Early intervention for eating disorders

Phillipa Jane Hay[1,2]

1. Translational Health Research Institute, School of Medicine, Western Sydney University, Sydney, Australia
2. Mental Health Services, Campbelltown Hospital, South West Sydney Local Health District (SWSLHD), Sydney, Australia

✉ Corresponding author: Phillipa Hay. Email: p.hay@westernsydney.edu.au

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 conclusion 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/m2) 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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