

PS03/19

Position statement on early intervention for eating disorders

May 2019

POSITION STATEMENT

Purpose of the document

This position statement sets out the Royal College of Psychiatrists' view, with supporting evidence, that early intervention for eating disorders (EDs) is essential. It also makes recommendations for actions to improve service provision in this area.

Overview

The principle of early diagnosis and treatment to optimise disease outcomes is widely accepted in medicine. It is based on the concept that there are different stages of illness with different prognostic and treatment implications.

Early intervention may help to prevent illness onset or lead to an improved course of illness, e.g. through enabling earlier recovery, reducing or averting risk of chronicity and complications, preventing/lowering distress and avoiding disruption in people's development and associated secondary disabilities. Successful early intervention critically depends on early detection of a disorder or its precursors and the commencement of effective treatment commensurate with the patient's stage of illness.

In psychiatry, these ideas have most strongly penetrated the psychosis field, where comprehensive early intervention programmes for first-episode cases have been introduced. One key focus of these programmes has been to reduce the duration of untreated psychosis (DUP) (i.e. time from onset to first treatment). This is based on a solid body of evidence showing that a shorter DUP is associated with better outcomes across multiple domains.

The EDs field has not seen any parallel developments. We focus here on outlining the rationale and need for this. Whilst primary prevention of EDs is also important, it is beyond the scope of this statement to address this here.

(a) The nature and scale of the problem

The EDs anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and related partial or mixed syndromes are common mental disorders which affect up to 15% of young women and up to 5.5% of young men in high-income countries (Schmidt *et al*, 2016a; Limbers *et al*, 2018). The peak age of onset of EDs is from mid-adolescence into emerging adulthood (age 15 to 25), i.e. at a developmentally-sensitive time (Micali *et al*, 2013). Average illness duration is about 6 years. Levels of psychological comorbidity,

including suicidality, are high from the early stages of illness and are associated with considerable functional impairment (Swanson *et al*, 2011).

AN is one of the most common chronic illnesses in adolescence, with incidence rates at least as high as that of type 1 diabetes (Gonzalez *et al*, 2007). One in 2–3 people with BN or BED are obese or will become obese, making them vulnerable to obesity-related complications (Hay *et al*, 2015; Kessler *et al*, 2013).

Mortality rates are almost twice as high for people with EDs than in the general population – and 5.86 times higher for people with AN (Arcelus *et al*, 2011), i.e. higher than for any other major psychiatric disorder (Hoang *et al*, 2014). In young people with AN aged 15–24 years, the mortality risk is also higher than for other serious diseases in adolescence, such as asthma or type 1 diabetes (Hoang *et al*, 2014).

The impact of EDs on families and carers is high, with burden being at least as high or higher than that of caring for a person with depression or schizophrenia (Martín *et al*, 2015; Graap *et al*, 2008; Treasure *et al*, 2001).

Estimates of the economic and social impact of EDs suggest a comparable disease burden for EDs as for anxiety and depression (Butterfly Foundation, 2012).

(b) Illness risk and illness stages

The aetiology of EDs is complex, with evidence for multiple overlapping and distinct biopsychosocial factors implicated in risk for different clinical EDs and/or disordered eating (Hilbert *et al*, 2014; Culbert *et al*, 2015). Increasingly, there is a broad acceptance of EDs as brain-based disorders and suggesting neurobiological overlaps between EDs, anxiety disorders and addictions (Berner *et al*, 2014; Dunlop *et al*, 2016; O'Hara *et al*, 2015; Steinglass *et al*, 2016; Vannucci *et al*, 2015; Treasure *et al*, 2018). There is also increasing recognition that just like in other serious disorders there are different illness stages, with brain responses being most malleable in the early stages of illness (Treasure *et al*, 2015). In contrast, in the later stages, the illness becomes more persistent with neurobiological evidence of compulsive, habitual and entrenched behaviours (e.g. O'Hara *et al*, 2015; Steinglass *et al*, 2016). Nonetheless, even in longstanding cases there is the potential for significant improvement in ED symptoms and quality of life (Eddy *et al*, 2017).

(c) Treatment and service utilisation

Clinical management of EDs is challenging for a number of reasons, including patients' self-stigmatisation as being undeserving, their ambivalence about treatment and the high medical risks and complexities arising from comorbidities. Effective evidence-based treatments include psychological therapies (such as family therapy focused on EDs for children and adolescents with AN and BN, cognitive-behavioural therapy (CBT) for BN and BED and a range of psychological therapies for adults with AN) together with nutritional management. Medication has a limited role in the treatment of EDs. Outcomes are best in young people with a short illness duration, e.g. up to 60% of adolescents with AN make a full remission with early expert treatment. In contrast, remission rates in adults with AN, i.e. those with a more established illness, are around 20–30% with a course of best available treatment (Zipfel *et al*, 2015). In BN and BED, 30 to 60% achieve full recovery with CBT (NICE, 2017).

A significant problem is that the majority of ED patients do not access evidence-based effective treatments. For example, only about one third of ED cases are detected by healthcare professionals (Keski-Rahkonen *et al*, 2016). In the UK, it has been estimated that only 23% of people with EDs receive treatment (compared with 80% of those with psychosis) (Layard *et al*, 2012).

Compared to other mental disorders in the UK, AN has the highest proportion of hospital admissions that are over 90 days long (26.8%) and the longest median length of stay (36 days) (Thompson *et al*, 2004). A survey of all UK specialist ED units revealed that the average duration of hospitalisation for AN patients is about 4 months (Royal College of Psychiatrists, 2012). Data from Scotland found that average admission duration was 141.4 days for adolescents and 113.0 days for adults (Morris *et al*, 2015). Two studies of AN, one of adolescents and the other of adults, found the annual service costs per patient to be 24,000 (Byford *et al*, 2007; Stuhldreher *et al*, 2015). In recent years, hospitalisations of young people with AN have risen dramatically (Herpertz-Dahlmann *et al*, 2014). Studies assessing hospitalisation trends from the 1960s to the present have shown a large increase in hospitalisation rates in England overall in recent years, in both first and repeat admissions, with the largest increase in young women aged 15–19 (Holland *et al*, 2016). By contrast, admission rates for other major mental disorders (schizophrenia, depression, bipolar) have declined during the same period (Green *et al*, 2014).

Key evidence

The case for early intervention in ED

The utility of illness stages and an early intervention approach in EDs was first examined nearly 15 years ago, giving this idea cautious support (Currin and Schmidt, 2005). A more recent systematic review concluded that for AN there is now considerable evidence to support a stage model of illness, with evidence of neurobiological progression and some evidence that stage-matched interventions optimise outcomes (Treasure *et al*, 2015). For BN and BED the evidence is more limited. Based on available evidence, the review suggested that early stage EDs should be defined as having an illness duration of ≤ 3 years, beyond which time treatment outcomes become poorer.

Although many studies have examined illness duration in EDs, very few provide information specifically on duration of untreated eating disorder (DUED), i.e. the time between onset and start of first treatment. DUED has two main components:

- 1 A period where people have symptoms, but don't recognise they have a problem or are not ready to seek help,
- 2 A period where they have sought help and are waiting for treatment.

The first component is patient-related, whereas the second encompasses service-related delays.

Recent studies report a duration of untreated ED (DUED) of 25–41 months for first episode cases (Neubauer *et al*, 2014; Gumz *et al*, 2017; BEAT, 2018), suggesting that many people only access treatment after the critical window of the first 3 illness years. Notably, emerging adults (aged 18–25) with EDs on average have a DUED which is 30% longer than that of adolescents below age 18 (Weigel *et al*, 2014), as they are more independent from their families, and have a more complicated care pathway to navigate into treatment. Thus, they are a particularly vulnerable group.

Service-related barriers to early intervention in ED

Primary care staff (e.g. GPs, school nurses and University health services) play a key role in early detection and management of EDs, and signposting to specialist services. Lack of awareness, knowledge or skills on the part of primary health care personnel may lead to underdiagnosis or delays. Access to services beyond primary care is determined by the availability and capacity of specialist services, but also by other factors, e.g. referral procedures and gate-keeping arrangements. In the UK, a recent survey by BEAT (2018) found people with EDs on average waited 6 months between seeing their GP and accessing specialist care.

Traditionally, many specialist ED services manage patient throughput with waiting lists. Yet, considerable evidence suggests that waiting for treatment is harmful (Furukawa *et al*, 2014). For example, in emerging adults with BN, those offered immediate online CBT with therapist guidance engaged more and had better outcomes than those who were given the same programme after a 3-month wait (Sanchez-Ortiz *et al*, 2011). A transdiagnostic study of CBT in EDs found that being on a waiting list led to greater treatment drop-out rates (Carter *et al*, 2012).

Finally, in relation to transitions between services, many young people may have to transition from Community Eating Disorder services for children and young people (CEDS-CYP) to Adult ED services (AEDS) at a critical point in their illness. Others transition between home and University services. This causes delays, disruption to care and deterioration.

Why act now?

In 2014, the Government announced additional funding to create designated CEDS-CYP up to the age of 18 across England. In parallel to this, a commissioning guide was published specifying characteristics and staffing levels of such services and associated access and waiting time standards (NHS England, 2019a).

The rationale for the creation of these services is grounded in data suggesting that specialist CEDS-CYP have better treatment engagement and outcomes and fewer hospital admissions and as such, are more cost-effective than non-specialist services (House *et al*, 2012; Gowers *et al*, 2010; Schmidt *et al*, 2017). Training for CEDS-CYP has been rolled out across England. Figures from the NHS Digital Strategic Data Collection System (SDCS) dataset show that during the period October 2018 to December 2019 approximately 81% of children and young people with an ED referred as 'urgent' accessed NICE concordant treatment in CEDS-CYP within one week. For non-urgent referrals this figure was around 87% within 4 weeks from the date of referral. These percentages have steadily improved since monitoring started in 2016, in the context of a marked rise in referrals (NHS England, 2019b).

No parallel funding has as yet been made available to AEDS. Nonetheless, a service model for emerging adults (age 18 to 30) with a recent onset illness (First Episode Rapid Early Intervention for Eating Disorders; FREED) has been developed (Schmidt *et al*, 2016b) and piloted (Brown *et al*, 2018; McClelland *et al*, 2018). Introduction of FREED as a service within a large adult ED service, resulted in:

- reduction of DUED from 19 to 13 months under optimal conditions
- improved outcomes for FREED patients compared to patients with a similar age and illness duration seen earlier in the same service.

FREED is currently being scaled up across England (www.health.org.uk/improvement-projects/freed-up-first-episode-and-rapid-early-intervention-service-for-young-people).

Summary and conclusions

EDs are serious brain-based mental disorders associated with significant comorbidity, disability and mortality and major burden on individuals, families and society. Whilst effective treatments exist, many patients do not access them early or at all. Hospitalisation rates are rising, especially amongst the young.

The early phase of EDs is a potentially critical period for preventing or modifying illness onset as well as the course and duration of the illness. As illness duration increases, response to treatment becomes poorer and full recovery becomes rarer. Taken together, available evidence supports early detection and awareness of symptom onset and rapid access to effective treatment to prevent the illness becoming established and improve the course and prognosis.

College position

Whilst the recent government funding and wider initiative for improving ED services for children and young people up to the age of 18 is to be welcomed, it does not cover the many emerging adults (age 18 to 30) who present with a first episode of an ED. Increasingly, emerging adulthood is recognised as a developmental period in its own right (Arnett *et al*, 2014). This period is characterised by major uncertainties and multiple transitions. The increased vulnerability of young people during this time is reflected in a longer DUED in this age group compared to adolescent ED patients (Weigel *et al*, 2014).

This situation creates an unacceptable health inequality. Patients under 18 years old can self-refer to CEDS-CYP and are seen and treated rapidly. In contrast, patients aged 18 or above from the same geographical area may be faced with multiple gate-keeping hurdles before accessing AEDS, causing substantial delays to their treatment.

The College's position is that there should be parity between CEDS-CYP and AEDS in terms of access and waiting times and service provision, in line with recommendations of the Parliamentary and Health Service Ombudsman's Report into the death of 19-year-old Averil Hart from anorexia nervosa (Parliamentary and Health Service Ombudsman, 2017).

The College recognises the need for timely treatment for all patients with EDs, irrespective of age, illness stage or duration, including those that may need continued support and care beyond their first episode. This will require substantial further investment, as currently many adult ED services are not adequately resourced to provide this.

Recommendations for action

- Commissioning bodies should make additional funding available to ensure that patients of all ages presenting with a first episode of an ED are given rapid access to evidence-based treatment, in line with NICE guidelines (NG 69, 2017), with parity in terms of access and waiting times across the age range and across all parts of the UK. This will maximise the likelihood of early full remission.
- AEDS should consider how to optimally involve parents/carers as partners throughout the treatment process in the context of working with young adults. Parents and other carers are important partners in facilitating early help-seeking, treatment adherence and recovery in EDs. (CEDs-CYP already routinely involve families at all stages of treatment.) All services should focus on helping parents/carers with their caring role as well their own psychological wellbeing.
- Community ED services should take an active role in linking with their local primary care, universities and schools and offer training in early detection, referral and sign posting for all age groups. CEDs-CYP and AEDS should work together to optimally coordinate this endeavour in their local area and agree clear protocols that support easy access to their services for patients, families and professionals.
- General practitioners and other primary care staff should make early referrals to ED services rather than using watchful waiting as a strategy for managing EDs.
- AEDS should not deny people with EDs access to treatment based on arbitrary severity criteria, such as body mass index (BMI) or comorbidity. This is potentially dangerous and demoralising for patients and is not in keeping with an early intervention model.
- Every attempt should be made to minimise the impact of transitions between services when young people are in their first treatment episode. CEDs-CYP, AEDS and commissioners should work together to agree transition protocols for how this should usually be managed, building in some flexibility around the time of transfer of care from CEDs-CYP to AEDS. Transition protocols

for severely medically-ill patients who are hospitalised should involve other relevant stakeholders, such as paediatric and general medical teams.

- Interventions and service models for early intervention in first episode EDs need to be developed and researched. This should, for example, include research on:
 - Illness-stage appropriate interventions
 - Key features of an effective early intervention service for EDs
 - Novel adjuncts to early intervention for EDs (e.g. through smartphone-delivered interventions, online or in-person peer support and mentoring or home-based treatments).
 - The relative merits of trans-age services and separate CEDS-CYP and AEDS
 - The impact of the introduction of early intervention services on service provision for patients with recurring or chronic illness.
 - Comprehensive health-economic analyses to assess the down-stream cost-savings of implementing early intervention.

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