



King's Research Portal

DOI:

[10.1002/eat.22519](https://doi.org/10.1002/eat.22519)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Schmidt, U. H., Brown, A. L., McClelland, J. K., Glennon, D., & Mounford, V. A. (2016). An Idea Worth Researching: Will a Comprehensive, Person-Centered, Team-Based Early Intervention Approach to First Episode Illness Improve Outcomes in Eating Disorders? *International Journal of Eating Disorders*.
<https://doi.org/10.1002/eat.22519>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

An Idea Worth Researching:

Will a comprehensive, person-centred, team-based early intervention approach to first episode illness improve outcomes in eating disorders?

Ulrike Schmidt, MD PhD FRCPsych^{1,2}, Amy Brown, DClinPsy², Jessica McClelland, PhD¹, Danielle Glennon², Victoria A. Mountford, DClinPsy^{1,2}.

Affiliations

¹: King's College London, Institute of Psychiatry, Psychology and Neuroscience, Section of Eating Disorders, London, UK

²: Eating Disorders Unit, South London and Maudsley NHS Foundation Trust, London, UK

Address for correspondence

Ulrike Schmidt, Professor of Eating Disorders, PO 59, Section of Eating Disorders, Institute of Psychiatry, Psychology and Neuroscience, De Crespigny Park London SE5 8AF. Email: ulrike.schmidt@kcl.ac.uk

Word count: 1545

Running Head:

EARLY INTERVENTION FOR FIRST EPISODE EATING DISORDERS

In serious physical disorders, and increasingly in psychiatry, illness stages (from high risk, through to prodromal, early and late stage illness) are being distinguished, with different prognostic and treatment implications. Early intervention may help to prevent onset or alter the course of illness, e.g. through delaying or averting unfavourable outcomes, or through avoiding disruption in people's development and associated secondary disabilities. Early intervention critically depends on early detection of a disorder or its precursors and the commencement of effective treatment, tailored to the patient's stage of illness.

In psychiatry, these ideas have most strongly penetrated the psychosis field, where comprehensive early intervention programs for first episode cases have been introduced. One key research focus has been the impact of the duration of untreated psychosis (DUP) (i.e. time from onset to first treatment) on different outcomes. Systematic reviews have shown that a shorter DUP is associated with better outcomes in relation to symptoms, functional outcomes and relapse rates. These are robust small to medium sized effects. Recent studies confirm the enduring impact of DUP even on very long-term term outcomes (> 10 years). The mechanisms by which DUP asserts its effect on outcome is unclear, but it has been suggested that DUP might be contributing to a neurodegenerative process. It is so far not clear what is the critical window of DUP, beyond which poor outcomes invariably occur. Some outcomes appear to be more sensitive to delayed treatment than others. Questions also exist regarding the measurement of DUP, both in relation to how best to define onset and end of DUP.

Despite these open questions, DUP is widely seen as a modifiable, independent risk factor and this has led to vigorous attempts to reduce DUP through primary care education campaigns, development of early intervention services for first episode and prodromal cases

and examination of delays in care-pathways. Several trials have demonstrated that specialised early intervention services that reduce DUP have better outcomes and greater treatment satisfaction than standard psychosis care. Evidence regarding early detection services is more mixed.

Astonishingly, in eating disorders (ED) no parallel developments have occurred. Whilst there is a sizeable literature on prevention of ED, this has not been married with any attempts to develop or research early intervention services for patients with first episode or early stage illness. This article will address the following questions: Why consider early intervention in ED? How can 'duration of untreated illness' be defined and measured in relation to ED? What are the barriers to early intervention in ED? What might a comprehensive stage-specific first episode ED service look like?

Why consider early intervention in ED?

Arguments for the utility of illness stages and an early intervention approach in ED were first examined 10 years ago¹, giving this idea cautious support. A recent systematic review concluded that for anorexia nervosa (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. For bulimia nervosa (BN) or binge eating disorder (BED) the evidence is more limited². The review suggested that based on available evidence early stage illness should be defined as an illness duration of ≤ 3 years.

Defining duration of untreated eating disorders (DUED)

Any definition of duration of untreated eating disorders (DUED)¹, needs to consider what constitutes 'onset' and what constitutes 'treatment'. Standardised and reliable assessment of

symptom duration and severity is possible via longitudinal interviews which use anchor points from patients' biography to enhance recall. We have previously argued that treatment is the point at which the patient begins an evidence-based intervention for their ED¹. Others have defined a further variable of interest, i.e. the duration of illness until first contact with health care services, to explore the processes preceding treatment initiation³.

Benchmarking DUED

Although many studies have examined illness duration in ED, very few provide information specifically on DUED, i.e. time to first treatment. Only two studies have assessed the time interval between onset and first treatment in AN, none have focused on DUED in other ED. A systematic review of six studies found the average DUED to be 21.6 months in AN⁴, in a further study it was 25 months⁵.

Barriers to early intervention in ED

There are several major barriers to shortening DUED and providing early intervention. These include: (a) Patient and family-related barriers: Young people with ED may be ambivalent about treatment and unaware of their disorder's dangers and consequences. They are often also sceptical of conventional health care services. Families are usually concerned and want to help but may inadvertently maintain the problem through lack of skills. (b) Primary-care based barriers: In many health care systems, primary care staff (e.g. family doctors) play a key role in early detection and management of ED, and sign-posting to specialist services. Lack of awareness, knowledge or skills on the part of primary health care personnel, may lead to under-diagnosis or delays. (c) Service-related barriers: These include (1) poor access to services, (2) waiting times within services and (3) poor transitions between services.

These are considered below.

Access to services is determined by the availability and capacity of specialist services, but also by other factors specific to different health care systems (e.g. insurance cover, referral procedures, gate-keeping arrangements). In the UK, a survey of young people with ED⁶ found that one third had to wait more than 18 weeks for treatment and another third had to wait up to 6 months to access care. Most young people surveyed said that their ED got significantly worse whilst they were waiting for treatment.

Many specialist ED services manage patient throughput with waiting lists. Yet, considerable evidence suggests that waiting for treatment is harmful. For example, a systematic review of cognitive behaviour therapy (CBT) in depression found that being on a waiting list produced worse outcomes than receiving no treatment⁷. Likewise, in young people with BN, we found that 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 wait⁸. In a recent AN trial we found that 80% of patients waiting for treatment either deteriorated or stayed unchanged and that those worst affected were younger and less motivated patients (Schmidt, personal communication). A transdiagnostic study of CBT in ED found that being on a waiting list led to greater treatment drop-out⁹. Thus, waiting for treatment has been described as a nocebo condition⁷.

Finally, in relation to transitions between services, some young people may have to transition from Child and Adolescent services to Adult services at a critical point in their illness and others transition between home and University services. This causes delays, disruption to care and deterioration.

What should a comprehensive person-centred team-based early intervention approach to first episode ED look like and how would it differ from standard care?

Ideally, such a service should span adolescence and emerging adulthood^{10,11} and provide services for young people from ~ age 15 to 25. This is a time of major developmental challenges/transitions occurring against a background of significant structural and functional change in the brain, and is the peak period of onset for ED. Details of such a service are listed in Figure 1, which highlights the importance of close links with primary care to facilitate early detection and early referral, the importance of active outreach and rapid engagement without waiting lists, a holistic assessment and individualised, developmentally appropriate treatment plan and the availability of evidence-based interventions which focus both on the family and the individual. Such a service is based on an illness model that emphasises malleability of biological and brain changes during early illness stages¹² and its central aim is to reduce DUED and facilitate early full recovery. The approach is pro-active and empowering.

This contrasts with conventional ED services where patient prioritization occurs by diagnosis or severity. Such services typically are either for children and adolescents or for adults, with predominantly either family-based or individual standard packages of care.

The way forward

Compared to psychosis, very little research has focused on development and delivery of ED service models and care pathways, and on early intervention services and associated concepts such as DUED. For example, a UK national survey¹³ found that many services are based on traditional out-patient/in-patient models, with all the service barriers this entails. The report recommends the development of innovative person-centred service models, tailored to

patients' needs. We have developed such a model for young adults with any ED, called "First Episode and Rapid Early Intervention Service for Eating Disorders" (FREED). This service focuses on emerging adults (aged 18 to 25) with any ED diagnosis and with early stage illness (≤ 3 years). The service model is that presented in figure 1. A service evaluation is currently in progress and we are planning to extend FREED to younger patients.

Additionally, a German consortium³ is exploring early intervention for AN only. These initiatives provide a spring-board for examining how feasible and acceptable such services are and whether through the introduction of such services DUED can be reduced and the course of illness altered. If proven effective such services could be extended to include population-based initiatives and interventions to identify and treat ultra-high risk and prodromal cases in primary care and schools.

Acknowledgement

Amy Brown and Jessica McClelland received salary support by the Health Foundation. Ulrike Schmidt receives salary support from the NIHR Biomedical Research Centre for Mental Health, South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology and Neuroscience, King's College London. The views expressed in this publication are those of the authors and not necessarily those of the National Health Service, the NIHR or the UK Department of Health.

References

1. Currin L, Schmidt U. A critical analysis of the utility of an early intervention approach in the eating disorders. *J Mental Health*. 2005; 14:, 611-624.
2. Treasure J, Stein D, Maguire S. Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence. *Early Interv Psychiatry*. 2015; 9: 173-84.
3. Gumz A, Uhlenbusch N, Weigel A, Wegscheider K, Romer G, Löwe B. Decreasing the duration of untreated illness for individuals with anorexia nervosa: study protocol of the evaluation of a systemic public health intervention at community level. *BMC Psychiatry*. 2014; 14: 300.
4. Schoemaker C. Does early intervention improve the prognosis in anorexia nervosa? A systematic review of the treatment-outcome literature. *Int J Eat Disord*. 1997; 21: 1-15.
5. Neubauer K, et al. Paths to first treatment and duration of untreated illness in anorexia nervosa: are there differences according to age of onset? *Eur Eat Disord Rev*. 2014; 22: 292-298.
6. www.b-eat.co.uk/assets/000/000/170/Waiting_times_survey_resultsv2_original.pdf (Accessed on 6.11.2015).
7. Furukawa TA, Noma H, Caldwell DM, Honyashiki M, Shinohara K, Imai H, Chen P, Hunot V, Churchill R. Waiting list may be a nocebo condition in psychotherapy trials: a contribution from network meta-analysis. *Acta Psychiatr Scand*. 2014; 130: 181-92.
8. Sánchez-Ortiz VC, Munro C, Stahl D, House J, Startup H, Treasure J, Williams C, Schmidt U. A randomized controlled trial of internet-based cognitive-behavioural therapy for bulimia nervosa or related disorders in a student population. *Psychol Med*. 2011; 41: 407-17.
9. Carter O, Pannekoek L, Fursland A, Allen KL, Lampard AM, Byrne SM. Increased

wait-list time predicts dropout from outpatient enhanced cognitive behaviour therapy (CBT-E) for eating disorders. *Behav Res Ther.* 2012 Aug;50(7-8):487-92.

10. McGorry PD, Goldstone SD, Parker AG, Rickwood DJ, Hickie IB. Cultures for mental health care of young people: an Australian blueprint for reform. *Lancet Psychiatry.* 2014 Dec;1(7):559-68.

11. Arnett JJ, Žukauskienė R, Sugimura K. The new life stage of emerging adulthood at ages 18-29 years: implications for mental health. *Lancet Psychiatry.* 2014 Dec;1(7):569-76.

12. Farrell NR, Lee AA, Deacon BJ. Biological or psychological? Effects of eating disorder psychoeducation on self-blame and recovery expectations among symptomatic individuals. *Behav Res Ther.* 2015;74: 32-7.

13. Royal College of Psychiatrists Council Report 170. Eating disorders in the UK: service distribution, service development and training.2012.

<http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf> (Accessed on 6.11.2015)

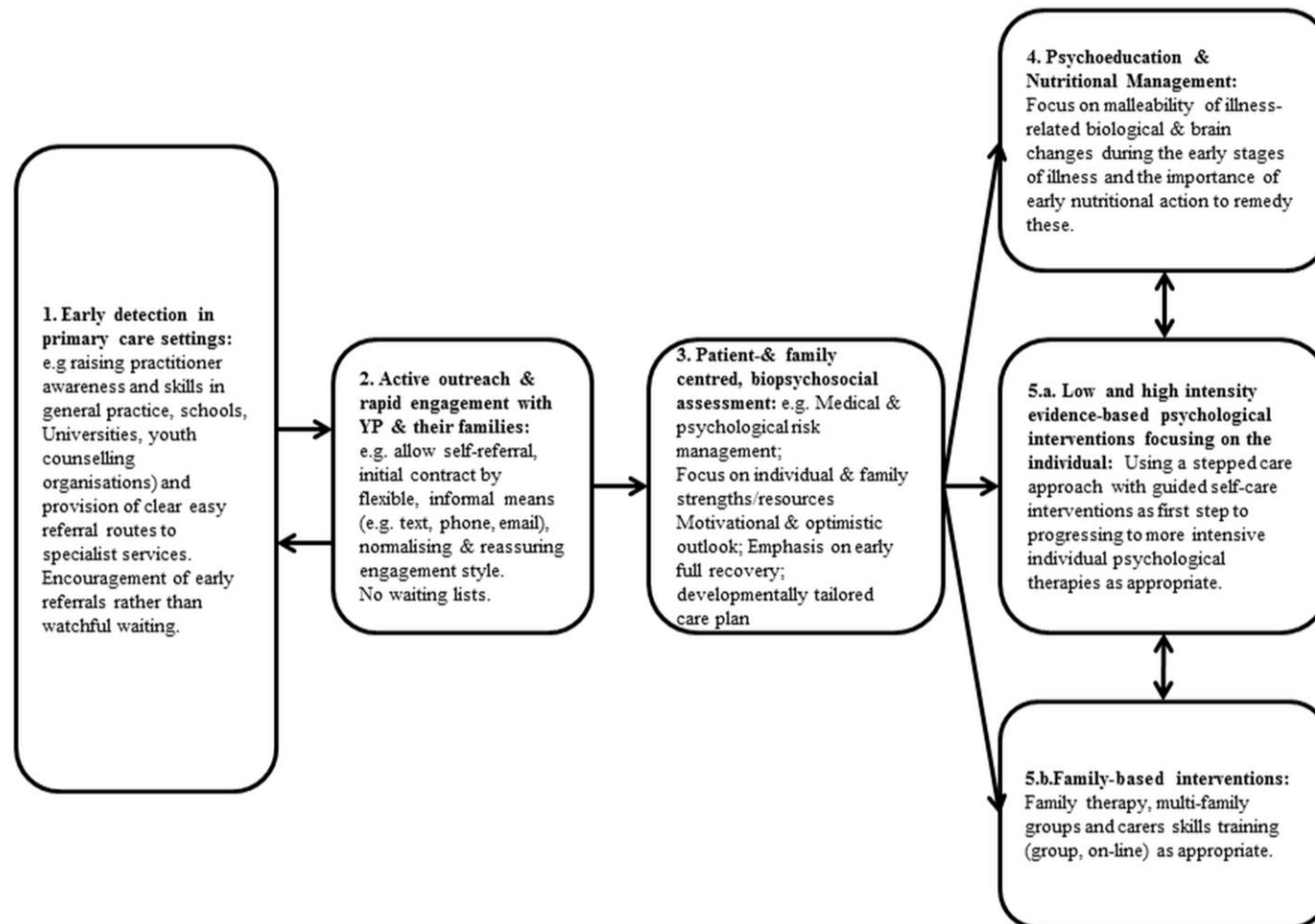


Figure 1: Key components of and patient journey within a model specialist early intervention service for young people (YP) with an ED. Early intervention depends on early detection and early referral and thus close links between primary care settings (1) and the specialist early intervention service are needed (with ED specialists raising awareness and providing guidance and skills training for primary care practitioners) and a flexible friendly pro-active referral and rapid engagement process without waiting lists (2). A holistic and non-stigmatising assessment (3) follows from which flow a range of evidence-based interventions (4,5a,5b), the exact nature, combination and potential sequence of which is agreed on collaboratively in a developmentally tailored care plan.