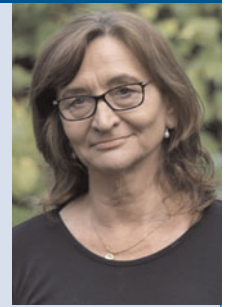


Guest Editorial

From awareness to action: an urgent call to reduce mortality and improve outcomes in eating disorders

Agnes Ayton, Ali Ibrahim, James Downs, Suzanne Baker, Ashish Kumar, Hope Virgo and Gerome Breen



Summary

High mortality rates and poor outcomes from eating disorders, especially anorexia nervosa, are largely preventable and require urgent action. A national strategy to address this should include prevention; early detection; timely access to integrated physical and psychological treatments; safe management of emergencies; suicide prevention; and investment in training, services and research.

Keywords

Anorexia nervosa; bulimia nervosa; mortality; feeding or eating disorders; prevention of deaths.

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Agnes Ayton (pictured) is Vice Chair of the Faculty of Eating Disorders at the Royal College of Psychiatrists (RCPsych) and a consultant psychiatrist with Oxford Health NHS Foundation Trust. **Ali Ibrahim** is a consultant child and adolescent psychiatrist with South London and Maudsley NHS Foundation Trust. **James Downs** is a patient representative for the Faculty of Eating Disorders at the RCPsych. **Suzanne Baker** is a carer representative for the RCPsych's Faculty of Eating Disorders and sits on the F.E.A.S.T. UK Task Force Executive Committee. **Ashish Kumar** is Chair of the Faculty of Eating Disorders at the RCPsych and Clinical Director of child and adolescent mental health services and a consultant psychiatrist with Mersey Care NHS Foundation Trust. **Hope Virgo** is an author, speaker, multi-award-winning mental health campaigner and founder of #DumpTheScales. **Gerome Breen** is a psychiatric geneticist and Professor of Psychiatric Genetics in the Medical Research Council's Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, King's College London.

The scientific literature consistently highlights that eating disorders, especially anorexia nervosa, have the highest mortality rate among all mental disorders. Although this serves to emphasise the seriousness of eating disorders, it may inadvertently lead to a lack of hope and pessimistic attitudes towards treatment among healthcare providers, patients and carers, as well as the self-fulfilling prophecy that death is an unavoidable outcome for some. This assumption, however, has been made without considering the inadequate and delayed access to evidence-based treatment for a substantial proportion of people with eating disorders. Furthermore, when initial treatments are ineffective in other medical specialties, such as metabolic disorders, efforts are made to find alternative strategies or investigate additional causes, and substantial investment is made available for research into novel treatments. Given that anorexia has recently been reconceptualised as a metabo-psychiatric disorder,¹ our approach should not be different.

A team of US clinicians has recently proposed the concept of 'terminal anorexia' for adults over the age of 30, who have been suffering from the illness for an extended period. They included a recommendation to provide guidance on palliative and hospice care for patients who have previously received high-quality multidisciplinary care, express a clear understanding that further treatment is likely futile and accept that death is a natural outcome. Medical assistance in dying (MAID) was also suggested to improve end-of-life experiences of these patients. This proposal has sparked international controversy, with clinicians, academics, patients and carers arguing that the concept of terminal anorexia cannot be defined and that introducing it is dangerous, particularly considering the limited availability of effective treatment.

In this article, we aim to examine the current evidence and outline the necessary steps to reduce and prevent premature deaths associated with eating disorders.

Methodological issues regarding mortality risk in eating disorders

Meta-analyses of multiple studies found that anorexia nervosa had a standardised mortality ratio of 5–6, whereas bulimia nervosa and eating disorders not otherwise specified (including binge eating disorder) both had a ratio of 1.9. Additionally, individuals with eating disorders had an 18-fold increased risk of suicide compared with the general population, although this finding has not been consistently replicated.² However, methodological limitations must be considered when interpreting mortality findings from various studies. Several common issues impede mortality research, including overrepresentation of severe cases owing to sampling bias from specialised treatment centres, small sample sizes, retrospective designs, heterogeneity among studies, a lack of standardised reporting and inconsistencies in recording causes of death. Moreover, men and certain ethnic groups are commonly under-represented in clinical samples. These issues lead to uncertainty about the true mortality rate and limit opportunities to learn from these cases.

Furthermore, diagnoses associated with mortality may change throughout the course of an individual's illness. This includes not only the type of eating disorder but also co-occurring physical and mental disorders that interact in different ways throughout the course of the illness and may contribute to death. This could explain why the UK's Office for National Statistics has few records of deaths caused primarily by eating disorders (42 cases in 2021).³ Given this complexity, a comprehensive analysis of extensive cohorts is necessary to understand the influence of comorbidities on mortality.

Preventable causes of death

The most common causes of death in anorexia nervosa are associated with physical consequences such as malnutrition or gastrointestinal, metabolic, cardiovascular or infectious complications. Patients with type 1 diabetes and eating disorders have an especially high risk of premature mortality. Importantly, each of these

conditions is treatable, indicating that the majority of deaths are preventable.

Suicide is the predominant cause of death in bulimia nervosa and binge eating disorders. Co-occurring psychiatric disorders, substance misuse, personality disorders and self-harm increase the risk of mortality. Despite this, these patients frequently fall between services. An integrated approach could improve these outcomes.

The role of inadequate access to effective treatment

Although the relationship between patient characteristics and mortality risks has been extensively studied, the impact of limited access to timely evidence-based treatment and of suboptimal practices, which contribute to poor outcomes and avoidable mortality, needs to receive more attention in the literature. Poor outcomes are the result of inadequately funded services and limited access to evidence-based treatment.

The 2017 report by the Parliamentary Health Service Ombudsman (PHSO) in the UK highlighted the role of service failures in preventable deaths and issued recommendations for preventing future deaths. These recommendations included training doctors and the broader healthcare workforce, improving the funding and quality of adult eating disorder services to achieve parity with child and adolescent services, and enhancing care coordination and collaboration among relevant agencies. In 2023, the PHSO reiterated these concerns, emphasising the insufficient progress made over the 6-year period, resulting in ongoing avoidable deaths (www.ombudsman.org.uk/news-and-blog/news/urgent-action-needed-prevent-eating-disorder-deaths). The mean age at death reported by the PHSO was 30 years. When compared with the UK life expectancy, this equates to a loss of more than 50 years of life:

‘Lives continue to be lost because of the lack of parity between child and adult services and poor coordination between those involved in treating patients.

There are also still issues with the training of medical professionals. This is fundamental to improving awareness among clinicians so they can identify and treat eating disorders.’

Missed opportunities for improving outcomes

An important missed opportunity to improve anorexia outcomes is the reversibility of malnutrition. Studies have consistently demonstrated that achieving a healthy weight strongly predicts positive outcomes.⁴ Despite this, it is not uncommon in some countries, including the UK, to discharge underweight patients with severe malnutrition due to long-term anorexia nervosa on the grounds that they do not respond well to treatment and that the focus should be on improving their quality of life, without taking into account the profound influence of malnutrition on quality of life and general functioning. However, there is a lack of empirical evidence to support the safety and effectiveness of this approach. In addition, the impact of chronic malnutrition on both physical and mental health cannot be underestimated. Most eating disorder services lack adequate access to suitable medical or paediatric facilities to provide safe refeeding and weight restoration for severely ill patients, which hinders outcomes, results in a prolonged course of illness and increases the mortality risk.

This was noted by a coroner in 2021, who emphasised that the high risk of mortality should not simply be accepted and that anorexia and other eating disorders are treatable, with even severe complications, such as malnutrition, being safely reversible. He emphasised the importance of improving access to treatment and

effectively monitoring the critically ill to reduce the risk of avoidable future deaths. These principles are relevant across eating disorder diagnoses, irrespective of weight status, where risk to life on physiological and psychological grounds may be considerable even among patients who appear to be well – a point emphasised in the Royal College of Psychiatrists’ Medical Emergencies in Eating Disorders (MEED) guidelines.

The benefits of integrated care

In a recent Italian 24-year longitudinal study of mortality rates of 1277 clinical patients with various eating disorders, including anorexia nervosa, bulimia nervosa and binge eating disorder, the overall mortality rates did not differ significantly from those for individuals of the same age and gender in the general population.⁵ The authors attributed this favourable outcome to the region’s unique approach, which integrates enhanced cognitive-behavioural therapy (CBT-E) for eating disorders across the care pathway. These findings are consistent with those of a UK study on integrated CBT-E for severe anorexia nervosa⁴ and highlight the benefits of integrated evidence-based treatment for people with severe eating disorders.

Unfortunately, the fragmentation of care across settings persists in many countries and this needs to be urgently addressed. In the UK, disparities in treatment access among children, adolescents and adults contribute to increased chronicity, complications and mortality rates in the adult population.

Summary and recommendations

Reducing the mortality rate associated with eating disorders is a long-overdue and attainable goal. Eating disorders can be life-threatening, but most deaths can be prevented by appropriate treatment, even in the most severe cases. Deterioration and complications can be avoided by timely intervention and implementation of good practice guidelines. Addressing both the psychological and medical needs of individuals with eating disorders is crucial for improving outcomes. By prioritising both aspects, we can shift our focus away from the concept of terminal anorexia and reduce overall mortality rates. Overemphasis on the psychological aspects of eating disorders can lead to a narrow perspective that ignores the significant impact of poor physical health on the patient and its severe impact on functioning.

Policymakers must actively support the campaigns of individuals with lived experience, charities, professional organisations and coroners for improved access to timely treatment without discrimination, whether according to age, gender, duration of illness or ability to pay. It is essential to engage with wider medical services, recognising the crucial role of primary care in early identification and treatment, as well as acute hospitals in the effective management of physical complications and emergencies, including safe refeeding.



The participation of diverse stakeholders, including people with lived experience, families, healthcare professionals, educators and policymakers, is vital in formulating a comprehensive strategy to minimise mortality rates and mitigate complications associated with eating disorders. This should include preventive measures, reduction of stigma, early recognition and treatment, safe management of emergencies and comorbidities, suicide prevention and seamless continuity of care for patients across age ranges and treatment settings.

The following strategies are needed to improve outcomes and reduce mortality rates in eating disorders:

- (a) education and training:
 - (i) healthcare professionals, such as doctors, nurses, psychologists, dietitians and other allied healthcare professionals, should receive appropriate training to identify all eating disorders
 - (ii) increase awareness and understanding of eating disorders in schools, higher education and social care settings;
- (b) early recognition and treatment:
 - (i) screen people at risk for eating disorders in healthcare, school, education and social care settings
 - (ii) increase public awareness campaigns to reduce stigma and encourage individuals and their families to seek help when they notice signs of an eating disorder
 - (iii) enhance collaboration between primary care and mental health services to facilitate early diagnosis and treatment;
- (c) adequate funding of services to implement good practice guidelines and monitor outcomes:
 - (i) additional targeted funding is necessary for adult eating disorder services to improve early access to evidence-based treatment for adults with eating disorders comparable to that for children and adolescents to reduce harm and chronicity
 - (ii) facilitate continuity of care by integrating treatment across the care pathway and relevant agencies
 - (iii) engage families and support networks in treatment to provide ongoing support and monitor progress
 - (iv) ensure reasonable adjustments for neurodivergent people
 - (v) monitor and publish real-life treatment and service innovation outcomes;
- (d) integrated care for comorbidities:
 - (i) implement an integrated care model that addresses co-occurring psychiatric conditions (such as substance misuse, self-harm) or medical conditions (such as type 1 diabetes) that increase the risk of death;
- (e) recognition and management of medical emergencies in eating disorders:
 - (i) provide specialised training to healthcare professionals on managing medical complications of all eating disorders, such as severe malnutrition and refeeding, electrolyte abnormalities and type 1 diabetes
 - (ii) ensure that emergency departments and acute hospitals have protocols in place for the rapid assessment and stabilisation of patients with life-threatening conditions related to eating disorders in line with the MEED guidelines;
- (f) suicide prevention:
 - (i) conduct routine suicide risk assessments for individuals with eating disorders
 - (ii) include eating disorders in suicide prevention programmes;
- (g) enhance research funding and capacity:
 - (i) with a focus on understanding biological factors and developing novel interventions, such as pharmacological treatments, neurobiological approaches, digital therapeutics, and development of research capacity
 - (ii) encourage interdisciplinary collaboration between scientists, clinicians, experts by experience and industry to accelerate the development of new prevention and treatment options
 - (iii) establish a national register of eating disorders to capture cohorts of patients with eating disorders and their

journey through the health and care system, which will aid in the development of a rich source of information for service development, offer opportunities for research collaboration and document causes of death in these patients.

Significant investments in training, prevention, treatment and research on eating disorders will yield substantial benefits for individuals and reduce societal costs. This approach would save many lives and consign the poor outcomes and high mortality rate associated with eating disorders to history.

Agnes Ayton , Faculty of Eating Disorders, Royal College of Psychiatrists, London, UK; Cotswold House, Oxford Health NHS Foundation Trust, Oxford, UK; and University of Oxford, Oxford, UK; **Ali Ibrahim**, Acorn Lodge, South London and Maudsley NHS Foundation Trust, London, UK; **James Downs** , Faculty of Eating Disorders, Royal College of Psychiatrists, London, UK; **Suzanne Baker**, Faculty of Eating Disorders, Royal College of Psychiatrists, London, UK; F.E.A.S.T. (Families Empowered and Supporting Treatment for Eating Disorders), London, UK; **Ashish Kumar**, Faculty of Eating Disorders, Royal College of Psychiatrists, London, UK; Child and Adolescent Mental Health Services, Mersey Care NHS Foundation Trust, Liverpool, UK; **Hope Virgo**, Health and Social Campaigners' Network International, Llandrindod Wells, UK; **Gerome Breen**, Social, Genetic, and Developmental Psychiatry Centre, Institute of Psychiatry, King's College London, London, UK

Correspondence: Agnes Ayton. Email: agnes.ayton@oxfordhealth.nhs.uk

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Data availability

Data availability is not applicable to this article as no new data were created or analysed in this work.

Author contributions

A.A., A.I., J.D., H.V. and A.K. conceived and developed the idea. A.A. completed the literature search and drafted the first version. All authors discussed the structure of the paper and contributed to the final manuscript.

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Declaration of interest

None.

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