Integrated treatment produces better results. Our longitudinal cohort study in the UK showed that integrated CBT-E performed significantly better in real-world settings than traditional inpatient treatment models. Seventy percent of patients with severe and extreme AN in this study who received integrated CBT-E throughout the care pathway had good outcomes at least one year later, compared to less than 5% who received TAU or through crisis pathways. Integrated CBT-E, discharge BMI and legal status were the most important predictors of good outcomes, but not age, comorbidity or admission BMI (17). These findings suggest that weight restoration to a healthy weight range is necessary, but not sufficient, for good outcomes. Integrated CBT-E and ongoing psychological treatment are required for long-term changes. Alternative transition models are being investigated (59, 60).

The effectiveness and cost effectiveness of CBT-E

CBT-E has proven effective in treating a range of eating disorders in several countries, including England, Australia, Denmark, Germany, Italy and the United States (22, 61, 62). Research has shown some variation in outcomes and highlighted factors that improve efficacy. The most effective studies were those trained and supervised by the Oxford group, indicating the importance of supervision and treatment fidelity. The Oxford team has developed a treatment fidelity scale to help supervisors and therapists with treatment delivery (63).

Trials show that CBT-E is highly effective for patients who are not significantly underweight, with approximately 80% completing treatment and two-thirds achieving full remission, which is well maintained over time (2). For underweight patients, remission rates were comparable; however, treatment completion rates dropped to approximately 65%. It has also been adapted for inpatient and day settings, with approximately 70% of non-underweight patients (BN or BED) achieving complete remission and others showing partial response.

Future directions and guidance for GPs

In order to refer patients with eating disorders accurately to the appropriate level of care, it is necessary for GPs to have a thorough understanding of the different methods by which CBT is administered. Early recognition of symptoms and prompt referral can significantly affect outcomes, and low-key, less intensive interventions, such as guided self-help, may be sufficient. However, intensive CBT-E models may be necessary for patients with severe and complex presentations. Coordination with mental health professionals and ongoing support are essential components of comprehensive care.

Future research needs to focus on improving outcomes for patients with severe and complex comorbidities and to compare CBT-E with other evidence-based treatment models (64). The aim will be to examine the most effective implementation strategy in practice.

Funding statement

No specific funding.

Conflict of interest declaration

The author declares that she has no affiliations with or involvement in any organisation or entity with any financial interest in the subject matter or materials discussed in this manuscript.

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Family therapy in the treatment of child and adolescent eating disorders

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Abstract

Family therapy is recommended as the first-line treatment for anorexia nervosa and bulimia nervosa in adolescents. There is also emerging evidence for family therapy as a treatment for avoidant/restrictive food intake disorder. The aim of this article is to provide an up-to-date overview of the family therapy approach to treating adolescent eating disorders. Family therapy emerged in the 1980s as an evidence-based approach to treating adolescent eating disorders. A core aspect of the treatment is an early emphasis on parents supporting their child to achieve behavioural change, whilst later helping the child to take responsibility for their eating. The treatment is supported by evidence from randomised controlled trials, but there have been relatively few trials comparing family therapy with individual treatments. To improve the evidence base for family therapy, we recommend greater involvement of people with lived experience of eating disorders in research; the development of "modular" treatment manuals; a focus on improving the validity and reliability of measures; and greater use of alternatives to randomised controlled trials, including experimental studies and use of real-world data.

Introduction

Family therapy is recommended as the first-line treatment for child and adolescent eating disorders across several national guidelines, including those for the United Kingdom, United States and Canada (1-3). Evidence supporting the use of family therapy for anorexia nervosa (AN) and bulimia nervosa (BN) comes from several randomised controlled trials (see Jewell et al. (4) for a detailed review), whilst more recently evidence is accruing for the effectiveness of family therapy in the treatment of avoidant/restrictive food intake disorder (ARFID) (5). However, the family therapy literature can be confusing, with a wide range of different terms and acronyms employed. The aim of this article is to provide an overview of family therapy written in simple terms, to describe what it is, and the evidence that supports it. We begin with a brief history of family therapy for eating disorders, before explaining some of the overlapping terms used in the literature. We then describe the different family therapy approaches for AN, BN and ARFID. We conclude with a discussion of the current state of family therapy practice and research in the field of eating disorders, along with recommendations to advance the field.

Why are there so many different terms for family therapy for eating disorders?

The field of family therapy for eating disorders is undoubtedly made more complex by the range of different, and often overlapping, terms. Readers are likely to come across terms such as the Maudsley approach, the Maudsley model of family therapy, family-based treatment (FBT) and eating disorder–focused family therapy. This can be confusing for professionals, patients and carers of people with eating disorders. To provide some clarity about these terms, and why there are so many of them, we believe it is necessary to provide a brief history of the field.

A brief history of family therapy for eating disorders

Family therapy developed as a form of psychological therapy from about the 1960s. Several of the early family therapists, such as Salvador Minuchin, had trained in psychoanalysis, in which patients are seen for one-to-one sessions with their therapist. These early family therapists became interested in seeing patients alongside their family members in order to influence or disrupt the family dynamics which they theorised were related to the patient's mental health problems. In the 1970s, family therapists working in several different centres across Europe and the United States began using family therapy to treat eating disorders. Most influentially, Minuchin and his colleagues developed the idea of the psychosomatic family (6). This was a set of family dynamics which were theorised to be present in families with a child with AN. These dynamics included being overly close (or "enmeshed"), overprotective, rigid and lacking the ability to resolve conflict. The aim of family therapy, therefore, was to disrupt these patterns of interaction. These ideas became influential in the field of family therapy but were also rightly attacked as being blaming of parents, as well as lacking support from evidence.

The 1980s saw the rise to prominence of a model of family therapy developed at the Maudsley Hospital in London. This Maudsley model drew from a variety of influences from different schools of family therapy, including Minuchin's structural model (7), strategic therapy (8) and the Milan group (9) and its later off-shoots (10). Psychodynamic influences were also present, and the overall approach can be characterised as integrative. The 1980s were a febrile time of

transition for family therapy, in which the joke going around amongst trainees was, "blink and you'll miss a paradigm shift" (11). By integrating the newer post-modern schools of family therapy, and by taking an agnostic position with regard to the aetiology of AN (12), the Maudsley team were able to counter the accusation of parent-blaming whilst also positioning the treatment within the zeitgeist of systemic therapy. Crucially, the results of their randomised controlled trial of family therapy (13) demonstrated superiority over individual therapy for adolescent patients with AN.

This form of family therapy was first manualised by Lock et al. (14); that is, the treatment was written as a manual to be used in research trials, as well as being available for clinicians to learn about the approach. This manual came to be referred to as FBT. Whilst the term FBT is used widely across the literature, those based in the United Kingdom will also come across the terms eating disorder–focused family therapy, AN-focused family therapy (FT-AN) and BN-focused family therapy (FT-BN), all of which are used in the National Institute for Health and Care Excellence (NICE) guidelines for eating disorders (1). In putting together their guidelines, NICE considered all the available evidence, particularly from randomised controlled trials. Whilst some of these trials used specific FBT manuals, some did not. As a result, NICE decided to use the language of FT-AN and FT-BN as umbrella terms to describe family therapy treatments for eating disorders.

For readers outside of eating disorders services and research, the terms FBT and eating disorder–focused family therapy can be considered synonyms. However, for those wishing to explore the literature further, we recommend the article by Gorrell, Simic and Le Grange (15) for an explanation of the nuanced differences between family therapy treatment approaches for eating disorders. The use of terms such as the "Maudsley method" or the "Maudsley approach" speak to the historical location and origins of the treatment, but whilst these terms still appear in some articles, they can be considered outdated. In this article, we will use the over-arching term "family therapy" as much as possible, although in describing the treatments we will refer to specific treatment manuals.

What does the research say?

Family therapy is the first-line or recommended treatment for adolescent AN and BN, supported by major guidelines from bodies covering the United Kingdom, United States and Canada (1-3). However, this status as the leading treatment is based on only a small number of randomised controlled trials. For adolescents with AN, Austin et al. (16) recently found family therapy to be superior to individual treatment in terms of weight gain at the end of treatment, based on four trials. There was no superiority in terms of eating disorder symptoms (such as preoccupation with weight and shape), nor was there any superiority of family therapy over individual treatment at follow-up. NICE conducted separate meta-analyses for family therapy for AN and BN (1). For adolescent AN, their analysis of three studies found no benefit of family therapy on remission at either end of treatment or follow-up, leading to the weaker recommendation to "consider", rather than "offer", family therapy for adolescent AN. By contrast, the stronger recommendation to offer family therapy was made by NICE for adolescent BN, based on three trials showing superior remission compared to individual approaches at follow-up, although not at the end of treatment.

In considering the paucity of evidence favouring family therapy over individual approaches, readers should take into account the challenges of conducting trials in eating disorders (17, 18). Not only is eating disorder research underfunded (19), but there are also challenges in developing trials that are ethical and provide an appealing enough "pitch" to potential participants such that they are willing to undergo randomisation (20). Whilst few randomised controlled trials have compared family therapy to individual treatment, several trials have randomised families to different formats of family therapy, such as seeing the adolescent patient and their parent/s together, called "conjoint", versus "separated" family therapy, in which parents meet the therapist separately (e.g., 21). Based on a meta-analysis of three studies, Austin et al. (16) found separated family therapy to achieve superior weight gain and overall rates of remission at the end of treatment compared to conjoint family therapy. Recent developments in the research field include the use of adaptive trials, in which there is some flexibility, such as adding new treatments at pre-specified review points (e.g., 22).

Two other developments are worth highlighting. First, several researchers have developed "multi-family therapy" formats in which several families are brought together to receive treatment. A study by Eisler et al. (23) found that adolescents who received multi-family therapy for AN in addition to "single" family therapy – that is, family therapy delivered to one family at a time – achieved better outcomes at the end of treatment, although not at follow-up. Multi-family therapy is typically delivered as an adjunctive (i.e., additional) treatment and, as such, the specific contribution made by multi-family therapy, as well as its cost-effectiveness, is currently unclear (24).

Finally, there has been a growth in family therapy research into ARFID. Currently, there are no evidence-based treatment recommendations to guide care for patients with ARFID (1, 2). In their recent scoping review of interventions, Willmott et al. (5) identified six family therapy treatment studies, of which three were adaptations of FBT for ARFID (e.g., 25). Family therapy interventions resulted in improvements including reduced ARFID symptoms and increases in body mass index (5).

Description of treatments

Family therapy for anorexia nervosa

Our description of family therapy for adolescent AN is based on the manual by the Maudsley team (26), in which they refer to it as FT-AN. This is an outpatient treatment consisting of 18 to 20 sessions over one year with periodic reviews to establish how regular sessions should be and how long treatment should last. Core features include a clear focus on working with the family to help their child to recover, coupled with a strong message that the family is not seen as the cause of the problem; expecting the parents to take a lead in managing their child's eating in the early stages of treatment; externalising the eating disorder, which refers to a way of speaking about the disorder as if it were external to the patient (see Lonergan et al. (27)); and a shifting of focus on to adolescent and family developmental life cycle issues in the later stages of treatment (28).

The professional's job is to support the parents or carers to take a central role in helping the young person manage their eating when they are not able to manage it themselves. This represents a temporary regression in the normal developmental trajectory for a teenager. The therapist provides the rationale that whilst the young person's judgement is clouded with strong anorexic cognitions, they are unlikely to be able to make choices in the best interest of their heath. This needs to be done without the young person feeling dismissed, as many will not identify as being under the harmful influence of an eating disorder. Providing psychoeducation to parents about the disorder can help young people feel that others understand and that they are not alone in their distress.

As described in the Maudsley service manual (26), which forms the basis for training in the approach within the United Kingdom, family therapy for AN is divided into four phases. Phase 1 aims to engage the family and establish a therapeutic alliance with the young person and their carer/s. The initial assessment is multidisciplinary, including psychiatric (confirming the diagnosis, identifying comorbid difficulties such as anxiety, depression, or self-harm), medical (evaluating physical risks), individual psychological (exploring motivation to change, identifying cognitive and temperamental characteristics of the young person) and systemic perspectives (developing a formulation and identifying areas of family strengths and resilience). The therapist offers information about the physiological and psychological effects of starvation (29), highlighting the fact that many of the phenomena associated with eating disorders are characteristic of anyone in a state of starvation.

During the final part of the assessment, a meal plan is presented as a "prescription", with the idea that food will act as medicine for this illness. Weekly appointments are typical during the early stages of treatment when the demands of feeding and weight restoration are intense on families. Single parents or those who are financially strained and so need to work full-time may not be able to provide the input expected of them. It can help to be creative in these circumstances, providing meal support via video call or by a trusted staff member at school if they are well enough to attend.

In Phase 2, the therapist continues to encourage parents to take a lead in managing their child's eating. The child is weighed by the therapist at the beginning of each session with the focus of the session then being dictated by the weight trajectory. Tasks will include exploration of what happens at mealtimes, increasing parents' sense of agency and sharing examples of what other families have done to overcome similar difficulties. Whilst the majority of the focus is on how the parents can help their child, it is important for the therapist to maintain a good engagement with the young person, discussing broader goals that can be achieved as physical health is gradually restored and reinforcing that whilst weight gain itself may be very anxiety-provoking, it can be linked to rewarding activities like resuming sports or going on a holiday. Encouraging young people to question their entrenched beliefs about food, dieting and their bodies as well as exploring the function of the illness in managing their emotions and relationships can help to reframe recovery for them.

Therapy moves to the third phase once weight restoration has been mostly achieved. This marks a move in therapy toward handing back age-appropriate responsibility to the patient and supporting parents to re-focus on their needs and those of other family members. The presence of an eating disorder, like any other serious and life-threatening condition, can cause great disruption to family organisation (30), which is explored and addressed during this phase. Other themes that can be explored in this phase include issues around adolescent independence, identity and self-esteem.

Ending treatment is the last phase of treatment. Themes during Phase 4 include discussions about relapse prevention, tolerance of uncertainty, reviewing the family journey through treatment, turning points and recovery narratives.

Multifamily therapy for anorexia nervosa

Multi-family therapy for adolescent AN has been manualised by Simic et al. (31) at the Maudsley Hospital. It builds on the general concepts of the Maudsley team's family therapy approach, delivered in a group therapy format for five to seven families at a time. Multi-family therapy starts with an introductory afternoon, highlighting the psychological and physical consequences of starvation. Parents and young people then meet a family who have previously been through the group who share their experiences. This meeting is followed by four intensive days of therapy with up

to five follow-up days over the next six to nine months. The idea behind the intensive nature of the treatment is to create a "hothouse effect" (32), providing opportunities for multiple levels of learning, reducing the sense of isolation and stigma and increasing the sense of hope and the possibility of change. As well as the programme of therapeutic sessions (33), families also have their meals and snacks together in communal areas, providing opportunities for "in vivo" learning and stimulating new perspectives.

Family therapy for bulimia nervosa

Family therapy for BN has been manualised by Le Grange and Lock (34) in their adaptation of FBT. The treatment involves three phases consisting of around 20 sessions in total and lasts for approximately six months. Phase 1 consists of weekly one-hour sessions over a period of around two to three months, during which the focus is collaborative work with the adolescent and their parent/s to devise strategies to break the binge/purge cycle of BN and establish a pattern of regular eating. This can take the form of detailed meal planning, with the therapist emphasising the importance of regular and dietetically balanced meals. Depending on the family, parents may also be encouraged to take an active approach to prevent bingeing and purging behaviours, for instance, by spending time together as a family after a meal. Each session begins with the therapist reviewing the binge/purge diary for the seven preceding days, as well as weighing the patient. The technique of externalisation is used to separate the patient from the illness.

In Phase 2, the focus shifts towards helping the adolescent to eat independently. Session frequency is typically reduced to once every two to three weeks. Sessions still begin with weighing and reviewing the binge/purge diary, and parents are encouraged to take an active role until the adolescent demonstrates that they can manage their eating independently. As Phase 2 proceeds and the adolescent gains greater independence in their eating, therapy sessions begin to address wider issues related to adolescent development and autonomy. When needed, therapists seek to reduce parental and sibling criticism of the patient. Finally, Phase 3 begins once there is an absence of bulimic symptoms, the adolescent's weight is stable and they are able to make decisions about eating independently. These final sessions address wider, family-specific issues which, for instance, could include consideration of lifecycle issues such as the adolescent leaving home in the future. Phase 3 can take up the final three to five sessions of a 20-session course of therapy, although the transition between phases is based on patient readiness, meaning that some families will move through phases more quickly or slowly than others.

Family therapy for avoidant/restrictive food intake disorder

Family therapy for ARFID has been manualised by Lock (35) as an adapted form of FBT. In keeping with FBT for AN and BN, the treatment draws on core principles including promoting externalisation of the illness and empowering parents as key agents in delivering behavioural change. The treatment is comprised of three phases. In Phase 1, the first session begins with exploring the impact of ARFID on the child and family, both during mealtimes and in other contexts, such as school or social situations. The therapist provides information about the serious nature of ARFID (e.g., medical difficulties the child might face) with the aim of increasing motivation for change in the parents. Given the heterogeneity in ARFID presentations, the focus in Phase 1 depends on the nature of the "drivers" of ARFID for the child. These drivers are lack of interest in food or eating, sensory sensitivity and fear of aversive consequences (e.g., fear of choking) (2), although, in practice, mixed presentations involving more than one driver are common (36). Thus, in Phase 1, treatment goals vary but could include weight gain, increasing the range of foods enjoyed or decreasing anxiety about eating. In line with other FBT manuals, parents are encouraged to take an active role during mealtimes to help their child to achieve change. In Phase 2, there is a transition towards the child taking greater responsibility for their eating, as is appropriate to their age. The therapist also helps the child and family to generalise their progress at mealtimes in the home to outside contexts such as school. Finally, Phase 3 applies only to adolescents and is focused on helping them to achieve independence within developmental norms, as well as promoting parental awareness and support of adolescent processes (35).

Discussion

Whilst family therapy enjoys a privileged position as the recommended treatment for AN and BN in adolescents, the evidence base is limited by a small number of randomised controlled trials, many of which have compared different formats of family therapy (4). Recommendations to conduct more randomised controlled trials are understandable, but such trials are expensive and challenging to conduct in the eating disorder field (18, 37). So, how can the family therapy for eating disorders field advance?

One priority for research is to gain a better understanding of how family therapy works. Put simply, if families and clinicians understand the mechanisms that are involved in successful treatment, there is a better chance of those elements being mobilised in practice. However, currently we cannot draw firm conclusions about how family therapy works (mediators), or who it works for (moderators), due to weaknesses in the available evidence base (38). Complicating things further, evidence-based models of family therapy for eating disorders did not develop based on a testable theoretical underpinning (39). Instead, family therapy incorporates a cluster of different theoretical influences, with practice guided by core tenets such as empowering parents (40). To make progress, researchers should work together with people with lived experience of eating disorders, their carers and clinicians to design studies that can

develop an evidence base for moderators and mediators of family therapy. Recent qualitative studies (41, 42) have begun to explore change mechanisms in family therapy, identifying themes including trust and mentalisation, the latter of which refers to a person's ability to reflect on mental processes in themselves and others (43). Although there is evidence from quantitative data that parental mentalising has an influence on treatment outcomes in family therapy for AN (44), available measures of concepts such as mentalisation require further validation in adolescents with eating disorders (45). Thus, to make progress in understanding mediators, researchers will also need to focus their attention on improving measures.

A second key issue for the field is the role of treatment manuals. Most of the evidence base for family therapy for eating disorders comes from studies of FBT, which, to our knowledge, is the only treatment to have developed scales to assess how closely clinicians adhere to the treatment manual. Having a way to measure adherence is important because, in the context of a trial, one needs to know whether clinicians delivering a treatment were in fact providing the same thing. However, it is known that clinicians struggle to deliver family therapy with a high degree of adherence to a manual, citing issues including insufficient management support and lack of training (46). Even within the context of a trial, Dimitropoulos et al. (47) found that study therapists did not stick closely to the manual beyond the initial weight restoration phase; however, the level of adherence was not related to treatment outcome for patients. One reason for this may be that clinicians adapt treatment to the needs of the family in front of them. For example, Dimitropoulos et al. (48) explored how clinicians adapt FBT for families from diverse cultural backgrounds, which is important given that the family therapy evidence base is predominantly built on White, educated samples in English-speaking countries. Other aspects of diversity covered in the study were single-parent and low-income families, whilst Loomes and Bryant-Waugh (49) have called for adaptations to family therapy for autistic young people.

Byrne and Fursland (37) have recently called for eating disorder treatments, including family therapy, to take steps towards greater personalisation, for instance through use of modular treatments. By this they mean the use of discrete treatment modules to work on specific areas, such as perfectionism. In the context of family therapy, this could involve greater integration with individual treatments such as cognitive behavioural therapy (CBT), which is currently a second-line treatment for adolescent AN and BN in the NICE (1) guidelines for eating disorders. Family therapy and CBT have yet to be compared in an adequately powered randomised controlled trial for adolescent AN, but evidence from a recent non-randomised trial found similar outcomes for both treatments (50) and there is increasing evidence for the effectiveness of CBT for adolescent AN in routine care (51). Modular treatment manuals could potentially see patients working through a mix of evidence-based individual and family treatment modules as agreed collaboratively between the patient, carers and clinicians.

This brings us to our final question: how can the field improve the quality of its evidence base when randomised controlled trials are so difficult to conduct? First, trials need to be as appealing as possible to potential participants. Adaptive trials are under-utilised in eating disorder research and viewed favourably both by people with lived experience of eating disorders and their carers (52), fitting well with the modular approach advocated by Byrne and Fursland (37). Second, the eating disorder field has been slow to embrace co-production into research (53). Researchers will need to work collaboratively with people with lived experience of eating disorders, and their carers, to ensure that clinical studies are ethically sound and relevant to their priorities (54). Third, there is a place for experimental studies which isolate a key process and investigate its unique influence on outcome (17). Such studies could advance our understanding of key mechanisms which family therapy should target and can be delivered with fewer time and cost demands than randomised controlled trials of treatments delivered from beginning to end. Finally, the development of large datasets combining routinely collected data from multiple centres, as is being developed in the United Kingdom (55, 56) represent an opportunity to answer research questions about treatment outcomes using real-world data (16). Indeed, such datasets could even allow for "target trials" (57) in which family therapy could be compared to alternative treatments such as CBT within an "emulated" trial design.

Conclusion

Family therapy is the recommended treatment of adolescent AN and BN. It also shows promise in the treatment of ARFID. However, the strength of the evidence in favour of family therapy compared to alternative treatments is modest. To develop the evidence base, we suggest the need to work collaboratively with young people and carers to design research studies and co-produce new, modular manuals; develop the validity and reliability of measures; undertake experimental studies to better understand the key mechanisms that family therapy should target; and utilise large datasets comprised of routinely collected data in order to answer research questions about what treatments work best and for whom.

Conflicts of interest

The authors declare they have no conflicts of interest.

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Other psychological management strategies for anorexia nervosa

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Abstract

In addition to having the highest rate of mortality among all psychiatric disorders and causing profound negative effects on quality of life, anorexia nervosa (AN) remains challenging to address. Apart from cognitive behavioural therapy and family therapy (FT), the current National Institute for Health and Care Excellence guidelines recommend several types of psychological therapy as first-line treatment for AN, including the Maudsley Model of Anorexia Nervosa Treatment for Adults, specialist supportive clinical management, and focal psychodynamic therapy for adults and adolescent-focused psychotherapy for young people. This article aims to describe these treatments and the existing evidence base. Research suggests that all recommended treatments for AN are equally effective at addressing core eating disorder psychopathology and increasing body mass index (BMI) in adults, while FT appears to be more effective at increasing BMI in young people. However, the evidence base remains very limited, and relapse rates can range from 9% to 52%. Barriers to conducting trials of interventions for AN include broader factors, such as lack of statistical power due to recruitment challenges, and illness-specific factors, such as patient resistance to change, cognitive rigidity and avoidance. Non-specific therapy-related factors, particularly therapeutic alliance, might play an important role in overall treatment outcomes. More longitudinal evidence and research into the effects of comorbidities is needed to draw stronger conclusions regarding the effectiveness of psychological management strategies for AN.

Keywords: anorexia nervosa, evidence-based treatments, first-line treatments, NICE guidelines

Abbreviations: AN = anorexia nervosa; AFP-AN = adolescent-focused psychotherapy for anorexia nervosa; BFST = behavioural family systems therapy; BMI = body mass index; CBT-ED = cognitive behavioural therapy for eating disorders; ED = eating disorder; EOIT = ego-oriented individual therapy; FBT = family-based therapy; FPT = focal psychodynamic therapy; FT = family therapy; IPT = interpersonal therapy; MANTRA = Maudsley Model of Anorexia Nervosa Treatment for Adults; NHS = National Health Service; NICE = National Institute for Health and Care Excellence; SSCM = specialist supportive clinical management; TAU = treatment as usual

Introduction

Anorexia nervosa (AN) is a debilitating mental health condition characterised by significantly low body weight and restrictive eating due to fear and concerns around weight, size, and shape (1). AN affects people of all ages, genders, sexual identities and ethnicities, with peak incidence in early adolescence; it is more prevalent among females (2). In addition to having the highest mortality rate among all psychiatric disorders (2, 3), it also appears to be particularly hard to manage, with relapse rates ranging between 9% and 52% (4), as people with AN tend to lack insight into the extent of their difficulties, be resistant to change and find it difficult to engage in treatment (5, 6).

The current National Institute for Health and Care Excellence (NICE) guidelines recommend several types of psychological therapy as first-line treatment for AN in adults, including eating disorder–focused cognitive behavioural therapy (CBT-ED), the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) and specialist supportive clinical management (SSCM) (7). If one of the above options is ineffective, the recommendation is to offer a treatment option from the list that the patient has not tried before, or to consider eating disorder–focused focal psychodynamic therapy (FPT); however, due to its training requirements, FPT is not currently widely available outside Germany, where it was developed.

For addressing AN in children and young people, the guidelines recommend AN-focused family therapy (FT-AN) with the possibility for the young person to receive occasional separate sessions. In cases where FT-AN is not possible (e.g., due to family breakdown) or ineffective, individual CBT-ED or adolescent-focused psychotherapy for AN (AFP-AN) should be considered.

CBT-ED appears to be the most common first-line treatment option offered by the National Health Service (NHS) in the UK for adults, while FT-AN is the predominating treatment option for young people. These two therapeutic modalities are described in detail elsewhere in this issue (pages 183 and 194). This review aims to describe the other NICE-recommended psychological interventions for adults and young people, including the focus of treatments, key principles, specific factors and the evidence base for MANTRA, SSCM, and FPT for adults, and AFP-AN for young people.

Maudsley Model of Anorexia Nervosa Treatment for Adults

MANTRA is an outpatient treatment based on a patient manual consisting of seven core modules delivered over the

course of 20 to 30 individual sessions (8). The modules cover topics such as getting started and finding motivation for recovery, working with support including family and others, improving nutrition, understanding AN, developing treatment goals, working towards change and relapse prevention. It was developed with the involvement of patients and carers and is based on both psychological and neurobiological research on maintaining factors for AN.

Module 1 invites individuals to evaluate their reasons and ability to change, and to reflect on some of the pros and cons of AN and recovery. Module 2 focuses on the importance of social support and relationships during recovery, while module 3 covers the importance of nutrition, consequences of malnutrition and initiation of change to nutritional intake. In module 4, the maintenance model of AN is explained and an individual formulation is developed. Module 5 considers goals and goal setting, while module 6 explores the process of change, encouraging individuals to work on their emotional intelligence, thinking styles and sense of identity. Finally, module 7 covers relapse prevention.

MANTRA proposes a cognitive-interpersonal maintenance model of AN, suggesting that individuals with AN often have certain vulnerability factors, such as tendencies towards anxious avoidance and obsessive-compulsive features, which contribute to the maintenance of the disorder (9). According to this model, AN is maintained by a combination of intrapersonal factors, such as patients' beliefs about the function of their illness, and interpersonal factors, such as positive and negative reinforcement received from reactions to their illness by people close to them. The vulnerability factors might be further exacerbated by starvation. As starvation tends to be perceived as functional and valuable to those with AN, eating might become an emotional threat (9).

Importantly, the vulnerability factors, alongside profound eating disorder (ED) symptoms that are visible to others, elicit a social response that essentially reinforces the maintenance of the disorder further (10). Thus, within MANTRA, cognitive, emotional, and interpersonal aspects of one's AN are considered and addressed. Some preliminary evidence suggests that MANTRA could also be adapted to a group setting (11).

Specialist supportive clinical management

SSCM is an intervention consisting of two main components, clinical management of AN symptoms and supportive therapy (12), and is delivered across 20 sessions or longer, depending on the severity of the disorder (7). It was initially developed as an active control treatment for a research trial investigating the efficacy of psychotherapies for AN (13) and so was formulated to have minimal overlap with CBT or interpersonal therapy (IPT).

The clinical management component focuses on weight restoration, psychoeducation, normalisation of eating and other core AN symptomology. The supportive therapy aspect of SSCM is more flexible than other NICE-recommended therapies, in that it allows the patient to raise life issues that they wish to work on (12, 14). The treatment can be separated into three phases. Phase one focuses on establishing the therapeutic alliance, creating an understanding of the patient's symptoms and identifying target symptoms and a target weight range, alongside consistent psychoeducation about physical and psychosocial aspects of the illness. In the core second phase, the emphasis is placed on normalising eating and restoring weight. In the final third phase, preparation for treatment termination begins alongside continued work on the target symptoms. Maintenance of positive change is explored and a relapse prevention plan is developed.

Unlike many other psychological treatments, SSCM does not have a theoretical model of causation and maintenance of AN, nor a specific structure (12), differing significantly from manual-based treatments such as CBT and MANTRA. While establishing a regular eating pattern and weight restoration are non-negotiable in terms of clinical management in the original SSCM intervention, the component of supportive therapy is based solely on what the patient wants to address within the context of their life on a session-by-session basis, and so can be very flexible and individualised. An adapted version of SSCM for those with severe and enduring AN focuses more on quality-of-life improvement rather than mandatory weight restoration (15).

Focal psychodynamic therapy

FPT was developed as a time-limited, standardised form of psychotherapy adapted to the specific needs of people with AN (16), with NICE recommending a total of 40 sessions over 40 weeks, which is a longer duration than some other recommended psychological interventions (7).

Unlike CBT or MANTRA, in FPT, the therapist takes a less directive stance and eating behaviours, as well as central ED symptoms, might not be the central focus, although regular eating remains as one of the central goals of therapy. Instead, FPT aims to explore the unconscious and conscious meanings of ED symptoms in terms of the patient's history and experiences, as well as the effects and manifestations of those symptoms on current relationships, including the relationship with the therapist (17). An emphasis is also placed on the therapeutic relationship and transference, or the way in which the patient's feelings might be projected onto their relationship with their therapist.

Like SSCM, the treatment can be subdivided into three stages (18). The first stage focuses mainly on therapeutic alliance, disorder ego-syntonicity (the way in which the disorder can become part of the person's identity) and self-esteem. The second stage places emphasis on the association between interpersonal relationships and ED symptoms

and behaviours. In the third stage, transference and termination of treatment are explored.

As in MANTRA, the importance of interpersonal factors, as well as the functional nature of ED symptoms, is recognised. Within FPT, symptoms might be viewed as defence mechanisms.

Adolescent-focused psychotherapy for anorexia nervosa

AFP-AN is an individual treatment for young people that originated from ego-oriented individual therapy (EOIT) (19). Treatment should consist of 32 to 40 individual sessions, with 8 to 12 additional family sessions as required for the young person (7). AFP is rooted in a self-psychology model that examines core developmental deficits associated with AN, suggesting that adolescents with AN avoid intolerable affective states associated with their development using food and/or weight (20). Common developmental difficulties may include grief or loss, abuse and/or neglect, child and/or family conflict, and avoidance of adolescent challenges. The AN in this context is understood to serve the purpose of allowing the young person to avoid the challenges and focus on preoccupation with something else (food and its control). Emotional regulation work, which promotes identifying, naming and tolerating emotions, is therefore an essential aspect of this framework.

The intervention consists of three stages, each with different therapeutic targets. The first stage focuses on building a therapeutic relationship between the young person and the therapist, and on formulating the young person's difficulties and functions of AN in managing developmental difficulties. In the second stage, issues associated with adolescence are identified (e.g., social identity, school) and development of age-appropriate independence is initiated. The third stage places emphasis on cultivating behaviours and management strategies to address problems and encouraging the young person to start applying and adapting the behaviours to establish independence.

While AFP-AN can be very flexible in terms of approach and can use a variety of strategies, including interpersonal, mindfulness, cognitive and behavioural strategies, the key difference between AFP-AN and CBT is that the focus of therapy is not on AN cognitions regarding food, weight and shape, but rather on the challenges adolescents with AN face (20). While acknowledging that weight gain and regular eating are essential parts of recovery, the focus on food and weight is secondary in AFP-AN, as opposed to being central in CBT-ED.

Family sessions, which are typically offered at the beginning of therapy, can include one or both parents or carers and create an opportunity for the family to gain insight into their child's AN, learn skills that can be adapted by the whole family, reflect on the skills the young person might start to practise as a result of therapy, and develop a more supportive home environment and better communication skills. However, unlike classic family therapy (or family-based therapy for AN, described in detail in another paper in this issue (page 194)), AFP does not identify family members as the "agents of change". Family members play a supportive role in helping the young person face their challenges, and the young person holds the responsibility of self-directed change (20).

Evidence base for adult interventions

The evidence base for the psychological interventions for AN remains limited. However, research suggests that all NICE-recommended treatments for adults with AN are equally effective and hence can all be offered as first-line interventions, although strictly defined rates of recovery remain low (4, 21). Clinical trials comparing CBT, MANTRA and SSCM show that all three treatments result in improvements in weight and ED symptoms, which are sustained at 12-month follow-up, with no significant differences in body mass index (BMI) changes or rates of symptom changes between treatment groups (13, 22, 23). Similar results have been yielded in the ANTOP study comparing CBT, FPT and treatment as usual (TAU), with all three treatment groups showing similar BMI increases post-treatment and at 12-month follow-up (24). A five-year follow-up of the ANTOP study revealed that BMI improvements persisted for all three groups with no further changes emerging between groups, suggesting that CBT-ED and FPT can result in long-term changes, especially if patients are treated at earlier stages of illness (25).

Both SSCM and CBT-ED have been shown to be effective at addressing severe and enduring AN, leading to improvements in quality of life, low mood, social adjustment, BMI and ED symptoms, with no significant differences post-treatment between groups (15). However, some slight differences emerged at 12-month follow-up, with CBT-ED resulting in lower ED symptoms, better social adjustment scores, and improved readiness for change. The differences might be attributed to the clearer structure and skill development of CBT-ED.

Some evidence suggests that, while being equally effective in terms of reducing ED psychopathology and increasing BMI, MANTRA appears to be rated as a more acceptable option by patients compared to SSCM (23). Importantly, improvements in symptoms and BMI were sustained over a 24-month period in both treatment groups, but MANTRA resulted in more profound weight gain, suggesting that it could be more suitable for more underweight patients (26). People engaged in MANTRA were also more willing to provide verbal feedback regarding the intervention and appeared to have a more positive experience of therapy. It is possible, therefore, that MANTRA could be more beneficial for people with a chronic or relapsing course of illness, which requires extensive or repeated treatment. A recent multicentre cohort study found that MANTRA could be an effective and acceptable treatment option for adolescents and emerging adults, resulting in better BMI and ED psychopathology improvements, as well as better remission rates

compared to TAU (27).

The original study suggesting SSCM as an active control treatment showed that SSCM, CBT and IPT resulted in equal improvements for people with AN (13). When considering a stepped-care treatment model, SSCM has been suggested as a more suitable intervention, particularly for people with higher motivation for change and recovery.

Evidence base for adolescent interventions

Evidence for the effectiveness of AFP-AN is even more limited compared to that for adult interventions, although more research is available on the effectiveness of FT which has led to the NICE recommendation of this approach as the first-line treatment for young people.

A comparison study between the precursor of AFP, EOIT, and behavioural family systems therapy (BFST) focusing on adolescent girls found that while improvements in BMI were evident in both groups, the improvements were superior in the BFST group (28). However, there were no differences in the number of adolescents who achieved their target weight by the end of the treatment, indicating that both family and individual interventions can be effective strategies for weight restoration. Both treatments seemed to result in improvements in eating attitudes, interoceptive awareness, depression, internalised behaviours and eating-related behavioural conflict, despite having different focuses (19).

More recent studies comparing AFP to FT found no significant differences in remission rates between groups post-treatment (29). However, FT became significantly superior to AFP at 6- and 12-month follow-up, with greater remission and recovery rates. Those who received FT were also hospitalised less often. Importantly, a longer follow-up study found remission and recovery rates to be stable in both groups two to four years after the intervention, indicating that both interventions can be effective long-term (30).

Family involvement in the treatment process appears to be beneficial (31). This does not argue against AFP, however, as family sessions are also recommended within the approach. AFP might be a more suitable option for older adolescents, where the influences of family naturally decrease and a need for independence and responsibility for self emerges. However, the small number of high-quality clinical trials and the lack of systematic evidence means that conclusive statements regarding superiority of any of the AN treatments for young people are difficult to make.

Non-specific factors

An interesting observation that arises from the current evidence base for psychological treatments for AN is the potential importance of non-specific therapy factors in overall intervention effectiveness. Some studies suggest that similarities in outcomes between treatments can be attributed to common features of most AN interventions, such as focus on establishing a healthier relationship with food and weight and addressing AN-specific and broader psychopathology (22). Apart from those features, all NICE-recommended treatments place strong emphasis on the therapeutic alliance, which is known to be one of the key non-specific factors of treatment adherence and success. A study of medical and surgical treatments has previously suggested that under general therapeutic conditions, where both the clinician and the patient have some level of faith in treatment and set up positive expectations, non-specific factors might account for most of the variance in treatment outcomes (32). The process evaluation of the MOSAIC trial comparing MANTRA and SSCM found that patients described both therapy-specific and therapy-non-specific factors, including therapeutic alliance, treatment duration and pacing, and external social support, as being equally important in their treatment journeys, further stressing the significance of those factors when considering research on the effectiveness of psychological treatments (33). Establishing the therapeutic alliance appears to be the key initial step for all NICE-recommended interventions for adults and young people, where the first stages of treatment are predominantly focused on building and strengthening that relationship. The valued nature of AN (34) and high ambivalence about change in people with AN also makes therapeutic alliance and shared goal setting particularly important to promote engagement and compliance.

Overall, the evidence base for AN treatment remains limited for both adults and young people and, in many ways, this is due to the nature of the illness. Patients with AN tend to be difficult to recruit and engage in treatment for the duration necessary for clinically meaningful trials and follow-ups (35, 36), and trials tend to lack statistical power (37). Some of the barriers to patient engagement include resistance to change, cognitive rigidity and avoidance tendencies (5, 6, 35). Moreover, relapse rates in AN appear to be high (4, 38), and more longitudinal evidence of treatment effectiveness in terms of sustained weight gain and reduced ED psychopathology is needed to draw stronger comparisons between treatments. More research into the effects of specific and non-specific factors on treatment outcomes would also be helpful when drawing comparisons between interventions and choosing the most appropriate option.

Conclusion

The recommendations given in NICE guidelines for the treatment and management of AN include a number of psychological treatment options apart from CBT-ED and FT-AN, which all appear to be equally effective in addressing core ED psychopathology and low BMI. All approaches share some similarities and differences, making it possible to pick a personalised intervention suitable for the needs of specific patients, although there is limited evidence to help

us to predict who might be most likely to benefit from which therapy. MANTRA might be more suitable for people with lower BMI, who find a flexible, yet structured, manual-based approach helpful. Further research needs to be conducted to explore and evaluate MANTRA adapted to group settings and adolescents. SSCM might be a helpful first-line intervention for people whose BMI is more stable, and who show greater readiness and motivation for change. Where other treatments appear to have been ineffective, FPT can be used to explore the meaning of AN symptoms more deeply. However, FPT has not been widely implemented in the UK due to the practical challenges of providing the necessary level of clinical training. AFP-AN could be more appropriate for mid-teenagers, as opposed to younger children, as they are likely to be in the process of separating and individuating from parents.

The need for more high-quality large-scale trials of AN treatment options remains pressing. These are required to evaluate each intervention further and to develop a better understanding of whether people with certain presentations and symptoms might benefit from a particular option more, leading to better personalisation of treatment. There is almost no evidence on whether comorbid conditions affect outcomes or require modifications to existing treatments. More longitudinal evidence is needed to draw stronger conclusions regarding treatment effectiveness and similarities or differences in long-term outcomes for different treatment groups.

Declaration of interests

The authors declare they have no conflict of interest.

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The Zen Garden virtual reality app for eating disorders: description and preliminary results

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Abstract

Virtual reality (VR) represents an emerging and promising tool to enhance standard care for patients with eating disorders. This small, uncontrolled, pilot study aims to provide a preliminary evaluation of the Zen Garden VR App in patients with anorexia nervosa (AN). The primary aim was to assess changes in mood, relaxation, anger, anxiety and weight and shape concerns. A secondary aim was to assess feedback from participants about the VR experience, its components and its possible application for people with AN. Self-reported baseline and post-intervention data were collected from a sample of inpatients with AN recruited at the Eating Disorders Service at the Bethlem Royal Hospital of the South London and Maudsley NHS Foundation Trust. Changes in clinical variables such as quality of mood, state of relaxation, anger, anxiety and weight and shape concerns from pre- to post-intervention were extracted, qualitatively revised and descriptively reported. Findings showed a global improvement after the VR Zen Garden App session, mainly in reducing levels of anxiety (Cohen's d = 1.07) and promoting relaxation (Cohen's d = 0.95). The music that was played during the intervention had a particularly positive effect. Despite promising and positive clinical implications, further studies are needed to confirm these preliminary results on wider samples of patients.

Keywords: virtual reality, anorexia nervosa, eating disorders

1. Introduction

Eating disorders (EDs) are characterised by a persistent disturbance of eating or eating-related behaviour resulting in the altered consumption or absorption of food that significantly impairs physical health or psychosocial functioning (1). Anorexia nervosa (AN) is one of the most prevalent types of EDs, affecting approximately 1% to 4% of European women and 0.3% to 0.7% of men (2), and is increasingly being diagnosed in younger patients (3, 4), with a typical onset age between 14 and 19 years (5, 6). Moreover, AN is one of the most severe EDs, with higher mortality rates due to medical complications from malnutrition and one in five deaths resulting from suicide (7, 8). Essential features of AN are persistent energy intake restriction, intense fear of gaining weight or of becoming fat, persistent behaviour that interferes with weight gain, and a disturbance in self-perceived weight or body image and shape (1). The course of AN is often chronic and can lead to permanent disability. Thus, novel intervention options are needed to enhance current treatments and improve acute and long-term outcomes.

In recent years, along with the progressive improvements in computer technology there has been an increasing interest in the possible applications of virtual reality (VR) technology in mental health. Indeed, VR offers unique advantages by providing an immersive and interactive experience within a safe and controlled environment that can simulate real-life situations to trigger or modulate emotional and behavioural responses, while allowing practitioners to monitor and guide the intervention in real-time or afterwards for diagnostic, therapeutic and educational purposes (9, 10). A recent systematic review (11) investigating the therapeutic role of VR in several areas of psychopathology analysed 721 articles and found that the strongest empirical use of VR was for exposure therapy in anxiety disorders, post-traumatic stress disorder (PTSD) and addiction disorders, as well as for cognitive training in dementia and social skill trainings in autism spectrum disorder (ASD).

VR has also been tested, with encouraging findings, in various types of psychological treatments including exposure therapy, psychoeducation, socioemotional learning, cognitive skills, emotional relaxation and stress-reduction, for many psychiatric disorders including major depression (12, 13), social anxiety and anxiety disorders (12, 14-16), PTSD (17), EDs (18), bipolar disorder (19), psychotic disorders (20), substance use disorders (21) and ASD (22).

VR is also an emerging and promising tool for patients with EDs (23-34). A systematic review conducted in 2018 (35) investigating the use of VR in patients with EDs highlighted how it could be used as a promising therapeutic tool in

virtual work on patients' body image and exposure to virtual food stimuli. Advantages may include automating and standardising ED psychoeducation, opportunities to practice emotion regulation skills, reprogramming attentional biases, enhancing insight by identifying body distortion, reducing weight stigma and biases, and augmenting exposure therapy (18). Interestingly, adding VR approaches has been shown to benefit people resistant to standard cognitive behavioural therapy treatment (28, 36). Three different randomised controlled trials (28, 31, 37) found that VR-enhanced cognitive behavioural therapy (CBT) for EDs showed greater improvements in body image, binge behaviour frequency and purge behaviour frequency in follow-ups (6 and 12 months). A systematic review and meta-analysis (38) of 19 studies using VR for binge eating disorder (BED) found a significant decrease in the frequency of binges in participants who underwent VR-enhanced CBT compared to CBT only (mean difference = 0.29, 95% confidence interval: 0.01–0.57). Another systematic review (39) evaluated the therapeutic applications of VR to improve body image perception in patients with AN and found an overall reduction of weight- and body-related anxiety responses. This evidence suggests that VR may be a useful tool to enhance current standard care for patients with EDs.

The aim of the present study was to evaluate the virtual reality experience with the Zen Garden App in patients with AN undergoing inpatient treatment. The specific aim was to address its effectiveness in improving mood, relaxation, anger, anxiety and weight and shape concerns. The secondary aim was to elicit feedback from participants about the VR experience.

2. Methods

2.1 Study participants

Six female inpatients aged between 18 and 33 years with a diagnosis of AN were recruited at the Inpatient Eating Disorders Service at the Bethlem Royal Hospital managed by the South London and Maudsley NHS Foundation Trust (SLaM) in London. Patients gave written informed consent to participate in the project. They also agreed for the anonymised data to be used for research purposes, further service development and publication.

2.2 Apparatus and tools

The VR Zen Garden App for people with AN was developed as a cooperative project between Maudsley Digital, the software company SyncVR medical, the clinical eating disorders team at SLaM and the Centre for Research in Eating and Weight Disorders (CREW) at King's College London (KCL). The project was approved by the Clinical Audit Ethical Approval Committee of the South London and Maudsley NHS Foundation Trust. The VR application was built by the SyncVR company and the Digital Innovation and Technology Services of SLaM and was installed on Pico Neo 3 VR headsets. An Oculus head-mounted display (HMD) headset and two controllers were used (Figure 1). The headset display had a 4K resolution of 3664 × 1920 pixels per eye, a field of view (FOV) of 98° and a support three-stage adjustment interpupillary distance (IPD) with an adaptable range of 54~73 mm. The two controllers had six-axis infrared sensors with six degrees of freedom (6DoF) somatosensory technology, a tracking ring, millimetre-level positioning and ultra-low latency, which provided continuous rotational and positional tracking. The sound had a 360° surround integrated stereo speaker, supporting 3D spatial sound.

Figure 1. Oculus head-mounted display visor and two controllers used during the Zen Garden VR session

A quality improvement questionnaire for this VR project was based on the validated Maudsley 3-item Visual Analogue Scale (M3VAS), which has previously been shown to have good internal consistency and convergent validity, with a Cronbach's alpha of 0.87 (40). The questionnaire has three main sections.

- Part 1 – completed before the VR experience: collecting personal information (e.g., age, gender, current treatment and duration, diagnosis, duration of the illness) and information regarding previous VR experiences.
- Part 2 – completed before the VR experience: collecting information about the current state of mind and the past two weeks. Participants rated the intensity and frequency of their experience over the past two weeks by making a mark on a 100-mm unmarked line regarding their quality of mood, state of relaxation, anger, anxiety and weight and shape concerns. A researcher then assigned the numerical score based on the position of the mark, using the left edge as 0 and the right as 100.

- Part 3 – completed after the VR experience: collecting information about possible changes patients might have experienced regarding their state of mood, relaxation, anger, anxiety and weight and shape concerns. Participants were again asked to rate their outcomes by making a mark on a visual unmarked line. A researcher then assigned the rating based on the position of the mark, using the left edge as -50 ("very much worse") and the right as +50 ("very much better"), with the central value of zero corresponding to "no change from baseline". Additional information was collected regarding the patient's opinion about how helpful they found the VR experience and its specific elements (the whole VR experience, the nature environment, the music and the opportunity to carry out activities such as walking around the Zen Garden and watering the plants), using a score from zero ("not helpful at all") to four ("very helpful"). Finally, the patients were asked in what way the VR experience could be helpful for people with AN (for relaxation, distraction and to counter boredom) both before and after mealtimes, with ratings from zero ("strongly disagree") to four ("strongly agree"), and any further suggestions or comments they might have on the VR experience.

2.3 Study design and procedure

After providing written consent, participants completed the first and second parts of the questionnaire consisting of demographic and baseline characteristics as described above. Subsequently, participants were invited to complete the VR experience session. They were individually guided by a researcher to familiarise themselves with the Oculus headset and controllers in a quiet room and then entered the Virtual Reality Zen Garden scenario. During the VR experience, patients were immersed in a relaxing and quiet environment composed of vast grass fields, a garden shed and a lake with a small bridge crossing it. During the VR experience, patients could listen to music by choosing from a playlist of 12 songs and spend time in relaxing activities, such as walking around the nature environment and watering the plants. The intervention was therefore characterised by a single session of VR, which took approximately 20 minutes. After the completion of the Zen Garden session, participants were asked to rate their feelings, moods and concerns about weight and shape by completing the third part of the questionnaire.

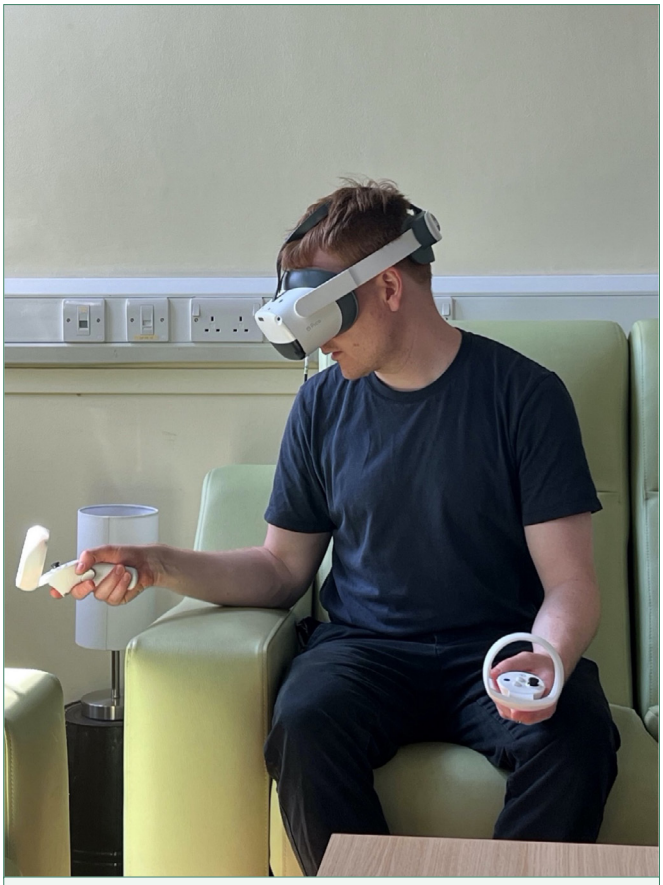

Figure 2. One of our staff members during the VR Zen Garden session

2.4 Data analysis

The sociodemographic and clinical variables extracted were age, gender, duration of the current treatment, duration of the illness, quality of mood, state of relaxation, anger, anxiety, weight and shape concerns and opinions regarding the VR experience. The changes in those variables after the VR session were collected, qualitatively revised and descriptively reported.

3. Results

The overall sample (n = 6) consisted of female inpatients with AN with a mean (± standard deviation (SD)) age of 26.3 ± 5.35 years. The mean duration of the current treatment in the inpatient service for the total sample was of 2.5 ± 0.84 months, and the mean duration of the illness was 6.7 ± 6.71 years. Only two of the six patients had previously had an experience with VR and both reported it as interesting and enjoyable.

3.1 Results of main outcomes

Baseline characteristics collected before the VR experience summarising their feelings over the previous two weeks are shown in Figure 3. The highest concerns related to body weight and shape, with a mean (± SD) score of 9.0 ± 1.24 in the overall sample. Participants also showed high anxiety levels and difficulties with relaxation, with total mean (± SD) scores of 8.4 ± 1.57 and 7.6 ± 1.47, respectively. The quality of mood had a mean (± SD) score of 6.6 ± 1.16 on a scale from 0 ("not at all depressed") to 10 ("extremely depressed"). Finally, the mean (± SD) score for anger in the total sample was 5.7 ± 2.54 (Figure 3).

After the VR experience, participants rated on a visual analogue scale changes in their feelings. These are graphically

represented in Figure 4.

The most pronounced changes were a decrease in anxiety and an improvement in the state of relaxation in the total sample, with standardised effect size (ES) Cohen's *d* of 1.07 and 0.95, respectively. There was also a significant improvement in mood, with an ES Cohen's *d* of 0.74 from baseline. Changes in anger and body weight and shape concerns were smaller, with an ES Cohen's *d* of 0.37 and 0.15, respectively. A summary of the baseline and post-VR session scores extracted from the visual analogue scale and outcome in terms of ESs is provided in Table 1.

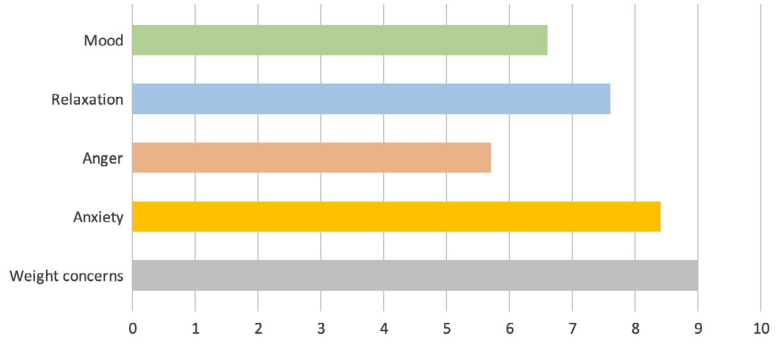

Figure 3. Distribution of baseline mean values on a scale from 0 (total wellbeing) to 10 (extremely impaired) in quality of mood, relaxation, anger, anxiety and weight and shape concerns for the overall sample.

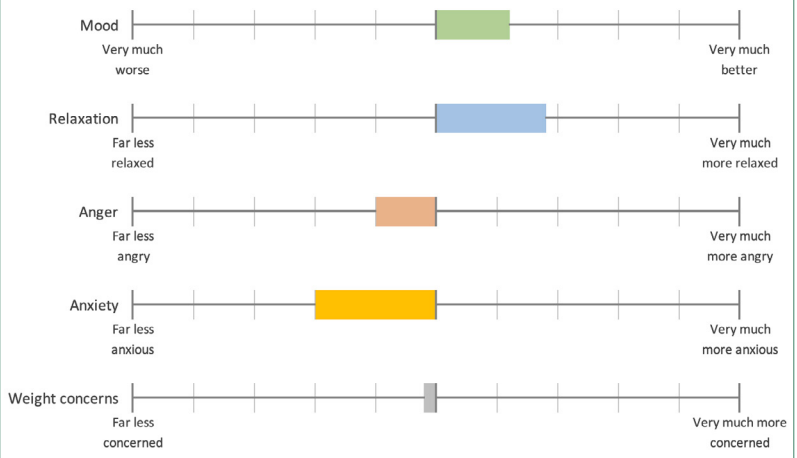

Figure 4. Mean change in quality of mood, relaxation, anger, anxiety and weight and shape concerns scores for the overall sample after the VR experience.

3.2 Feedback about the Zen Garden VR experience

The overall opinion on the Zen Garden VR experience, from all of the patients, was that it could help people with AN: 16.7% (n = 1) referred it as "slightly helpful", 50% (n = 3) as "somewhat helpful" and 33.3% (n = 2) as "very helpful". More than 50% of patients found the opportunity to walk around the environment as "very helpful" (n = 3) or "extremely helpful" (n = 1), and 83.3% reported that the Zen Garden was a "somewhat helpful" (n = 3) or "very helpful" (n = 2) element of the session (Table S1).

Regarding the role of the music, 16.7% (n = 1) of the sample reported that the option to choose and listen to music during the VR session was "slightly helpful", 33.3% (n = 2) as "somewhat helpful", 33.3% (n = 2) as "very helpful" and 16.7% (n = 1) as "extremely helpful". The playlist of songs available during the VR session is shown in Table 2.

The opportunity to water the plants and/or explore were less positively rated. 16.7% (n = 1) of the sample considered it as "not helpful at all", 33.3% (n = 2) as "slightly helpful", 50% (n = 3) as "somewhat helpful".

Detailed information on the frequencies and percentages of answers of patients with AN concerning the Zen Garden VR experience and its components can be found in the supplementary material (Table S1).

Participants reported that the Zen Garden VR App might be useful as a form of distraction and relaxation (83.4% and 66.7%, respectively, of the overall sample agreed or strongly agreed that they would use it for this purpose), whereas 83.3% of the sample agreed that there was potential in using it after mealtimes and 66.7% suggested that it had potential to be used before mealtimes.

Detailed information on frequencies and percentages of answers concerning the potential purpose for which the app could be used are provided in the supplementary material (Table S2).

4. Discussion

This study reports the preliminary results describing the Zen Garden VR App for inpatients with AN. Anxiety was reduced and there is the possibility that this would augment the experience of inhibitory learning, particularly after meals when food fears are at their highest.

Concerns regarding weight and body shape, which form part of the feared future consequences of eating, were least impacted by the Zen Garden VR App. More targeted approaches, such as imaginal exposure relating to future experiences of body shame (30) and the inhibitory learning model during exposure interventions to improve avoidance and safety behaviours as maintenance factors of the disorder (41), might add value.

Another relevant consideration of the Zen Garden VR App and its features regards the role of music during the intervention. We found that exposure to food in a virtual environment led to an increase in disgust and fear (42) and we

	Sample (N)	Baseline score (mean ± SD)	After VR score (mean ± SD)	Cohen's *d* (ES)
Anxiety	6	8.4 ± 1.57	6.4 ± 2.14	1.07
Relaxation	6	7.6 ± 1.47	5.8 ± 2.25	0.95
Mood	6	6.6 ± 1.16	5.4 ± 1.98	0.74
Anger	6	5.7 ± 2.54	4.7 ± 2.88	0.37
Weight and shape concerns	6	9.0 ± 1.24	8.8 ± 1.38	0.15

Table 1. Standardised effect size Cohen's *d* and outcome of anxiety levels, relaxation, quality of mood, anger and weight and shape concerns in the overall sample.

Abbreviations: ES = effect size; SD = standard deviation; VR = virtual reality

considered that music might improve inhibitory learning, leading to more positive associations between eating. We had found in our pilot studies that inpatients with AN preferred music rather than a vocal script to support eating (43). Therefore, Mozart's Toy Symphony was also included in the Zen Garden VR App song's list because when used in previous research it was found to be a positive tool for AN meal support in reducing attention bias to food and anxiety (43).

In this VR program, the music could be personalised, which is a feature of treatment that is valued. Our survey revealed that the opportunity to choose songs and listen to music during the VR session was one of the most helpful items provided by the app.

It is now widely accepted that music could have an important positive role in mental health (44, 45). Indeed, music therapy (MT) represents a promising complementary approach to usual psychiatric care and an increasingly recognised effective support for people with different mental disorders (46-49). The effects of MT in people with EDs include positive modulation of emotions and memories (46), and a form of scaffolding to help discover their recovered identity, build resilience and reinforce psychotherapy by developing healthy coping skills (50, 51).

A randomised controlled trial conducted in 2019 assessing the role of MT in patients with obsessive-compulsive disorder (OCD), using Peter B. Helland's piano melody Together as music intervention, found a significant reduction in obsessive-compulsive symptoms and obsessions and compulsion in the treatment group compared to controls (52). Given the common comorbidity between OCD and AN, we also included Peter B. Helland's piano melody in the Zen Garden VR App song list.

Song	Musical genre
Transformers - *Arrival to Earth*	Movie, piano, cover
Linkin Park - *In the End*	Rock, metal, piano
Peder B. Helland - *Together*	Piano
Inception - *Time*	Movie, piano, cover
Beth Hart and Joe Bonamassa - *I'd Rather go Blind*	Funk, song
Promentory - *Violin Cover*	Movie, violin
Filipe Gouveia e Melo - *The Pain of Silence*	Piano, classic
Dragon Palace - *Okami*	Orchestral, Asian
Leopold Mozart - *Toy Symphony*	Classical
Heal - *San Holo*	Trap, electro
Funkadelic - *Maggot Brain*	Funk, song
Aakash Gandhi - *Dancing Star*	Piano

Table 2. List of songs with composer, title and musical genre provided in the Zen Garden VR app.

Although this brief report provided encouraging preliminary results regarding the Zen Garden VR App for inpatients with AN, several limitations of the study must be considered. The main limitation is the small sample of patients measured at one time point, so we could not substantiate whether the benefits of a single use were sustained over time. In addition to the small sample size, the lack of a control group makes it difficult to generalise these preliminary results. Therefore, further studies are needed in this regard.

5. Conclusions

This study found that the Zen Garden VR App has the potential to augment treatment for people with AN. Indeed, it could represent a useful tool to reduce anxiety in these patients. It is possible that VR could usefully augment and personalise care for people with an EDs by creating simulations of the real-life challenges faced by these patients, such as shopping for food, eating in social situations or emotional responses to triggers, such as calorie labels on menus. Additionally, VR could provide a safe space for patients to confront and overcome body shaming experiences or distorted body image perceptions, gradually desensitising them to these stressors in a controlled and supportive environment.

Supplementary material

The supplementary material for this article can be found online at https://www.cepip.org/article/zen-garden-virtual-reality-app-eating-disorders-description-and-preliminary-results

Author contributions

DG: conceptualisation, methodology, investigation, data curation, formal analysis, writing – original draft preparation, writing – review and editing; SK: conceptualisation, methodology, investigation; MB: investigation; AM: investigation; MK: conceptualisation, visualisation, validation; LDO: validation, visualisation; JT: conceptualisation, methodology, validation, visualisation, writing – review and editing, supervision; HH: conceptualisation, methodology, validation, visualisation, writing – review and editing, supervision. All authors have read and agreed to the published version of the manuscript.

Funding

JT has received salary support from the NIHR BRC at the South London and Maudsley NHS Foundation Trust (SLaM) and KCL. HH has received salary support from the NIHR BRC at the South London and Maudsley NHS Foundation Trust (SLaM) and KCL.

Informed consent statement

Informed consent was obtained from all subjects involved in the study.

Conflicts of interest

The authors declare no conflicts of interest.

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The pharmacological treatment of eating disorders: new guidelines and gender-specific aspects

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Abstract

Even though psychopharmacology has made substantial progress in many areas of psychiatry since the discovery of antipsychotics and antidepressants in the 1950s, the evidence base for pharmacological treatments in the field of eating disorders has been lagging. The World Federation of Societies of Biological Psychiatry guidelines update 2023 on the pharmacological treatment of eating disorders provides a comprehensive summary of pharmacological studies and recommendations for anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), avoidant/restrictive food intake disorder, pica and rumination disorder. However, there are very few studies in adolescents, implying that evidence-based recommendations in this population are difficult to make. Gender-specific aspects have also been addressed in the guidelines update, such as the small number of male patients included in pharmacological studies in AN and BN. Furthermore, the guidelines recommend against the treatment of female AN patients with testosterone, mention that topiramate for the treatment of BN and BED is contraindicated during pregnancy and that fluoxetine and its metabolite norfluoxetine inhibit the metabolism of the anti-breast cancer prodrug tamoxifen to its active metabolite endoxifen.

Keywords: eating disorder, anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, pharmacological treatment, gender

1. Historical remarks

1.1 Eating disorders

A cornerstone in the history of eating disorders (EDs) was the meeting of the "Clinical Society of London" in 1873, when Sir William Gull coined the term "anorexia nervosa" (AN) (1). The diagnosis of "bulimia nervosa" (BN) was first suggested by Gerald Russell in a paper published in 1979 (2). Only one year later, in 1980, BN was included into the 3rd edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM). Binge eating disorder (BED) was described in 1959 by psychiatrist Albert Stunkard in his paper, "Eating Patterns and Obesity" (3). The 5th edition of the DSM (DSM-5), which was issued in 2013 (4), finally introduced BED as a separate ED. The DSM-5 also recognises avoidant/restrictive food intake disorder (ARFID), pica and rumination disorder (RD) as autonomous disorders in the respective DSM-5 chapter on "Feeding and Eating Disorders". The diagnoses in the DSM-5 are comparable to those in the more recently published ICD-11 (5).

1.2 Psychopharmacology

From the start of the 19th century up to the 1950s, the psychiatric asylum numbers increased steadily in Europe and North America despite big efforts of deinstitutionalisation. In 1950, however, chlorpromazine, the first antipsychotic drug, was synthesised, and two years later, Pierre Deniker recognised its therapeutic effect on schizophrenia (6). This discovery led to a massive improvement in the therapy of psychosis. Before 1950, only 6% of patients with schizophrenia were ever discharged. However, after the introduction of chlorpromazine, 67% of patients with schizophrenia could be discharged after inpatient treatment; between 1955 and 1968, the residential psychiatric population in the United States decreased by 30% (7). A similar therapeutic breakthrough was achieved in affective disorders based on the discovery of the antidepressant effect of imipramine by Roland Kuhn in 1956 (8). Chlorpromazine, imipramine and other new psychopharmacological drugs allowed the mentally ill to recover, be discharged from psychiatric asylums and hospitals, live in their own homes and obtain employment.

1.3 Psychopharmacology of eating disorders

Because of anecdotal reports of success with antipsychotics, the use of first-generation antipsychotics to treat AN was investigated in open and uncontrolled, and also in randomised controlled trials in the 1970s and 1980s. However, the newly discovered psychopharmacological agents did not gain general acceptance for the treatment of EDs at that time and it seemed like patients with EDs could not benefit from the great breakthrough psychopharmacological therapies had achieved in other areas of psychiatry (9).

Between the 1980s and today, the situation changed due to diagnostic and psychopharmacological advances. Re-

garding new psychopharmacological developments, the selective serotonin reuptake inhibitor (SSRI) fluoxetine came into the market in 1986. It was tested in patients with BN, yielding positive results (10), and approved by the US Food and Drug Administration in 1987.

In AN, however, no pharmacological treatment has been approved. This might be one of the reasons why the prognosis for AN is still poor. A recent cohort study over 22 years published by Eddy and colleagues showed that only just over 30% of patients with AN had recovered after 9 years (11), although the prognosis for early onset AN may be better (12, 13).

1.4 Guidelines for the pharmacological treatment of eating disorders

In 2011, clinicians and researchers of the World Federation of Societies of Biological Psychiatry (WFSBP) published a comprehensive review of all published psychopharmacological studies in EDs up to then (14). This was the first version of the WFSBP guidelines on the pharmacological treatment of EDs. Since 2011, the DSM-5 was issued in 2013 recognising BED, ARFID, pica and RD as independent feeding disorders/EDs, and in 2019, novel guidance was developed by the WFSBP on how to grade evidence for clinical guideline development (15). According to this guidance, strong evidence that an intervention is effective can only be concluded if two positive, independent, high-quality, randomised controlled trials (RCTs) find that the medication helps in a clinically and statistically significant way. The quality of an RCT can, for example, be assessed using the Scottish Intercollegiate Guidelines Network (SIGN) rating (16). However, a strong recommendation can only be given to a medication with strong evidence if it shows safety, tolerability and a good adherence rate. This guidance was then applied in the new WFSBP guidelines update 2023 on the pharmacological treatment of EDs (17).

2. Eating disorders according to DSM-5 and ICD-11

As already mentioned, both DSM-5 and ICD-11 recognise AN, BN, BED, ARFID, pica and RD as feeding disorders or EDs. The main criteria for the diagnosis of AN are a significantly low body weight in the context of age, sex and physical health, an intense fear of weight gain and a disturbed body perception. In ICD-11, rapid weight loss (e.g., more than 20% of total body weight within 6 months) may replace the low body weight diagnostic feature for AN as long as other diagnostic requirements are met, meaning AN can be diagnosed at any weight. In the DSM-5, this would be atypical AN. Criteria for the diagnosis of BN are recurrent binges, recurrent vomiting, excessive physical activity or fasting and excessive occupation with food, figure and weight. Criteria for the diagnosis of BED are recurrent binge eating with control loss but no compensatory measures for weight reduction. Additional important symptoms are eating without being hungry, feelings of embarrassment, disgust or guilt after a binge and suffering distress due to these eating habits. ARFID is a feeding disorder/ED characterised by restrictions regarding the amount or the range of food consumed, or by a fear of the adverse consequences of eating, such as choking or vomiting. People with ARFID are underweight, have nutritional deficiencies, rely on supplements or enteral feeding and/or have significantly impaired psychosocial functioning as a result of their eating patterns that are more severe than simply being selective with one's food. Unlike those with AN, people with ARFID are not excessively preoccupied with body image, weight or shape. ARFID can occur at any age and any weight. Pica is a compulsive feeding disorder or ED in which people eat non-food items such as dirt, clay, paint, glue, hair, cigarette ashes and faeces. The disorder is more common in young children between the ages of 2 to 6 years. RD is an illness that involves repetitive, habitual regurgitation of food that might be partly digested. The affected patient may re-chew and re-swallow the food or spit it out (4).

3. Pathophysiological considerations

Appetite-regulating neurocircuits: Appetite and body weight are biologically regulated by specific neurocircuits. The three most important neurocircuits are the self-regulatory, the hedonic and the homeostatic systems (18). These systems relate to the reasons why we eat or do not eat. For example, we may adhere to a specific diet because of a certain ideal of beauty or for ethical or somatic reasons (for example, food allergies). This happens in the self-regulatory system because it embeds eating into the social context, creates individual values and performs self-regulatory control. Its main centre lies in the prefrontal cortex.

Another reason for us to eat is enjoyment. The function of the hedonic system is to elicit the desire to eat and to evoke pleasure during food consumption. Its neurons and synapses can be found mainly in the prefrontal cortex, the basal ganglia and the thalamus.

Being hungry also creates an urge to eat to ensure that we consume sufficient energy to keep our body functioning. This hunger originates from the homeostatic system that integrates peripheral signals of food consumption and energy storages and regulates appetite. The hypothalamus plays a prominent role in this system.

Appetite-regulating signal molecules: Figure 1 shows that these neurocircuits are related and which signalling molecules, including neurotransmitters and hormones, they use. Important neurotransmitters of the self-regulation system are serotonin, noradrenaline, acetylcholine, the excitatory transmitter glutamate and the inhibitory messenger gamma-aminobutyric acid (GABA). The main neurotransmitters of the hedonic system are dopamine, opioids and cannabinoids. Signalling molecules of the homeostatic system include peripheral appetite-regulating hormones like

leptin, ghrelin, insulin and glucagon-like peptide-1 (GLP-1), hypothalamic appetite regulators like neuropeptide Y (NPY), agouti-related peptide (AgRP), α-melanocyte-stimulating hormone (α-MSH), cocaine- and amphetamine-regulated transcript (CART) and the neurotransmitter histamine (9). These signal molecules and their receptors can be targeted using pharmacological interventions to influence eating behaviour, food-related thoughts and emotions and body weight.

4. Medication for anorexia nervosa

For AN, the WFSBP guidelines update 2023 identified 70 relevant articles; 38 articles were new since 2011. The highest evidence was found for the antipsychotic agent olanzapine at a daily dose between 2.5 and 10 mg based on four positive RCTs (19-22), but the evidence is restricted to weight gain as an outcome. However, a low adherence rate was found for olanzapine in AN. Furthermore, the effect in young people is not clear as the only small RCT in adolescents showed no significant differences in weight gain, resting energy expenditure and psychological symptoms (23). Therefore, the WFSBP guidelines update 2023 concluded that olanzapine has strong evidence for weight gain only, but only a limited recommendation in AN (17). Olanzapine is an antagonist at dopamine, serotonin and histamine receptors.

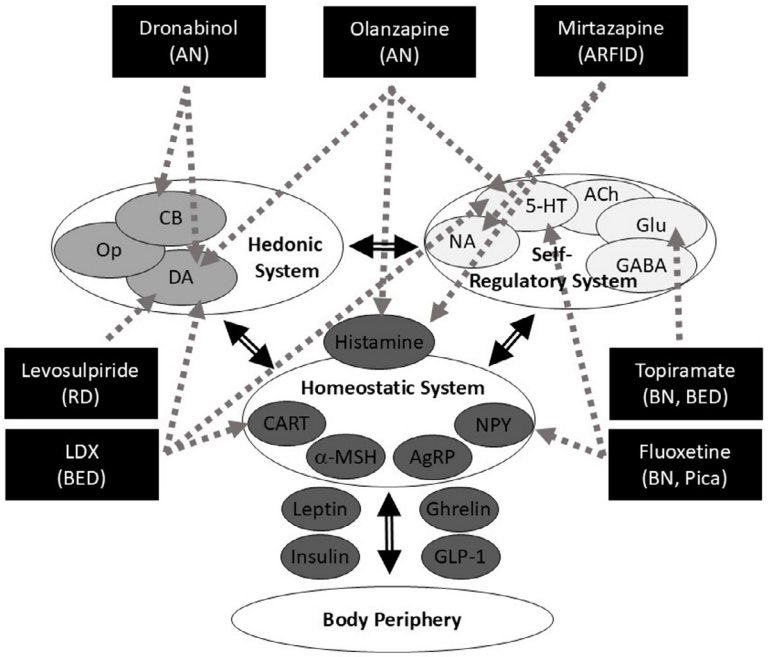

Figure 1: Appetite-regulating neurocircuits (hedonic, self-regulatory and homeostatic systems), related signalling molecules and eating disorder (ED) medications that are discussed in this article. The cannabinoid (CB) receptor agonist dronabinol, which has some evidence for its use in anorexia nervosa (AN), also influences the dopamine (DA) system. Olanzapine is an antagonist at (DA), serotonin (5-HT) and histamine receptors, with strong evidence for weight gain in AN. The antidepressant mirtazapine is an antihistaminergic α_2-receptor blocker with evidence for its use in avoidant/restrictive food intake disorder (ARFID) from a retrospective chart review and two case reports. Topiramate influences cellular sodium and calcium channels as well as glutamate (Glu) and gamma-aminobutyric acid (GABA) receptors. It is recommended by the WFSBP guidelines for use in bulimia nervosa (BN) and binge eating disorder (BED). The selective serotonin reuptake inhibitor (SSRI) fluoxetine, which also influences neuropeptide Y (NPY), is approved for the treatment of BN. There is also evidence from case reports for its use in pica. Lisdexamfetamine (LDX) influences serotonin, dopamine and cocaine- and amphetamine-regulated transcript (CART). It has been approved for the treatment of BED in several countries (not the UK). Levosulpiride blocks presynaptic dopaminergic receptors and has helped ~one-third of patients with rumination disorder (RD) in an open study. Further abbreviations: opioids (Op), noradrenaline (NA), acetylcholine (Ach), agouti-related peptide (AgRP), α-melanocyte-stimulating hormone (α-MSH), glucagon-like peptide-1 (GLP-1). The figure is amended from (9).

Regarding children and adolescents with AN, the Canadian practice guidelines for the treatment of children and adolescents with eating disorders (24) have stated that in specific contexts, consideration of olanzapine use may be undertaken for the adjunct treatment of low weight children and adolescents with AN. These guidelines further explain that given its propensity for adverse effects, olanzapine should only be considered with appropriate consultation and monitoring by trained specialists in child and adolescent psychiatry or paediatrics who have expertise in the treatment of children and adolescents with EDs. When utilised, olanzapine should be initiated at a very low dose of 0.625 to 1.25 mg and titrated carefully (24).

The cannabinoid receptor agonist dronabinol has also been tested in people with AN. The daily dose was 5 mg. The beneficial effects on body weight, ED psychopathology and physical activity was published in two articles by Andries and colleagues in 2014 and 2015 (25, 26). Thus, the WFSBP EDs Task Force bestowed a limited level of evidence and a limited recommendation to use dronabinol (17). However, dronabinol is a controlled drug in the UK and is not licensed for the use of AN. Table 1 shows the medications with the highest recommendation and evidence for each ED.

The only medications with a high level of recommendation are fluoxetine and topiramate for BN and topiramate and lisdexamfetamine for BED. The WFSBP guidelines update 2023 reviewed clinical trials across the life span. However, as most RCTs were performed in adults, clinicians treating children and adolescents should consult more specific guidelines such as the Canadian practice guidelines for the treatment of children and adolescents with eating disorders (24).

Diagnosis	Medication	Daily dose	Level of evidence†	Grade of recommendation‡
Anorexia nervosa	Olanzapine	2.5-10 mg	A*	2
	Dronabinol	5 mg	B	2
Bulimia nervosa	Fluoxetine	20-60 mg	A	1
	Topiramate	75-200 mg	A	1
Binge eating disorder	Lisdexamfetamine	30-70 mg	A	1
	Topiramate	75-600 mg	A	1
ARFID	Mirtazapine	7.5-45 mg	C	3
Pica	Fluoxetine	20-60 mg	C	3
Rumination disorder	Levosulpiride	75 mg	C	3

Table 1. Medications with the highest level of evidence and grade of recommendation for each eating disorder according to the WFSBP guidelines update 2023 on the pharmacological treatment of eating disorders (17).

Notes: † Level of evidence: A: strong evidence that the intervention is effective; B: limited evidence that the intervention is effective; C: low evidence that the intervention is effective. ‡ Grade of recommendation: 1: strong recommendation for using the intervention; 2: limited recommendation for using the intervention; 3: weak recommendation for using the intervention. * Evidence restricted to weight gain.

5. Medication for bulimia nervosa

In BN, the task force identified 70 relevant articles. However, only 13 articles have been published since the first WFSBP guidelines in 2011. Thus, there has been limited progress regarding the pharmacological treatment of BN.

Fluoxetine is approved for the treatment of BN. The dose is between 20 and 60 mg per day. Four RCTs with a "high quality" SIGN rating (27-30) found a statistically significant superiority of fluoxetine regarding binge eating and vomiting. Thus, there is strong evidence that fluoxetine is effective in BN, and this leads to a strong recommendation for fluoxetine in BN. However, there is only one study in the adolescent population (31). This open trial of 60 mg fluoxetine daily in 10 young people showed reductions in binge frequency and the medication was well tolerated. For further case series and case reports of the use of fluoxetine in children and adolescents, see (24). The Canadian practice guidelines for the treatment of children and adolescents with eating disorders list fluoxetine as additional promising medication for BN but highlight that more research is required before definitive recommendations can be made (25).

Two RCTs which tested topiramate in BN have shown significant superiority compared to placebo regarding binge eating and vomiting (32-34). Topiramate must be started at a low dose of 25 mg per day to avoid cognitive problems such as impairments in verbal fluency (35), and the dose can be increased to 400 mg per day. As topiramate was well tolerated, it can be recommended for use in BN as well (17). However, it is not approved for the treatment of BN and fluoxetine should be tried first if a pharmacological treatment is necessary.

6. Medication for binge eating disorder

The WFSBP EDs Task Force identified 68 relevant articles pertaining to BED, of which 24 were new. All were in adult patients. Recent RCTs investigated lisdexamfetamine (LDX) at a dose of 50 or 70 mg per day. Evidence from four RCTs (36-39) and one relapse-prevention RCT (37) demonstrate that LDX is effective in the treatment of BED regarding binge eating frequency and body weight. Therefore, the task force bestowed strong evidence and a strong recommendation for the use of LDX in BED. LDX is approved for attention deficit hyperactivity disorder (ADHD) but not BN in the UK. It has, however, been approved for the treatment of BED in the US, Canada, Brazil, Puerto Rico, Mexico and Israel.

Three RCTs have tested topiramate in BED (40-42). The researchers used a dose between 25 and 600 mg per day and they found significant superiority of topiramate regarding binge eating frequency and body weight. Therefore, the task force decided to bestow level A evidence and a grade 1 recommendation to topiramate (17). However, topiramate is not approved for the treatment of BED in the UK.

7. Medication for avoidant/restrictive food intake disorder

Apart from BED, DSM-5 and ICD-11 introduced ARFID, pica and RD as new independent feeding disorders/EDs. No randomised controlled pharmacological study has been performed and published in ARFID. Three of the seven articles on pharmacological treatment for ARFID, most of which referred to children and young people, reported treatment with mirtazapine, namely one retrospective chart review (43) and two case reports (44, 45). Therefore, there is little evidence that mirtazapine is effective in ARFID, and this translates to a weak recommendation for its use in ARFID. Other medications used were antihistamines and antipsychotics, all with low levels of evidence.

8. Medication for pica

Pica is usually not an independent phenomenon but appears in the context of other mental or physical disorders. The task force identified eight articles pertaining to the pharmacological treatment of pica. The successful use of fluoxe-

tine for pica was reported in two case reports of patients with pica and obsessive-compulsive disorder (OCD) (46, 47), and two case reports of patients with pica and a neurodegenerative disorder (48, 49). Thus, there is low evidence that fluoxetine is effective in pica, and this translates to a weak recommendation for its use (17). However, in a patient with pica, it is advisable to examine for psychiatric comorbidities, such as OCD or a neurodegenerative disease, and select the pharmacological treatment taking all available information into account. Further successful single case reports are available for the treatment with SSRIs, antipsychotics and ADHD medication.

9. Medication for rumination disorder

The task force identified two articles for the pharmacological treatment of RD. One open study in adult patients tested levosulpiride, an antipsychotic with prokinetic activity. Whilst it did not help all patients, more than a third (38%) of the adults included benefitted from this medication (50). As we have evidence from one open study, this translates to a weak recommendation for its use in RD (17).

Another medication tested in RD was baclofen, which is a GABA agonist. In one double-blind crossover study in adult patients, 63% of patients reported symptom improvement with baclofen compared to 26% in the placebo period (51). However, baclofen has been reported to have serious adverse effects such as psychosis, depression, balance disorder with falls, and difficulties in verbal expression. Thus, despite evidence from a double-blind crossover study, the recommendation of the WFSBP for the use of baclofen in RD is weak (17).

10. Gender-specific aspects of the pharmacological treatment of EDs

Gender distribution of ED epidemiology: The prevalence of AN in the general population is about 1% among women and 0.1% in men. Similarly, BN is 10 times more common in females than in males, with a prevalence between 1 and 2% among women. BED is the most prevalent of all the EDs worldwide, with a prevalence of about 3% in the whole population including men and women who have a similar risk of BED (52). The prevalence estimates for ARFID in the general population vary substantially, ranging from 0.3% to 15.5% in children and adolescents and from 0.8% to 4.5% among adults with a sex ratio of ~1:1 (53). There is little epidemiological information on the prevalence of pica and RD.

Lack of studies in male patients with AN and BN: Due to the unbalanced gender distribution of AN and BN, most participants in studies testing medication in AN or BN are female. For example, of the 152 patients with AN included in the largest RCT of olanzapine for AN (22), only seven were male. In the largest RCT for fluoxetine in BN (28), of 398 patients with BN, only 17 were male. Thus, it is questionable whether firm conclusions for the pharmacological treatment of males can be drawn from these studies.

Female sex hormones to treat osteopenia in female patients with AN: The question of whether female sex hormones could help with osteopenia in AN was not addressed in the updated WFSBP guidelines, but it is clinically highly relevant. The evidence for exogenous oestrogen or progesterone to treat osteopenia in AN is scarce. Oral ethinyl oestradiol in the form of the oral combined pill does not appear to be effective, but transdermal 17β-oestradiol may increase bone mineral density. Thus, this treatment may be considered in patients where other options have been exhausted (54). However, endogenous oestrogen production usually follows weight restoration during the recovery from AN.

Testosterone for female patients with AN: Kimball et al. (55) reported an RCT in 90 female patients with AN, testing 300 µg transdermal testosterone daily or a placebo patch for 24 weeks. However, testosterone was associated with less weight gain and did not lead to improvements in depression, anxiety or disordered eating symptoms compared with placebo in women with AN. Thus, the task force recommended against the use of transdermal testosterone.

Oxytocin for female patients with AN: Russell et al. (56) studied the effect of intranasal oxytocin in two pilot studies of female inpatients with AN. In the oxytocin group, eating concerns and cognitive rigidity were reduced after oxytocin application but no effect on weight was reported. Burmester et al. (unpublished data) found a negative effect of intranasal oxytocin on social cognition in female adolescents with ED who had higher baseline social stress; an effect that was not found in controls whose social stress reduced, as predicted.

Pregnancy: Topiramate has approval for epileptic seizures and migraine. It is contraindicated in pregnancy and in women of childbearing potential if they are not using a highly effective method of contraception.

Breast cancer: Fluoxetine is widely approved for the treatment of BN. However, fluoxetine and its metabolite norfluoxetine are potent inhibitors of the cytochrome P450 (CYP) isoenzymes CYP2D6 and CYP2C19. Therefore, caution is advised when combining fluoxetine with CYP2D6 and CYP2C19 substrates such as amitriptyline, atomoxetine, clomipramine, imipramine, and several antipsychotics. CYP2D6 inhibition also leads to decreased metabolism of the prodrug tamoxifen to its active metabolite endoxifen. Therefore, fluoxetine must not be given to women who receive tamoxifen treatment, a hormone therapy for breast cancer. Finally, fluoxetine should not be combined with monoamine oxidase inhibitors.

11. Discussion

The update of the WFSBP guidelines for the pharmacological treatment of EDs is currently the most comprehensive review of pharmacological studies in EDs. It also provides an evaluation of the reported evidence and makes recom-

mendations for pharmacological treatment. It follows clear and transparent guidance to rate the level of evidence and the grade of recommendation (15, 17). Several other international and national guidelines, such as the National Institute for Health and Care Excellence guideline, "Eating disorders: Recognition and treatment" (57), barely mention specific medications for the treatment of EDs because the evidence is relatively weak. Pharmacological trials in this population are a priority for research.

However, the WFSBP guidelines update 2023 on the pharmacological treatment of EDs has its limitations. It focused on the pharmacological treatment of EDs only. It did not compare the pharmacological treatment with non-pharmacological biological, psychotherapeutic or other treatment approaches. Whether a study was successful or not was decided with reference to the main outcome and improvement of diagnostic criteria. Other important outcomes were neglected, for example, anxiety and sleep disturbances in AN, patient-reported outcome measures or patient-reported experience measures.

Additionally, comorbidities were neglected. This is, for example, important if a patient suffers from depression and AN. The antidepressant bupropion is contraindicated in AN because of weight loss and an increased risk of seizures. If a patient suffers from depression or bipolar disorder and BED, mirtazapine and olanzapine should be avoided due to the risk of weight gain. Information about the treatment for frequent health consequences and comorbidities of EDs can be found in the paper by Himmerich et al. (58).

The WFSBP guidelines cover pica and RD (5) because they appear as feeding disorders and EDs in DSM-5 (4). However, in England, the National Health Service (NHS) children's ED services are generally not commissioned to treat these diagnoses as per NHS England Access and Waiting Time guidance.

Most pharmacological trials in EDs have a relatively short duration of between 6 and 16 weeks. Therefore, we had to develop guidelines without knowing what the long-term effects are.

Gender aspects seem to have particular importance for the pharmacological treatment of EDs for female, male, pregnant and breast cancer patients. Further, gender aspects that should receive more attention by future research are the pharmacological effects in transgender people with EDs as well as the psychological and physical effects of sex hormones in EDs.

Declaration of Interest

Hubertus Himmerich is the chief investigator of a proof-of-concept study testing psilocybin in AN which is an industry cooperation between SLaM, COMPASS Pathfinder Limited and Worldwide Clinical Trials Limited.

Funding

Hubertus Himmerich and Janet Treasure have received salary support from the National Institute of Health and Care Research (NIHR) Mental Health Biomedical Research Centre (BRC) at South London and Maudsley NHS Foundation Trust (SLaM) and King's College London (KCL). DN is supported by the National Institute for Health and Care Research Applied Research Collaboration Northwest London and the Imperial BRC. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

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Neurosurgery for severe anorexia nervosa

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Abstract

Anorexia nervosa (AN) is primarily a mental disorder, characterised in modern society by disturbed attitudes towards weight, body shape and calorie balance. In earlier eras, anorexia did exist but religious or other values, rather than body image concerns, underlaid the obsessive-compulsive features. Serious physical and psychological complications cause high levels of disability and mortality. Early psychological intervention improves outcomes, but 20% develop severe and enduring symptoms and it has the highest mortality rate of any psychiatric disorder. AN has a biological component and shares significant genetic and neural network abnormalities with other mental illnesses, especially with obsessive-compulsive disorder (OCD). Functional neurosurgery, including stereotactic ablation (SA) and deep brain stimulation (DBS), are low-risk interventions that disrupt abnormal synchronised activity in neural circuits. Primarily used in movement disorders, these interventions are increasingly used in mental disorders, with evidence of efficacy from multiple randomised controlled trials in OCD and Gilles de la Tourette syndrome. Open-label studies of SA and DBS for AN report a large positive effect size on core psychopathology, quality of life and body mass index, sustained over many years. Early comorbid OCD symptoms and restricting AN subtype may be good prognostic predictors of response. Several surgical, psychological, logistical and financial factors may favour SA over DBS. However, the available evidence is limited and further studies are required to determine patient perception of, selection for and response to neurosurgery. AN is a potentially rewarding area for greater collaboration between eating disorders experts and functional neurosurgeons and offers hope to severely affected patients who have run out of treatment options.

Abbreviations: AN = anorexia nervosa; BMI = body mass index; DBS = deep brain stimulation; EDE = eating disorders examination; FUS = focused ultrasound; GK = gamma knife; HAM-A = Hamilton Anxiety Scale; HAM-D = Hamilton Depression Rating Scale; OCD = obsessive-compulsive disorder; PD = Parkinson disease; SA = stereotactic ablation; SCG = subcallosal cingulate gyrus; VC/VS = ventral capsule/ventral striatum; Y-BOCS = Yale-Brown Obsessive-Compulsive Scale

Introduction

Anorexia nervosa (AN) is an eating disorder characterised by disturbed attitudes towards weight, body shape, eating and calorie balance. This drives severe weight loss behaviours, such as dietary restriction, purging and excessive physical activity. Although adolescent girls and young women are particularly at risk, the condition can affect anyone, regardless of age, sex, culture or race.

AN is primarily a mental disorder with marked disturbance of cognitive and emotional functions. It often follows a protracted or relapsing course, leading to serious physical and psychological complications and comorbidities, and causes high levels of disability and mortality. AN leads to a poor quality of life, disrupted relationships, emotional distress, social isolation and economic disadvantage. Young people may experience pubertal delay and disruption to education. Post-pubertal women are usually amenorrhoeic, with risk of osteoporosis as well as fertility issues. AN places a heavy burden on individuals, families and society (1, 2).

In high-income countries, the reported lifetime prevalence of AN in the general population is around 1% in women and <0.5% in men (3). Accurate point prevalence is estimated as 0.3% to 0.5% in adults but relies on data from individuals who present to health services (4). AN typically begins in early-to-mid adolescence but can emerge at any age. In adults, females are eight times more likely to be affected, recovery rates are lower and mortality rates are higher (5).

Treatment and prognosis: Early intervention improves outcome. Many factors affect AN management and prognosis, including age of onset, severity of malnourishment and comorbidities such as depression, anxiety or trauma. Established treatments include psychological and family-based interventions and nutritional support, with escalating levels of outpatient and inpatient care. There is limited high-level evidence on the effectiveness of pharmacological therapies (2). With the best available medical and psychological treatment for AN, around 50% recover and 30% show some improvement. However, 20% remain chronically ill and develop a severe and enduring form of the illness that is particularly hard to treat. Severe enduring eating disorders have been characterised as "SEED" or "SEAN" (severe and enduring AN) (5, 6). However, the implication of a poor or even terminal prognosis could lead to a sense of hopelessness in both patients and clinicians. As a result, these terms have been assertively challenged by many professionals and by people with a lived experience of eating disorders.

Mortality: AN has the highest mortality rate of any psychiatric disorder. This is partly caused by its physical complications, and partly an increased suicide rate, accounting for 20% to 40% of deaths (7). A meta-analysis of 36 studies reported a standardised mortality ratio of 5.9 (95% confidence interval: 4.2–8.3) (8). Another study based on 119 study series (n = 5,590 patients) found a significant effect of duration of illness (n = 3,147), with 9.4% mortality in those with >10 years duration (5).

Health economics: Calculating the economic burden of AN on healthcare systems is complex. A recent systematic review placed the mean annual healthcare costs between €2,993 to €55,270 per patient (9). Economic evaluation of treatment in the UK revealed a cost of £34,531 (SD, £52,430; range, £86,000–£282,508) per patient for inpatient care (n = 47) and £40,794 (SD, £63,652; range, £1,483–£274,838) per patient for outpatient care (n = 43) over a two-year period between the years 2000 and 2003 (10).

The biological aetiology of anorexia nervosa

There is mounting evidence that AN has a biological aetiology as well as a psychological one. AN has a strong familial tendency that is absent in adoptive siblings. Female relatives of an affected individual are up to 11 times more likely to develop AN. Furthermore, twin studies show heritability estimates of 0.48 to 0.74. This remains true even in twins reared apart, eliminating the influence of environmental factors (11). A genome-wide study identified eight risk loci, pointing to a biological component to AN (12).

Significant genetic correlations exist with other psychiatric disorders or traits, by far the highest with obsessive-compulsive disorder (OCD), but also with anxiety disorders and major depression. AN also shares phenotypic similarities with these conditions; for example, individuals with AN and OCD exhibit cognitive inflexibility with decreased set-shifting ability and perseverative cognitive style (13, 14). A large population based, multi-generational and twin study found that females with OCD had a 16-fold increased chance of having a comorbid diagnosis of AN. Moreover, first- and second-degree relatives of patients with OCD had an increased risk of AN (15).

Yet another commonality between OCD and AN is dysfunction in emotive and reward/punishment brain networks (16). Brain connectivity studies in AN have shown increased structural and functional connectivity in a reward-related network connecting ventral striatum to orbitofrontal cortex (via the anterior limb of the internal capsule). This abnormality persisted even following weight restoration (17). Similar network dysfunction was also demonstrated in another multimodal MRI connectivity analysis (18).

Functional neurosurgery in neurological disorders

Stereotactic ablation (SA) and deep brain stimulation (DBS) are established surgical treatments that effectively treat the symptoms of several neurological disorders such as Parkinson disease (PD), dystonia and tremor (19). The hypothesis driving such approaches is that pathological changes within the brain result in maladaptive neural circuits that "drive" specific symptoms, impacting on everyday function and reducing quality of life (20).

SA is traditionally performed using radiofrequency ablation. During this procedure, a stereotactic frame is used to guide a radiofrequency probe to the target via a small burrhole. A tiny volume of brain tissue around the tip of the probe is then coagulated using a high-frequency electrical current (Figure 1A; Box 1). Alternatively, incisionless methods can be employed to make stereotactic lesions, such as

Box 1. Patient experience during radiofrequency ablation

"Radiofrequency ablation" is a relatively simple procedure for expert brain surgeons and is done under a local anaesthetic. This means the patient can chat with the friendly neurosurgical team throughout the procedure.

The team infiltrates some local anaesthetic into the scalp and after a few minutes they attach the frame – a "stereotactic frame" – to the patient's head using surgical screws. This can feel a bit uncomfortable but is not painful. People say that the applied frame feels "like a tight hat". This is followed by an MRI scan. This process of attaching the frame and completing the scan takes about 30 minutes. Now we are ready for the actual surgery.

The surgeon makes a scalp incision around 3 cm long, about 2 cm behind the hairline and 4 cm to one side. The hair can be parted to allow the incision and no shaving is required. Next, a small hole is made in the skull using a neurosurgical drill that takes less than a minute. This is usually referred to as a "burrhole". This is like being at a good dentist in that the patient hears the noise and feels some vibration, but there is no pain.

The frame now guides the surgeon's probe to the exact part of the brain identified on the MRI. A high-frequency electrical current is then used to make the lesion. Since the brain has no sensory nerve endings, the patient feels nothing at all. The probe is removed and the procedure repeated on the other side. Now that the main business of the procedure is done, the surgeon uses small titanium plates to cover the burrholes and closes the scalp incisions with stitches or staples.

Finally, another MRI scan is performed to check that all is well, and the frame is removed. The marks of the frame attachment heal and disappear in about a week. The operation itself takes about three quarters of an hour, so even with the MRI scans and preparations, the whole process only takes about three hours in total.

Neurosurgery under local anaesthesia sounds like a daunting prospect and it is certainly not undertaken without careful consideration and meticulous attention to surgical technique. However, patients often comment afterwards that the experience was less traumatic than having a tooth filled. This is because the top of the head is much less sensitive than the mouth and has far fewer nerve endings.

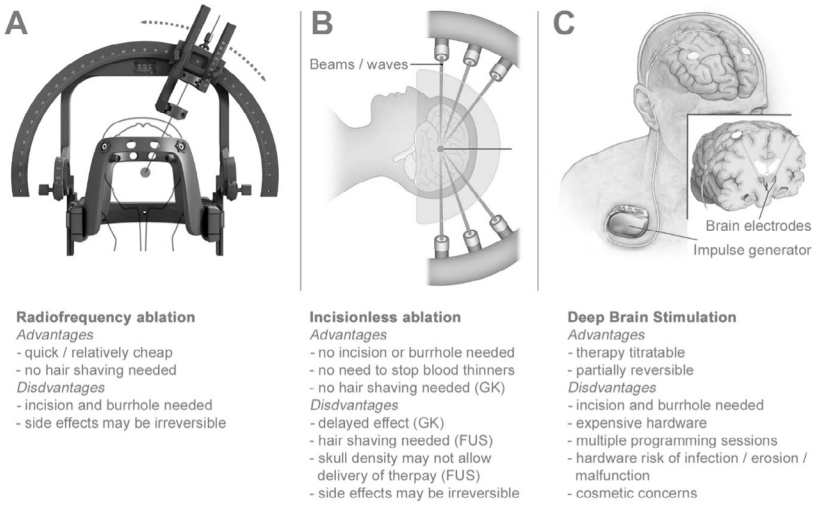

Figure 1. Principles of functional neurosurgery.

A. A stereotactic frame allows calculation of geometric coordinates of a visualised anatomical structure on specific MRI sequences. A minimally invasive approach then allows precise delivery of a radiofrequency probe to the desired anatomical location. A tiny volume of brain tissue around the tip of the probe is coagulated using a high-frequency electrical current.

B. Incisionless methods can be employed to make stereotactic lesions. MRI is again used to visualise the anatomical target. Focused gamma knife waves (from numerous radioactive cobalt sources) or ultrasound waves (from numerous piezoelectric crystals) deposit energy in the target, resulting in formation of a precise lesion.

C. Deep brain stimulation involves implanting brain electrodes that are connected to an internal impulse generator to drive a small high-frequency electrical current that disrupts neural transmission in adjacent brain tissue.

Abbreviations: FUS = focused ultrasound; GK = gamma knife.

gamma knife and MR-guided focused ultrasound (Figure 1B). DBS requires permanent implantation of brain electrodes and an impulse generator that drives a small high-frequency electrical current (Figure 1C). This effectively disrupts neural transmission in adjacent brain tissue and has the added benefit of a degree of reversibility. Each approach has specific advantages and disadvantages that are reviewed in Figure 1.

The same anatomical target can be used to alleviate a specific set of symptoms, regardless of the aetiopathogenesis of the disease itself. An example of this is the efficacy of SA or DBS of the motor nucleus of the thalamus on tremor, whether caused by cerebellar dysfunction (essential tremor), basal ganglia dysfunction (PD) or midbrain dysfunction (for example, Holmes tremor) (Figure 2).

Why consider neurosurgery in mental disorders?

As with some neurological disorders, many mental disorders are increasingly recognised as the product of abnormal activity within brain circuits (21). Class I evidence from multiple randomised, controlled trials supports the use of neurosurgical approaches in the treatment of some mental disorders, including OCD and Gilles de la Tourette syndrome (22-25). As with neurological movement disorders, there is some evidence to suggest that neurosurgery for mental disorders is a symptomatic treatment, regardless of the underlying diagnosis. For example, a recent meta-analysis of lesional neuropsychiatry revealed that anterior capsulotomy (disruption of the anterior limb of the internal capsule) resulted in a large and significant reduction in anxiety, regardless of the underlying psychiatric diagnosis (26).

How safe is stereotactic functional neurosurgery?

On the one hand, many non-specialists underestimate the physical and psychosocial dangers of AN. Imaging and other studies have demonstrated structural and functional damage to the starved brain (27). On the other hand, non-surgeons often overestimate the risk of modern neurosurgery. The most devastating complication in functional neurosurgery is haemorrhage leading to neurological deficit or death. However, this is exceedingly rare. Infection is exceptional in lesioning procedures; however, in DBS, the hardware may need to be explanted, leading to withdrawal of therapy. In a recent publication from our own institution, 4 of 650 DBS patients (0.6%) suffered transient neurological symptoms secondary to intracranial haemorrhage. Infection led to hardware removal in 21 of 650 patients (3.2%). Importantly, mortality was zero (28).

Psychiatrists are often concerned about the possible psychological sequelae of stereotactic ablative functional neurosurgery. Although data are scarce, several studies have compared detailed neuropsychology battery test results before and after SA for depression. All studies concluded that neurocognitive and personality testing were not significantly different at follow-up (29-32). Another study reported long-term improvements in fluency, inhibition function, set-shifting, decision-making and IQ scores in patients undergoing capsulotomy for OCD (33).

Should we consider neurosurgery in anorexia nervosa?

Anorexia is a pressing healthcare issue in dire need of novel treatments, especially for patients with longstanding illness. Campaigners and compassionate service providers will no longer tolerate a passive stance to such conditions and are demanding appropriate interventions. There is reluctance on both sides to enforce multiple admissions for the individual at exceedingly high financial cost. Despite such intensive interventions, recovery rates remain low at this stage of the disorder. This is exacerbated by difficulties gaining access to eating disorders services in the UK and

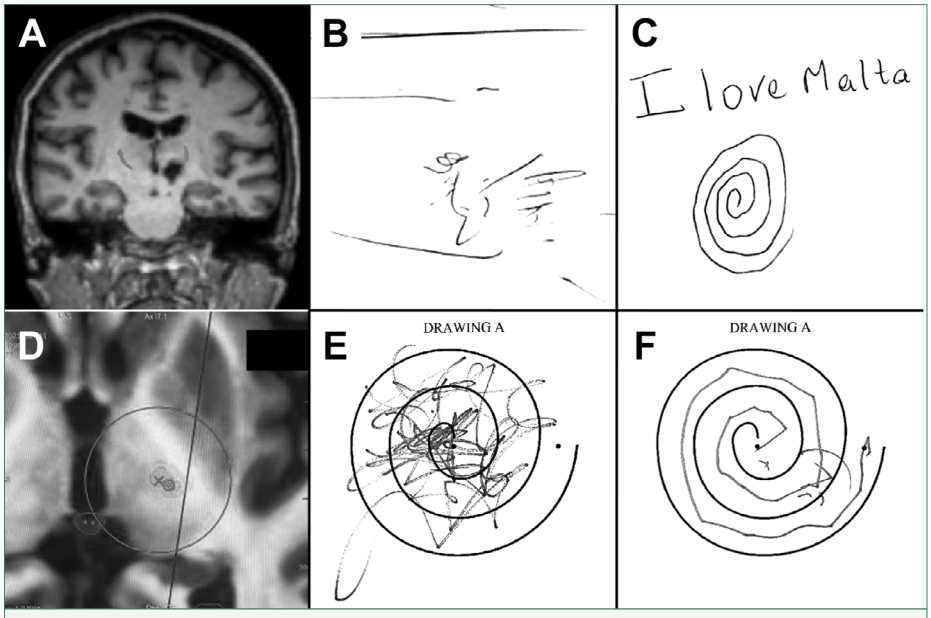

Figure 2. Using the same anatomical target in functional neurosurgery can treat specific symptoms, irrespective of the underlying pathology or surgical method.

Top row: Patient with Holmes tremor.

A. Coronal T1-weighted MRI showing left midbrain/thalamic cavernoma. **B.** Handwriting before surgery where the patient had difficulty keeping the pen in contact with the paper because of severe "flapping" tremor **C.** Handwriting after left radiofrequency thalamotomy.

Bottom row: Patient with severe essential tremor.

D. Axial FAT1 MRI showing planning of left focused ultrasound thalamotomy. **E.** Handwriting before surgery where the patient had difficulty following an Archimedes spiral because of severe tremor **F.** Handwriting after left focused ultrasound thalamotomy.

comparable nations. Meaningful improvement in the most severely affected individuals could break this cycle, improve quality of life and reduce the high mortality and morbidity associated with this condition.

As discussed above, there is an undeniable biological contribution to the aetiology of AN and considerable overlap with other psychiatric disorders, especially with OCD. A recent systematic review concluded that the obsessive-compulsive symptoms in AN are phenomenologically similar, though not identical to OCD alone (34). This is reinforced by genetic findings in the two disorders that were found to relate to the same areas of the brain (35). Therefore, the evidence-based success of neurosurgery in patients with severe refractory OCD gives hope that similar results may be achievable in AN, especially in patients with comorbid OCD symptoms. Moreover, the high mortality in individuals with AN on the extreme end of the clinical spectrum, combined with the relatively low risk of neurosurgical intervention, makes the option of neurosurgery particularly relevant.

What is known about stereotactic ablation for anorexia nervosa?

Stereotactic capsulotomy and stereotactic anterior cingulotomy are neurosurgical procedures performed for severe refractory OCD (Figure 3A and 3B). In patients who respond, reduction in anxiety and improvement in mood are accompanied by an improvement in the Yale-Brown Obsessive Compulsive Score (Y-BOCS), breaking the OCD cycle. Since stereotactic interventions are symptomatic therapies, this raises the hope that capsulotomy in individuals with AN, who also suffer from symptoms of OCD and anxiety, may lead to reduction in obsessive thoughts and anxiety pertaining to food and body image. Together with improvement in mood, this may provide numerous mechanistic opportunities to break the "anorexia cycle".

In a serendipitous observation, a patient with OCD, who also had AN, underwent bilateral anterior capsulotomy and reported significant improvement in both conditions (36). A more recent report of bilateral lesioning of the anterior capsule, cingulum and nucleus accumbens in a patient with comorbid AN and OCD resulted in improvement in both conditions (37). Notable in both reports is that gain in weight was accompanied by improvement in the underlying psychopathology (Box 2).

The largest dataset available is from an open-label study in 74 patients who underwent anterior capsulotomy for AN in Shanghai. Average (SD) body

Box 2. Outcome measures in anorexia nervosa

Outcome measurement in AN is challenging in areas of qualitative experience. Mental health professionals are still working to develop, validate and improve measures. These often involve self-rated or observer-rated questionnaires, and there is all too little uniformity across studies in their use. Since AN involves, at its core, an inability to tolerate a healthy body weight, it is convenient to use body mass index (BMI) as both a measure of how close to a healthy weight the psychopathology permits as well as a measurement of physical benefit. There is considerable evidence that nutritional recovery from starvation is essential – though not always sufficient – for psychosocial recovery from AN.

One limitation to the use of BMI in AN is that most good inpatient centres can impose weight gain on patients, using the Mental Health Act if necessary. Such weight gain may be transient and is not, in this case, an index of psychological recovery, or indeed of physical safety, if only short-lived. The best research therefore uses both BMI and symptom questionnaire measures in evaluation and pursues long-term follow-up.

mass index (BMI) improved from 13.6 (1.6) to 18.2 (3.4), $p < 0.001$, at 12 months and 19.3 (3.6) kg/m^2, $p < 0.001$, at 36 months after surgery. Significant improvements were also noted in anxiety as measured by scores on the Hamilton Anxiety Scale (HAM-A) from 21.6 (7.0), $p < 0.001$, to 13.1 (8.3) at 12 months and 12.3 (9.3), $p < 0.001$, three years after surgery. Improvement was also seen in mood, with mean Hamilton Depression Rating Scale (HAM-D) scores improving from 27.7 (11.1) to 16.9 (12.2), $p = 0.001$, at 12 months and 16.6 (13.9), $p < 0.001$, at 36 months after surgery. Long-term adverse events were disinhibition (6 patients), memory loss (3 patients), and lethargy (4 patients), although the severity of these was not described. Once again, weight gain improved together with the underlying psychopathology (38).

Incisionless neurosurgery for AN is in its infancy. A Madrid group has reported 40% improvement in BMI and 30% improvement in health-related quality-of-life scores after gamma knife anterior cingulotomy in six patients with AN (39). As yet, there are no publications on MR-guided focused ultrasound for AN. The need to undergo a complete head shave prior to focused ultrasound treatment may be problematic for individuals with significant body image concerns.

What is known about deep brain stimulation for anorexia nervosa?

Open-label pilot studies of DBS in AN have had some promising results. A recent meta-analysis identified four clinical studies with ≥4 participants. The anatomical targets used include the subcallosal cingulate gyrus (SCG) and the ventral capsule/ventral striatum (VC/VS) (a similar anatomical target to that used in capsulotomy) (Figure 3C).

In a study from Toronto, 16 patients with "treatment-refractory anorexia nervosa" underwent SCG DBS (40). One year after surgery, average BMI improved from 13.8 (1.5) to 17.3 (3.4) kg/m^2, $p = 0.0009$. Moreover, there were significant improvements in anxiety (mean (SD) Beck Anxiety Inventory scores, 38.0 (15.6) vs. 27.1 (18.4), $p = 0.035$) and mood (mean HAM-D scores, 19.4 (6.8) to 8.8 (7.6), $p = 0.00015$) (40). The same group has recently published longer-term outcome data in 22 patients with DBS for AN. Two patients died of complications of AN and there were several serious adverse events related to DBS, including seizures (n = 4) and surgical infections leading to hardware removal (n = 3). In the 15 patients who had ≥3 years of follow-up, mean BMI increased significantly from 14.0 at baseline to 16.3 kg/m^2 ($p = 0.003$). However, significant psychometric improvement was not maintained at cohort level (41).

A Spanish (Barcelona and Madrid) group have presented early open-label data in eight patients with AN who underwent DBS of either the SCG (n = 4) or VC/VS (n = 4). When examining preliminary results after six months, there was a significant increase in BMI ($p = 0.02$) in patients who did not undergo preoperative inpatient care to raise BMI. Across all participants, the authors also observed significant improvement in SF-36 quality-of-life scores ($p = 0.03$). Three of the eight patients suffered cutaneous complications that required further surgical intervention. This study represents the initial phase of a planned randomised, double-blind, controlled crossover clinical trial and longer-term data are eagerly awaited (42).

The Shanghai group that reported on capsulotomy for AN have also published their experience with 28 women with AN undergoing VC/VS DBS. They noted significant improvements in BMI and psychopathology after six months that were maintained at two-year follow-up. BMI improved from 13.0 (1.9) to 17.7 (3.5) kg/m^2 ($p < 0.001$), Y-BOCS from 20.5 (8.9) to 13.0 (9.6) ($p < 0.001$), HAM-A from 21.4 (8.5) to 12.6 (6.5) ($p < 0.001$) and HAM-D from 26.9 (12.0) to 15.9 (12.3) ($p < 0.001$). DBS was more effective for weight restoration in the restricting AN subtype than for the binge/purge subtype. The device had to be explanted in one patient (43).

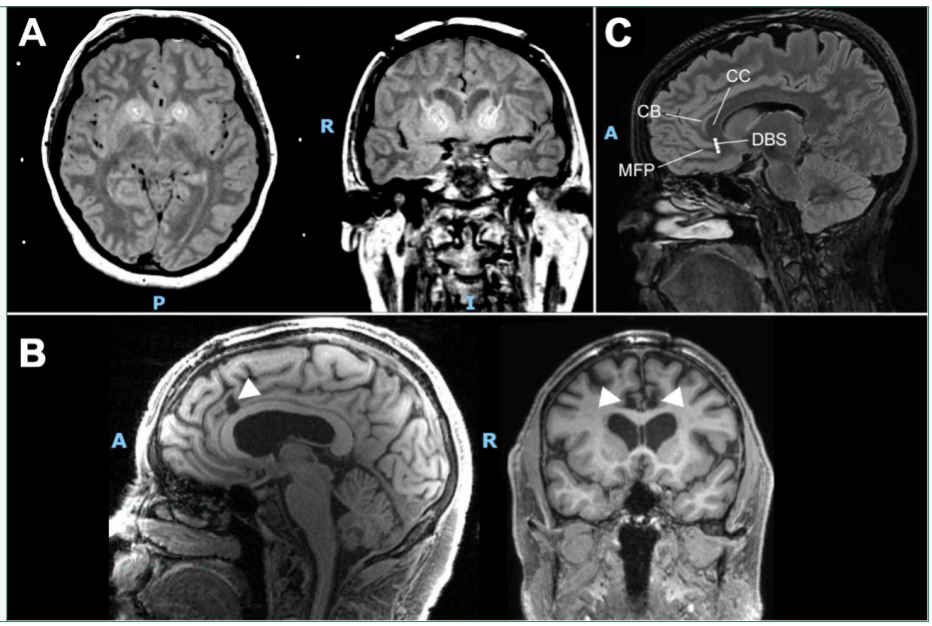

Figure 3. MRI after neurosurgery for mental disorders

A. Axial and coronal proton density–weighted MRI immediately after bilateral radiofrequency anterior capsulotomy. The hyperintense signal is mostly oedema and the permanent lesions are only around 3 mm in diameter.

B. Sagittal and coronal T1-weighted MRI, one year after radiofrequency anterior cingulotomy (arrowheads).

C. Sagittal MRI (fluid-attenuated inversion recovery) showing corpus callosum (CC), cingulate bundle (CB), medial frontal projection (MFP) and stylised deep brain stimulation (DBS) lead in the subcallosal cingulate gyrus, spanning both CB and MFP.

A further study from Amsterdam reported on four patients with AN who underwent VC/VS DBS. After 12 months, mean BMI improved from 12.5 (1.7) to 17.8 (1.7) kg/m^2 ($p = 0.028$). This was accompanied by significant improvement in psychopathology, including "preoccupation and rituals" and "restraint and eating concern". Mood also improved significantly with changes in the HAM-D and HAM-A scales of 36.7% and 47.9%, respectively. Two hypomanic episodes were reported as serious adverse events that were probably related to the intervention. The authors, a very experienced group in DBS for OCD, commented on the challenging nature of performing a DBS study in AN patients, and reported several severe adverse events, including "transient hypomanic and impulsive symptoms … and self-destructive behaviour" (44).

After collating the results of these four studies (n = 56), a recent meta-analysis concluded that DBS had a significant positive effect on BMI with a large effect size and without heterogeneity. DBS also had a significant beneficial effect on psychopathology, including eating disorder symptoms ($p = 0.006$), depression ($p < 0.001$), OCD symptoms ($p < 0.001$), anxiety ($p < 0.001$) and quality of life ($p < 0.001$). There was no suggestion of publication bias. The authors concluded that DBS can be an effective last-resort treatment option in selected cases of severe treatment-refractory AN, under strict monitoring and scientific evaluation of the effects (45).

Following the above meta-analysis, a further study of VC/VS DBS was published by the Oxford group in seven patients with AN. During an initial 12-month open-label period, three of seven patients had a positive response (defined as >35% improvement in the Eating Disorders Examination (EDE) score). Responders also experienced significant reductions in depression and anxiety scores. However, there were no significant changes in BMI. No serious adverse events were reported. This study also included a two-week double-blind, randomised, crossover study at the end of the open-label period with stimulation on/off. However, the short crossover period, small study size and relatively low initial response rate compared to other DBS studies make these findings difficult to interpret. Interestingly, the authors noted that the three responders had early-onset comorbid OCD and, for them, DBS "was experienced as a game-changing intervention" (46).

Stereotactic ablation after failed deep brain stimulation for anorexia nervosa

The Shanghai group have published an interesting case report where a patient with life-threatening, treatment-resistant restricting-subtype AN did not respond to VC/VS DBS. The DBS system was explanted and "rescue" bilateral anterior capsulotomy was performed. The was followed by long-lasting restoration of body weight (BMI 13.3 to 22.1 kg/m^2) and significant sustained remission in psychopathology and quality-of-life scores after seven years of follow-up. This individual also suffered from extreme comorbid OCD with Y-BOCS II scores falling from 46/50 prior to capsulotomy to 0/50 at long-term follow-up (47).

Ethical concerns with neurosurgery for anorexia nervosa

Functional neurosurgery should only be performed within the context of an experienced multidisciplinary team. In the case of AN, it is essential that this includes a functional neurosurgeon and a specialist eating disorders psychiatrist. Ensuring an individual has capacity and provides informed consent are essential aspects of any medical intervention. However, there are additional concerns in AN. There are deep cultural taboos against interfering with the mind and brain, and the profession of psychiatry still carries a burden of shame for having inflicted crude frontal lobotomies on psychiatric patients. Some individuals may not want to undergo SA because of its perceived irreversibility and their continuing ambivalence about losing their drive to lose weight; others may not wish to have an implanted device that may be seen as a form of "physician control" (48, 49). Moreover, surgery for mental disorders should only be performed in carefully selected patients within a framework of strong clinical governance and safeguarding (50). In England, mental health legislation ensures that every patient is reviewed by the Mental Health Board of the Care Quality Commission prior to undergoing surgery (51). This process ensures that vulnerable patients can provide consent, are fully informed of the potential risks and benefits and have symptoms refractory to other therapies that are severe enough to warrant a neurosurgical intervention.

Should we consider stereotactic ablation over deep brain stimulation in severe anorexia nervosa?

Although there are no "head-to-head" studies of SA and DBS in AN, there is some suggestion that SA may be preferable to DBS. Practically all the evidence for neurosurgery in AN is from open-label, uncontrolled studies. Nevertheless, the ultimate effect size on BMI is impressive. The largest study of capsulotomy in AN reported a mean improvement in BMI of 41.9% at three-year follow-up (n = 74) (38). A systematic review of DBS for AN calculated a mean improvement of 24.8% after a mean follow-up of 17 months (n = 118) (52). To put this into perspective, the highest level of evidence for pharmacotherapy in AN, a randomised controlled trial of olanzapine versus placebo, showed a mean BMI increase of 6.3% over four months, with no data available on longer follow-up (53). Of course, one cannot directly compare the results of randomised controlled drug studies with open-label trials of neurosurgical interventions, where the placebo effect is likely to be high. This is especially true of DBS that involves not only surgery, but multiple programming sessions. However, the effect size of capsulotomy on BMI appears to be even larger than DBS and is worthy of further investigation. A single head-to-head comparison exists in the form of a case report where capsulotomy led to significant long-term improvement of core AN symptoms and BMI after VC/VS DBS failed to make an impact (47).

Importantly, the evidence accumulated so far suggests that both neurosurgical interventions are accompanied by improvement in the underlying psychopathology, including anxiety, obsessive thoughts and compulsive behaviours. These lead to significant and sustained improvements in quality of life.

Reported deaths are limited to DBS patients (albeit not shown to be related to the intervention) suffering from erosion, infection, hypomania and seizures – complications that have not been reported and are unlikely to occur after stereotactic capsulotomy. On the other hand, 18% of patients undergoing capsulotomy reported some degree of disinhibition, memory loss or lethargy.

Other important aspects to be considered include the following.

Surgical factors: SA can be performed under local or general anaesthesia whereas DBS requires general anaesthesia for implantation of the cables and pulse generator. Patients with long-term AN often suffer from numerous cardiovascular, endocrine and metabolic abnormalities that increase the risk of general anaesthesia (2). Moreover, the thin skin and delicate tissues covering implanted DBS hardware is more likely to lead to erosion and infection, as is evident from published studies of DBS for AN.

Psychological factors: Body image concerns related to surgery are less likely with ablation as the scalp incisions are hidden behind the hairline. On the other hand, implanted hardware is likely to be visible and palpable through thin skin and scars on the chest wall are required for the implantable pulse generator. Adverse neuropsychological effects may occur with either procedure and could be permanent with ablation. However, the evidence available suggests that these are unlikely. DBS may also raise concerns about the potential for symptom rebound if DBS therapy is withdrawn because of hardware malfunction or infection requiring removal.

Cost and logistics: The cost of DBS is much higher than for ablation. A bilateral DBS implant with a rechargeable pulse generator can cost >£20 000 in hardware alone. Moreover, a specialised nurse or neuromodulation consultant is required to programme the DBS system over multiple sessions. This can be costly and time-consuming, even when programming patients undergoing "routine" DBS for PD, placing a significant load on already stretched healthcare systems. Finally, experienced DBS teams are rarely co-located with eating disorder specialists. Visiting different hospital settings can be a significant burden on patients. On the other hand, SA is a one-off procedure that is much faster and cheaper than DBS and does not require regular additional visits to the neurosurgeon/neuromodulation specialist over and above those to the eating disorder specialist.

Although there are many reasons why we should consider SA in long-term AN, ethical research into all promising therapies should be encouraged as each will have potential advantages and disadvantages. Ultimately, well-informed adult participants with capacity should be free to decide whether they wish to undergo a particular procedure and/or participate in an ethically approved research project.

Which anorexia nervosa patients should we consider for neurosurgery?

At the current stage of knowledge, neurosurgery should be restricted to adult patients with severe and enduring AN who have the capacity to provide informed consent. The criteria for severity and duration should be agreed by eating disorders experts with reference to the patient's age, length of illness and treatment history. There should be evidence of repeated unsuccessful previous treatments, with failure to improve or rapid relapse post-intervention. Treatments should have included courses of intensive specialist eating disorder inpatient treatment, both voluntary and compulsory, focusing on refeeding; and evidence-based specialist psychotherapies. To improve the chance of response, the available data suggests that comorbid OCD symptoms may be a predictor of good outcome. Patients with medical conditions that substantially increase the risk of a neurosurgical procedure should be excluded. It goes without saying that surgery should be undertaken only in highly reputable specialist centres with a good track record of surgery for psychiatric disorders, and in the context of ethical research protocols.

Limitations

The overall number of reported patients who have undergone functional neurosurgery for AN is relatively small. Moreover, the bulk of the data available for stereotactic capsulotomy in AN derives from a single relatively large study from Shanghai. It remains to be seen whether these results can be reproduced by other centres.

Conclusion

AN is a pressing healthcare issue in dire need of novel treatments, particularly when it has become chronic with associated severe psychosocial and psychical disability. Difficulty gaining access to eating disorder services is exacerbated by the high need for multiple admissions for the individual at exceedingly high cost. Despite intensive interventions, recovery rates remain low. Meaningful improvement in the most severely affected individuals could break this cycle, improve quality of life and reduce the high mortality and morbidity associated with this condition. Functional neurosurgery for AN seems promising but there is much scope and need for further research. It is not yet clear how patients, carers and clinicians will perceive the idea of different neurosurgical procedures for AN. Patient selection criteria will need to be developed and refined. Although several outcome measures have been used, clear definitions of response

and remission in AN remain elusive.

Over the past century, patients with movement disorders have benefitted greatly from collaboration between neurologists and neurosurgeons. Patients with mental disorders should also benefit from increased collaboration between the clinical neurosciences. The available evidence is far from conclusive. However, it suggests that AN is a potentially rewarding area for greater collaboration between functional neurosurgeons, psychiatrists specialising in eating disorders and their patients.

Funding and acknowledgements

The Functional Neurosurgery Unit is supported by the National Institute for Health and Care Research University College London Hospitals Biomedical Research Centre.

Declarations of interest

Ludvic Zrinzo acts as a consultant for Medtronic, Boston Scientific, and Insightec.

Jane Morris has written and edited books on eating disorders for CUP and Springer.

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Informing the development of intensive outpatient programmes for eating disorders in children and young people: learning from service leads' experience

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Abstract

Introduction: The field of eating disorders (EDs) has evolved dramatically in recent years, with an increasing focus on community treatment because of better acceptability, both to children and young people (CYP) and parents/carers. Furthermore, this may provide a more cost-effective approach than inpatient care.

Aim: This study aimed to explore the perspectives of service leads operating intensive outpatient programs (IOPs) for CYP with EDs. To achieve this, we convened advisory groups composed of current service leads and conducted focus group sessions.

Methods: Advisory groups of service leads in established IOPs across England participated in focus group sessions to discuss initial successes and challenges in setting up IOPs for CYP with EDs. Four virtual focus groups were conducted via Microsoft Teams between December 2022 and January 2023. Sessions were recorded, transcribed and analysed using inductive thematic analysis to identify key themes.

Results: Four main themes were identified for the successful running of IOPs, (1) approach, (2) team considerations, (3) patient considerations and (4) commissioning. A key sub-theme emphasised the importance of flexible and creative approaches in IOPs to supplement existing evidence-based therapies.

Conclusion: IOPs for EDs appear to enable improved community treatment tailored to individual patient needs. They are flexible, equally effective and less disruptive to the young person's development than inpatient care.

Introduction

Background

Eating disorders (EDs) represent a diverse and complex spectrum of mental health conditions characterised by significant psychological, physical and social risks. Among these, anorexia nervosa is particularly concerning, as it is associated with the highest mortality rate of any psychiatric disorder (1). Following the COVID-19 pandemic, there has been a dramatic increase in both the number of ED presentations and their clinical severity. This has increased demand for ED-related hospitalisations and other intensive treatment options (2). Because the number of inpatient beds has stayed the same, alternative non-institutional care options have been encouraged (3).

Eating disorder services

The current provision for community ED services in England consists of outpatient services, referred to as "core ED services" in this paper. Enhanced provisions include daycare, intensive outpatient programmes (IOPs) and inpatient services. Daycare services are limited and available in only a few areas, offering structured daytime support without overnight stays. IOPs, a more recent option, provide an intensive, flexible treatment approach, offering several weekly sessions for patients requiring additional support but not inpatient care. IOPs serve as a step-up from outpatient care to prevent admission or as a step-down for those transitioning from inpatient care back into the community. Inpatient services include acute paediatric/medical units for medical stabilisation and adolescent psychiatric or ED units focusing on mental health components of care. This raises the question of whether the current service model effectively addresses patient needs or if an alternative approach would better enhance patient care and outcomes.

Research by Derenne (4) has highlighted the importance of early and easy access to specialist ED services. It significantly enhances the likelihood of effective intervention and reduces the risk of the disorder becoming more severe and entrenched over time. This was the basis of the 2017 investment into child and adolescent community ED services. The landscape of EDs has evolved dramatically in recent years, notably following the COVID-19 pandemic, with an upsurge in referrals and increasing clinical severity at initial presentation (5). The pandemic resulted in more than a doubling of routine and urgent referrals to ED services, with longer waiting times leading to patients becoming more unwell at presentation (5).

A systematic review that looked at the impact of the COVID-19 pandemic on EDs demonstrated a sizeable increase in paediatric admissions into general and specialist child and adolescent units (5). This spike in activity and demand for resources required services to consider a flexible, creative, yet enhanced way of working with patients in a community setting, before the step up to daycare or inpatient services (6).

The Child and Adolescent Mental Health Services Provider Collaborative was set up in April 2020 (7) to reduce the number of young people treated far away from home and the length of inpatient stays. This action was consistent with the findings of a study that compared the effectiveness of inpatient and outpatient care (8), which demonstrated that for the core EDs (anorexia nervosa, bulimia nervosa and binge eating disorder), there might be little or no difference between specialist inpatient care and active outpatient or combined brief hospital and outpatient care in weight gain at 12 months after the start of treatment. This study highlighted the importance of outpatient services by demonstrating similar outcomes to inpatient treatment for patients with EDs. It showed that there was no apparent difference in outcome for patients with ED being treated in inpatient settings compared with those being treated in the community. Furthermore, community options have been found to be more cost-effective. The concept of the IOP is consistent with these findings, offering an enhanced community option with high-quality clinical care closer to the patient's home.

Beating Eating Disorders (Beat), a UK-based charity dedicated to supporting individuals affected by EDs and improving awareness about these conditions (1), has recommended that investment in these intensive programmes be resourced from cost savings from the resulting reduction in inpatient care. In contrast, the net savings generated through the intensive teams should be reinvested in early intervention to enable more positive outcomes.

A scoping review (2) highlighted two critical studies on IOP outcomes for EDs. One study showed that an IOP offer resulted in significantly better weight gain than a standard outpatient offer. Another study showed that an IOP had similar outcomes in terms of weight and ED symptoms to a daycare offer but was more cost-effective (2).

Beat (1) identified that the benefits of IOPs were not only financial but that there was evidence to suggest that families felt more empowered and that treatment gains could be directly applied to the home environment, leading to more sustained change. In addition, IOPs have been found to minimise disruption to education and social relationships; they also provide a sense of normality compared to inpatient units, reducing the impact on the individual's outcome developmental trajectory both in the immediate and long terms.

Aims

This study aims to explore the successes and challenges of establishing and managing IOPs for children and young people (CYP) with EDs. The findings will contribute to the initial draft of the Revised National Access and Waiting Time Standards for Eating Disorders (9) by building on an understanding of the current landscape and the obstacles faced in delivering effective care.

Methods

Participants and sampling

Advisory groups were convened, comprising existing service leads in established IOPs, to provide insights into the successes and challenges of these programs through several focus groups (FGs). Participants were recruited through advertisements distributed via the mailing lists of the Eating Disorder Specialist Interest Groups (EDSIG) and the British Eating Disorder Society and through direct invitations to known experts leading such services.

Procedure

All participants provided verbal or written consent to participate and for the FGs to be recorded for transcription. Participants were divided into four online FGs through Microsoft Teams between December 2022 and January 2023. Each FG lasted 90 minutes. All responses were pseudo-anonymised.

The topic guide for the FGs was developed collaboratively with the group of professional ED colleagues who were part of the Child and Young People Task and Finish Group for the Access and Waiting Time Standard revision (due for publication in 2025). The FGs were semi-structured, with topic guide questions and space for discussion. The topic guide used in the FGs is provided in Appendix 1.

FG1 and FG3 covered the first half of the topic guide, and FG2 and FG4 covered the latter half. The FGs were led by one author (E.C.) who directly interacted with the group and asked the questions. The other author (K.S.) was involved in setting up and recording the FGs and then transcribing the recordings verbatim.

Analysis

Discussions were transcribed verbatim using the Microsoft Teams automatic caption generation software and manually checked for accuracy. The transcriptions were analysed inductively following Braun and Clarke's six phases of thematic analysis (10). Themes and subthemes were clearly defined to reflect the discussion's content accurately.

Data saturation

Assessing data saturation followed the Guest paper approach (11), which used the following three components: (1) base size, the total number of new themes generated from the first two FGs, which covered the whole topic guide; (2) run length, assessing how many new themes emerged in FG3 and FG4 and additional runs of the whole topic guide; and (3) new information threshold, where after each run, the proportion of new information, or the "saturation ratio", was calculated, with data saturation achieved at equal to or less than 5% of new information generated.

Results

Participants

A total of 14 participants (12 female, 2 male) contributed to the study. Due to some participants attending multiple FGs, the total attendance count exceeded the number of unique participants. On average, five participants attended each FG, with specific group sizes as follows: FG1 = 5, FG2 = 4, FG3 = 5 and FG4 = 6.

The participants were affiliated with NHS trusts across nine regions in England: London, Oxford, Surrey, Gloucestershire, Leicester, Cheshire, Manchester, Northumberland and Cumbria. Across all FGs, representation included six participants from London trusts, three from Surrey trusts, two from Manchester trusts, two from Cheshire trusts, two from Leicestershire trusts and one each from Oxford, Gloucestershire and Cumbria trusts. These numbers reflect cumulative participation, accounting for individuals who contributed to more than one FG.

All participants held senior roles within IOPs and were actively involved in establishing these services. The professional roles represented included consultant psychiatrists (n = 6), operational team leads (n = 3), clinical lead nurse specialists (n = 3), a clinical psychologist (n = 1), and a senior occupational therapist (n = 1).

Thematic analysis

Four higher-order themes emerged from the FGs: approach, team considerations, patient considerations and commissioning. These are indicated alongside the lower-order themes in Figure 1.

Data saturation

The base size was the number of themes that emerged from the first two FGs, which identified 17 themes. The third and fourth FGs met data saturation, as the proportion of new information added was 0%. This is below the 5% threshold needed to achieve data saturation. Appendix 2 contains details of the data saturation analysis.

Approach

A prominent theme emerging from all the FG discussions was the approaches taken to maximise the success of IOPs. These included the importance of having an individualised approach that may need to consider creative ways of engaging the young person.

Flexibility

One of the most prominent subthemes was the importance of the service being "flexible" to address individual patient and family needs. This meant that professionals found themselves "thinking outside the box" and finding creative ways of engaging patients.

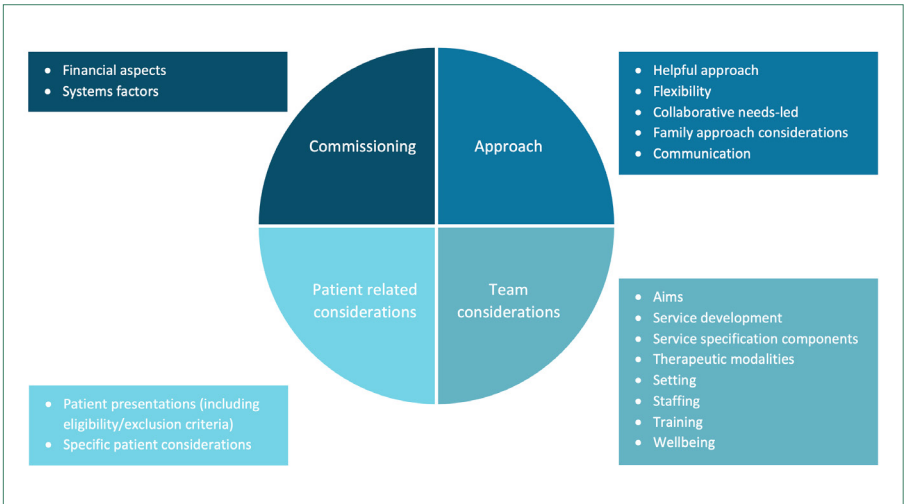

Figure 1. Themes and subthemes generated from focus groups

The idea of flexibility arose in various areas, including the intensity and duration of treatment, location (e.g., community clinic, paediatric ward, patient's home, virtual support), thinking creatively about ways of engaging patients and providing additional support alongside the evidence-based treatment offered by the core ED team. There was a consensus that working in adaptable ways with less rigidity allowed each patient's needs to be managed within the individual and family context in which they arose. It was noted that, by being flexible, health professionals were seen to be more responsive and attuned to changes in presentation rather than following a specific protocol for a "one size fits all" approach.

Helpful approaches

It was found that demonstrating a motivational, empowering and validating approach allowed patients to develop more self-efficacy in their treatment and stronger therapeutic alliances with staff. Stronger relational foundations made it easier for staff to challenge behaviours and enable meaningful changes. Parents found it helpful when staff modelled containment – the therapeutic process by which a caregiver or therapist provides a stable, empathetic and non-judgemental environment that helps individuals manage and process their intense emotions. The relational containment that develops through the IOP enables parents to trust the process and feel empowered, which, in turn, allows the young people to trust their parents and helps them feel safe. This process helps to unlock the young person's "stuckness" and allows them to progress in their treatment (12). Professionals found that it was favourable to allow families to build up confidence in tackling the ED to prevent issues of dependence developing.

Collaborative needs-led

Collaborative working emerged as a crucial approach for engaging with patients, families and the broader network of professionals, fostering a sense of ownership and promoting personal responsibility. A needs-led approach enabled a more targeted and individualised focus, tailoring care to each patient's specific requirements. Outside the constraints of the Mental Health Act of 1983, informal work with patients was noted to foster more trusting relationships, leading to increased cooperation. Consistent communication among health professionals was identified as critical to maintaining cohesive care and preventing fractures in service delivery.

Family approaches

Observing the young person and the family in their home environment allowed a deeper insight into family life and relationships. Supporting families by giving parents time and space to address their concerns, offering containment for distress and encouraging families to draw on support networks was helpful. One trust offered caregivers cafés, allowing families to connect, provide peer support and share ideas to reduce feelings of isolation.

Communication

Trust was built by having honest and open dialogues with patients and their families. Similarly, setting clear expectations of what the IOP offers was helpful. Specific communication challenges were identified, namely team conflict, staff burnout, less reflective capacity and staff struggling to contain their anxiety regarding complex cases.

Communication across different services was deemed essential to ensure continuity of care, including linking with the inpatient wards, regular community teams and paediatric wards. However, it was noted that different services often had other priorities, which could impact patient care if not discussed and navigated sensitively, allowing a collaborative care plan to be developed. For example, bed pressures on acute services could result in a patient being discharged as soon as they were medically stable despite still struggling to eat solid food. In contrast, ED community services would argue that extending the admission might support the reintroduction of regular eating in a contained

Sub-theme	Quotation
Flexibility	"We adapt very quickly according to our problems in running the service. Part of the culture of the team is constantly thinking what is working, what is not, let us change it and see what happens." FG1, P1.
	"I think it is about flexibility and tailoring everything to that family and individual." FG1, P4.
Helpful	"Intensive intervention for me is about first of all empowerment, but empowerment for lots of different people probably." FG1, P3.
	"Managing high state of concern and anxiety and that tends to be the first bit that we work with. We just offer that consistent and hopefully compassionate support as well." FG4, P6.
Collaborative needs-led	"We also work voluntarily and cooperatively with patients. So, we have a different relationship to the Tier 4." FG1, P1.
	"Through intensive work within the family, we identify key problems that needed addressing and from a different perspective as well." FG1, P2.
Family approach	"As the intensive team we have the ability to not just get to know young people, but we get to know the parents really well." FG1, P3.
	"Lots of families can, you know, put on a front in the clinic. People behave differently in their own homes. There's something important about it being in vivo as opposed to in the clinic." FG1, P2.
	"What are the needs of families? And no two families in my experience over 22 years and in a scene with ED nor ED is the same." FG1, P4.
Communication	"Setting clear expectations and boundaries of 'Look OK, we know this is part of a wider picture, but for the next six weeks, this is what we can support you with again'." FG4, P3.
	"You get to know the family on kind of a deeper level, I guess. And so, then when it comes to coaching, because of the relationship, you can kind of challenge the parents a bit more." FG1, P3.

Table 1. Quotations for the theme "Approach"

environment and, with their support, avert a specialist ED unit (SEDU) admission.

Team Considerations

Another significant theme was Team Considerations. Several sub-themes arose, as follows.

Aims

Some common aims for IOPs emerged. These were as follows: offering enhanced support within the community; reducing the number of admissions and length of inpatient stay; providing a more cost-effective treatment option; maintaining a realistic view of what can be offered; having a clear definition of what the IOP should involve, with consideration of local context; providing integrative transitional care between paediatric wards and inpatient units; offering evidence-based treatment; and managing psychological and physical risks.

Service development

Service development considers the appropriateness and limitations of IOPs.

IOPs may not be the preferred pathway in certain circumstances, and it is essential to recognise when they are not working for a young person or family. Participants highlighted that individuals with severe medical complications, active suicidality, psychosis or substance use disorders often require the intensive monitoring of inpatient care. Additionally, logistical challenges, such as long travel distances or insufficient family support, can hinder the feasibility of IOPs. Tailored assessments remain crucial to determining the most suitable care approach for each individual.

Service specification

Due to the geographical areas covered by the services, travel duration was necessary to consider when setting up IOP services. In addition, the IOP model showed some variation in what was offered between different trusts.

Therapeutic modalities

Various therapeutic modalities were utilised in IOPs across England. Family-based treatment was the primary option.

Sub-theme	Quotation
Aims	"We have developed our intensive pathway because of the significant increase in referrals for acute food and food restriction type problems and the difficulties in managing those on paediatric wards." FG4, P2.
	"Young people can become emotionally and developmentally behind from having inpatient admissions." FG1, P4.
	"The clear remit of intensive pathways is in reducing Tier 4 admissions." FG1, P1.
Service development	"I think we also have to be careful that with intensive treatment we are not keeping going and going and going and going to the detriment of that young person." FG2, P3.
	"I think we pretty much knew within two weeks whether people are going to be able to do it in the community." FG1, P4.
Service specification	"There is a huge amount of geographical variation and so it is difficult to have a blueprint for a service because what works in one area is not necessarily going to work in another area." FG4, P2.
	"You've got to bear in mind the amount of travel time and whether it, you know, whether you actually employing staff to sit in their cars most of the time rather than to actually be dealing with families." FG2, P1.
Therapeutic modalities	"And I guess the models we follow include [family therapy for anorexia nervosa] type principles, [family-based therapy] and [cognitive behavioural therapy] elements as well that might be appropriate." FG2, P4.
Setting	"So, we have an in-reach and outreach section of what we're delivering. If we've got a patient in paediatrics, then we go in and we support them there. We kind of follow wherever the patient is." FG2, P4.
	"When they're at risk of Tier 4, that's when we think about the enhanced pathway and we add in very little, we enhance what's already there." FG2, P3.
Staffing	"And a much higher staff-to-patient ratio so that we can add in two workers per family, and everybody is trained in [family therapy for anorexia nervosa]." FG3, P2.
	"I think the [occupational therapy] complement is you know fantastic in kind of thinking about that loss of identity and supporting young people on that side of things." FG2, P4.
Training	"Integrated working is actually what we've been doing and offering consultation to non-ED clinicians to kind of think about that." FG2, P3.
	"We rolled out huge amount of training and support, but because the entire staff cohort is pretty much different now a year later, we're now revisiting that again." FG4, P1.
Wellbeing	"That kind of very supportive or reflective pace, we do an awful lot of group formulation." FG4, P1.
	"Obviously there's regular clinical supervision that everybody has and a monthly intensive care pathway professional meeting where we're just brainstorming some of these things." FG4, P5.

Table 2. Quotations for the theme "Team considerations"

IOPs also utilised additional therapies to help with specific ED symptoms, such as body image distortion,and co-morbidities, such as trauma, obsessive-compulsive disorder, depression or emotional dysregulation. These included cognitive behavioural therapy for eating disorders, dialectical behavioural therapy, cognitive analytical therapy, eye movement desensitisation and reprocessing, self-care and systemic working. For parents, specific interventions included coaching, training in meal support and parent groups.

Setting

The intensive pathway can provide various settings depending on the patient's context, including enhanced, hybrid, home-based, and in-reach services. Enhanced services offer more than the standard outpatient care, with more than two sessions per week. Hybrid services combine in-person and virtual reviews and support. Home-based services mainly or entirely occur in the patient's home environment. In-reach services provide support while a patient is in an inpatient or in a SEDU.

Staffing

From a staffing perspective, running an IOP involved multiple aspects. Leads recognised the need for higher staff-to-patient ratios and a cohesive multidisciplinary team, including psychiatrists, nursing staff, psychologists and occupational therapists.

Training

Areas of learning that were essential for working within an IOP included therapeutic training, managing difficult conversations, advanced communication and physical health training (performing phlebotomy, nasogastric (NG) tube insertion and electrocardiograms (ECGs)). It was recognised that training needs to evolve in response to new demands and presentations, alongside accommodating staff turnover and ensuring that new staff are adequately trained. Teaching colleagues at the interface of intensive pathways, including community, paediatric and primary care teams, is essential.

Wellbeing

Maintaining the wellbeing of the professionals is crucial for the service to function optimally and for staff to model resilience. This was felt to be particularly relevant with the ongoing pressures faced by working for the NHS after the global COVID-19 pandemic and the significant rise in ED referrals. The first step was to educate colleagues on identifying burnout in themselves and each other. Reflective spaces were found to help process the challenging aspects of the work together and to reduce isolation with these experiences, alongside regular supervision to maintain coping.

Patient considerations

Another core theme was patient considerations, which were subdivided into patient presentations and specific patient considerations.

Patient presentations

There were many commonalities in patient presentations between the different IOPs. The patients were generally medically compromised and on a deteriorating trajectory, had high complexity, were at risk of hospital admission and had rapid weight loss over a short period. In addition, there were sometimes safeguarding concerns and atypical presentations with extreme functional impairment. Some services did not accept patients who did not meet the full criteria for a diagnosis of an ED or who were exhibiting high levels of interpersonal violence. There were specific patient groups, for example, those requiring NG feeding, those with a comorbid personality disorder or traits and those with neurodiversity, which divided professionals on whether IOPs were an appropriate service for them. There was no universal agreement between different service localities. Patients with comorbid personality difficulties benefited from psychotherapeutic work, supporting the management of the personality traits. It was helpful for ED professionals to have specific training on understanding autism because many neurodiverse patients have EDs. The PEACE pathways (13) were developed for adults with comorbid EDs and autism, emphasising the need for an individualised approach. While the PEACE pathway is adult-specific, adaptations for CYP, such as the BOB PEACE Project, apply similar principles to this younger demographic (13).

Specific patient considerations

Engagement with the IOP, management of dual diagnosis, transition of care between different healthcare interfaces, trajectory consideration, competitiveness, attachment, comorbidities (see above) and consideration of patient dynamics and ambivalence around recovery are all patient-specific considerations that were highlighted.

Commissioning

A further theme focused on commissioning, covering financial and systematic factors.

Sub-theme	Quotation
Patient presentations	"What we're having to do now is fill that gap of really, complex cases where there's nowhere to go and we have to come up with some kind of creative solution to calm the anxiety of the paediatric ward or the social care." FG4, P4.
	"We do not do [nasogastric tubes], it would just be a minefield, and I don't think we can safely manage it now. So unfortunately, if there are [nasogastric tubes] then it would have to be inpatient management." FG2, P4.
	"The majority of patients that we are seeing are neurodivergent. And so actually, they need longer to get used to us, to build up a relationship, and to feel safe with us. So that is why we have kind of extended the pathways a bit." FG2, P4.
Specific patient considerations	"And something that's been positive has been supporting transition from a paediatric unit to home or supporting transition from specialist units to home." FG3, P1.
	"And just trying to, if I guess, almost being that safety blanket to help reintegration to the community, so it's not quite so overwhelming and sometimes that also looks like kind of going into schools and helping manage kind of concerns around eating." FG4, P2.
	"There's a few that are wanting to be more severe and a little bit of competition, competition of why am I not Tier 4 or what? That kind of mentality of the ED cognitions." FG4, P3.

Table 3. Quotations for the theme "Patient considerations"

Financial aspects

A business case with a precise aim, rationale and performance indicators was helpful when requesting and negotiating commissioner funding. Demonstrating that IOPs are cost-effective and clinically practical will be vital to establishing their clinical utility within the ED service framework.

Systemic factors

Teams must work together within a systemic framework to improve and create a holistic care plan. Resources must be allocated so that aspects such as staffing, individualised care offers and available funding are optimally utilised while ensuring care is not provided on a postcode-lottery basis.

Discussion

This study provided an opportunity to explore the critical features of setting up and running existing IOPs for EDs.

Key findings

Fourteen health professionals attended the FGs. Thematic analysis identified four core themes and 17 associated subthemes that might be useful when setting up and running an IOP service.

Relevance

There is an increasing demand for specialist outpatient and intensive treatment options for ED services in the UK and across Europe (14), which has led to the implementation of alternative intensive services, including IOPs. However, despite preliminary evidence of their effectiveness, IOPs remain limited to specific areas in the UK and are not widely accessible (15).

The findings of this report demonstrate that existing IOP services vary in several aspects including modality, setting, therapeutic model, eligibility criteria, intensity and whether they are standalone or adjunct services. These variations appear to depend on resource availability based on geographical location and local funding, in combination with clinical decision making. The variety in IOP implementations described in the current report is in keeping with a scop-

Sub-theme	Quotation
Financial aspects	"We don't want something to be sort of dogmatic across the board, but we want to give pointers because each service then needs to adapt it. And what capacity there and their population, borough distances." FG2, P3.
	"In terms of justifying the implementation of intensive outreach services, it's about using evidence at what is best in terms of patient prognosis, you know, i.e., preventing relapse and you know good qualities of life and so on." FG4, P2.
System factors	"Thinking from a commissioning perspective, if there is such a great variety, it can make it difficult then to have consistency when commissioners making decisions about these things." FG1, P2.
	"I think the key is when we're looking at getting resources and things, what's helped with our commissioners is being clear." FG2, P2.
	"It's very helpful for us or has been with the access and waiting times when they've specified structures of staffing." FG1, P3.

Table 4. Quotations for the theme "Commissioning"

ing review on IOPs published in 2023 (2), in which similar differences in service design were found. These differences highlight the importance of studies to evaluate the effectiveness of IOPs and the obstacles to setting up these services. The current report aims directly to address these issues.

Interpretation of findings

Approach

The focus on helpful approaches allowed for strong relational foundations with the CYPs and their families. This mobilised change more successfully by providing an environment where ED behaviours could be challenged, complex topics could be discussed more efficiently and patients could be supported to form social attachments again.

It is recognised that strong therapeutic relationships can allow an increase in mentalisation for CYPs and their families and facilitate the individual to think about their internal world and those of others. This ability to believe is often impoverished in those with EDs, which can contribute to the perpetuation of the disorder (16). The intensity of IOPs can offer essential support for parents through containment and avoiding parental burnout, resulting in better outcomes. Parental burnout, in particular, can have a detrimental impact on treatment outcomes for patients with EDs (17).

Intensive input increased families' confidence, making the system around the young person feel more robust; it has been shown that forming a positive alliance with parents and adolescents can improve outcomes in EDs (17).

Team considerations

A crucial responsibility of the IOP team is to identify when the approach is not working for an individual. Although NICE guidelines (18) recommend that most patients with EDs should be treated in the community, inpatient admission must be considered if physical health becomes severely compromised. Staff must be aware of the limitations of IOP interventions and liaise with the relevant services to support patients. Contributors to the current report suggested that the efficacy of the IOP should be evident as early as two weeks into the programme.

Patient considerations

There were mixed views on the inclusion of patients with comorbid autism or personality disorder in IOPs. Whether this is feasible in a given context will mainly depend on staff training and the particular skills of the multidisciplinary team. Another contentious aspect was whether to accept patients who are undergoing nasogastric tube feeding in the community without the risk of causing iatrogenic harm, including iatrogenic anorexia, a term describing the inadvertent role clinicians may play in maintaining EDs (19).

Commissioning

The importance of capturing the clinical effectiveness of IOPs to demonstrate their cost-effectiveness was also highlighted, along with the importance of clear aims for commissioners.

Inpatient treatment for EDs is significantly more expensive than community-based treatment options, both in the short term and the long term, as evidenced by studies such as that by Crow et al. (20), which highlight the higher costs associated with inpatient care. Moreover, patients discharged from inpatient care and provided with access to intensive community options can be supported to have shorter future admissions, which are more cost-effective (21). Implementing IOPs aligns with the NHS long-term plan for CYP with EDs, which recommends treating patients closer to home (7).

Strengths and limitations

This report was one of the first to indicate how health professionals can set up and run IOPs for CYP with EDs in England. It aims to describe existing principles of practice. It is not a formal evaluation or research study; more formal research still needs to be performed.

The participants recruited were in clinical and managerial roles for their IOP, which allowed an expert view of the organisational aspects. However, this may also have been a limitation, and a broader range of views should be sought in future evaluations.

A further limitation was that participants in the FGs worked in trusts in England, with no representation from Scotland, Wales, or Northern Ireland, which limits the generalisability of the results across the United Kingdom. The number of participants was also relatively small.

It was beyond the scope of this report to gather views from patients and carers/families on their experiences of IOPs, although it is noted how imperative it is to integrate all views when developing an acceptable and successful service.

Future work

IOPs for EDs offer a flexible and effective alternative to inpatient care, enabling tailored community treatment that minimises disruption to a young person's development. Enhancing outpatient support facilitates managing higher levels of risk within the community setting. However, while promising themes have emerged from existing services,

further studies exploring patient, family and clinician experiences with IOPs will provide valuable insights to guide their evolving development and implementation.

Supplementary material

The supplementary material for this article can be found online at https://www.cepip.org/article/informing-development-intensive-outpatient-programmes-eating-disorders-children-and

Declaration of interest

The authors have no conflicts of interest.

Funding

No funding was received in relation to this manuscript.

Acknowledgements

The authors thank the participants who gave up their time and shared their expertise on IOPs during the focus groups.

Author contributions

EC conceptualised and designed the report. EC and KS were involved in formulating the report. EC and KS organised, facilitated, and analysed the focus groups. EC and KS drafted and edited the paper. Both authors read and approved the final manuscript for submission.

Transparency declaration

Both authors affirm that the manuscript is an honest, accurate, and transparent account of the reported themes, that no important aspects of the report have been omitted, and that any discrepancies from the report as planned (and, if relevant, registered) have been explained.

Data availability

The data supporting this report's findings are available on request from the corresponding author, EC. The complete data is not publicly available because it contains information that could compromise the participants' privacy.

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Eating and feeding management of eating disorders and the role of the dietitian

More than just a meal plan: the wider role of the dietitian in eating disorder treatment

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Abstract

Eating disorders are serious psychiatric conditions which severely compromise the ability to engage in normal day-to-day living. National guidance recommends that patients are treated not by individuals but a multidisciplinary team. In the past, dietitians have been excluded from some manualised treatments for eating disorders and this has led to poor investment within some teams. However, the dietetic role goes beyond refeeding management and meal planning. This paper highlights the multiple areas where dietitians have been embedded within specialist teams and have developed advanced practice. It also explores how dietitians can bring their expertise to all areas of eating disorder treatment, including meal support, prescribing, nasogastric feeding and therapy, including, but not limited to, all variations of eating disorder cognitive behavioural therapy, family therapies for eating disorders, guided self-help and specialist supportive clinical management.

Keywords: dietitian, feeding and eating disorders, outpatient, inpatient, nutritional therapy, dietetic counselling

Introduction

Eating disorders (EDs) are multidimensional heterogeneous conditions, interlinked with complex psychosocial features, and are associated with some of the highest premature psychiatric mortality rates (1-3). Across all EDs, features include disordered eating and problematic compensatory behaviours, which can have a significant negative impact on mental health and wellbeing (4-6). Consequently, the inclusion of medical, psychological and dietetic input as part of a multidisciplinary team (MDT) approach has been recommended by consecutive national practice guidelines (7-9) and clinical practice standards (10, 11).

Dietitians are an under-represented profession within ED services (12) and their unique skills and knowledge are underutilised if they are restricted to simply devising meal plans or conducting one-off appointments. This paper aims to challenge the current status quo by exploring, outlining and defining the unique contributions and benefits that the dietetic profession brings to the management of EDs across treatment approaches and core aspects of nutritional care management.

The important role of dietetics in the treatment of individuals with a broad spectrum of severe mental illness has been highlighted (13), yet there remains a paucity of evidence regarding the unique contributions offered by a dietitian

(14, 15). It is difficult to extrapolate the unique contribution made by the dietitian when clinicians are working in a multiprofessional way across transdiagnostic treatment domains. A recent cross-sectional study noted that barriers to effective dietetic service provision include a lack of awareness by other clinicians of the dietetic role, in particular the capacity of dietitians to perform roles outside of refeeding management (13).

Dietitians are in a uniquely advantageous position to be able to bridge the core transdiagnostic domains of successful ED treatment, namely medical, nutritional and psychological management (16).

A skilled understanding of nutritional science and the consequences of malnutrition, together with behaviour change skills, positions this core dietetic expertise as integral in nutritional counselling (16). Dietitians must also possess the prerequisite skills required of any discipline to train and to deliver additional and advanced treatments safely. The important role of the dietitian as part of the MDT was highlighted by the results of a recent Delphi study which concluded that, from the perspective of service users and carers, the incorporation of the dietitian into patient care was welcomed positively (17).

Despite this, a 2020 review of the nutritional content of published adult ED treatment manuals found that only 36% recommended specific dietetic input as part of the MDT (18). Of further concern, this review concluded that 60% of such manuals contained unsubstantiated nutritional information, with only 9% including content written by a dietitian. Indeed, two of the most widely used and clinically adopted treatment manuals across age ranges, family-based therapy (FBT) and enhanced cognitive behavioural therapy (CBT-E), do not directly refer to the involvement of a dietitian (19, 20). Instead, the potential role of the dietitian is superseded by family oversight and guidance from a non-nutritionally trained mental health clinician. There are differences in approach to treatment between avoidant/restrictive food intake disorder (ARFID), anorexia nervosa (AN) and bulimia nervosa (BN); however, in ARFID the dietetic input is particularly important as ARFID is commonly associated with nutritional deficiencies (21). Specialist dietitians can be involved in delivering therapy after undertaking further training or by joining sessions led by other clinicians.

Supporting nutritional adequacy

Food is a central focus of ED psychopathology and some of the most challenging work patients undertake in ED treatment happens at the table, where the fears and distress occur and impact on a person's ability to eat (22, 23). Therefore, providing real-time support to overcome the restrictive rules, rituals and behaviours people with EDs have around food is vital for helping people manage the day-to-day difficulties their ED presents to them. Despite this, the skills and processes required to facilitate well-delivered and effective support at mealtimes is an under-researched and often overlooked area of ED care (24).

In addition to their core skillset, dietitians have a unique knowledge of the psycho-socio-cultural aspects of eating (25). This means that they are well placed to work collaboratively with individuals through the nutrition care process, not only to manage malnutrition and support nutritional rehabilitation, but also to tailor supported mealtime interventions to create the right conditions to achieve their food and eating goals. Dietitians are also able to help parents, young people and other clinicians in the MDT to navigate the recovery journey. Dietitians can critically analyse and stay abreast of societal trends and developments in foods, such as probiotics and clean eating, and can readily engage in discussions with young people to correct misunderstandings and influence more informed behaviours.

Dietitians are invaluable in the management of people with EDs who have comorbidities, for example, diabetes mellitus type 1, nutritional allergies and coeliac disease (26, 27). In some instances, this may also include facilitating the supportive use of nasogastric tube (NGT) feeding. Dietitians are uniquely positioned within the MDT and are well placed to have supportive conversations with patients regarding the need for this intervention and, importantly, how and when it might be discontinued. This skillset is especially important when considering the most medically unstable and psychologically unwell patients for whom treatment may include NGT feeding under restraint, which has significant psychological impact (28).

There is limited understanding of patient and healthcare professional perceptions and experiences of receiving and delivering dietetic care. A study by Heafala et al. (29) explored the perspectives of people with lived experience of an ED and reported that some described dietitians as "invaluable" for supporting their understanding of the role of nutrition in recovery, while working as part of a wider MDT, and that working with a dietitian was helpful for challenging self-limiting beliefs and behaviours, as well as facilitating behaviour change.

This evidence for the positive impact of dietetic intervention highlights the need for more research into the opportunities for dietetic support for patients, carers and healthcare professionals in managing the day-to-day difficulties of living with an ED.

Cognitive behavioural therapies adapted for eating disorders

CBT-E is designed to address the cognitive and behavioural processes that are maintaining the individual's ED. Core maintaining factors include malnutrition and dietary restraint, which dietitians are well placed to address. While standalone dietetic treatment is not supported as an intervention for EDs (30), research suggests that involving a dietitian in CBT-E may increase treatment efficacy (31). CBT-E training and supervision is widely available (20). For the MDT,

CBT-E offers a common language and a means of delivering a consistent message from team members. Once CBT-E training is completed, there are two options for the dietitian.

The first option is to work alongside the team and simply use the CBT-E principles within clinical practice. This can include re-establishing a pattern of regular eating, weight stability or weight gain, tackling dietary restraint, establishing monitoring of food and drink intake as well as any compensatory behaviours, and agreeing next steps or homework.

The second option is for the dietitian and a mental health professional to work together to deliver treatment. A new and recent strategy proposed in Australia is interprofessional CBT-E. This more formalised approach delegates interventions related to malnutrition, including dietary restriction and low body weight, as well as dietary restraint, to the dietitian while other mental health professionals deliver the content related to cognitive and behaviour change (31).

The novel treatment approach of adapting CBT-E and formally integrating dietetic treatment, where dietitians deliver content related to malnutrition and dietary restraint, has the potential to improve treatment outcomes.

Eating disorder–focused family therapy

For recovery, someone with an ED has to learn what to eat, how much to eat, when and why. They have to establish, or re-establish, a healthy relationship with food.

As a member of the MDT, the role of the dietitian is to identify the severity of malnutrition, the presence of disordered eating habits and deficits in nutritional skills and knowledge that inhibit the attainment of adequate nutrition (16). Especially in ED-focused family therapy, dietitians complement the MDT by supporting parents with practical aspects of meal planning, preparation and management at mealtimes, alongside psychoeducation for both parents and the young person on EDs, including the impact of low body weight on physical health and brain function (32). This is particularly important to allow the parents to regain their confidence which, in many cases, may have been eroded by their child's illness. It is important, however, that once parental confidence is regained, reliance on the dietitian is gradually reduced.

Dietitians have expert training and knowledge to support the management of medical risk associated with severe malnutrition, in conjunction with medical professionals. These risks are common in the early stages of an ED (16). In contrast, Mörkl et al. (32), in a study of nutritional literacy among 1000 mental health professionals in 52 countries, found that the majority of psychiatrists and psychologists (74 and 66%, respectively) had no training in nutrition. Mörkl et al. suggested this may be a reason for a lack of confidence among clinicians in discussing nutrition with patients and the limited nutritional education they were able to offer.

Although guidelines focus on the dietitian's role in treating and managing AN, the dietitian must align with the MDT and should not be treating young people with AN as sole practitioners (33). The role of the dietitian in providing nutritional advice within the MDT is particularly important, as research has shown that the nutritional knowledge of mental health practitioners is no better than that of a lay person (34). This was highlighted in a 2011 study in Australia (35) which found that non-dietitian health professionals had similar levels of nutritional knowledge to individuals with EDs. When there are comorbidities, suspected or proven food allergies or intolerances, or other overlapping medical conditions such as diabetes, the specialist skills of the dietitian are also needed.

Phase two of the therapeutic process, involving the gradual handing back of control of eating and food choices to the individual, is particularly well supported by the skills and knowledge of dietitians.

Phase three aims to return the individual to a normal developmental trajectory, which may include addressing psychological work.

Maudsley Model of Anorexia Treatment for Adults

Although the Maudsley Model of Anorexia Treatment for Adults (MANTRA) is a psychological therapy, it cannot be delivered without medical and nutritional risk monitoring and practitioners are encouraged to individualise MANTRA, delivering it flexibly. The dietitian can monitor nutrition, alongside delivering the nutritional psychoeducation and nutrition change sections (36).

The MANTRA nutritional section is unhelpful for some patients when delivered via workbook alone; for example, where self-evaluation of calories is encouraged. Dietitians can offer alternative ways to self-assess diet and energy intake without using calories, moving away from the focus on detail and numbers which are maintaining behaviours for many. Patients have stated that practical advice around nutrition would, in their opinion, improve the MANTRA treatment (37).

Nutritional needs can be complex. The MANTRA manual offers an overview of the basic nutritional needs of an omnivore without consideration for additional nutritional complexities. Dietitians are able to assess the nutritional adequacy of diets such as vegan, dairy-free, allergy and gluten-free, and address any under-nutrition or over-nutrition. They will also calculate the energy requirements needed to address the starved state that results from inadequate calorific intake and can offer psychoeducation to address nutritional or weight-based questions, thereby lowering anxiety.

Individualising MANTRA to the needs of the person includes a personalised nutrition approach. Legally, dietitians are the only healthcare professionals able to prescribe individualised meal plans and manipulate diet to treat disease (38).

Dietitians play their part in the delivery of MANTRA alongside the MDT by supporting individuals to meet their nutritional needs and addressing thinking styles around food. This may include, for example, encouraging a move away from calories to household or hand portioning and by offering advice on balancing meals and snacks. Addressing these issues allows the psychological therapist to focus on the other areas of MANTRA, such as interpersonal difficulties, without being drawn into conversations around food, weight or nutrition.

Schmidt et al. (36) stated that the dietitian's role within MANTRA is an initial dietetic assessment, with follow-up appointments as needed. However, for personalised nutritional advice to be offered, some teams are moving towards a co-delivery of MANTRA, with a psychological therapist working alongside the dietitian throughout the course of treatment. Alternatively, the dietitian might deliver the nutrition sections at specified time points.

Specialist supportive clinical management

Specialist supportive clinical management (SSCM) was developed by a team of psychiatrists and psychologists. However, since much of the psychoeducation is nutrition focused (39), the potential contribution of dietitians in SSCM should not be overlooked. SSCM has been the subject of four randomised controlled trials as well as a separate trial in which SSCM was modified for the treatment of longstanding EDs with a focus on quality of life and not weight restoration (40). Kiely et al. (41) outlined the six principles of SSCM and highlighted that SSCM can be delivered by a variety of clinicians; the dietetic input can be flexible as part of the overall SSCM strategy. Kiely at al. (41) included dietetics within their reconceptualisation of SCCM as a supportive role alongside other MDT members. It has also been suggested that dietitians could work in an assessment role, alongside the therapist, or in a consultancy role.

The target features of the ED laid out in the SCCM workbook by McIntosh et al. (39) relate to ED behaviours, physical/emotional consequences and related problems. The majority of these features are addressed as part of dietetic treatment plans. Kiely at al. (41) have suggested that if these features are not improving, dietetic support can be a valuable resource that allows a closer focus on these aspects, in contrast to the "broad brush strokes" approach that might be adopted by the principal clinician. Dietitians have the skills to offer specialist support and advice on person-centred nutrition and focus on physical health and weight restoration. Patient experience of SSCM shows that a focus on nutrition is often seen as a helpful aspect of the therapy (37).

Binge eating disorder and guided self-help

Dietitians are well placed to identify, assess, and treat binge eating disorder (BED) using interventions such as guided self-help (GSH) and CBT-E. BED is commonly associated with multiple comorbid conditions, including mood disorders, anxiety, substance misuse, impulse control issues, obesity, type 2 diabetes and various pain syndromes (42).

Approximately 30% of patients accessing community weight management services have features of BED (43). Research by Nickel et al. (44) indicates a frequent association of BED with neurodiversity, which has become an area of growing interest. Dietitians are skilled in screening and identifying EDs in settings and populations in which neurodevelopmental conditions are prevalent.

GSH is a first-line treatment for BED in all age groups in the UK National Institute for Health and Care Excellence guidance for the recognition and treatment of EDs (8). Dietitians working within weight management settings have been successfully trained to identify and deliver GSH treatment to individuals who have BED or disordered/emotional eating. The results of a study by Traviss-Turner et al. (43), showed that dietitians were very effective in delivering GSH to patients with BED, with results comparable to GSH delivered by mental health practitioners. A more recent study of a digitalised GSH intervention for BED in patients with diabetes was co-developed, delivered and co-supervised by dietitians (45).

A review of treatment manuals for EDs in 2023 found that only 36% recommended consultation with a dietitian as part of an MDT approach (17), and only 9% included content written by a dietitian. It was found that 60% of the manuals did not meet current evidence-based practice criteria. It is suggested that all manuals with nutritional content are written with appropriately trained and experienced dietitians in this field; they should be revised to reflect current research and the current evidence base and have a clear indication of when a referral to a dietitian is needed.

In summary, GSH intervention is appropriate for dietitian delivery to patients with BED in the context of obesity and diabetes. Research indicates the potential for other dietetic-led services to deliver GSH and to support patients with binge eating accessing the service.

Avoidant/restrictive food intake disorder

Nutritional deficiencies and suboptimal growth are core components of the diagnostic criteria of ARFID, and it is essential that dietitians are included as part of the assessment and treatment pathway, as stated in the NHS England framework (46). Dietitians are the only registered professionals within the NHS who can assess age-specific nutritional adequacy in relation to macronutrient and micronutrient content of diet and who can recognise the likely impact of

suboptimal intakes (47).

The dietitian's role includes taking a detailed feeding and development history, with a focus on nutritional intake and its impact on growth, as well as reviewing growth and development. Dietitians are skilled in taking detailed diet histories and analysing dietary intake from food diaries, which are essential elements of every assessment. They are also able to guide and interpret blood biochemistry where specific nutrients are thought to be deficient and advise on suitable vitamin and mineral supplementation (48). Many people with ARFID will need short-term prescriptions of a range of oral nutritional supplements to support weight and meet nutritional needs while they undertake psychological-based treatments. These treatment strategies may include cognitive behavioural therapy for ARFID, FBT for ARFID and food exposure. All of these interventions should be supported by a specialist ARFID dietitian with advanced training (47).

Prescribing

Dietitians can hold supplementary non-medical prescribing (NMP) rights, following completion of an approved programme. Supplementary prescribing differs from independent prescribing as prescribers are only able to prescribe a medicine within their clinical competence and as part of an agreed patient-specific clinical management plan. The clinical management plan outlines an agreed list of medications related to medical conditions and the prescriber is able to review these as part of an agreed partnership with a doctor (46, 49).

NMP dietitians can prescribe only clinically appropriate medicines within their own competencies and must comply with current legislation, professional guidance and workplace policies for prescribing (50). This could include medication to support the management of refeeding syndrome, for example, prescribing replacement of electrolytes such as potassium, magnesium and phosphate, and the prescribing of refeeding medications such as thiamine, vitamin B complex and suitable multivitamins. The role can include management of other vitamin and mineral deficiencies, for example, calcium carbonate, cholecalciferol and ferrous fumarate, and treatment of hypoglycaemia related to EDs. Another important area is to support appropriate prescribing of medications related to gastrointestinal issues often experienced in clients with EDs. These could include laxatives, proton-pump inhibitors and bisacodyl. Nutritional advice is offered alongside the pharmaceuticals (51).

Becoming an NMP allows for more efficient nutritional care for patients, involving both nutrition and pharmacology, and ultimately supports the client to access the assistance needed in a safe, effective and timely manner.

Discussion

Dietitians can actively participate in, and potentially enhance, various therapeutic models and aspects of treatment at every stage, provided they have undertaken adequate training and have both appropriate supervision and adequate hours within the team. There is a potential future role involving dietitian-led treatment interventions and services, including enhanced roles open to dietitians working with people with EDs.

Research carried out by McMaster et al. (17) suggests that patients and carers highly value the input from a dietitian at both the assessment stage and during treatment.

Despite the demonstrable value of dietetic involvement, a scoping review of English ED dietetic services has revealed underfunding for both children and young people and adults (52). This jeopardises the treatment of individuals with EDs and may constrain the clinical and therapeutic roles of the dietitian.

The field of mental health dietetics is evolving rapidly, with well-established models such as that pioneered in Australia (11), which includes ED skills credentialing, leading the way. A recent systematic review (14) supports the concept that the skills of the dietitian extend beyond refeeding, meal planning and provision of nutritional education alone. Dietitians are well placed to be able to combine their expertise in the field of nutrition with psychotherapeutic modalities when working with other members of the MDT.

Future directions for clinical and research work

Identifying outcomes that may be appropriate for dietetic interventions in the context of a multi-professional treatment approach can be problematic. We suggest the need for research in the following areas.

- Supporting nutritional adequacy, specifically exploring the benefit of dietetic involvement on the anxiogenic and iatrogenic effects of restraint feeding.
- A comparison between CBT-E and adapted CBT-E, in which the nutritional content is delivered by dietitians, would strengthen the argument for dietetic inclusion.
- Targeted evaluation of the impact of dietitian involvement in the form of psychoeducative support and tailored refeeding guidance during phase 1 of FT-AN/BN on clinical outcomes, parental refeeding confidence and the nutritional knowledge of the MDT.
- Research exploring the diversity of biopsychosocial characteristics across adult ED populations, for example, the proportion with allergies or religious, cultural or ethical exclusions and the role of the dietetic profession within

MANTRA.

- Development of the role of the dietitian potentially to take the lead professional role of supporting the patient using a SSCM and GSH for the BED framework.
- An evaluation of how outcomes and patient experiences of ARFID treatment and delivery may be influenced by dietitian involvement.
- Enhanced dietetic involvement in NMP might help to increase efficiencies in line with national workforce objectives and provide greater opportunity for evaluation of the patient experience.

Conclusion

Dietitians hold a unique position that enables them to offer nutritional therapy to individuals at every stage of ED recovery. There are emerging and exciting roles for dietitians within the field of ED treatment. The importance of dietitians within the MDT is becoming more widely recognised and consequently there is a broadening scope for the involvement of dietetic practice across services. To harness the potential of dietitians, and to continue to expand the scope of their work, it is important to acknowledge their expertise while providing thorough training, increasing allocation of resources and maintaining consistent supervision.

Declaration of interest

The authors declare that they have no conflicts of interest.

Funding

No funding was received for this publication.

Glossary

AN: Anorexia nervosa.

ARFID: Avoidant/restrictive food intake disorder. Described for the first time in the Diagnostic and Statistical Manual of Mental Health Disorders Fifth Edition (DSM-5), and the World Health Organization International Classification of Diseases 11th Revision (ICD 11).

BED: Binge eating disorder.

BN: Bulimia nervosa.

CBT-E: Enhanced cognitive behavioural therapy. A psychological treatment and form of cognitive behavioural therapy which uses cognitive and behavioural strategies together with psychoeducation. CBT-E treats all eating disorders and may be used across adolescents and adults in both community and inpatient settings.

ED: Eating disorders.

FBT: Family-based therapy. The leading evidence-based treatment for children and young people struggling with eating disorders, such as AN and BN. Divided into three phases: phase 1 focuses on the rapid restoration of physical health, orchestrated by parents; phase 2 involves gradually giving responsibility regarding eating back to the adolescent, to whatever extent is age-appropriate and normal for a particular family; phase 3 involves a review of adolescent development and evaluation of progress towards a return to normal family life.

FT-AN, FT-BN: Family therapy for AN, family therapy for BN. Adaptations of FBT developed by the Maudsley Hospital.

GSH: Guided self-help. A focused, low-cost, low-intensity, CBT-based treatment for BED that is an example of non-medical prescribing. GSH can be delivered via a workbook or digitally online, supported by a guide who has undertaken training and supervision in line with the University College London psychological competencies framework, as outlined by Health Education England.

MANTRA: Maudsley Model of Anorexia Nervosa Treatment for Adults. A manualised integrative therapy which addresses cognitive, emotional, relational and biological factors which tend to maintain AN and helps people to find alternative and more adaptive ways of coping. MANTRA is one of the three treatment options recommended for adult patients with AN.

MDT: Multidisciplinary team.

NGT: Nasogastric tube.

NMP: Non-medical prescribing. Refers to any prescribing completed by a healthcare professional other than a doctor or dentist.

SP: Supplementary prescribing. Prescription of medicines by non-medical healthcare professionals within an agreed clinical management plan in partnership with an independent prescriber. Dietitians can become supplementary prescribers and are legally permitted to prescribe medicines, including those that are off-label, off-licence or unlicensed, borderline substances, selected list scheme drugs and schedule 2, 3, 4 or 5 controlled drugs.

SSCM: Specialist supportive clinical management. A combination of clinical management and supportive psychotherapy for AN. Initially developed as a placebo treatment for clinical trials of MANTRA.

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Advances in the dietetic management of eating disorders

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Abstract

Eating disorders (EDs) are highly complex illnesses, compromising both physical and mental health. Dietetic management of EDs has advanced over time, in line with research and clinical practice in the field. Progress in dietetic practice relates to the core domains of refeeding syndrome management, nutritional rehabilitation and nutritional psychoeducation. Advances in these domains are discussed in this narrative review. Future trends in health and disease that may shape further advances in the dietetic management of EDs are highlighted and their potential impact on nutritional interventions hypothesised. This review highlights the integral role of dietitians as part of an eating disorder multidisciplinary team. The skills and knowledge of the dietetic profession continues to advance and evolve in line with the expanding ED evidence base, supporting evidence-based dietetic practice and the ongoing development of nutritional strategies in this area.

1. Introduction

Dietetics was first defined as "the application of the science of nutrition to the human being in health and disease" (1). However, the role of the dietitian has evolved over time, from a profession that purely focused on food provision for hospitalised patients to a role that necessitates broad knowledge and specialist skills to enable practitioners to lead on clinical, educational, managerial and research tasks (2). Dietitians are skilled in assisting clients with their understanding of the effects of nutrition on health, supporting other health professionals to improve their understanding of the role of nutrition in illness, providing group education sessions on various aspects of nutrition and engaging in academic writing and publication of research (3). The ability to communicate and work collaboratively is therefore central to every dietitian's role across clinical specialities, and particularly in working with clients with eating disorders (EDs).

EDs are highly complex illnesses, compromising both physical and mental health (4). The conceptualisation of EDs has grown over the past decade to include diagnoses such as binge eating disorder and avoidant/restrictive food intake disorder (ARFID), in addition to the more well-known disorders of anorexia nervosa (AN) and bulimia nervosa (BN) (5, 6). Disordered eating and psychological morbidity are symptoms common to all eating disorder presentations that pose risks to health (7). Management of ED symptoms and treatment of the underlying causes necessitates the involvement of a skilled multidisciplinary team (MDT) (8), including a dietitian.

Dietetic interventions are recommended as part of the specialist MDT, wherein therapy and medical management are central parts of treatment that are delivered by professionals qualified in psychiatry, psychology and family therapy including nurse therapists and paediatricians/physicians (7, 9). Dietitians are skilled in the assessment and management of malnutrition, disordered eating patterns and nutritional-related deficiencies (1, 10). Dietitians are well placed to support nutritional issues arising from these illnesses and are considered to form a central part of the MDT (10, 11). All ED professionals play a role in the nutritional management of EDs, such as discussions about meal plans and reviews of progress with eating and weight changes. Dietitians lead on specific nutritional issues including the management of acute refeeding syndrome (RS) risk, bespoke meal planning for weight gain, identifying and managing nutritional deficiencies and providing specific nutritional psychoeducation.

Dietetic management of ED care has advanced over time, in keeping with research and clinical practice in the field. Historically, limited literature regarding the dietetic management of patients with an ED existed and no manualised dietetic interventions were available (12). Over recent years, the role of dietetics in ED treatment has been explored in

adult populations and the views of MDT members, clients and dietitians have been used to develop consensus guidelines in this area (12-14). These advances have enabled the evaluation of dietetic practice in ED, definition of the role of the dietitian in the ED MDT and the development of specific dietetic resources for this client group (15).

A systematic review conducted by Yang et al. evaluated published literature relating to the role of the dietitian in ED care to determine the effect of dietetic input and contribute to the understanding of this role in ED treatment (13). One key finding was that dietetic input improved weight and nutritional intake. However, the small number of studies available on the topic was a limitation. Another review conducted by Heafala et al. investigated the dietitian's role in ED treatment by analysing literature related to the views and experiences of ED staff (16). Themes that emerged evidenced the role of dietitians as collaborators, educators and counsellors in ED teams. Progress in dietetic practice relates to the core domains of RS management, nutritional rehabilitation and nutritional psychoeducation. This narrative review will focus on advances in the dietetic management of EDs in relation to these domains.

2. Refeeding syndrome management

RS is a potentially fatal clinical condition that can occur during the nutritional rehabilitation of malnourished patients (17). Low body weight, rapid weight loss and severe restriction of dietary intake are all risk factors for RS. The condition can manifest as cardiac arrhythmias, cardiac failure and arrest, coma and sudden death (18). The majority of research on RS management in EDs is focused on AN, given that restrictive eating, weight loss and low weight are salient characteristics of this disorder (19).

Historically, "start low and advance slow" was the recommended approach to restoring nutritional intake in patients deemed at risk of the condition (20, 21). Cautious approaches to nutritional rehabilitation, including low energy starting rates with incremental increases towards total energy requirements and prophylactic phosphate supplementation, were advocated to negate the risk of complications occurring (22). Recognition of risks associated with underfeeding already malnourished patients has challenged previous guidance in this area and advocated for a less conservative approach (23, 24). Key ED literature has also identified that greater weight gain during initial treatment predicts full remission after one year, placing further emphasis on the swift restoration of regular and adequate nutrition (25).

There has been a growing body of evidence supporting less conservative refeeding practices in AN, such as higher energy initial feeding without stepped increases or prophylactic phosphate administration (18, 26, 27). National guidance and recommendations on the management of RS risk in EDs has been reviewed and updated to incorporate the findings of pivotal research studies (7). Most research to date has focused on young people with AN, with national guidance calling for increased research focused on adults. Three key dietetic-led studies investigating RS in adolescents with AN have supported advancements both in clinical practice and national guidance on refeeding management in EDs (18, 26, 27).

The randomised controlled trial conducted by O'Connor and colleagues provided the first conclusive evidence supporting less conservative refeeding practices in adolescent patients. Benefits such as greater initial weight gain resulted from higher energy starting rates, in the absence of increased refeeding complications. These findings supported initial refeeding commencing at a higher rate (1200 kcal/d) than was recommended by national guidance at that time (500 kcal/d) and supported advancements in clinical practice (26, 28).

In light of the growing number of studies investigating approaches to refeeding practices in AN, Garber and colleagues systematically reviewed this literature in 2016 (18). The conclusions drawn from this review advocated higher calorie feeding in AN for moderately but not severely malnourished patients. Garber et al. conducted another significant study in 2021, comparing the short-term efficacy, safety and cost savings of higher (2000 kcal/d) versus lower (1400 kcal/d) calorie feeding in AN (27). Findings from this study indicated that initial higher calorie refeeding was safe, effective and did not increase complications associated with refeeding in this population of moderately malnourished adolescents. Cost savings were also demonstrated as a result of reduced length of hospital admissions related to swift refeeding (27). The updated UK national guidance, Managing Emergencies in Eating Disorders (7), has replaced the previous junior MaRSiPAN and adult MaRSiPAN (Management of Really Sick Patients with Anorexia Nervosa) reports (28) and has incorporated these key findings.

Dietitians have a core role in the management of RS risk in ED care (29) and have been crucial in supporting the advancements observed in this over the past decade. The dietitian's role remains embedded within the MDT responsible for treating all aspects of an ED. Whilst dietitians are generally responsible for nutritional aspects of refeeding malnourished patients (e.g., distribution of energy in feeds through the day, use of oral nutritional supplements, enteral feeding and micronutrient supplementation), medical, nursing and psychiatric staff are integral to the safe management of risk associated with this early stage of treatment (7, 9).

3. Nutritional rehabilitation

The initial steps in treatment for EDs focus on medical stabilisation (where required), the management of medical and psychiatric risks and the restoration of regular and sufficient nutrition (7, 19). Nutritional rehabilitation, alongside psy-

chological treatment and continued management of risks, is an integral part of ED treatment that typically follows on from this first stabilisation phase. The role of dietetics has expanded and evolved over time to ensure evidence-based practice in the treatment of EDs, with a particular focus in recent years on newer diagnoses such as ARFID and atypical presentation of EDs such as non-underweight AN, termed atypical anorexia nervosa (AAN) (5, 13). Recognition of the strong overlap between autism and EDs has also led to advances in treatments for this common comorbidity, including adaptations to dietetic interventions and guidance documents (30). Advances in the nutritional assessment and management of ARFID, AAN and comorbid autism and ED will be focused on here.

3.1 Avoidant/restrictive food intake disorder

ARFID, added to the DSM-5 under the revised *Feeding and Eating Disorders* chapter in 2013, is characterised by restrictive eating that is associated with failure to meet nutritional requirements leading to faltering growth in children, significant weight loss and/or persistent low weight and compromised physical health (31). Nutritional deficiencies and impaired psychosocial functioning are common issues requiring specialist MDT treatment (5). The core feature of ARFID that distinguishes it from other EDs (i.e., AN and BN) is the lack of disturbance in the way one's body weight or shape is experienced (6).

	ARFID	AN
Weight at presentation	Underweight/normal/overweight	Underweight (typical) Normal/overweight (atypical)
Peak age at onset	4-13 years	13-15 years
Gender distribution	Higher proportion of males	Higher proportion of females
Composition of diet	Limited amount/range of foods, often based on appearance, texture, taste etc.	Limited amount/range based on calorie content Range may also be reduced if cutting out feared foods
Attitude towards gaining weight	Generally not concerned by weight gain or want to gain weight	Fear of weight gain
Attitude towards feeding by NGT	Require use of tube feeding more often and readily accept calorie content	May detest use of tube feeding as worried about calorie content
Comorbidity	Increased incidence of anxiety Increased incidence of comorbid medical illness	Increased incidence of depression Lower incidence of associated medical illness

Table 1. A comparison of avoidant/restrictive food intake disorder and anorexia nervosa (adapted from Coglan and Otasowie (32))
Abbreviations: AN = anorexia nervosa; ARFID = avoidant/restrictive food intake disorder; NGT = nasogastric tube

Treatment for ARFID includes psychological, medical and nutritional assessment and management by appropriately qualified and experienced health professionals. A collaborative MDT approach is imperative for the effective and safe treatment of ARFID (33). Over the past decade, research and evidence related to the management of ARFID has greatly expanded, including nutritional approaches and dietetic practice in this area (34). Advancements in the diagnosis of ARFID specified in the DSM-5, such as subtyping, have supported the development of dietetic interventions (35). These subtypes describe food avoidance based on the following three key drivers: an apparent lack of interest in eating or food; nutritional avoidance based on the sensory characteristics of food; or concerns about the aversive consequences of eating (6, 31, 32).

The nature of dietetic intervention is dependent upon ARFID subtype, in addition to the level of nutritional risk (36). Ensuring adequate nutrition in terms of both energy intake and sufficient dietary variety to avoid nutritional deficiencies are common goals across subtypes (32). In presentations of sensory-based food avoidance or fears around the aversive consequences of eating, preferred foods are encouraged to sustain adequate energy intake, whilst graded food exposure is simultaneously used to introduce previously rejected or feared foods (32). Where an apparent disinterest in food or eating is the driver of the avoidance, strategies recommended include the implementation of structured routines around mealtimes and behavioural expectations around eating, whilst also increasing meal portion sizes to promote sufficient energy intake (37).

Nutritional support may be offered via food-based interventions, oral nutritional supplementation, enteral feeding interventions or a combination of these feeding methods depending on level of nutritional risk and motivating factors for food avoidance (33, 38). Collaborative MDT working is essential to support recovery and dietitians are central members of these treating teams, providing important nutritional interventions.

3.2 Atypical anorexia nervosa

Patients who are not clinically underweight but have lost significant amounts of weight and otherwise resemble all characteristics of AN are now diagnosed with other specified feeding or eating disorder (OSFED) (6, 39). AAN, a term

used clinically to describe this patient group, is listed as an example of a presentation within OSFED. Recognition of AAN as a distinct presentation remains relatively new, with a limited but quickly expanding evidence base related to its management and outcomes (40). Research and evidence relating to medical complications of AAN is limited (41). Available literature relating to this subset of patients indicates that physical and psychological morbidity are similar to AN (42, 43). Patients diagnosed with AAN frequently require acute hospital admission to treat medical complications related to weight loss and malnutrition, despite the absence of severe underweight (44).

AN	OSFED (e.g., AAN)
A. Restriction in energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory and physical health.	All criteria are met, except despite significant weight loss, the individual's weight is within or above the normal range.
B. Intense fear of gaining weight or becoming fat, even though underweight.	
C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation or denial of the seriousness of the current low body weight.	

Table 2. A comparison of anorexia nervosa and other specified feeding or eating disorder (adapted from Brennan et al. (40))
Abbreviations: AAN = atypical anorexia nervosa; AN = anorexia nervosa; OSFED = other specified feeding or eating disorder

Despite the absence of underweight, malnutrition and nutritional risks are common in AAN (45). A number of key dietetic-led studies comparing patients with AN and AAN have supported recognition of the nutritional risks associated with this presentation (40, 41). Whitelaw et al. compared the effects of weight loss in comparison to underweight on medical and nutritional risk in adolescents with AN and AAN and concluded that weight loss was a stronger predictor of many physical complications that cause hospital admission than underweight (43). Similarly, Garber et al. also found that weight loss history was associated with markers of malnutrition across a range of body weights, independent of underweight (44).

Research on AAN has evidenced the importance of nutritional recovery and supports a similar dietetic approach as advised in AN (45). Specific advancements in dietetic management of AAN relate to the assessment and management of RS and adaptations to early phases of treatment, which often focuses on weight restoration in typical presentations. The primary aim of treatment in both AN and AAN is to restore regular and adequate nutrition, whilst managing medical and psychiatric risks. Assessment and management of RS risk is required in AAN due to the rapid weight loss often observed in these patients (46). The recognition of rapid weight loss as a key indicator of RS risk in the absence of low weight has supported routine nutritional and physical health assessment across weight ranges, rather than limited to those that are underweight (40).

Dietitians have also been recognised for their crucial role in individualising treatment in AAN, in particular, in adapting and creating bespoke meal plans or nutritional advice, supporting a patient-centred approach. This has been particularly apparent during the initial phases of the treatment, where nutritional rehabilitation most often takes place, in atypical cases presenting at healthy weights (47). Whilst some patients with AAN may present above the recommended body mass index (BMI), weight loss is not recommended until the ED has resolved (45). Dietetic interventions should focus on restoring regular and balanced eating whilst challenging food rules and restrictions that are driven by the ED, regardless of whether weight falls within underweight, healthy or overweight categories (42, 48). Historically, physical health and nutritional risk assessment were limited to the underweight, leading to symptoms being missed and diagnoses and treatment being delayed in the AAN population (49, 50). Dietetic advances have supported more inclusive and robust practices in the management of AAN.

3.3 Autism and EDs

In recent years, research has shown a strong link between autism, a neurodevelopmental disorder characterised by problems in social and communicative functioning and restricted patterns of behaviour, and EDs (51). The relationship between autism and EDs has been explained by common underlying neuropsychological and social problems (51). In addition, poorer treatment outcomes have been observed in this relatively commonly occurring comorbidity (52). As such, there has been a focus on the development of adaptations to ED treatment to support the characteristics of those presenting with comorbid autism better (30). PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience) was developed to support people with these co-occurring conditions and provides guidance on helpful treatment adaptations (30). As part of the PEACE pathway, dietetic interventions for EDs were reviewed and adaptations recommended to support the advancement of dietetic practice in this area.

Key adaptations recommended for the dietetic management of patients with ED and autism relate to both assessment and intervention. Adaptations to dietetic assessment include seeking information that may be more relevant to the care of people with autistic features, such as information on eating behaviour in childhood, sensory sensitiv-

ities, preferences related to the way food is presented or rules around food and eating that predate the ED (30, 51). Research on autism and ED from the PEACE pathway has also informed advances in dietetic treatment that better support the thinking styles of patients with autism characteristics. Expectations of nutritional rehabilitation may differ in terms of the pace of dietary change, as well as the extent of dietary variety that is encouraged. As such, the use of oral nutritional supplements and vitamin and mineral supplements should be considered to ensure nutritional requirements are met (30). Dietetic management of this complex presentation should always be as part of specialist MDT treatment and research investigating further helpful treatment adaptations is ongoing.

4. Nutritional psychoeducation

Following the expansion of dietetic literature in EDs, the development of manualised dietetic interventions further advanced dietetic practice and nutritional psychoeducation (12). The study by McMaster et al. advised on five dietitian-delivered outpatient sessions that cover the core aspects of the nutritional management of EDs (refeeding, nutritional rehabilitation, social eating, food variety and flexibility and further treatment planning) (12). Pre- and post-intervention assessments are also illustrated in the study (12). Another pivotal research paper by Hart et al. proposed the first eating disorder–specific food guide, the REAL Food Guide (15).

4.1 The REAL Food Guide

The REAL Food Guide (Recovery from EAting disorders for Life) is a framework that uses core principles of nutrition but with consideration of the beliefs and misinformation that are frequently endorsed by individuals with EDs (15). Prior to this, only generic food guides were widely available and typically these advocated for weight loss in the context of the obesity epidemic (53). One such guide was the Eatwell plate, published in the UK in 2016, reflecting the national government's agenda regarding rising obesity rates. As a result, it promoted healthy eating with the aim of weight loss (53). It included calorie guides and advised against high-fat and sugary foods, or foods often enjoyed in a social context, inferring that these were not part of a healthy diet. In response to this, a consensus statement was produced by the British Dietetic Association Mental Health Specialist Group highlighting concerns about the Eatwell plate and declaring it inappropriate for use in ED recovery (54).

The REAL Food Guide was produced in Australia in 2018 to support recovery goals for those experiencing ED. It emphasises food variety and including energy-dense foods to aid recovery. It also included "fun" or "social" foods in recovery, acknowledging that these foods are part of normalised eating behaviours (15). Although it is widely used in the UK by ED dietitians, several limitations have been noted, such as the lack of vegetarian- or vegan-specific recommendations, its application to the inpatient setting and its application to those with ED who are less than 18 years old (15).

4.2 Dietetic management of veganism and eating disorders

Although the link between vegetarianism and the development of EDs is well established in the literature (55, 56), the relationship between veganism and EDs is unclear. Despite this, an increasing number of vegan patients are presenting to ED services (55). This, alongside an improved awareness of equality and human rights legislation, supported the drive towards the development of additional nutritional resources to support these patients during recovery.

Restoring regular eating and nutritional restoration is required to treat EDs, and as treatment progresses it is important to challenge rules established by the ED and/or challenge feared foods. Conflict could potentially arise between a patient and a treating team if, in line with the ED developing, socially acceptable dietary restrictions are adopted, as these could be masking or justifying ED behaviours in the avoidance of foods. In modern society there is an abundance of dietary choice and restrictions available, ranging from gluten free to milk free to vegetarian and veganism. Veganism is becoming more culturally acceptable in the Western world and ED clinicians report an increased prevalence above the national average within the ED population (55). As a result, dietitians have developed practice guidelines regarding the acceptance of veganism and how to support recovery (54). A vegan REAL Food Guide has also been developed to help clinicians support patients with EDs whilst following a vegan diet (55). These advances aim to support a more collaborative and inclusive approach to nutritional interventions for ED sufferers.

5. Future trends and potential impact on dietetic practice in EDs

The dietetic management of EDs has advanced and evolved over the past decade, in line with the ever-evolving landscape of human health and disease over time. Research and trends that may impact on dietetic interventions with ED service users are considerations for further advances in dietetic practice.

One such research avenue includes the role of the gut microbiome in the pathogenesis and maintenance of EDs (57, 58), in gastrointestinal symptoms experienced by patients with EDs, in comorbid conditions such as depression and anxiety disorders, and in various aspects of physical health of the individual (59). Modifying the gut microbiome through the types of foods consumed, probiotics and prebiotics are likely trends that individuals with EDs may want to follow, and dietitians will be well placed in guiding them, based on current and rigorous evidence.

Another topic in recent news is the effect of ultra-processed foods (60) on cardiovascular health and obesity trends

(61) and their possible effect on binge eating (62). These messages may feed into the fear of foods that individuals with EDs experience, and dietitians may encounter resistance to their message that sufferers need to include a variety of foods, including "fun foods", within their nutritional intake. The dietitian may need to decipher the evidence and work with the individual towards a measured stance on nutrition. These trends may support future advances in nutritional approaches and interventions used within ED care.

6. Conclusion

This review has highlighted and discussed just a small number of pivotal advances in the dietetic management of EDs. Dietitians are integral members of the ED MDT, providing valuable contributions to research, national guidance and clinical practice in ED management. Their role has progressed beyond being simple advisors on nutrition to being more holistic care providers within the ED team. Research will continue to shape evidence-based dietetic practice and support further advances and contributions to ED care from the profession.

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Long-term nasogastric tube feeding under physical restraint: indications for best practice

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Abstract

Nasogastric tube (NGT) feeding is a common medical intervention used to help malnourished patients meet their nutritional needs. Occasionally this is used to help patients with restrictive eating disorders if they are unable to meet their nutritional requirements through oral diet or supplements when appropriate meal support is given. NGT feeding against a patient's will, requiring physical interventions to maintain their safety, can be used to stabilise a patient medically in lifesaving scenarios. Recent research highlighted the extent of this practice within mental health wards in England, with 622 patients reported to have received this intervention in a one-year period. The length of time for which this intervention was required ranged from a single feed to 17 patients receiving it for over a year, and one patient for six years. These findings have raised ethical and legal concerns regarding the extent of this restrictive intervention and the associated physical, emotional and psychological risks it carries for the patient, as well as the emotional and psychological risk to the inpatient peer group, parents/carers and the staff involved. This paper aims to suggest the best ethical, legal and clinical practice regarding this intervention for those practicing in England and Wales.

Keywords: nasogastric tube feeding, ethical, legal, physical restraint, restrictive practice, best practice

Introduction

Restrictive eating disorders (EDs) can result in malnutrition and this can have detrimental impacts on patient physical health both in the short term, with acute medical instability such as deranged biochemistry, hypothermia and bradycardia, and the long term, with chronic medical problems such as osteoporosis, infertility and dental deterioration. There is guidance available for clinicians to monitor patient physical health (1) and this indicates that a medical admission may be required to save a patient's life or promote medical stability. Most treatment for those with EDs is offered in the community setting (2), with specialist inpatient mental health admissions considered if community treatment has been unsuccessful, refused or is required to contain an emergency.

These admissions are not without challenges, as the nature of EDs is such that the nutrition required is often perceived by the patient as terrifying and distressing. Traditional approaches of offering individualised meal support from highly experienced clinicians, alongside generic meal plans, bespoke meal plans with the patient's safe foods and/or oral nutritional supplements as meal alternatives may not be sufficient for some patients. In these cases, supportive nasogastric tube (NGT) feeding may be considered as this can promote weight gain (3-5) and improve psychological outcomes (6); most patients will be able to understand that this is a necessary short-term medical procedure and consent to it. However, for a few patients, voluntary NGT feeding is refused or sabotaged. If this occurs and their physical health is deteriorating, then NGT feeding against their will may be considered.

Restrictive practices can be defined as "making someone do something they don't want to do or stopping someone doing something they want to do" (7). Restrictive practices are occasionally required to maintain the safety of a patient or other people and should only be implemented if all other, less-restrictive options have not worked, as set out above. It is the treating team's responsibility to hold hope that every patient will be able to eat when the right support is in place, even if they have been unable to do this previously. Ensuring that all patients are given meal support from experienced clinicians alongside food is essential and the least-restrictive option. As NGT feeding under physical restraint is a highly restrictive clinical intervention, it should only be used if all other treatment options have been progressively and sufficiently exhausted as set out above. It may also be appropriate if someone is sabotaging a

supportive NGT feed to the extent that their physical health is at risk; examples of sabotage may be from self-induced vomiting or using a hidden syringe to remove feeds once delivered.

Recent research reported the extent of NGT feeding under physical restraint in mental health wards in England. A total of 622 patients received this intervention during 2020, of whom 486 were in child and adolescent mental health (CAMHS) units, either specialist eating disorder units (SEDUs) or generic units, and 136 were in adult SEDUs (8). This research reported that some patients required just a single NGT feed under physical restraint, whereas 17 patients received this intervention for over a year. The mean duration that this intervention was required for was 29.1 weeks. These data raise both ethical and legal concerns, which will now be discussed in the context of English law, which applies where these data were collected, as there is no doubt that these patients were fed past the point of medical stability.

Clinical considerations

Over the past five years, clinical practice regarding the delivery of NGT feeds when physical restraint is needed has changed significantly. Research suggests that there was a significant range in practice within UK CAMHS mental health inpatient wards. Fifteen percent of CAMHS SEDUs and 27% of generic mental health wards reported using enteral pumps to deliver an NGT feed over an hour or more and some units reported that they would use NGT feeding under restraint up to six times a day (9). This led to a consensus statement, developed using a modified Delphi approach, producing guidance to ensure that this intervention is carried out as safely and quickly as possible in line with least-restrictive practice (10, 11). Specific recommendations with regard to reducing the number of feeds per day, increasing the volume of each feed and delivering via a push syringe bolus rather than enteral pump have reduced the time patients spend in physical restraints for NGT feeds (10). Consequently, patients experience minimal interference with their inpatient treatment and have more time to engage in therapeutic support, education or life skills that support recovery.

Legal considerations

We do not discuss here the frameworks in England and Wales such as the Mental Health Act (MHA) 1983 or the Mental Capacity Act (MCA) 2005 which explain how NGT feeding under restraint can be delivered lawfully. More important, we think, is to take a step back and look at the framework within which those decisions are taken, as this is not always properly understood.

The Human Rights Act 1998, which applies to the whole of the UK, requires clinicians to act in accordance with the obligations imposed by the European Convention on Human Rights (ECHR). The ECHR imposes obligations that are both "positive" and "negative". Positive human rights obligations are obligations to do things, for example, to take appropriate steps to secure the life of a patient at risk of death (to comply with Article 2 of the ECHR). Conversely, negative obligations are obligations not to do things, for example, depriving a patient of their liberty without following a procedure prescribed by law would be a breach of Article 5 of ECHR. It is important that clinicians act in ways that balance these two sets of obligations. One way of thinking of this is to understand that positive obligations explain why clinicians are taking the steps they are taking, whereas the negative obligations exist to ensure that clinicians think through those steps and ensure that there are appropriate checks and balances in place, some of which are described below.

An important question that clinicians should be asking themselves is whether their treatment plan is necessary and proportionate. If proposed treatments are not necessary, for example, if there is no real risk to the patient's life, then it would be very difficult to justify the resulting interference with the patient's rights (for example, to autonomy, under Article 8 of the ECHR). However, even if the proposed treatments might be said to be necessary, it is still vital to ask whether they are in fact proportionate to the gravity of the risk identified, especially given the potential for such treatments to traumatise the patient, their family and, separately, but importantly, the treating team (12).

If a patient is gaining weight, past the point of medical instability, over a period of many weeks or months and sufficient physical health restoration has been secured by means of NGT feeding under physical restraint, the question of whether this practice remains necessary and proportionate must be reconsidered. At this point, it is likely that continued restrictions are no longer proportionate to the risk of deterioration in physical health. Therefore, attempts should be made to wean off physical restraint, moving towards consensual and supportive NGT feeding and then re-establishing an oral diet to manage the risk of deterioration in physical health or weight loss. It is important to note that some clinicians will state that "if we stop feeding and they don't eat, the eating disorder will get stronger" and that, because of this view, NGT feeding under restraint may be maintained appropriately. NGT feeding under restraint should only be continued if it is clinically indicated and not because of the clinician's anxieties around the patient not having adequate nutrition.

Applying the framework above raises, or should raise, concerns when patients are reported to have received NGT feeding under physical restraint for significant periods of time.

Box 1. Ethical considerations in nasogastric tube feeding under physical restraint

- The respect for, and promotion of, patient autonomy and choice, including considering their current and previously expressed wishes, even if they lack the ability to make a decision.
- The overall interests of the patient, balancing potential risks against potential benefits of any treatment option.
- The disruption to everyday life and the enablement of normal maturity, which includes development of identity, independence and emotional regulation.
- The ability of the patient to make treatment decisions, recognising that patients with eating disorders can have subtly impaired abilities to make treatment decisions about the eating disorder even if they are articulate people who remain capable of making other decisions for themselves.
- The balance of the short-term benefits (medical stabilisation) against the long-term harms (risk of traumatisation and enmeshment of illness) of the coercive practice.
- *How* coercive practice is done and not just *whether* it is done – the importance of trust and compassion increases as the choice diminishes and the patient experiences increasing coercion.
- The importance of human relationships such as trust, feeling heard and understood, feeling supported, understanding, and knowing in advance when and why coercive treatment is needed.
- The importance of the clinicians surrounding the patient being trusted as experts who can act in the patient's interests so that the patient can feel able to hand control over to them.

Ethical considerations

There are several different ethical principles which need to be balanced when NGT under restraint is considered, especially when it is used past the point of medical stabilisation. Box 1 lists some of these ethical considerations.

In considering the ethical issues of NGT feeding under restraint, it is key that clinicians should not view the situation as a dichotomous, black-and-white decision. Contrary to how some may perceive it, the decision is rarely between highly coercive feeding versus leaving a patient without treatment with the certainty of death. Neither should the decision be made as a single jump from "eating by oneself without the use of compulsory treatment orders" to "NGT feeding under restraint under compulsory treatment orders". There is a hierarchy of levels of pressure/coercion and degree of patient cooperation and assent. Clinicians should always strive to minimise the level, duration and amount of coercion needed and maximise the degree of cooperation and collaboration possible. They need to consider how best to achieve the goals of ensuring patients are safely receiving the nutrition and care they require, while keeping restrictive practices to a minimum in number and degree of aversiveness and traumatic impact.

The degree of coercion and restrictive practice is maximum when a patient needs NGT feeding under restraint. Therefore, the treating team should be working hard with the patient and family to reduce the level of restrictive practice needed and to provide as much choice and autonomy as possible, while appreciating the level of support that patients may need to achieve that. This should be a responsive and dynamic process – a "dance" which takes place within the interface between patient, clinicians and family members – to achieve the best option in the current situation for each individual patient, which will then inevitably change as the situation changes. This is a very individualised treatment plan and should not be based on any general hospital protocol.

Moving towards best practice

The authors propose that best practice could be along the following clinical, ethical and legal principles.

Clinical principles

At times, it is difficult for clinicians to have lengthy conversations with their patient around the need for restrictive practices such as NGT feeding under physical restraint. Some decisions need to be made swiftly to preserve life. However, whenever possible, best practice can be suggested as having these conversations away from the crisis, potentially before admission or at the start (13). Asking the patient if this intervention is required: "What are your wishes? How can we best support you before, during and after this intervention?" This advanced care planning will allow the patient's views to be clearly recorded and will keep them involved in the treatment process. Without this, there is a risk of the patient "giving up" and feeling that treatment is "being done to them" rather than "being done with them".

Ethical principles

It is important for clinicians to find the optimal balance between aiming for the best and longest period of medical stability and minimising the period where restrictive practice is required. Moving the patients towards lower levels of coercion and restrictive practice should be a constant priority, balancing the need for some patients to have extended restrictive practices to establish a physically healthy weight and re-establish normal eating practices, without repeated cycles of rapid weight loss and coercion. At the same time, it is important not to give up on patients – there is a real risk that withdrawal of active treatment and palliative care is being considered for some patients who may yet recover, if only they had experienced the right treatment with trusted clinicians at a time when they were ready to think about, tolerate and embrace recovery.

Legal principles

Clinicians should think clearly about questions of necessity and proportionality first, before jumping to decide whether to use specific frameworks such as mental health or mental capacity legislation. Furthermore, clinicians should be willing to take the patient's case to a clinical ethics committee to elicit a further perspective. If there is still doubt regarding the legal basis of treatment then, as the last resort, clinicians should place the question before the courts as to whether the balance has been correctly struck, as court orders would provide the correct oversight for the most complicated cases.

Conclusion

This paper has used experts in their field to suggest the best ethical, legal and clinical practice regarding long-term NGT feeding under physical restraint for those practicing in England and Wales. Advanced care planning with patients who are at risk of this intervention at the point of admission allows collaboration away from a physical health crisis and could help to keep patients actively involved in their treatment. Clinical teams should think clearly about questions of necessity and proportionality as they move patients towards lower levels of coercion and restrictive practice.

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Ethics in eating disorders

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Abstract

Eating disorders and their treatment present many ethical dilemmas. These are severe mental illnesses that have considerable consequences on all areas of sufferers' lives. Eating disorders are associated with reduced quality of life, high carer and societal burden and significant mortality. Whilst treatments evolve, it is widely acknowledged that our understanding of these conditions and effective treatment pathways is frustratingly inadequate. Eating disorders are philosophically perplexing in that they are experienced as part of the self and can become highly valued coping mechanisms. As a result, many patients will at some point deny aspects of their condition and avoid or refuse treatment. How should we approach challenging questions such as the following? Should treatment be enforced? Can a patient decide? Is coercion ever acceptable? Should patients be assisted in dying? An exploration of ethical principles can provide a framework, but the complexities of individual circumstances require a comprehensive, compassionate and flexible approach to these most fundamental issues. Ethical considerations must always be kept at the forefront of clinical decision-making.

Keywords: eating disorders, ethics, autonomy, capacity, decision-making

What is ethics?

Ethics is a branch of philosophy that is concerned with the question, "what is the morally right course of action in this particular situation?", and underpins every clinical decision. Medical ethics aims to assist in finding a solution to these problems. This is achieved through guiding an impartial, informed approach that considers the relative merits of the available options in the search to determine the best course of action. Medical ethics does not offer absolute or definitive answers but should guide a coherent and rational approach to clinical decision-making.

Principlism, as set out by Beauchamp and Childress, is the most widely adopted ethical approach applied in current clinical practice (1). It outlines four universal basic principles that define the moral obligations of clinicians; these are beneficence, non-maleficence, respect for autonomy and justice. Beneficence is the obligation of a clinician to act for the benefit of the patient and promote their welfare. Non-maleficence is the duty of a clinician not to harm the patient. The practical consideration of non-maleficence lies in weighing the benefits against burdens of possible interventions. The principle of autonomy recognises individuality, in that we all have intrinsic and unconditional worth. We have the right to make decisions and exercise self-determination. Autonomous decisions are contingent on one's capacity to make that choice. Justice is generally interpreted as fair, equitable and appropriate treatment.

Beneficence and non-maleficence can be traced back to the time of Hippocrates and would generally be regarded as fundamental, inarguable doctrines in clinical practice. Respect for autonomy has gained primacy in contemporary medicine, which is congruent with societal and cultural shifts towards personal freedom. Most notable is the steady shift from medical paternalism to a patient-centred approach that relies on determination of capacity and the use of informed consent. Whilst these principles are singularly uncontentious, dilemmas arise when they conflict.

Ethics based on principles incorporates a deontological or "rules-based" approach with a focus on the nature of the action and a utilitarian stance that is reliant on the outcome. In the healthcare setting, virtue ethics also has something to add. This highlights the importance of the character of the clinician and seeks to answer, "what would a kind, honest, benevolent, caring person do in these circumstances?", which places the actor (clinician) under the spotlight and emphasises the importance of self-knowledge and self-reflection. This seems key, as the process of balancing conflicting principles is recognised to be highly subjective.

Clinicians should therefore have a good understanding of ethical principles and experience in systematically evaluating them from each of these viewpoints. Embedding this approach within clinical teams will enable sound ethical decision-making in clinical practice.

What is it about eating disorders that makes them ethically challenging?

There are a number of features of these illnesses and current treatment approaches that are uniquely perplexing for clinicians. We must first attempt to understand why patients commonly deny the severity of illness, lack insight and resist treatments.

Identity and values

Conflict is commonly encountered in the treatment of eating disorders because overvalued ideas about weight and shape are core symptoms that drive eating disordered behaviours to prevent weight restoration. Treatment aims to challenge these behaviours in order to regulate eating and weight (2). Eating disordered psychopathology is by definition ego-syntonic, or in other words, experienced as part of the self and congruent with one's values and life goals (3). Treatment may be viewed as inherently incongruent with, or even threatening to, the sense of self (4). Additionally, an eating disorder can be experienced as a solution to wider difficulties, particularly in terms of emotional regulation. It becomes a strongly valued coping mechanism.

Developmental process

The incidence of eating disorders is highest during the adolescent period and there is some evidence of impact in increasingly younger children (5). This is a critical developmental stage, with the process of identity formation a key task (6). Retreat into an eating disorder can feel like a safer option at this time and the illness then hijacks or halts the process; an "anorexic identity" is adopted. Because a stable sense of identity has not formed prior to developing the illness, a tangible alternative option to the eating disordered self, an "authentic self", can be elusive (7). The natural process of individuation and progression towards independence is interrupted. Addressing this interplay between the development of a stable sense of self and the eating disorder is a critical part of many therapeutic approaches.

Severity

Eating disorders considerably impair physical health and disrupt psychosocial functioning. Psychiatric comorbidity is the norm and medical risk associated with being underweight, malnutrition and purging can be life-threatening (8). Mortality associated with all eating disorders is significant and for anorexia nervosa widely reported to be among the highest of all psychiatric disorders. Death results from complications associated with malnutrition or electrolyte disturbance through purging. Suicide accounts for 1 in 5 patients who die with anorexia nervosa (8-10).

Evidence for effective treatment

Eating disorders are notoriously under-researched, resulting in uncertainty as to their pathophysiology and effective management strategies. This is particularly the case for anorexia nervosa. The National Institute for Health and Care Excellence (NICE) acknowledges the "low-to-very-low" quality of evidence for psychological treatments for adult anorexia nervosa (2). Randomised controlled trials are underpowered to show superiority for any specific therapy and even the best current treatments bring about significant improvement in only 50% of patients, with 20% remaining severely ill (11, 12). However, early intervention appears to improve outcomes (13, 14), which may provide ethical justification for a tipping of the balance towards a more proactive/coercive approach. There are clearly significant gaps in our understanding of the effectiveness and acceptability of current interventions (15) and further research is urgently needed.

Treatment approach

Due to the complexity of both psychiatric and physical symptoms, treatment often requires a coordinated approach between the patient, family members, general practitioner, general psychiatric teams, eating disorder services and physicians (16). Discontinuity and disruption of care has a significant impact on the establishment of a therapeutic alliance and thus how beneficial treatment will be.

The most common ethical dilemmas require a determination of risk versus benefit (beneficence and non-maleficence), particularly in the face of treatment refusal when respect for autonomy may conflict with our duty to protect. We must therefore consider the nature of these illnesses and evidence for the effectiveness of the treatments we currently provide.

Misunderstanding and stigma

Misunderstanding and stigma regarding eating disorders is endemic. Compared with other mental illnesses, eating disorders are more commonly viewed as less severe, self-inflicted and under an individual's control (17). Crucially, studies have shown that these beliefs are held by professionals as well as the public (18). Stigma is a barrier to help-seeking and accessing treatment in a group who already feel substantial shame and guilt. Our understanding and theoretical view of an illness fundamentally informs our approach. The danger of stigma must be recognised as it affects all aspects of care from families, employers, health professionals and policymakers. Stigma has a pernicious impact on investment in research and clinical services. It is vitally important that clinicians recognise and reflect on their own prejudices in this respect, as engagement in treatment and perception of care is heavily influenced by the therapeutic alliance and level of trust a patient has in their clinician.

Ethical dilemmas

Treatment refusal

We have an understanding of why patients with eating disorders may struggle to accept, or even refuse, treatment.

Enforced treatment is considered when there is significant medical or psychiatric risk, when such treatment is life-saving. Severe underweight, rapid weight loss, medical risk associated with purging or risk of severe self-harm are the most common indicators (2, 19, 20). From an ethical standpoint, the controversial decision of whether to embark on compulsory treatment hinges on a judgement of risk versus benefit (maleficence versus beneficence), where the autonomy of the patient is juxtaposed with the obligation of the clinicians to save lives.

The infringement of a patient's right to self-determination is deemed by some to be fundamentally wrong (21). There are also clinical concerns regarding this approach which see it as counterproductive. An oppositional patient who is forced to gain weight may "eat his/her way out of hospital" with no psychological benefit. Enforced weight gain can increase the risk of developing additional eating problems, such as the use of covert compensatory behaviours. The result may be a worsening of illness with an increased likelihood of rapid relapse on discharge. Worryingly, compulsory treatment risks damaging the trust in clinicians and eroding the therapeutic relationship, which may undermine the likelihood of future engagement in treatment (22).

Unfortunately, empirical data on the effectiveness of compulsory treatment is sparse, and with differing criteria it is difficult to draw firm conclusions (23). The potential benefits of compulsory treatment are most evident in the short-term when intervention can certainly be life-saving. Long-term outcomes appear to be similar to those who are treated voluntarily, with no significant difference in mortality rates (24, 25). Given that those treated compulsorily arguably have more severe illness at baseline and would not have engaged with treatment otherwise, this suggests that compulsory treatment may not be detrimental and may be beneficial in the long-term. In practice, compulsory treatment is used as a life-saving measure and the question is when to treat rather than whether to treat.

Qualitative studies of patient and parent views offer valuable perspectives (26-28). As expected, a wide range of views emerge from these studies. It is recognised that enforced feeding can relieve feelings of guilt about accepting nutrition and treatment, and as such give some patients the "permission to eat". There is also evidence that some patients retrospectively agree that compulsory treatment was the right course of action (26), and that the degree of satisfaction after discharge is similar for voluntary and involuntary admissions (27). However, Rienecke et al. highlight the diversity of experiences. They report that involuntary treatment is recognised in retrospect as beneficial by those who were doing well; however, those who continue to struggle with their eating disorder report negative consequences (28).

What is clear is that the nature of the relationship between the patient and the clinical team is key and can be the most important determinant of whether any aspect of treatment is experienced as coercive or as an act of compassion (26, 28, 29). We will return to this later in the discussion about the futility of treatment.

The legal mechanism for compulsory treatment in England and Wales is outlined in the Mental Health Act (1983) (30). It provides legal justification for treatment of a mental disorder without consent when criteria relating to the nature, severity and risk associated with the illness are met. Most jurisdictions have some form of mental health legislation recognising the special vulnerability of those with severe mental illness and the need for protection and treatment in the case of treatment refusal (21, 31, 32). From an ethical standpoint, a utilitarian/paternalistic approach has taken precedence over a more libertarian stance in these circumstances. With clear sociocultural shifts away from paternalism since the latter half of the last century, the right to self-determination in healthcare decisions has gained prominence. There is a corresponding move towards a heavier reliance on an assessment of mental capacity in all clinical decision-making, and parity between decisions regarding physical and mental health. Whilst this may have face value, it necessitates a close and careful look at how capacity is conceptualised and determined in different patient populations.

Decisional capacity

Mental capacity is a prerequisite for self-determination in relation to healthcare decision-making. The Mental Capacity Act (2005) (33) outlines the process of assessment of capacity and how to approach treatment in those deemed not to have capacity in relation to a particular decision. In cases involving adults there is an assumption of capacity, and all practicable steps must be taken to enhance the patient's ability to make an autonomous choice. Unwise decisions should not be regarded as evidence of a lack of capacity, and the least restrictive course should always be taken. Minors can consent if they have sufficient understanding and intelligence to understand fully what is

Box 1. Format for the assessment of capacity in eating disorders (adapted from Tan and Richards (41))

- Ability to understand and retain information
- Ability to use information
- Appreciation of information and facts of the decision
- Presence of compulsions
- Changes in values due to the eating disorder
- Changes in identity due to the eating disorder
- Presence of depressive features, loss of hope and affective elements
- Presence of neuropsychological deficits
- Mentalisation ability

involved in a proposed treatment, including its purpose, nature, likely effects and risks, chances of success and the availability of other options. There is a determination of "Gillick competence" (34). In the absence of Gillick competence, consent must be provided by someone with parental responsibility or the court.

Capacity in anorexia nervosa

The legal test of capacity is largely intellectual. It relies on an ability to understand relevant information, have an appreciation for the consequences and undertake a process of reasoning in order to make and communicate a decision. When standardised instruments such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (35) are used, even patients with severe anorexia nervosa can be judged to have decisional capacity regarding treatment, with low concordance with clinical judgements of capacity (36, 37).

Patients with eating disorders are often highly articulate and persuasive in their reasoning (20, 38). Research has shown, however, that there may be more subtle impairments related to the specific psychological aspects of the illness. The previous discussion regarding values, identity and valued nature of the illness again come into focus. A determination of what is an authentic desire and what is illness-driven or a "pathological value" is crucial (4, 38, 39).

Neuropsychological difficulties, such as inefficient set-shifting and poor central coherence are a feature of eating disorders and considered to be important maintaining factors. They appear to be trait characteristics, but this cognitive inflexibility is also exacerbated by underweight. The bias towards local, as opposed to global, functioning is highly likely to affect the reasoning and appreciation aspects of decision-making (40). In other words, the focus on detail clouds the bigger-picture considerations, for example, the current meal as opposed to the broader impact of illness.

An explorative study on this issue concluded that diminished mental capacity occurs in a third of patients with severe anorexia nervosa and is associated with a low BMI (although not exclusively), less appreciation of illness and treatment, previous treatment for anorexia nervosa, low social functioning and poor set-shifting. This study also highlights the importance of considering the emotional state of the patient and mentalisation ability (36).

Aside from the complex clinical picture, the determination of capacity is highly subjective and considerably impacted by the experience, beliefs and attitude of the assessor. Takimoto uncovered vastly differing views and outcomes in a survey of physicians in Japan, the UK and the USA (37). Determining consensus and guidance on the treacherous task of capacity assessment in those with eating disorders is of the highest priority.

Coercive treatment approaches

It is important to acknowledge that restrictive treatment is not confined to enforced feeding. The use of leverage is fairly commonplace in the treatment of eating disorders. Leverage in mental health treatment can be exercised in a multitude of ways, ranging from persuasion to inducements and "threats of coercion" (42). Practices such as supervision at mealtimes, monitoring bathroom use, exercise restriction and routine weighing and physical health monitoring could be perceived as coercive. Clinicians must recognise that whilst these approaches have clear clinical benefits they are not without risk. We have a duty to review the relative merits of such approaches and explain the rationale for all aspects of treatment in order to justify their use in particular circumstances.

Palliative care and medical aid in dying

The question of whether it is ever ethically justifiable to withdraw life-saving treatment or to assist in the death of someone with anorexia nervosa is one of the most troubling and controversial issues. In patients with severe and enduring illness who persistently refuse treatment, the determination of the relative risk and benefit of further intervention can be particularly problematic. The legal and ethical concerns surrounding this issue have received growing attention (23, 43, 44). In the UK, since 2012 there have been a number of appeals to the Court of Protection (45) to determine a legal route. A judgement of incapacity has, in most cases, led to a "best interests" decision not to compel life-saving treatment (46-51).

In Canada, a new category of "terminal anorexia nervosa" has been proposed as an expansion of the country's criteria for medically assisted dying to those suffering with a mental disorder (52, 53). The debate surrounding this is clinically and philosophically challenging.

Proponents of the withdrawal of treatment in certain circumstances offer a number of arguments. It is proposed that for some people who persistently resist treatment, the benefits are outweighed by the burden/harm of such intervention. It is not difficult to argue that enforced feeding, for example, whilst life-preserving is highly traumatic. Respect for patient autonomy and the right to exert personal values of a life worth living may be the most compassionate approach, affording someone the right to determine when "enough is enough". In these extreme circumstances it is proposed that palliative care to ameliorate suffering, as opposed to continued treatment attempts, is ethically imperative. It is suggested that consensus in this area would allow the development of clinical and policy guidelines and validate the experience of this limited but significant group of patients.

The proposed criteria for "terminal anorexia nervosa" are as follows. (1) diagnosis of anorexia nervosa; (2) age 30 years or over; (3) prior persistent engagement with high-quality, multi-disciplinary, eating disorders care; and (4) consistent,

clear expression by an individual who possesses decision-making capacity that they understand that treatment is futile, choose to stop prolonging their lives and accept that death will be the natural outcome. A prognosis of less than six months is suggested, using evidence of duration of life in hunger strikers, and it is concluded that this is congruent with current practice in determining a terminal diagnosis (52).

Unsurprisingly, there is considerable opposition to this proposal. Some reject euthanasia and other forms of assistance in dying on the fundamental principle of the sanctity of life, emphasising the view that all human life has inherent value and should be preserved regardless of suffering or illness. Clinicians and patients have expressed multiple concerns highlighting the damaging and potentially dangerous effect of the debate itself, in addition to criticism of the validity of the suggested criteria (54-58).

Box 2. Ethical considerations in clinical practice

- Reflect on own attitudes and beliefs as these will influence decision-making
- Develop a therapeutic alliance as this is key
- Use motivational approaches
- Identify reasons for treatment refusals
- Provide careful explanations of treatment options
- Weigh the risks and the benefits of interventions
- Involve important others, for example, family members
- Negotiate where possible and use the least restrictive approach
- Avoid conflict
- Carry out thorough capacity assessments
- Enhance autonomy and aim for collaborative decision-making
- Team discussion and regular review of all aspects of care
- Consider legal means of enforcing treatment when refusal is judged to constitute a serious risk
- Consider different treatment focus in those with longstanding illness where standard treatment has not been helpful

The current lack of knowledge regarding underlying mechanisms, effective treatments and predictors of outcome are key clinical objections to the concept of futility (54-56). Anorexia nervosa is a potentially treatable condition and recovery is possible at any stage, even after decades of illness (59, 60). Whilst there have been attempts at developing a staging model for anorexia nervosa, we simply do not understand enough about the course of the illness to define clear prognostic indicators. In other words, we cannot currently be confident about which treatment is likely to be more effective for whom, or who is more or less likely to recover even after years of illness.

The widespread scarcity of resources and lack of standardisation in treatment approaches across services brings the determination of the third criterion, previous "high-quality care", into question (15, 61). Consideration of the impact of comorbid conditions, particularly obsessive-compulsive disorder, depression, personality disorder and neurodevelopmental conditions such as autism, also requires considerable attention due to the additive impact on hope for recovery.

The determination of capacity again becomes key. When we consider the wide variability of opinion and practice it seems clear that we are not currently in a position to feel confident about how this criterion will be assessed, particularly concerning such high-stakes decisions (36, 37).

What this debate highlights is the devastating impact of severe illness and repeated attempts at treatment on patients, family members and clinicians. This can inevitably lead to pessimism and a loss of hope. However, resources should be directed at exploring how we can "give sufferers the right to *truly* live - not just exist, survive, or wait to die" (55). A harm-reduction approach is infinitely more ethically justifiable (62, 63). An explicit shift of focus, from full recovery and weight restoration to one that aims to improve quality of life while minimising harm, also enhances personal autonomy and, most importantly, protects future autonomy.

Conclusion

Eating disorders are clinically and philosophically complex conditions. This is due, in part, to the unique nature of these illnesses and limitations in the current understanding of the underlying mechanisms and the most effective interventions. Clinical decision-making is highly subjective and there is currently no consensus, particularly in guiding treatment for the most severely unwell. In addition to a worldwide lack of resources in the field, this results in inadequate or inappropriate care for many sufferers.

Determining the balance between the safeguarding of autonomy and treating severe illness or the withdrawal of treatment should be approached with caution and after careful consideration. It is imperative that the ethical aspects of treatment are addressed alongside clinical parameters. Further research and the development of evidence-based treatment pathways for complex cases should alleviate some of the controversy regarding the most challenging treatment decisions.

On an individual basis, all clinicians must strive to practice to the highest ethical standards. This can be achieved through self-reflection and the development of skills in applying core ethical principles to clinical practice. Compe-

tence in collaboratively exploring the most thorny issues with patients, families and within teams should ensure the provision of compassionate, timely, patient-centred care. Treating patients in this way is also likely to be more effective.

Declaration of interest

The author declares that they have no conflicts of interest.

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Audit on the role of the eating disorder psychiatrist

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Abstract

Consultant eating disorder (ED) psychiatrists play a lead role among the multidisciplinary team within ED services, as their skill set equips them to manage these complex disorders effectively using a multidimensional approach.

The aim of this audit was to determine the degree of alignment of consultant ED psychiatrist roles with the 2014 Royal College of Psychiatrists guidelines (1), focusing on clinical work, leadership and educational responsibilities. Fifteen consultant ED psychiatrists were interviewed and their self-reported roles were compared to the guideline set by the Royal College.

The data showed that clinical responsibilities were the most consistently performed (100%), while educational roles, specifically external education, were least represented (13.3%). Leadership responsibilities, mainly service development, were also prominent (80.0%) but some psychiatrists reported insufficient time for other responsibilities, such as therapeutic work and training. No psychiatrist was able to fulfil all of the roles described in the 2014 guidelines. This audit highlights the differences between Royal College expectations and current practice, emphasising the importance of further investment in consultant ED psychiatry to enhance service delivery.

Introduction

Consultant psychiatrists working in eating disorder (ED) services form an integral part of the multidisciplinary team needed to manage these multidimensional disorders. Eating disorders have a complex presentation of psychological and physical symptoms, and the breadth of the medical and psychiatric skills that consultant ED psychiatrists possess means they are able to offer a holistic and well-rounded oversight of the treatment of these disorders.

This audit aims to investigate the adherence of the consultant ED psychiatrist role to the "gold standard" described in 2014 by the Royal College of Psychiatrists (1), based on interviews with current ED psychiatrists. According to the Royal College, consultant ED psychiatrists are expected to provide clinical care, leadership and educational roles in their positions.

Methodology

The self-reported roles and responsibilities of consultant ED psychiatrists were compared with those described by the Royal College in a 2014 statement (1) and later established as the national standard necessary for psychiatrists working in ED services.

The audit was advertised via the Faculty of Eating Disorders Royal College Network and the online community EDSIG (the Eating Disorder Special Interest Group) mailing list, inviting consultant ED psychiatrists to participate. Ultimately, 15 consultants from across the UK took part in semi-structured telephone interviews conducted between 14 July and 8 September 2018. Interviews were conducted by one of the authors (EC) and transcribed concurrently. The participants worked across the age groups, with seven psychiatrists working in child and adolescent services and eight working in adult services. Verbal consent to participate was given by each interviewee.

As this was an audit requested by the Royal College and not clinical research, ethics approval was not required. Interviews were not qualitatively analysed as this falls outside the scope of the audit.

Three main domains were identified within the role and subcategories, which are outlined in the results (see Table 1). Interview notes were cross referenced against Royal College roles by four of the authors (NR, NW, IG and SB) and then crosschecked by one author (NR).

Category	Role	No. engaging in role (N = 15)	%
Clinical	Psychiatric, medical and risk assessments	15	100.0
	Liaison with other services	8	53.3
	Clinical supervision	8	53.3
	Delivering psychological therapy	5	33.3
Educational	Staff training	5	33.3
	External education around eating disorders	2	13.3
	Supporting trainees	5	33.3
Leadership	Maintenance and development of services, service leadership/service development	12	80.0
	Lead in audit and standards	4	26.7
	Supporting team in case management, e.g., in multidisciplinary teams (clinical leadership)	10	66.7
Research	Engaging in research	3	20.0

Table 1. Reporting on the fulfilment of roles by consultant eating disorder psychiatrists

Results

The subcategories identified showed that consultant ED psychiatrists cover a wide range of responsibilities. Clinical aspects of their role were better represented than other aspects. It was also noted that research and educational opportunities, specifically external ED education, were the least practiced areas within their job plan.

The most represented roles were psychiatric, medical and risk assessments (n = 15, 100.0%); maintenance and development of services, service leadership and service development (n = 12, 80.0%); and supporting their teams in case management (n = 10, 66.7%).

Conducting clinical assessments was the only category identified by all interviewees, highlighting how integral this is to their role. Liaison with other services was referenced by just over half of those interviewed.

Despite psychiatrists learning to deliver psychological therapies during core training, and some even receiving additional training in therapy afterward, few psychiatrists had the opportunity to deliver therapeutic interventions. The gold standard itself does not clarify which therapeutic interventions would be offered in an ED context, although family therapy (n = 6, 40%) and cognitive behavioural therapy (n = 7, 46.7%) training were commonly mentioned by participants. Therapy intervention was the most poorly represented of the clinical roles (n = 5, 33.3%).

"I don't think it is cost-effective to use me as a therapist." (Participant 3)

"The way the service is set up, none of the psychiatrists have the opportunity to practice these [therapeutic] skills." (Participant 8)

Those who did not provide therapeutic interventions reported conflicts within their roles or time constraints as barriers to this.

Training roles within the ED teams and wider NHS trust were poorly represented in the sample, with only one-third mentioning roles in staff training or supporting trainees. This lack was noticed by those interviewed, with multiple psychiatrists highlighting the absence of an ED training pathway.

"There are no trainees, and they would struggle to recruit as there is no training program for [the] eating disorder specialty." (Participant 6)

Providing education on EDs to a wider community setting was detailed in the Royal College document (1) but mentioned by only two of the psychiatrists interviewed (13.3%), making it the most poorly represented aspect.

Most consultant psychiatrists (n = 12, 80%) did take a lead role in the services, with some expressing dissatisfaction specifically with managerial responsibility. In some services, consultant ED psychiatrists were expected to lead on clinical work and focus on direct patient care but were unfortunately not empowered to take service leadership roles. Others referenced being involved in commissioning groups and having input in the wider management of their organisations. The necessity of attending managerial meetings was also highlighted as a barrier to other activities.

"Consultant psychiatrists are trained for leadership and service development which should include QI [quality improvement], staff development and sometimes research and teaching." (Participant 3)

Discussion

By capturing the day-to-day role of a varied group of consultant ED psychiatrists, this audit has highlighted the gap between the reality of the role and what the Royal College document (1) has outlined that the role should be. Despite their holistic training, the current audit suggests that consultant ED psychiatrists mainly contribute to clinical work, in

particular assessment, formulation and diagnosis, as well as leadership and team management activities.

The clinical time of consultant ED psychiatrists is spent on physical care and risk management of patients, with this being prioritised over other clinical tasks, such as therapeutic interventions. Some psychiatrists identified a lack of funding for full-time psychiatry posts, which could put services at risk in the long term and, in turn, lead to a devaluing and erosion of the role, to the detriment of patient care.

The role that psychiatrists provide in maintaining their services, through recruitment, attending managerial meetings and securing funding, is an essential aspect of specialist ED services continuing. However, some who were interviewed identified a lack of protected time for this, which added pressure to their job plan. It would be helpful to see NHS trusts valuing their input by ensuring that such clinical leadership and strategic roles are accounted for in the psychiatrist job plan.

The Royal College of Psychiatrists sets out the expectation that consultant psychiatrists in all specialties will be up to date on evidence-based approaches and will contribute to knowledge development by supporting research. This audit shows that engagement in research is not currently being actualised within ED services, which may inhibit the development of new evidence-based approaches.

In conclusion, this audit identified clear gaps in the provision of psychiatry across services. There is a need to consider how this role could be further actualised and developed in response to this. For example, an increase in psychiatry recruitment and retention, both in terms of increasing the interest of doctors in specialising in psychiatry and improving the training pathway for the ED specialty. The authors acknowledge that this means additional investment, however, consultant expertise improves service quality and adds to the effectiveness of the multidisciplinary team. Despite the financial pressures that the NHS is facing, service providers should not underestimate the importance of recruiting consultant psychiatrists who add value to ED teams across the various domains.

Further research that may be beneficial in this area could include an analysis of how many consultant ED psychiatry roles are currently in place or open in the NHS, as well as a more thorough analysis of the current compared with potential training pathways for this subspeciality.

Author contributions

EC: audit conception and design, data collection, manuscript preparation and critical comments. NR: manuscript preparation and critical comments. NW: manuscript preparation and critical comments. RJ: manuscript preparation. IG: manuscript preparation. SB: manuscript preparation. DN: audit conception and design, data collection, manuscript preparation and critical comments.

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Recent advances and future directions in the management of eating disorders

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Abstract

The aim of this paper is to describe recent and future advances in eating disorder treatment. The development of new treatments represents a pressing issue, given that current treatments, which are predominantly forms of psychotherapy or inpatient treatment (for those at high medical risk), have variable and limited efficacy, with short-term recovery levels between 30% to 50% for the first stage of treatment. If initial treatment efforts fail, there is uncertainty about what strategy should be next considered. Developments in aetiological understanding, through defining biomarkers, working with animal models and neurobiological investigations, have encouraged the consideration of a broader range of treatments. Brain-directed strategies such as neurostimulation, exposure-based learning, psychedelics, metabolically targeted treatments including leptin and incretin receptor agonists, and the therapeutic use of the arts have been recently investigated. New technologies such as virtual reality–based and brain training–based interventions have been found to enhance standard forms of treatment. Unfortunately, the limited funding for eating disorder research has meant that advances into clinical practice have been limited. However, given the size of the problem and its protracted nature, it is important that work to progress and evaluate new treatment pathways, such as that in depression or schizophrenia, is prioritised.

1. Introduction

Progress in eating disorder research has been hampered by the poor level of funding for research and service development in this area. Treatment guidelines for eating disorders have remained relatively unchanged over the last 10 to 20 years, recommending various forms of psychotherapy that produce moderate effects. Involving the family in the treatment of anorexia nervosa (AN) produces larger effects, especially in adolescence (1).

Recent developments in our understanding of the aetiology of eating disorders have inspired new approaches. It should be acknowledged that family members of people with eating disorders have played an important role in this change of focus by supporting and/or founding charities that funded the acquisition of the large cohorts of people with AN that are needed for genetic studies. These studies have led to the discovery that both neural and metabolic systems are associated with the risk of developing AN (2, 3), shifting the emphasis from social onto biological causes. Collaborative efforts between research centres have enabled the impact of AN on brain structure and function to be more clearly defined. For example, the ENIGMA consortium has reported on the profound impact of starvation on brain structure and function, whereby AN, compared to other psychiatric disorders, has the greatest loss in cortical thickness (4). This has led to research aimed at improving neuroplastic processes (5). This paper aims to provide an overview of some these new approaches.

1.1 The varieties of eating disorders

The standard varieties of eating disorders defined in the DSM-5 include AN, bulimia nervosa (BN), binge eating disorder (BED), avoidant/restrictive food intake disorder (ARFID), pica and rumination disorder. The literature relating to the latter three conditions is limited and will not be considered in this paper.

1.2 Models of eating disorders

Table 1 outlines some of the factors thought to be associated with the predisposition, precipitation and perpetuation of eating disorders. Theoretically, treatment should target these factors, but there are gaps in the status of this knowledge. Although there was an initial emphasis on transdiagnostic processes, some of the biological aspects diverge. Most of the information on environmental or developmental predisposing factors is sourced from longitudinal studies and relates to binge-spectrum disorders, given their higher prevalence. In contrast, clinical studies and research into biomarkers focuses mainly on AN, often within the inpatient context.

1.3 Predisposing factors

The genetic risk profile for eating disorders is broadly similar to many other psychiatric disorders, although the profile for AN has most overlap with that of obsessive-compulsive disorder (3), and the profile for binge-spectrum disorders overlaps with addictions and attention deficit hyperactivity disorder (2). Interestingly, the metabolic genetic risk profile differs widely across the eating disorder spectrum. The profile for binge-spectrum disorders is associated with

	AN	BN	BED
Predisposing traits	Compulsivity	Impulsivity	Impulsivity
	Sensitivity to punishment	Sensitivity to reward	Sensitivity to reward
	Satiation sensitivity	-	Appetite sensitivity
Environment	Trauma	Trauma++	Trauma++
	Social comparison	Social comparison	Social comparison
Trigger	Negative energy balance	Negative energy balance	Negative energy balance
Perpetuating	↓ Brain volume	-	Addictive process:
	↓ Social cognition		↑ Craving
	↓ Memory		↓ Reward
	Psychosexual regression - isolation	-	Self-disgust, shame
	Stress, anxiety, treatment-resistant depression	Stress, anxiety, treatment-resistant depression	Stress, anxiety, treatment-resistant depression

Table 1. Models of eating disorders: factors that contribute to predisposition, precipitation and perpetuation
Abbreviations: AN = anorexia nervosa; BED = binge eating disorder; BN = bulimia nervosa

higher waist and hip circumference, being overweight, obesity and extreme body mass index (BMI) (2), whereas the profile of AN is in the opposite direction (negative relationship with body size, obesity, BMI, insulin resistance, fasting insulin and leptin) (3). Another contrast is that binge-spectrum disorders have increased sensitivity to reward, whereas AN is also associated with sensitivity to punishment (6, 7). These temperamental traits and behavioural styles shape the background predispositions to the form that an eating disorder might take.

1.4 Precipitating and perpetuating factors

Trends of eating disorders over time have shown a steady increase in binge-spectrum disorders from 1979, following Russell's seminal paper (8), whereas the incidence of AN has remained roughly steady, apart from an increase in people aged 10 to 14 years (9). However, since the COVID-19 pandemic, the incidence of severe cases of AN has increased (10). The time course of the increase in binge-spectrum disorders parallels the increase in obesity in many populations. Changes in diet (particularly associated with the hyperabundance of ultra-processed foods), eating behaviour, food poverty and weight stigma have been implicated in all weight and eating conditions. These specific environmental contexts combine with other forms of marginalisation or trauma, as well as genetic predisposition, to increase the risk of developing an eating disorder.

Environmental background adversity is less pronounced with AN; however, the prolonged starvation that follows from the onset of the restricted eating leads to medical instability, with secondary effects that impact on brain structure and function. These consequences can impact on psychosexual development and lead to problems in social cognition and memory, which may impact on the ability to develop a recovery identity (11). These brain changes and the protracted course of AN can lead to social alienation, stress and the development of a form of depression or anhedonia that is resistant to standard pharmacological treatments.

2. First-line treatments

For binge-spectrum disorders (BN and BED) and AN, first-line treatments consist of cognitive behavioural therapy (CBT)-based approaches adapted for eating disorders. Involving the family in treatment at an age-appropriate level is particularly important for AN (1). Additionally, inpatient, day patient or home-based treatment strategies are used if the physical state is compromised (12).

Treatments for AN that focus on the underlying predisposing traits and the secondary impact of starvation include the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) (13, 14) and temperament-based therapy with support (15).

Approximately one-third of adult cases of AN do not respond to these first-line approaches. New approaches to treatment are being considered for these groups with a longstanding form of illness, who often have additional comorbidities, and develop medical, psychological and social consequences from protracted ill health (16).

3. Second-line treatments

A variety of new approaches have been introduced to target some of the emotional, social and cognitive features of eating disorders that are associated with a poor response to first-line treatments. For example, new strategies to augment treatment for binge-spectrum disorders, focusing on moderating impulsivity, have been introduced, whereas a focus on compulsive patterns of behaviour have directed new approaches for AN. These potential new second-line treatments are discussed in the following sections.

3.1 New psychotherapeutic and cognitive strategies

3.1.1 Externalising strategies

One of the unique and puzzling aspects of AN is that many patients do not consider themselves to have a problem. Indeed, they may value aspects of their eating disorder. This can cause disruptions in their relationships with supporters (professionals and family), who are often extremely concerned, and can lead to delays in seeking treatment and decreased motivation to engage in treatment.

Many psychological therapies for AN, such as family-based therapy and MANTRA, use externalisation strategies to modify this ambivalence about recovery. Externalising refers to the process whereby the individual is guided, through various methods, to re-perceive their illness as separate to, rather than a part of, the self. Art therapies, often with the use of forms of transitional objects (letters, photographs, playlists, toys etc.), are used to externalise the illness and may be useful in individual or group approaches (17).

New techniques to augment externalisation include dialogue therapy, which uses chair work, where the patient converses with different aspects of the self, or the self in different stages of recovery, to explore ambivalence (18). Avatar treatment (developed for the treatment of schizophrenia) is a similar approach in which the therapist speaks as the eating disorder through a digitally constructed bespoke avatar and coaches the patient to talk back to the AN voice (19, 20). A small feasibility study using this avatar-based approach for eight sessions in 10 patients with AN found lower levels of distress associated with the eating disorder voice and higher levels of self-compassion. Feedback from patients was that avatar therapy had helped with their ability to stand up to the illness, make positive changes around eating and increase their motivation to recover (20). Additionally, a study of computer-assisted avatar-based treatment in subclinical eating disorder cases (n = 48) found a reduction in eating disorder–specific symptomatology (21).

3.1.2 Exposure-based treatments

Exposure-based treatments involve engagement with, rather than the avoidance of, emotionally laden triggering situations relating to food, body image and social encounters, which are common sources of fear and distress in AN.

Supported eating is a key component of the higher levels of care for AN (22, 23) but is less frequently used as a part of outpatient care (24). However, creative use of virtual exposure has offered the possibility of using new strategies to combat fear and avoidance in the outpatient setting. Virtual reality (VR) can facilitate novel and personalised exposure experiences and encompass a range of engagement with a wide variety of food-related (25-27), body-image and socially threatening stimuli (28, 29), in a variety of contexts.

Exposure treatment involves a process of reversing fear by developing inhibitory learning (30). The feared outcome from eating in eating disorders is usually an expected future consequence, such as becoming "fat", and facing the associated social stigma. This cannot be disconfirmed in the short term. However, approaches such as imaginal exposure, which target these future expectancies, has shown good effects when used in a transdiagnostic sample (31, 32). Body image problems can also be addressed in VR with the use of avatars that allow users to experience different body perspectives (33, 34). A meta-analysis of VR techniques for people with binge-purging eating disorders found reductions in binge eating and body image problems (35). Moreover, a promising study found that VR-based body exposure therapy was an effective second-line treatment for those with BN and BED who had a poor outcome with CBT (36).

3.2 Brain stimulation techniques

A variety of new techniques have been developed to stimulate specific areas of the brain, both invasively, with intracranial electrodes, or through using non-invasive brain stimulation, such as magnetic or direct-current stimulation (37).

3.2.1 Transcranial magnetic stimulation (TMS)

TMS is a brain stimulation technique that is modulated over a specific area of the brain to enhance or inhibit electrical activity by increasing or decreasing the excitability of targeted neurons (38). Pulsing patterns of TMS are varied depending on the desired outcome, ranging from single pulses that last milliseconds to repeated trains lasting minutes (39).

TMS to the dorsolateral prefrontal cortex (dlPFC) has been applied to participants with a wide variety of behavioural traits that are relevant for people with eating disorders, such as decision-making, risk-taking and impulsivity. The dlPFC has been linked to food craving and consumption and is implicated in self-control in a dietary context (38). In trials with a sham comparison group, significant therapeutic effects were found for cravings (large effects), depressive symptoms (moderate effects), obsessive or compulsive symptoms and anxiety (small effects) (40).

A literature review of 16 studies using TMS applied to people with AN found that the treatments were safe and well accepted (41). A pilot randomised trial included in the systematic review above was conducted on 34 patients (mean age of 34 years, with an average BMI of 16 and an average illness duration of 14 years). Participants were randomised to real or sham TMS applied to the left dlPFC. The treatment was acceptable and at four months produced a large

reduction in depression (42). Although there was little impact on weight or eating at four months, their preference for higher-calorie foods was increased (43). A subgroup of 24 patients were followed for 18 months, during which those allocated to the sham condition were offered active treatment. Increases in BMI were found in both real (mean = 2.13, standard deviation (SD) = 3.2) and sham (mean = 0.79, SD = 1.56) TMS groups, with a moderately larger effect in those initially allocated to real TMS (44). The participants reported acceptability of the treatment, noting that they became more positive, open-minded and flexible following the intervention, but they also noted that it was time-consuming (45).

3.2.2 Transcranial direct current stimulation (tDCS)

tDCS generates a low-intensity electrical current between two electrodes to modulate activity in underlying neuronal circuits (46). As described in the TMS section above, the target has often been the dlPFC. A systematic review of tDCS to the dlPFC in people with binge-type eating disorders and behavioural addictions found seven papers reporting a reduction in food cravings (47). Later studies including sham-controlled designs also reported small-to-moderate reductions in food cravings (48, 49), and a meta-analysis found that inhibitory control was increased (50). Overall, tDCS has shown potential in improving the symptoms of BN in adults.

A recent systematic review examined the effect of tDCS in children and young people, concluding that studies with a more robust design are needed to determine the place of this intervention in clinical treatments (51).

3.2.3 Deep brain stimulation

Invasive brain stimulation strategies have been tested in small groups of patients with severe AN, exploring target areas including the subcallosal cingulate cortex (SCC), nucleus accumbens, bed nucleus of the stria terminalis and ventral anterior limb of the internal capsule. There have been several systematic reviews summarising the evidence. A review of 11 studies published between 2010 and 2020 found that out of 53 patients who began with an abnormal BMI before treatment, 22 patients (41.5%) had achieved normal BMI on follow-up (52) and a later systematic review of 11 studies (n = 36 patients with a low BMI of 12.58 ± 1.4 and a protracted illness) reported some benefits, concluding that stimulation directed at the SCC produced the most change in BMI at six months (53).

3.2.4 Brain training to overcome extremes in emotional, behavioural or social styles

A systematic review found that a variety of impulsivity-targeted approaches aimed to strengthen inhibition have shown promise in the treatment of binge eating (54). An app-based inhibitory control training towards palatable binge foods (the Food Training app) was explored in a feasibility study as an augmentation to treatment as usual, where 80 patients with BN were randomised to treatment as usual with or without augmentation with the Food Training app. Those randomised to the app showed a reduction in preferences towards binge foods and in eating disorder psychopathology (55, 56). Inhibitory control training in combination with neurostimulation techniques was also used successfully for people with binge-type eating disorders (57).

Cognitive bias modification strategies have been developed to target habitual eating disorder attitudes and behaviours including concerns about appearance and self-worth (58). For example, a small positive result was found in a feasibility study which trained people to moderate their negative interpretation of ambiguous social stimuli (59).

3.3 Pharmacological treatments

New international guidelines on the pharmacological treatment of eating disorders have been produced by the World Federation of Societies of Biological Psychiatry (WFSBP) (60). In AN, there is a limited recommendation for olanzapine because the available evidence is restricted to weight gain, with an uncertain effect on psychopathology. In BN, there are recommendations for fluoxetine or topiramate. For BED, lisdexamfetamine and topiramate might be considered. However, these drugs are not yet licensed for this indication in the UK.

This section will explore pharmacological treatments that are currently in development for the treatment of eating disorders, focusing on AN.

3.3.1 Cannabinoids

A feasibility study of dronabinol (delta-9-tetrahydrocannabinol) reported positive outcomes in a double-blind crossover trial (61, 62). However, this level of evidence was only given a grade of 2 by the WFSBP guidelines and this controlled drug is not licensed for use in AN in the UK.

3.3.2 Psilocybin

Psilocybin is a hallucinogenic with mechanistic action via serotonin pathways (5-HT) and has high affinity for the 5-HT2A receptor (63). Serotonergic dysfunction has been considered to contribute to the appetite and mood problems seen in AN (64). One hypothesis is that psilocybin may inhibit maladaptive behaviours and thought patterns that contribute to AN maintenance (65, 66). Furthermore, trials using psilocybin in treatment-resistant depression have demonstrated safety (67) and improvements in depression severity and anxiety (68, 69),which are two typical comorbidities of AN.

An open-label feasibility study, including 10 adult participants with AN (both in the acute or partial remission state), showed encouraging results (70). Participants were given 25 mg of synthetic psilocybin accompanied by psychological support. After three months, five patients had an increase in BMI and four participants had a decrease in weight concern. There were minimal adverse events, although two participants developed asymptomatic hypoglycaemia post-treatment, which resolved within a day. Several small randomised trials are currently underway to examine the feasibility and preliminary efficacy.

3.3.3 Ketamine

Ketamine is a N-methyl-D-aspartate receptor antagonist and dissociative anaesthetic that in low doses (for example, 0.5 mg/kg intravenously) has antidepressant effects. Several narrative reviews have presented the case for using ketamine in patients with AN, due to its rapid (albeit transient) antidepressant effects and targets on neuroplastic processes (71-73), and its impact on animal models of AN (74). A 1998 case series of people with AN given a ketamine infusion found that 9 of 15 had a reduction in depression and improvements in AN behaviour and psychopathology (75). Other case series of ketamine treatment for AN support this finding, demonstrating reductions in depression and improvements in eating behaviour (76-78). There has also been a case report of recovery in an individual with severe BN (79). Larger case series and feasibility studies are in progress.

3.3.4 Human recombinant leptin (metreleptin)

A series of studies have examined the hypothesis that hypoleptinaemia might be involved in the psychopathology of AN. A Mendelian randomisation study concluded that low endogenous leptin synthesis was a risk factor for developing AN (80). Furthermore, in activity-based (running wheel) animal models of AN, leptin delivered subcutaneously through mini pumps suppressed the development of hyperactivity following food restriction (81).

A case series of three female patients with acute AN treated with metreleptin for 6 to 14 days reported a pronounced and beneficial clinical response in terms of depression, activity and some aspects of eating disorder psychopathology which disappeared when the metreleptin was stopped (82). A case report of a male adolescent showed a similar profile of short-term effects (83), and a case report of a female adolescent showed an increase in appetite during the metreleptin phase of the study with continued weight gain of 15 kg over the following six months (84). The main outcomes that improved quickly were mood, hyperactivity and endocrine markers, whereas improvements in appetite were more variable.

3.3.5 Appetite-regulating hormones

Appetite-regulating hormones are of interest for both eating disorders and obesity (85, 86). A range of new treatments have been developed that target hormonal pathways, including incretin signalling, and introduced for the treatment of obesity. Preliminary studies have suggested that liraglutide (87) and semaglutide (88) reduce binge eating and weight in people with obesity and binge eating symptoms. Moreover, dulaglutide had a similar effect on people with type 2 diabetes and binge eating symptoms (89), as did liraglutide in higher-weight patients with binge eating symptoms (90). However, minimally supervised or unsupervised use of these drugs can cause problems, such as a severe lack of appetite and thirst (91).

3.4 The use the arts as adjunctive therapy

The MRC in the UK is funding research that incorporates the voice of lived experience and arts into treatment (92). Research in inpatients with AN has shown that most patients use music to cope with difficult emotions and as a distraction from their thoughts and feelings (93). A systematic review of studies on the effects of music in people with or at risk for EDs suggested that the therapeutic application of music may be beneficial in patients with AN and BN (94, 95). This review included, for example, a study by Cardi et al. (96) which found that inpatients with AN benefited from listening to classical music, which reduced distress and increased the consumption of a smoothie test meal. A systematic review of three studies using arts strategies (97) found improvements in quality of life and psychopathological symptoms, with qualitative findings indicating greater self-expression, self-awareness, new perspectives, distraction and pride. The evidence base for such therapies shows potential but is still in development.

4. The future: understanding the mechanisms underpinning eating disorders

New technologies have been used to define the biomarkers associated with eating disorders and to explore their functional role in animal models of all eating disorders, such as the food addiction, activity-based, restraint or social stress paradigms (98). Biomarkers in the brain, body and microbiome have been found, including the gut microbiome (99), immune and endocrine markers such as neurotrophins and proinflammatory cytokines (42, 100), markers of neuronal damage (for example, neurofilament light (101)) and also structural brain markers (4, 102-104).

New possible biomarkers of interest include liver-expressed antimicrobial peptide (LEAP-2) and acyl-Co-A-binding protein. Anomalies in the reciprocal relationship between ghrelin (GHR; orexigenic) and LEAP-2 (which reduces appetite) have been found in eating disorders (105) and obesity (106). Undernutrition is usually marked by low levels of LEAP-2, however patients with AN had an increase in both LEAP-2 levels and ghrelin in the acute, poorly nourished

state (107). Additionally, those with stable weight restoration six months after discharge from inpatient care had higher levels of LEAP-2 than those with continuing problems, indicating the potential for LEAP-2 changes to predict unstable remission (107). Another potential biomarker, acyl-Co-A-binding protein, is an orexigenic biomarker which is modulated by stress in animal models and was found to be lower in patients with AN (108, 109) and associated with a poor prognosis in those with the binge purge form of AN (110). These models and the mechanisms they have revealed may lead to potential new treatments. For example, donepezil, an acetyl cholinesterase inhibitor, was found to reduce self-starvation behaviours in the activity-based anorexia model (111, 112) and improved weight and eating behaviours in a small case series (n = 6) of people with AN (113). The further identification of predictive and prognostic biomarkers is a priority in the efforts towards stratifying and identifying personalised treatments for individuals with eating disorders.

5. Conclusions

As research into the aetiology of eating disorders increases, a wider range of therapeutic targets is revealed. However, there remain many unanswered questions about how to personalise treatments. One possibility is to introduce a tiered care pathway for people with eating disorders, such as that shown in Table 2. A pathway for binge-spectrum disorders already exists, starting with guided self-help, followed by CBT. The next step might include adjunctive VR exposure-based treatment (36) and/or medication, such as lisdexamfetamine or possibly incretins.

Tier	Treatment for binge-spectrum eating disorders	Treatment for anorexia nervosa
1	Guided self-help	Recruiting and skilling up social support (family treatments) by building attachments
2	CBT	CBT, MANTRA supplemented by motivational and externalisation strategies
3	Virtual reality-augmented psychotherapy targeting food and body image and social relationships Cue exposure-focused treatments	Virtual reality-augmented psychotherapy targeting food and body image and social relationships Cue exposure-focused treatments
4	Augmentation with lisdexamfetamine or topiramate (to augment treatment) TMS	Augmentation with TMS and/or psychedelics (psilocybin, ketamine)
5	Incretin receptor agonists if comorbidity with obesity or type 2 diabetes (work in progress)	Appetite system targets

Table 2: A potential tiered treatment pathway for eating disorders

Abbreviations: CBT = cognitive behavioural therapy; MANTRA = Maudsley Model of Anorexia Nervosa Treatment for Adults; TMS = transcranial magnetic stimulation

The pathway for AN is less clear cut. It may be that non-invasive neurostimulation techniques, typical/atypical forms of psychedelic medication (e.g., psilocybin, ketamine) or treatments derived from novel aspects of the appetite system are introduced in future, but currently there are only small feasibility studies investigating these. Further, a wide number of outcomes spanning 6 to 18 months may need to be considered, as changes in the traditional metrics of treatment success (e.g., weight and eating disorder psychopathology) may be slow, although there may be proximal indicators of change (e.g., depression, anhedonia, quality of life (114)).

A range of services that facilitate a variety of outcomes may be needed. Music or other creative therapies might be considered as add-ons to treatment as usual for all eating disorder presentations, both for emotional coping and to maximise opportunities for the development of a multifaceted identity.

All patients would benefit from no waiting list delays (115), as any approach to get help might represent a shift in their ambivalence, opening a crucial window in their readiness for change. Other key facets of an optimal service are a team with a wide range of clinical expertise, including collaboration with carers and peer support workers who can represent beacons of hope that recovery is possible, no matter how severe or protracted the illness. Nevertheless, it is apparent that there currently exists a gap in treatment provision for individuals who may not be at the stage of readiness (both in motivation and ability) for change. The development of treatment approaches to maximise both motivation and neurobiological ability (i.e., neuroplasticity) for change is needed.

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115. McDaid D, Treasure J, Fernandez-Aranda F, Herpertz-Dahlmann B, Quoidbach V, Dickson S, et al. Quantifying the economic value of earlier and enhanced management of anorexia nervosa for adults in England, Germany and Spain: improving the care pathway. European Psychiatry. 2024:1-39.

Eating disorder resources

Compiled by Umairah Malik, Alex Bell and Michael Vasey

About this section

In this section you will find a list of UK and international eating disorder organisations, books, podcasts and other resources providing information and support for people with eating disorders, their families and clinicians.

To find resources that might be particularly relevant to you, look for the coloured markers.

- If you have an eating disorder, or think you might have an eating disorder, these resources might be particularly relevant to you.
- If you are a family member, friend or carer of someone with an eating disorder, these resources might be particularly relevant to you.
- If you are a clinician or other professional with responsibility for someone with an eating disorder, these resources might be particularly relevant to you.
- Organisations that are focused on providing help in a particular country or region are identified by the national flags for those countries, but you might still find the resources helpful if you live in another country.
- Organisations that provide support and resources that are accessible to all are indicated by a globe symbol.

We hope that you find these resources helpful.

Eating disorder organisations

Beat Eating Disorders

beateatingdisorders.org.uk | help@beateatingdisorders.org.uk | 0808 801 0677 (from within UK only)

Beat is the UK's eating disorder charity, with a vision of an end to the pain and suffering caused by eating disorders, offering a national helpline to provide information and support for people with eating disorders, their families, friends and carers.

Beat campaigns to increase knowledge among healthcare and other relevant professionals, and for better funding for high-quality treatment, so that when people take the vital steps towards recovery, the right help is available to them.

A selection of the resources available on the Beat website can be found below.

Resources for people with direct experience, carers and professionals

Beat's national helpline is open from 3pm to 8pm, Monday to Friday. Support on the helpline is available by phone, email, webchat, social media and letter. It is open to people of all ages and backgrounds, offering support and information about eating disorders to people worried about themselves or a loved one, and for professionals.

Helpfinder is an online directory of eating disorder support services in the UK.

If you would like to learn more about eating disorders, there is some more information here.

People with direct experience

Beat also offers a number of online support groups for those with eating disorders. You don't have to have a formal diagnosis to use any of them.

If you are struggling to know where to start in accessing support, this page offers a step-by-step guide on what you can do next.

People with direct experience and carers

There are many downloads and resources available on Beat's website, including a reading list, a carer's pack and a GP leaflet. This can be taken to a first appointment to seek a referral to an eating disorder specialist.

If, in the course of you seeking help, you or a loved one is denied treatment for, or information about, an eating disorder, this page is designed to help you overturn that decision.

Carers

Beat has different training and coaching programmes for anyone who is supporting or caring for someone with an eating disorder, with more information available here.

POD is Beat's Peer Support and Online Development platform for carers, a space designed for people who are supporting a loved one with an eating disorder. It is an e-learning platform and community for carers with access to online modules, resources and spaces to talk with peers to help you better support your loved one.

Professionals

In collaboration with NHS England, the eating disorders training for health and care staff programme is designed to ensure that healthcare staff are trained to understand, identify and respond appropriately when faced with a patient with a possible eating disorder. This includes modules for medical students, foundation doctors, the nursing workforce, GPs, the primary care workforce, dietitians, oral health teams, community pharmacy teams and those in acute medical settings. It also includes training on medical monitoring.

Beat also offers training for school and university staff, as well as holding regular workshops for healthcare professionals and those who work with people with eating disorders.

SPOT (School Professionals Online Training) is an e-learning platform offering a range of interactive modules, monthly Q & A sessions and interactive webinars delivered by expert clinicians for school professionals.

PEACE Pathway

peacepathway.org

PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience) supports autistic people who have an eating disorder, their loved ones and clinicians.

PEACE offers a support network for sharing materials, tips and knowledge, with the aim of creating a community of autistic people with eating disorders, their carers and clinicians.

PEACE supports clinicians to develop their knowledge and confidence so that they can better support autistic people with an eating disorder under their care.

The PEACE website provides blogs and resources developed specifically for autistic people with an eating disorder, their carers and clinicians.

See the article on page 47 of this issue for an account of the development of the BOB (Buckinghamshire, Oxfordshire and Berkshire) PEACE Pathway for children and young people.

FREED

freedfromed.co.uk

FREED (First Episode Rapid Early Intervention for Eating Disorders) is a service for those aged 16 to 25 years who have had an eating disorder for three years or less to provide rapid access to specialised evidence-based treatment and support tailored to their needs.

FREED is a flexible, evidence-based treatment approach, focused on early intervention.

The FREED network consists of all eating disorder services that have implemented the FREED treatment approach and provides access to evidence-based protocols and patient resources to support early intervention in eating disorders.

GPs and other health professionals can access helpful guides or register for online training via the FREED website.

First Steps Eating Disorders

firststepsed.co.uk | info@firststepsed.co.uk | +44 (0)300 102 1685

First Steps Eating Disorders is a multi-award-winning charity providing care and support for children and their families, young people and adults in the UK affected by eating difficulties and disorders.

First Steps offers counselling and psychotherapy in the form of one-to-one professional and group support, nutritional therapy, workshops and support groups.

Supports family members and carers with workshops, support groups, psychotherapy, open-access resources and blogs.

Offers education and training in eating disorders to universities and schools for groups including students, teachers, assistants, university staff and other employees.

Be Body Positive

bebodypositive.org.uk | hello@bebodypositive.org.uk

Be Body Positive is an early intervention resources for young people with eating disorders, caregivers and professionals, created by eating disorder clinicians and reviewed by young people and caregivers.

For more information on the development of Be Body Positive, and the resources available, see the article on page 167 of this issue.

Butterfly Foundation

butterfly.org.au | +61 1 800 33 4673

Australian national charity for people affected by eating disorders and body image issues, their families, friends and communities.

Provides innovative, evidence-based support services, treatment and resources, prevention and early intervention programmes.

Operates a national helpline providing support over the phone, via email and online, staffed by trained counsellors experienced in assisting with eating disorders and body image issues.

Offers a wide range of programmes for service providers and recovery groups, and prevention programmes including Positive Body Image workshops to schools and workplaces.

Inside-Out Institute

insideoutinstitute.org.au | elearning@insideoutinstitute.org.au

Australia's national institute for research, translation and clinical excellence in eating disorders.

At the forefront of developing new and emerging technologies for the delivery of quality, evidence-based clinical care for people with eating disorders, and training for health professionals in the identification and treatment of people with eating disorders.

Provides support for evidence-based clinical decision making for GPs, online early screening, evidence-based eTherapies and pathways for care of people with eating disorders.

F.E.A.S.T. (Families Empowered and Supporting Treatment for Eating Disorders)

feast-ed.org | info@feast-ed.org

F.E.A.S.T. is a global support and education community of and for parents of individuals with eating disorders.

F.E.A.S.T. focuses on educating and teaching skills to parents to help them understand their child's eating disorder and to support them in accessing appropriate treatment, and provides information to help them recover and thrive.

Offers free programmes and services providing families with support, information, skills and tools.

Bodywhys

bodywhys.ie | alex@bodywhys.ie | +353 (0)1 210 7906

The national voluntary organisation supporting people affected by eating disorders in Ireland.

Offers a telephone helpline, email support service, online chat and virtual support groups, a guide to treatment, service directory, access to the HSE eating disorders self-care and information app and other eating disorder resources.

Offers support and guidance for families of individuals with an eating disorder, guidelines for GPs and support for schools.

Academy for Eating Disorders (AED)

aedweb.org | +1 703 234 4079

Provides a forum for physicians, psychiatrists, psychologists, nutritionists, academic researchers, students and experts through lived experience to connect and collaborate.

AED aims to:

- promote effective treatment and care of individuals with eating disorders and associated disorders
- develop and advance initiatives for primary and secondary prevention of eating disorders
- provide education and dissemination of knowledge regarding eating disorders to members of the Academy, other professionals and the general public
- stimulate and support research in the field
- advocate on behalf of individuals with eating disorders, the public and eating disorder professionals
- assist in the development of guidelines for training, practice and professional conduct in the field.

Kelty Eating Disorders

keltymentalhealth.ca | keltycentre@cw.bc.ca | +1 604 875 2084 or 1 800 665 1822

Provides information and resources to people of all ages with an eating disorder or disordered eating in British Columbia.

Offers peer support, information and resources, help in navigating the healthcare system, free educational events and webinars for parents, caregivers and school professionals.

Resources available on the Kelty website are developed with clinical experts, are reviewed by a Parent Advisory Council and are updated regularly to ensure information is accurate and up-to-date.

Help can be accessed by phone, email, Zoom call or in person.

All services are offered free of charge.

National Eating Disorder Association (NEDA)

nationaleatingdisorders.org | info@nationaleatingdisorders.org | +1 212 575 6200

NEDA is the largest nonprofit organisation dedicated to supporting individuals and families affected by eating disorders in the United States with the aim of advancing research, building community and raising awareness.

Provides programmes and services that are designed to assist those affected by an eating disorder to access the help and support they need.

National Center for Excellence for Eating Disorders (NCEED)

nceedus.org

NCEED is the first centre of excellence dedicated to eating disorders in the USA with the aim of advancing education and training of healthcare providers and to promote public awareness of eating disorders and eating disorder treatment.

Provides up-to-date, reliable and evidence-based information with the goal of ensuring all individuals with eating disorders are identified, treated and supported in recovery.

Offers resources for individuals, healthcare providers, family members and friends.

NHS Eating Disorders

www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview

Information on eating disorders for a general audience including guidance on recognising symptoms and warning signs, getting help, options for treatment and links to other resources.

ARFID Awareness UK

arfidawarenessuk.org | info@arfidawarenessuk.org

The UK's only registered charity dedicated to raising awareness and furthering information about avoidant/restrictive food intake disorder.

Provides individuals, parents, carers and medical professionals with up-to-date relevant information, research and support.

Committed to supporting medical professionals across varying specialities by equipping them with the information they need to ensure early diagnosis and access to appropriate care for their patients.

National Centre for Eating Disorders (NCFED)

eating-disorders.org.uk | admin@ncfed.com | +44 (0)845 838 2040

Offers personal, telephone or Skype counselling for eating disorder treatment and recovery, including one-off personal assessments.

Provides up-to-date training courses for all health professionals working with eating disorders in adults and young people, and the opportunity to join a professional network to access supervision, mentoring and guidance.

Offers support and advice for carers and friends.

Provides information about eating disorders, body image and topical issues for sufferers, carers, students and the media.

Eating Disorder Hope

eatingdisorderhope.com

An online community offering resources, education, support and inspiration to people with anorexia nervosa, bulimia nervosa, binge eating disorder, body image issues and other disordered eating behaviours.

Offers resources including blogs and articles by therapists, doctors, psychiatrists and other leaders in the field.

Provides free access to disordered eating treatment options, support groups, recovery tools and treatment programmes.

Resources cover topics including relationship skills, coping skills and co-occurring issues including depression, anxiety, bipolar disorder, post-traumatic stress disorder and obsessive-compulsive disorder.

Seed Eating Disorder Support Services

seed.charity | support@seed.charity | +44 (0)7300 298388

Voluntary eating disorder support group of, and for, people with firsthand experience of eating disorders.

Aims to support individuals with eating disorders and their families and carers.

Offers information, resources, an educational toolkit for schools and a monthly online support group meeting.

National Association of Anorexia Nervosa and Associated Disorders (ANAD)

anad.org | hello@anad.org | +1 888 375 7767

Leading non-profit eating disorder organisation in the United States, providing free peer support services to people with eating disorders and body image concerns.

The Recovery Club

therecoveryclub.org

A peer support group for people with eating disorders and their loved ones, offering a community blog and other eating disorder resources, including books, podcasts and social media profiles aimed at supporting those who are recovering from an eating disorder.

Overeaters Anonymous

oagb.org.uk

International "fellowship of individuals" offering anonymous support groups for people with problems with compulsive eating or compulsive overeating.

Members are supported in a twelve-step recovery programme modelled on the established Alcoholics Anonymous programme.

Groups are organised in 10 regions and over 75 countries worldwide, and are free to attend.

REDCAN (Regional Eating Disorders Charity Alliance and Network)

redcan.org.uk

Alliance of eating disorder charities in the UK, supporting anyone affected by an eating disorder and related conditions.

Provides eating disorder resources, links to local charities and face-to-face support.

Eating Disorders Association Northern Ireland

eatingdisordersni.co.uk | info@eatingdisordersni.co.uk | +44 (0)28 9023 5959

Local, community-centred organisation providing peer support for people with eating disorders and their loved ones in Northern Ireland.

Campaigns for improvement in eating disorder services and aims to increase awareness and support the development of skills in the wider community.

National Eating Disorder Collaboration (NEDC)

nedc.com.au | info@nedc.com.au

An initiative of the Australian Government Department of Health and Aged Care, the NEDC offers a large body of comprehensive, evidence-based information and resources with the aim of establishing standards for the prevention and treatment of eating disorder.

Engages a wide group of stakeholders including clinicians, researchers, people with lived experience, families and other experts with the aim of:

- developing and helping implement a consistent, evidence-based national approach to the prevention and management of eating disorder in Australia
- providing a vital collaboration and strategic platform for the Australian eating disorder sector
- supporting the development of a skilled clinical and lived experience workforce
- synthesising lived experience, research evidence and clinical expertise in consistent, national standards for prevention, identification and treatment of eating disorder
- implementing evidence based national standards.

Share Our Recovery Through Eating Disorders (SORTED)

mhmwales.org.uk/Sorted.htm | sorted@mhmwales.org | +44 (0)1656 651450

Peer-to-peer support for people with eating disorders, their families, caregivers and friends, in Wales.

Offers the opportunity for individuals with similar concerns about eating disorders or disordered eating to meet safely and confidentially to share their experiences.

Eating Disorders Support

eatingdisorderssupport.co.uk | support@eatingdisorderssupport.co.uk | +44 (0)1494 793223

Offers regular online and in-person support groups for individuals with eating disorders and those who support them.

Links to further online eating disorder resources are available through the website.

SupportED

supportedscotland.org | hello@supportedscotland.org | +44 (0)7716 639067

Community eating disorder charity in Scotland, supporting people with eating disorders, their families and carers.

Offers in-person and online support groups, befriending services, information and resources.

MindEd

minded.org.uk | mindedenquiries@hee.nhs.uk

Offers free educational resources on mental health topics, including feeding problems and eating disorders, for adults working with, or caring for, people with mental health problems, including those with learning disabilities and autistic people.

Information is quality assured by experts and designed to be easy to understand.

Resources can be used by groups including teachers, health and mental health professionals, social workers, youth service volunteers and school counsellors, among others, to support their professional development.

New Maudsley Carers

newmaudsleycarers-kent.co.uk | jenny@newmaudsleycarers-kent.co.uk | +44 (0)7887 840470

Offers resources, worksheets, skills workshops and support groups for people caring for a loved one with an eating disorder.

Eating Disorders Victoria

eatingdisorders.org.au | +61 1 300 550 236

Offers services informed by the lived experience of people with eating disorders and those that have cared for them in the state of Victoria.

Aims to provide empathetic and helpful support at every stage from early intervention and diagnosis to treatment, relapse, maintenance and recovery.

Provides tailored, accessible, peer-led support services to people affected by eating disorders and champions education, policy and funding initiatives to drive systemic change.

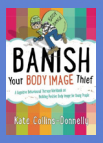
Books on eating disorders

Getting better bit(e) by bit(e): a survival kit for sufferers of bulimia nervosa and binge eating disorders
Janet Treasure and Ulrike Schmidt
Routledge

The eating disorder recovery journal
Cara Lisette and Victoria Barron
Jessica Kingsley Publishers

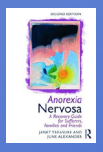
ED says U said: eating disorder translator
June Alexander and Cate Sangster
Jessica Kingsley Publishers

Banish your body image thief: a cognitive behavioural therapy workbook on building positive body image for young people
Kate Collins-Donnelly
Jessica Kingsley Publishers

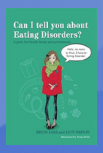


The picky eater's recovery book: overcoming avoidant/restrictive food intake disorder
Jennifer J Thomas
Cambridge University Press

Anorexia nervosa: a recovery guide for sufferers, families and friends
Janet Treasure and June Alexander
Routledge



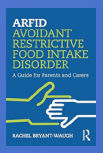
Can I tell you about eating disorders? A guide for friends, family and professionals
Bryan Lask and Lucy Watson
Jessica Kingsley Publishers



Overcome binge eating: the proven program to learn why you binge and how you can stop
Christopher G Fairburn
Guilford Press

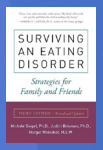
8 keys to recovery from an eating disorder
Carolyn Costin, Gwen Schubert Grabb and Babette Rothschild
W W Norton and Company

ARFID Avoidant restrictive food intake disorder: a guide for parents and carers
Rachel Bryant-Waugh
Routledge

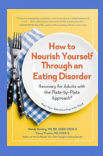


Food refusal and avoidant eating in children including those with autism spectrum conditions
Gillian Harris and Eilzabeth Shea
Jessica Kingsley Publishers

Surviving an eating disorder: strategies for families and friends
Michele Siegel, Judith Brisman and Margot Weinshel
Harper Perennial



How to nourish yourself through an eating disorder
Wendy Sterling and Casey Crosbie
The Experiment LLC



Give food a chance - childhood eating disorders: a treatment manual for parents and providers
Julie O'Toole
Independent

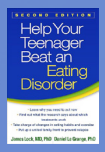
Anorexia and other eating disorders: how to help your child eat well and be well
Eva Musby
Piatkus

Brave girl eating: the inspirational true story of one family's battle with anorexia
Harriet Brown
Piatkus

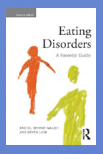
Supporting autistic people with eating disorders: a guide to adapting treatment and supporting recovery
Kate Tchanturia
Jessica Kingsley Publishers

My kid is back: empowering parents to beat anorexia nervosa
June Alexander and Daniel Le Grange
Routledge

Help your teenager beat an eating disorder
James Lock and Daniel Le Grange
Guilford Press

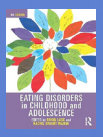


Eating disorders: a parents' guide
Rachel Bryant-Waugh
Routledge

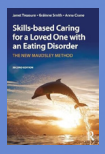


Overcoming anorexia nervosa: a self-help guide using cognitive behavioural techniques
Patricia Graham and Chris Freeman
Robinson

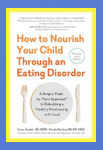
Eating disorders in childhood and adolescence
Bryan Lask and Rachel Bryant-Waugh
Routledge



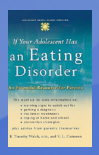
Skills-based caring for a loved one with an eating disorder: the New Maudsley Method
Janet Treasure, Gráinne Smith and Anna Crane
Routledge



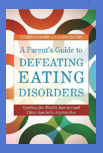
How to nourish your child through an eating disorder
Casey Crosbie and Wendy Sterling
The Experiment LLC



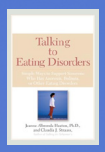
If your adolescent has an eating disorder: an essential resource for parents
B Timothy Walsh and VL Cameron
Oxford University Press



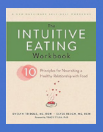
A parent's guide to defeating eating disorders
Ahmed Boachie and Karin Jasper
Jessica Kingsley Publishers



Talking to eating disorders: simple ways to support someone with anorexia, bulimia or other eating disorders
Jeanne Albronda Heaton and Claudia J Strauss
Penguin

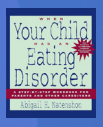


The intuitive eating workbook: ten principles for nourishing a healthy relationship with food
Evelyn Tribole and Elyse Resch
New Harbinger

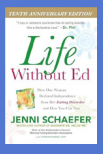


Getting better bite by bite: a survival kit for sufferers of bulimia nervosa and binge eating disorders
Ulrike Schmidt, Janet Treasure and June Alexander
Routledge

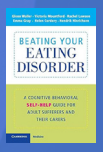
When your child has an eating disorder: a step-by-step workbook for parents and other caregivers
Abigail H Natenshon
Jossey-Bass



Life without ED: how one woman declared independence from her eating disorder and how you can too
Jenni Schaefer
McGraw-Hill Education

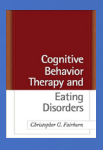


Beating your eating disorder: a cognitive-behavioural self-help guide for adult sufferers and their carers
Glenn Waller
Cambridge University Press



Cognitive-behavioral therapy for avoidant/restrictive food intake disorder: children, adolescents and adults
Jennifer J Thomas and Kamryn T Eddy
Cambridge University Press

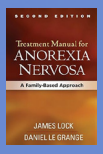
Cognitive behavior therapy and eating disorders
Christopher G Fairburn
Guilford Press



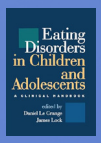
Family-based treatment for avoidant/restrictive food intake disorder
James D Lock
Routledge

Survive FBT: skills manual for parents undertaking family-based therapy (FBT) for child and adolescent anorexia nervosa
Maria Ganci
LMD Publishing

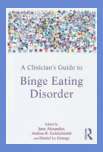
Treatment manual for anorexia nervosa: a family-based approach
James Lock and Daniel Le Grange
Guilford Press



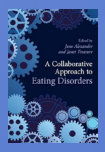
Eating disorders in children and adolescents: a clinical handbook
Daniel Le Grange and James Lock (editors)
Guilford Press



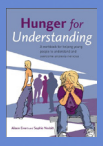
A clinician's guide to binge eating disorder
June Alexander, Andrea B Goldschmidt and Daniel Le Grange (editors)
Taylor and Francis



A collaborative approach to eating disorders
June Alexander and Janet Treasure (editors)
Routledge



Hunger for understanding: a workbook for helping young people to understand and overcome anorexia nervosa
Alison Eivors and Sophie Nesbitt
Wiley



Food to eat: guided, hopeful and trusted recipes for eating disorder recovery
Lori Lieberman and Cate Sangster
CreateSpace Independent Publishing

My super sweet recovery cookbook: recipes designed to help people with eating disorders in their recovery
Nicola Davis
Brown Dog Books

Eating disorder podcasts

Rewired
The eating disorder recovery podcast.
Episodes alternate between conversations focused on lived experience of eating disorders and recovery and discussion with guests and experts in the field.

Just Eat Normally
Hosted by psychologist Dr Rachel Evans.
Conversations with experts in eating disorder recovery and eating disorder survivors intended to help those in recovery from an eating disorder.

Finding Your Freedom with Food
The eating disorder therapist podcast supporting eating disorder recovery with tips, information and guest interviews.
Hosted by eating disorder therapist Harriet Frew.

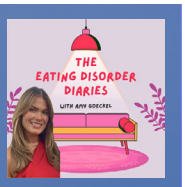
Bodywhys Podcast
Podcast from Bodywhys, the Eating Disorder Association of Ireland.
Episodes cover lived experience, body image, social media, eating disorder interventions, neurodivergence and the experiences of siblings of individuals with an eating disorder.

The Mindful Dietitian
Conversations with dietitians committed to body inclusive practice.
Hosted by Fiona Sutherland.

The Eating Disorder Diaries

For people struggling with an eating disorder or mental health in general.

Amy Goeckel talks about her experiences of recovery from bulimia nervosa and talks with others with similar experiences of recovery from an eating disorder.



The Weigh Up: Eating Disorder Diaries

Eating disorder podcast from the BBC.

Recovering anorexic Molly guides you through the truths of eating disorders and learns how others have found their way up.

The Full of Beans Podcast

Weekly podcast featuring conversations with people with lived experience of an eating disorder, researchers, clinicians and eating disorder charities, with the aim of increasing understanding and reducing the stigma associated with eating disorders.

Big Ideas in Eating Disorders

Clinical psychologist Dr Kathy Pike talks with leaders in the field of eating disorders including researchers, clinicians and people with lived experience, who share the big ideas that they believe can improve the lives of people at risk of developing, or currently living with, an eating disorder.

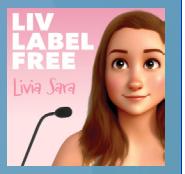
Feck It, Fun, Fabulous and Free Eating Disorder Recovery

A podcast about eating disorder recovery, providing frequent bite-size episodes offering information, inspiration, motivation and hope, as well as some relevant research and neuroscience, to help anyone with an eating disorder in their recovery.

Liv Label Free

Neurodivergent eating disorder recovery.

Provides insights into the link between neurodivergence and eating disorders, and strategies for recovery through conversations and stories of lived experience. Hosted by Livia Sara.



Understanding Disordered Eating

Eating disorder recovery and body image healing.

Rachelle Heinemann discusses issues related to body image, restriction, bingeing, purging, compulsive exercise and eating disorder-related behaviours.

Every Body Podcast

Discusses topics related to eating disorders, eating disorder recovery, weight, body confidence and self identity, from the perspective of people with lived experience.

Ease with Food Podcast

For disordered eating recovery and a happy relationship with food and self.

Tips for eating disorder and disordered eating recovery, and conversation about all things health and wellness related. Hosted by registered nutritionist, ACCPH therapist and eating disorder recovery coach, Shannon Western.

For more podcasts on topics related to eating disorders and eating disorder recovery, search on Spotify or Apple Podcasts

The front and back cover images for this issue were created by young people with eating disorders and were originally featured on the Butterfly Foundation website, butterfly.org.au.

The creator of the back cover image, **Hallie**, described her work in the following way.

"I'm 16 years old and just this year I was diagnosed with anorexia. My life just felt so out of control and it was like the one thing I could 'control' was how much I ate and exercise. It became such an obsessive thing, taking up my headspace 24/7. We moved at the start of this year and I had to start a new school in a completely new environment. This artwork represents the obsessive thoughts that circulate in my head almost every second of every day. I wanted to represent the vulnerable state in which eating disorders affect young women." – Hallie

CEPiP.org

Cutting Edge Psychiatry in Practice

NHS
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NHS Foundation Trust

Providing up-to-date information in a way that is of practical value to GPs and psychiatrists in training