Word count: 1997 (excluding references, appendix and title)

How to address the treatment gap for patients with eating disorders (EDs) and help their recovery?

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1. Introduction and background:

Eating disorders (EDs) are complex neuropsychiatric conditions. NICE succinctly outline EDs as being 'characterised by persistent disturbance of eating or eating-related behaviour which leads to altered intake or absorption of food and causes significant impairment to health and psychosocial functioning'.[1] Commonly, there are four main categories of EDs: anorexia nervosa, bulimia nervosa, binge eating disorder (BED) and 'other specified feeding or eating disorder' (OFSED).

Within the context of EDs, the term 'treatment gap' can be defined as the difference in the proportion of people who have an eating disorder (i.e. prevalence) and the proportion of those individuals whom actually receive care.[2] Beat, a UK-based ED charity, estimate that around 1.25 million within the UK have an eating disorder but state that there is insufficient research regarding the prevalence of EDs in the UK.[3] However, a 2019 systematic literature review investigated the 2000-2018 time period and found that there was an increase in the prevalence of EDs amongst both men and women.[4] Likely contributable factors to this increase include the COVID-19 pandemic. A 2023 systematic review found COVID-19 to have increased the number of ED hospitalisations and symptomology, due to decreased access to care, changes to routine and social isolation.[5]

Subsequently, this is applying pressure on access to ED treatment, with the gap widening between those who have ED and those whom are successfully accessing treatment. The demand for services is increasing and hence, there is a need to urgently resolve this, especially since EDs have the highest mortality rate of any other mental illness.[6]

This essay will propose the following four evidence-based recommendations to help address the treatment gap for ED patients:

- Improving clinician diagnostic skill for ED detection in primary care via more novel and effective screening tools.
- Quicker provision, deliverance and standardisation of 'transitional' cognitive behavioural therapy (CBT) and dialectical behavioural therapy (DBT) by primary healthcare providers.
- Instillation of early intervention ED secondary care teams across the UK.
- Educating parents/legal guardians of patients with ED and utilising their relationships for patients to receive prompt help.

2. Proposed recommendations to address the treatment gap:

Improving clinician diagnostic skill for ED detection in primary care via more novel and effective screening tools

Clinicians working within primary care, mostly general practitioners (GPs), can form an integral part of early detection of eating disorders. A study conducted in 2024 highlighted the importance of considering primary healthcare settings as an essential site in delivering early intervention services for EDs.[7] Screening tools are useful in early detection of health conditions, especially in EDs when many patients attempt to subtly mask their symptoms. It is not coherently obvious by simple visual observation if a patient has an ED; there is a misconception that sufferers all appear emaciated. Although this may be true in some cases of anorexia nervosa, those suffering from bulimia may actually be within the normal weight range and those with binge-eating disorder are often overweight.

GPs should be expertly educated by ED psychiatrists on simple, yet effective screening tools to help detect EDs when patients may initially present in clinic. Professor John Morgan at Leeds Partnership NHS Foundation Trust designed the five-question SCOFF screening tool to indicate a possible ED (see Appendix).[8] A score of two or more positive answers is a positive screen for an ED and as a result, can prompt general practitioners to make an appropriate referral. A comparative study from 2002, invited sequential women attenders from two London-based general practices to be verbally asked the SCOFF questions.[9] The questionnaire detected all cases of anorexia and bulimia nervosa and thus contributed to its effectiveness as an efficient and quick screening tool for general practitioners to utilise. However, downsides to SCOFF is that it does not screen and detect presentations of BED and OFSED, it possesses inflexible cut-off points and may fail to identify individuals at risk.

There is an emergence of more novel screening tools for early detection of EDs. For example, a longitudinal survey conducted in 2021 looked into using a digital screening tool, the InsideOut Institute-Screener (IOI-S).[10] IOI-S covers six facets of common ED psychopathology (e.g. ‘how is your relationship with food?’) and scores respondent’s answers via a 5-point Likert scale (see Appendix). The survey found that IOI-S demonstrated excellent psychometric properties and was effective in identifying individuals whom may be at risk of an ED; unlike the SCOFF questionnaire.

Quicker provision, deliverance and standardisation of ‘transitional’ cognitive behavioural therapy (CBT) and dialectical behavioural therapy (DBT) by primary healthcare providers

CBT has been proven to be one of the mainstay treatments for EDs. NICE recommend that for adults with EDs, individual eating-disorder-focused cognitive behavioural therapy (CBT-ED) should be considered as specialist psychological treatment.[1] However, there is currently a large wait time between ED patients from being referred to and being seen by ED specialist services, increasing the treatment gap and delaying help received by vulnerable patients. There is evidence which highlights that there is a relationship between prognostic outcome from an ED and duration of waiting time to

receive treatment i.e. longer the wait, the worse the prognostic outcome for ED recovery.[11]

Currently, many general practices within the UK offer the Improving Access to Psychological Therapies (IAPT) programme (recently renamed to Talking Therapies). This initiative aims to increase access to evidence-based psychological therapies (e.g. CBT) for patients experiencing common mental health problems, from anxiety to depression. A referral to Talking Therapies is either made by the GP (or the patient themself) and then the patient is matched to an accredited practitioner, who delivers a short-course of psychological therapy. This programme approximately treats over 560,000 patients per year within the UK and around 50% of patients treated via Talking Therapies recover, and two-thirds show worthwhile benefits.[12] Data from NHS Digital in 2022, shows that 88.9% of referrals waited less than 6 weeks to access Talking Therapies, and the mean number of therapy sessions is 7.9.[13]

Talking Therapies can be further enhanced to address the ED treatment gap by becoming a 'transitional' service provider of CBT-ED, whilst patients await to be seen by ED specialists at a secondary care level. Talking Therapies already provides support for body dysmorphia but practitioners could be trained about the basics of CBT-ED and deliver relevant, introductory CBT material to ED patients. This allows for a scope of a better support network for those with ED, especially those at high risk. Once the patient has received confirmation of a successful specialist referral and an appointment has been made, the patient can be safely discharged from Talking Therapies, having already started to develop key CBT skills and coping techniques.

Instillation of early intervention ED secondary care teams across the UK

As previously mentioned, early intervention for EDs can help reduce mortality and improve the chance of recovery. Research emphasises that it is ideal to try and reach patients with an ED within the first three years of illness.[14] With waiting times for official assessments by psychiatrists becoming more prolonged, specialist early intervention teams could help reduce wait times.

For example, FREED (First Episode Rapid Early Intervention for Eating Disorders) is a service for 16 to 25 year-olds who have had an ED for three years of less.[15] It is a flexible evidence-based treatment approach whose primary focus is to intervene early and provide rapid access to specialised treatment sooner, rather than later. FREED was developed and tested by the South London and Maudsley NHS Trust Foundation's Eating Disorders Unit and King's College London. They compared FREED with the normal service provision and found that FREED reduced the amount of time an ED was left untreated and that most made full recovery within one year. This again highlights the importance of treating eating disorders within the early stages to help improve prognosis, alongside address the current treatment gap.

Eating Disorder Specialists from across the United Kingdom could follow suit and form early intervention centres for EDs. Such centres can consist of a small and dedicated team, ranging from clinical psychologists and dieticians to psychiatrists. This could also relieve pressure and burden on ED secondary care teams as they can focus more

on providing intense treatment for complex EDs, especially those with late presentations.

Educating parents/legal guardians of patients with ED and utilising their relationships for patients to receive prompt help

A major hurdle in the detection, treatment and recovery of ED is patient denial. There are two types of patient denial: one in which there is a neurobiologically impaired self-awareness and the second being deliberate denial or refusal of self-disclosure.[16] A retrospective study undertaken in 2008 looked at the factors that influence ED patients to deny their illness.[17] Both deniability and ambivalent attitudes can lead to patient avoidance in seeking help from healthcare professionals. Therefore, parents/legal guardians should be educated on the tell-tale signs and symptoms of EDs, including the subtly and 'faking good' behaviours some patients may relay (e.g. "my stomach is not feeling well so I cannot eat right now").

Healthcare professionals, such as psychologists and psychiatrists, could work closely with ED charities (e.g. Beat), to run campaigns in which awareness of EDs is raised within parent and teacher meetings and clubs at schools, colleges, universities and parent workplaces. If parents/legal guardians are educated on the signs and symptoms of EDs, they can help their child to seek professional support, which increases the chance of early intervention and treatment. With parents/legal guardians being best placed to know their child's behaviourisms, they can help detect abnormal ED behaviours earlier.

Also, charities can provide support to parents whom suspect an ED in their child, by providing tools on functional self-compassion. Low self-compassion underpins ED pathology in many patients, which can further weaken the patient's own insight into their illness.[18] If parents can gently help their child see this deficiency in perception and increase self-esteem, self-compassion and self-adoration towards their body image, patients may begin to increase their understanding of the threat posed by their ED.

Furthermore, a Swedish study concluded that EDs in parents were associated with ED in children, contributing to the popular hypothesis that it is possible for intergenerational transmission of ED.[19] This further supports increased involvement of parents in the early detection of EDs as parental history of an ED, can prompt early identification of high-risk ED patients and may be useful for targeted prevention.

3. Personal insight:

I recovered from anorexia nervosa (binge-purge subtype) in 2019. Therefore, I have seen first-hand as to how pertinent it is that we address the treatment gap. If my parents were aware of EDs, they could have detected its signs and symptoms and encouraged me to seek professional help sooner. When I finally presented in primary care, I was fortunate to have an understanding GP whom appropriately screened and

referred me. However, I waited many months until my first appointment with the hospital ED specialist team. Whilst waiting, I continued to deteriorate and had no professional safety net or support system. An early intervention centre, could have provided that tailored support and prevented the worsening of my anorexia nervosa. Alternatively, being equipped with the basics of CBT from my local IAPT service could have helped to build the foundations for future treatment and provided the opportunity to address my coinciding depression and anxiety.

4. Going forward:

Overall, this essay has proposed four key recommendations to help address the treatment gap for patients with eating disorders and aid their recovery. Further qualitative research should take place, in which retrospective insights are gathered from those whom have recovered from an ED, helping to improve accessible facilitation of effective ED care. Additionally, allocated funding towards EDs should be further assessed to ensure sufficiency so that service provision can be enhanced. Working groups consistent of psychiatrists, psychologists, parents and recovered patients can help promote a more collaborative approach in addressing the treatment gap for ED patients. Only by working together can we tackle EDs and decrease its mortality rate so that patients can recover and reclaim their lives for a more hopeful future.

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Appendix:

SCOFF Questionnaire

S – Do you make yourself **S**ick because you feel uncomfortably full?

C – Do you worry that you lost **C**ontrol over how much you eat?

O – Have you recently lost more than **O**ne stone (6.35 kg) in a three-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?

An answer of 'yes' to two or more questions warrants further questioning and more comprehensive assessment.

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InsideOut Institute-Screener (IOI-S)

1. How is your relationship with food?
(For example: is food and eating worry free, or is it full of worry and stress?)

1. Worry and Stress Free
2. A bit problematic
3. Moderately problematic
4. Very problematic
5. Full of worry and stress

2. Does your weight, body or shape make you feel bad about yourself?
(For example: the number on the scale, the shape of your body or a part of your body.)

1. Never
2. A little bit
3. Sometimes
4. Quite a bit
5. All the time

3. Do you feel like food, weight or your body shape dominates your life?
(For example: experiencing constant thoughts about food, weight or your body.)

1. Never
2. A little bit
3. Sometimes
4. Quite a bit
5. All the time

4. Do you feel anxious or distressed when you are not in control of your food?
(For example: when others cook or prepare food for you or when eating out.)

1. Never
2. A little bit
3. Sometimes
4. Quite a bit
5. All the time

5. Do you ever feel like you will not be able to stop eating or have lost control around food?
(For example: feeling that you have no control around food, that you binge eat or fear that you will binge eat.)

1. Never
2. A little bit
3. Sometimes
4. Quite a bit
5. All the time

6. When you think you have eaten too much, do you do anything to make up for it?
(For example: skipping the next meal, going light on the next meal, working it off with exercise, purging via vomiting or taking laxatives, diuretics or diet pills.)

1. Never
2. A little bit
3. Sometimes
4. Quite a bit
5. All the time

Scoring

The IOI-S is rated on a 5-point Likert scale, where 1 point is given for 'Never' and 5 points for 'All the time', except for question 1, where 1 point is given for 'Worry and stress free' and 5 points for 'Full of worry and stress'. Items do not refer to a particular timeframe, e.g., the previous 28 days—rather they are about how an individual *typically* feels and are designed to "start a conversation".
Add answers up for a sum total score between 6 and 30 points.

IOI-S Total Score thresholds

≤12 Low risk: Individual is at low risk of developing an eating disorder

13 – 15 Moderate risk: Individual is at moderate risk of developing an eating disorder (MONITOR)

16 – 18 High risk: Individual is at high risk of developing an eating disorder and should be regularly monitored as well as engaged in appropriate psychoeducation with a healthcare professional or GP (ENGAGE)

≥19 Showing signs: Individual likely has a sub-threshold or threshold eating disorder and should be referred to specialist services for further assessment (REFER). Scores closer to 30 can be understood as indicating greater symptom severity.