Food for thought: Bringing eating disorders out of the shadows

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Food for thought: Bringing eating disorders out of the shadows

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For Peer Review

Abstract

Eating disorders are prevalent, potentially lethal, and treatable and yet remain underprioritised within clinical care, research, and policy. Further, with rising public health focus on obesity, there is heightened risk for inadvertent exacerbation of disordered eating and further marginalisation of these serious mental disorders. This editorial calls for corrective action. (50 words)

For Peer Review

In the wake of a damning report from the Parliamentary Ombudsman into the death of Averil Hart at the age of 19 from anorexia nervosa (1), it behoves us to take stock of the way that eating disorders are perceived, prioritised and funded, in both clinical and academic domains. The report found that the National Health Service organisations involved in Averil's care failed her in their departure from established guidelines for communication among service providers, monitoring, and therapeutic interventions. These failures, in turn, resulted in a catastrophic and potentially avoidable outcome: a young woman's tragic death.

The main recommendation of the Ombudsman's report was a review of training for all junior doctors to improve understanding of these complex conditions. Other recommendations refer to the need to train and recruit an adequate health workforce and address geographical disparities in service provision for adults. The latter is particularly highlighted by contrast to the recently established dedicated community eating disorders teams for patients under 18 in every area of England. We endorse these recommendations. They powerfully acknowledge that eating disorders are the concern of all front line health providers - not just physicians. In Averil's case, these health professionals hailed from primary care, student services, emergency care, acute medical care and mental health services.

We assert, however, that this tragedy is grounded in an even broader and more diffuse context than shortfalls in the network of care providers – that eating disorders are underprioritised relative to their associated health burden, even within the domain of mental health. We argue that eating disorders, despite their prevalence, lethality, and devastating social and health consequences, and not withstanding recent advances in aetiological understanding and therapeutic endeavours, remain marginalised and neglected in healthcare writ large. This underprioritisation, moreover, extends across several dimensions that impact political will and resources of all kinds—human, financial, scientific, policy, and health systems—requisite to safeguarding vulnerable individuals and communities from neglect leading to adverse health outcomes. Bringing eating disorders out of the shadows is to reckon not just with their clinical invisibility, but arguably the social invisibility that perpetuates their marginalisation even among other mental disorders.

One of the challenges in remedying this situation lies in correcting the inaccurate and unfortunate framing of eating disorders as niche disorders affecting a limited demographic. Eating disorders must be understood as the common and serious mental health problems they are, and every clinician should be familiar with recognizing and managing them. Indeed, evidence suggests that up to 13% of people by the age of 20 have met diagnostic criteria for an eating disorder. Among UK adolescent girls, the highest risk demographic, 40.7% have some form of disordered eating behaviour (fasting, purging, or binge eating), 11.3% at a level compatible with an eating disorder diagnosis (2). Eating disorders are not just a risk for adolescent girls however; incidence among young males is rising, as is recognition among older women and men. Yet eating disorders together with substance use disorders were the only disorders excluded from the 2014 UK adult psychiatric morbidity survey (APMS), an omission we hope to see rectified in the next survey. This was despite strong advocacy for their inclusion, and a high number of positive screening responses in the 2007 survey.

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The marginalisation of eating disorders in UK health surveillance is mirrored elsewhere on the globe; eating disorders having been included in only a handful of World Mental Health surveys outside of the Global North. As a result, nationally representative prevalence data are largely unavailable for low- and middle-income countries (LMICs). Herein lies the first obstacle to recognition – the dearth of epidemiologic data from the Global South. The sparse data available for burden of disease estimates in LMICs, namely the number of disability-adjusted life years (DALYs) and years lived with disability (YLDs) attributable to eating disorders, both limits and distorts our understanding of emerging trends in prevalence. On the other hand, robust data have demonstrated increasing eating disorder risk in relation to particular social contexts and exposures such as changes in body shape ideals, the food environment, and weight stigma, as well as emergence of eating disorders in populations previously thought to be relatively protected (3).

We argue that the omission of eating disorders from research and policy on mental health across the globe perpetuates their social invisibility by appearing to legitimize their low prioritisation. An example is that eating disorders remain absent from the table of contents of the mhGAP, a compendium of treatment management algorithms for mental disorders developed by the World Health Organization (WHO) and intended for deployment by non-specialty clinicians in LMICs. And despite eating disorders having been identified as a priority area for adolescent health by the WHO in 2003, the vast majority of countries implementing the WHO's Global School-based Health Survey for risk behaviour surveillance inexplicably omit questions on eating disorder symptoms (3).

Eating disorders routinely go undetected in clinical and other frontline settings, too. There are complex reasons for this particular vulnerability, some difficult to avoid and some which may have factored into Averil's tragic death. Although anorexia nervosa often presents with emaciation, the other clinically significant eating disorders can present without any physical signs or laboratory abnormalities. Clinical detection, therefore, may rely upon a patient's willingness and ability to share information about body and weight concerns, and behaviours such as binge eating and purging. Although some behaviours are observable, they may escape notice by family, peers, and clinicians unless directly enquired about. This clinical invisibility means it is especially important for clinicians to become proactive—and inclusive of all demographics—in exploring symptoms and following up on treatment plans. Misconceptions regarding capacity to consent may also be a factor, such that refusal of care in an articulate young person over 16 might be accepted without question or judged unethical to contest, regardless of clinical features.

An opportunity to redress such oversights and misconceptions was missed by the omission of eating disorders and, specifically, anorexia nervosa, from a highly influential report entitled "Improving the physical health of adults with severe mental illness (SMI): essential actions" (4), the aims of which were to improve the physical health of adults with SMI across the NHS, to help achieve the same standards of physical healthcare as the general population and reduce the risk of premature death. The absence is egregious insofar as anorexia nervosa has the highest mortality among psychiatric disorders. Such risks are clearly articulated and inform recommendations in the MARSIPAN (Management of Really Sick Patients with Anorexia Nervosa) and Junior MARSIPAN reports published by the Royal

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College of Psychiatrists. The MARSIPAN reports were widely welcomed and disseminated amongst eating disorders specialists, and cited in the NICE eating disorders guideline, but have had a limited profile and endorsement in the wider psychiatric and medical communities in the UK.

Difficulties defining the boundary between health and pathology are likely relevant to the minimisation of eating disorders. Several of the symptoms and signs are dimensional, making the distinction between normal and pathological behaviours obscured by social norms that vary considerably across time and social context. Behaviours seen as positive, and even encouraged, in someone who is overweight (e.g., restriction of 'unhealthy' foods, weight loss, and vigorous exercise) are pathological in someone underweight or indeed reflect unhealthy behaviours across the weight spectrum. And it can be hard to discern the mental anguish that accompanies these behaviours: that a neutral, or even pleasurable, activity for one individual, such as exposure to highly palatable foods, can be an aversive or harmful experience for another.

Yet it is this normalisation of disordered eating behaviours that makes the need for their improved detection so urgent. The war against obesity is gathering pace and we all, and in particular our children, are being advised to monitor our calorie intake, count our steps, cut fat and sugar from our diets, and be classified by our BMI on a regular basis. Obesity is both a risk factor for and a comorbidity with eating disorders, yet screening for eating disorders has barely received mention in the stampede to take action against obesity. Those with, or at risk of, eating disorders appear to be collateral damage, overshadowed by their more visible neighbour. Eating disorders advocacy groups have tried to make their voices heard but without data, and arguably even with it, it is easy for advocates to feel unheard. A 2007 Lancet editorial asked "Is it time for a public-health approach to eating disorders?" (5). Eleven years later the answer must surely be a resounding "yes" to a public health strategy for eating disorders, and one that is integrated with obesity policy.

In conclusion, the Parliamentary Health Ombudsman's report summarises events that culminated in a tragic convergence of human error, systems deficiencies, and challenges inherent in the clinical management of the potentially lethal mental disorder that is anorexia nervosa. We hope that further personal tragedies do not ensue before the clear necessity to change practice and improve outcomes stimulates corrective actions. We are calling for parity for eating disorders in all aspects of data collection, training, academic funding and service delivery, and for eating disorders to be a central consideration to public health policy on obesity and mental health.

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