

Beneath the tip of the iceberg: Why so many people with eating disorders are not referred for treatment

Deborah Mitchison, Christopher Basten, Scott Griffiths, Stuart B Murray

Eating disorders contribute substantially to global disability burden in terms of prevalence (Australian estimate is 17.2%),¹ mental and physical morbidity, duration of illness and early mortality.² With figures suggesting that 77% of people with an eating disorder never receive specialised treatment,³ it is clear that eating disorder clinicians are only treating patients who are on the 'tip of the iceberg'. The broad scope of a general practitioner's (GP's) practice inhibits the detection of each and every underlying condition, yet low referral rates are a part of this issue. People with eating disorders do present to primary care for treatment of associated health conditions;⁴ thus, improving detection within this setting represents an opportunity to increase access to evidence-based treatment. We attempt to unravel two prevailing stereotypes that have an impact on how eating disorders are perceived, ultimately influencing detection and referral behaviours.

Stereotype 1 – Eating disorders only include anorexia nervosa and bulimia nervosa

Eating disorders are typically perceived by the public to be characterised by either self-inflicted starvation, resulting in emaciation (ie anorexia nervosa), or periodic overeating and vomiting

(ie bulimia nervosa). However, anorexia nervosa and bulimia nervosa together represent only around 10% of all eating disorder cases in the community.¹ Binge eating disorder (BED), characterised by recurrent binge eating in the absence of weight-loss behaviour, is three times more common than anorexia nervosa, or as common as anorexia nervosa and bulimia nervosa combined;¹ however, patients with BED are rarely referred for mental health treatment. A narrow view of what diagnoses typify an eating disorder creates 'blind spots' in health professionals' ability to detect the full spectrum of eating disorders. Furthermore, detection is hampered by ongoing classification problems in the *Diagnostic and statistical manual of mental disorders* (DSM) and International Classification of Diseases (ICD) – principally, that the residual ('other'/'unspecified') diagnosis represents up to 80% of eating disorder cases.¹

Stereotype 2 – Eating disorders are the domain of young women

Traditionally, eating disorders were perceived as disorders that afflicted young, Western women. This gave rise to research based on samples from this demographic, and it is the findings from this research that have laid the foundation for how we diagnose and treat people with eating disorders today.

Such sampling biases have resulted in a dearth of knowledge about eating disorders in population groups for which treatment-seeking is low (eg those who are male, older, obese), despite growing evidence that eating disorders are widely distributed.⁵⁻⁷

This has undoubtedly contributed to poor 'eating disorder literacy'⁸ among healthcare providers and thus, the continuation of treatment gaps. For instance, although obese individuals are more likely to have bulimia nervosa and BED,^{1,9} people who are obese and have eating disorders are much more likely to be given dietary and exercise advice (ie rather than a referral for treatment of an eating disorder). This may inadvertently serve to increase the severity of the eating disorder and obesity. Further, our own research has found that equal numbers of men and women in the population meet the criteria for bulimia nervosa and 'other' eating disorders.¹ We also found that symptoms of eating disorders are increasing at the fastest rates over time in males and adults aged older than 45 years.⁵ Finally, muscularity-oriented disordered eating represents a spectrum of eating disorder psychopathology mainly afflicting males that largely goes under the 'diagnostic radar'.¹⁰

Recommendations

These stereotypes have contributed to weaknesses in knowledge regarding

the nature and prevalence of eating disorders, and a discordance between the demographic and clinical correlates of eating disorders in community-based studies versus those referred to specialised treatment (ie largely young females with anorexia nervosa or bulimia nervosa).

Detection rates of non-stereotypical eating disorders in primary care settings could be improved by dissemination of existing resources through channels that are accessed by physicians (eg undergraduate curricula, GP newsletters, peer-reviewed journals). Examples include the *Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines for Eating Disorders*¹¹ and *Eating Disorder: A Professional Resource for General Practitioners*, published by the National Eating Disorder Collaboration.¹² Improved access to such information is likely over the coming years, with the implementation of government initiatives such as the NSW Service Plan for People with Eating Disorders 2013–2018.¹³ Importantly, these resources include quick screening tools, such as the SCOFF (Box 1), to assist eating disorder detection for time-poor physicians. Beyond accurate detection in primary care, other relevant issues to address include:

- Access to treatment for eating disorders being currently hampered by lack of availability, and financial/time costs to individuals/families.
- Diagnostic reform, particularly the

provision of criteria for the full range of presentations under the banner of eating disorders.

Advances in all these areas will assist detection and referral to specialist treatment for people with eating disorders who are currently represented in the 'submerged' sector of the proverbial iceberg.

Authors

Deborah Mitchison PhD, Research Fellow, Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, NSW; Clinical Psychologist, Basten and Associates: Clinical Psychologists, Sydney, NSW.
deborah.mitchison@mq.edu.au

Christopher Basten PhD, Director and Principal Clinical Psychologist, Basten and Associates: Clinical Psychologists, Sydney, NSW; Adjunct Fellow, Department of Psychology, Macquarie University, Sydney, NSW

Scott Griffiths PhD, NHMRC Early Career Fellow, Melbourne School of Psychological Sciences, University of Melbourne, Melbourne, Vic; Adjunct Fellow, Department of Psychology, Macquarie University, Sydney, NSW

Stuart B Murray PhD, Assistant Professor, Department of Psychiatry, University of California, San Francisco, CA, USA

Conflict of interests and funding: None.

Provenance and peer review: Not commissioned, externally peer reviewed.

References

1. Hay P, Mitchison D, Lopez Collado AE, González-Chica DA, Stocks N, Touyz S. Burden and health-related quality of life of eating disorders, including avoidant/restrictive food intake disorder (ARFID), in the Australian population. *J Eat Disord* 2017;Epub ahead of publication.
2. Arcelus J, Mitchell AJ, Wales J, Nielsen S. Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Arch Gen Psychiatry* 2011;68(7):724–31.

3. Hart LM, Granillo MT, Jorm AF, Paxton SJ. Unmet need for treatment in the eating disorders: A systematic review of eating disorder specific treatment seeking among community cases. *Clin Psychol Rev* 2011;31(5):727–35.
4. Mond JM, Myers TC, Crosby RD, Hay PJ, Mitchell JE. Bulimic eating disorders in primary care: Hidden morbidity still? *J Clin Psychol Med Settings* 2010;17(1):56–63.
5. Mitchison D, Hay P, Slewa-Younan S, Mond J. The changing demographic profile of eating disorder behaviors in the community. *BMC Public Health* 2014;14:943.
6. Mitchison D, Hay PJ. The epidemiology of eating disorders: Genetic, environmental, and societal factors. *Clin Epidemiol* 2014;6:89–97.
7. Mitchison D, Mond J, Slewa-Younan S, Hay P. Sex differences in health-related quality of life impairment associated with eating disorder features: A general population study. *Int J Eat Disord* 2013;46(4):375–80.
8. Mond JM. Eating disorders 'mental health literacy': An introduction. *J Ment Health* 2014;23(2):51–54.
9. da Luz FQ, Sainsbury A, Mannan H, Touyz S, Mitchison D, Hay P. Prevalence of obesity and comorbid eating disorder behaviors in South Australia from 1995 to 2015. *Int J Obes (Lond)* 2017;Epub ahead of publication.
10. Murray SB, Griffiths S, Mond JM. Evolving eating disorder psychopathology: Conceptualizing muscularity-oriented disordered eating. *Br J Psychiatry* 2016;208(5):414–15.
11. Hay P, Chinn D, Forbes D, et al. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for eating disorders. Melbourne: The Royal Australian and New Zealand College of Psychiatrists, 2014. Available at www.ranzcp.org/Files/Resources/Publications/CPG/Clinician/Eating-Disorders-CPG.aspx [Accessed 7 June 2017].
12. The National Eating Disorders Collaboration. Eating disorder: A professional resource for general practitioners. Crows Nest, NSW: NEDC, 2014. Available at www.nedc.com.au/files/Resources/GPs%20Resource.pdf [Accessed 7 June 2017].
13. NSW Health. NSW service plan for people with eating disorders 2013–2018. Sydney: NSW Health, 2013. Available at www.health.nsw.gov.au/mentalhealth/publications/Publications/service-plan-eating-disorders-2013-2018.pdf [Accessed 7 June 2017].
14. Freund KM, Graham SM, Lesky LG, Moskowitz MA. Detection of bulimia in a primary care setting. *J Gen Intern Med* 1993;8(5):236–42.

Box 1. Screening for eating disorders

SCOFF questionnaire*

- 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[†] in a 3 month period?
 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?

One point for every 'yes'; a score of ≥ 2 indicates a likely case of anorexia nervosa or bulimia

Additional validated screening questions for bulimia nervosa and binge eating disorder¹⁴

1. Are you satisfied with your eating patterns?
2. Do you ever eat in secret?

*Reproduced from Morgan JF, Reid F, Lacey JH. The SCOFF questionnaire: Assessment of a new screening tool for eating disorders. *BMJ* 1999;319:1467, with permission from BMJ Publishing Group Ltd.

[†]One stone = 6.35 kg