


## RESEARCH ARTICLE

# Optimising care pathways for adult anorexia nervosa. What is the evidence to guide the provision of high-quality, cost-effective services?

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## Funding information

National Institute for Health Research; European Regional Development Fund

## Abstract

The aim of this paper is to consider how changes in service planning and delivery might improve the care pathways for adult anorexia nervosa. Although anorexia nervosa has a long history in Europe, its framing as a mental disorder is quite recent. The changing forms and increasing epidemiology of eating disorders has led to the expansion of specialised services. Although some services provide care over the entire clinical course, more often services are divided into those that care for children and adolescents or adults. The transition needs to be carefully managed as currently these services may have a different ethos and expectations. Services for adults have a broad range of diversity (diagnostic subtype, medical severity, comorbidity, stage of illness and psychosocial functioning) all of which impacts on prognosis. A tailored, approach to treatment planning could optimise the pathway. Facilitating early help seeking and rapid diagnosis in primary care and reducing specialised services waiting lists for assessment and treatment could be a form of secondary prevention. The use of precision models and /or continuous outcome monitoring might reduce the third of patients who require more intensive care by applying augmentation strategies. Finally, gains from intensive care might be sustained by relapse prevention interventions and community support to bridge

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the transition home. Together these measures might reduce the proportion of patients (currently a third) with ill health for over 20 years. For this group rehabilitation strategies may improve functioning until new treatment emerge.

#### KEYWORDS

anorexia nervosa, care pathways, cost effectiveness, eating disorders, service planning

## 1 | INTRODUCTION

In this paper, we consider care pathways for adult anorexia nervosa from the European perspective in order to provide the context for a European project on improving the value of treatment. We use information from UK, Spain and Germany as case studies.

## 2 | THE HISTORICAL DEVELOPMENT OF SERVICES

The historical precedent for the treatment of adult anorexia nervosa was admission for refeeding to an internal medical setting, in England (Gull, 1874), as also Spain and Germany (Partagaz, 1903; Salto-Lavall, 1883). This form of care continued until the 1970s. During the latter part of the 20th century, an increase in the prevalence and incidence of ED in Europe has been observed (Galmiche, Déchelotte, Lambert, & Tavolacci, 2019; Specialised inpatient units and community teams were developed within psychiatric or psychosomatic (in Germany) settings. In the UK, approximately 50 % of the inpatient units were developed by private health care providers (although these were commissioned and paid for by the NHS as were the outpatient services). Most of the Spanish units were publically funded by a universal care system. In Germany, all patients with an eating disorder are covered by private or statutory health insurance adult patients and in and outpatients are treated in Departments for Psychosomatic Medicine and Psychotherapy (Zipfel, Herzog, Kruse, & Henningsen, 2016). Specialised therapy centres for patients with eating disorders that can treat the entire age range and all diagnoses of eating disorders are still the exception in Germany, Spain and the UK. This gradual evolution has led to a wide diversity in the type of service available. In Germany, for example, special counselling centres are available for mild/early cases and in the UK, the Improving Access to Psychological Therapies programme service in some areas is used for less severe cases. Across Europe, alternative forms of specialised intensive care have been introduced (home treatments, day and

### Highlights

When considering the care pathway for adults with anorexia nervosa there are several pinch points which if remediated may improve patient flow and outcomes.

- First, improving awareness and recognition in primary care to facilitate early engagement in treatment.
- Second, reduce the time to access specialist treatment.
- Third, increasing the effectiveness of routine treatment (outpatient) possibly through a triage system with a precision planning and continuous monitoring with the provision of augmentation strategies.
- Fourth, the impact of inpatient care can be optimised by interventions that bridge the transition home and increase community support.
- Finally, a rehabilitation approach and new treatment strategies for those who do not respond to standard treatment.

residential care, specialised group therapies for ED subtypes/gender, etc.; Agüera et al., 2015, 2017; Anastasiadou et al., 2020; Serrano-Troncoso et al., 2020; Herpertz-Dahlmann, van Elburg, Castro-Fornieles, & Schmidt, 2015).

In the UK, many of the first specialist units were developed in academic settings. In Germany, a centre at the University Hospital of Tübingen (KOMET) in which several university disciplines (including Psychiatry, Endocrinology and Gynaecology, and others) co develop and evaluate innovative treatments under the direction of the Department of Psychosomatic Medicine and Child and Adolescent Psychiatry. In Spain, multidisciplinary teams and research networks were developed in order to improve translational research around ED and obesity (CIBERobn; <https://www.ciberobn.es>).

### 3 | STAKEHOLDER APPRAISAL OF EATING DISORDER SERVICES

Consumer concerns about services within Spain and the UK has led to a move to review and revise service structures and workforce training (Ombudsman, 2017, p. 2; Yárnoz-Esquiroz, Lacasa, Riestra, C., & Frühbeck, 2019). Surveys of patients, carers and other stakeholders have established the key ingredients of a high-quality ED service, namely well-coordinated care delivered by a knowledgeable and specialist treatment team centred around the patient and their social support (Escobar-Koch, et al., 2010; van Furth, van der Meer, & Cowan, 2016; Hart & Wade, 2019; Nishizono-Maher, Escobar-Koch, & Ringwood, 2010). A recent systematic review proposed three main themes (better use of primary care to engage patients; the involvement of a range of services from primary care through to acute medical services with mutual collaboration between professionals, patients and families (Johns, Taylor, John, & Tan, 2019). Also given the evolving knowledge base, it is important that services should be able to appraise, integrate and implement new evidence into their clinical practice. Central EU policies with funding and training to reach these standards have been developed or being developed.

### 4 | POLICY AND SERVICES

As a case example, some of the UK policy documents that underpin changes in services and workforce training are shown in Table 1. These changes in the UK and Spain include better integration with primary and acute care services and less use of out of area inpatient bed.

### 5 | THE CARE PATHWAYS

Primary care in the UK, Spain and Germany, general practitioners are the primary gatekeeper to access specialist services. However, a characteristic feature of anorexia nervosa is that individuals do not consider themselves to have an illness. Therefore, as young adults they may not seek, and/or avoid and delay treatment for some time. The process of help seeking and referral to services can take between 2 and 5 years in adult services (Austin, et al., 2020). However, it is worth noting that for 2 years before the diagnosis was established in Welsh primary care settings, there had been an increase in visits associated with prescriptions for psychological or gastrointestinal complaints suggesting diagnostic delay is also of relevance (Demmler, Brophy, Marchant, John, &

Tan, 2020). Moreover the incidence of anorexia nervosa detected in primary care in the UK and Spain has remained constant over the last 3 decades (Aguilar Hurtado et al., 2004; Micali, Hagberg, Petersen, & Treasure, 2013) whereas other sources of ascertainment suggest that there may have been an increase in numbers (Galmiche et al., 2019). In Germany, the average increase in diagnoses for one large insurer between 2011 and 2016 was 7.5% (<https://www.aerzteblatt.de/nachrichten/94751/Esststoerungen-auf-dem-Vormarsch>). Late detection and treatment delays are associated with poorer prognosis (Andres-Perpiña et al., 2020; Fernández-Aranda et al., 2020) and increased burden (Yárnoz-Esquiroz et al., 2019) and therefore improving awareness and early diagnosis and access to treatment may reduce the increase in severity illness which has been manifest in the UK in terms of increased bed use (Holland, Hall, Yeates, & Goldacre, 2016).

However in Germany, a public health intervention aimed at shortening the delay (36.5 months ( $SD = 68.2$ ) in accessing treatment failed to find any impact (Gumz, Weigel, Wegscheider, Romer, & Löwe, 2018). On the other hand, the preliminary findings from a digital intervention (Pro youth) designed to reduce delays in help seeking found that approximately 17 % were motivated to seek help following the intervention (Moessner, Minarik, Özer, & Bauer, 2016). Stigma and low mental health literacy were noted as barriers to help seeking.

In the UK depending on how services are, commissioned GPs may refer onto a generic psychiatric or psychological therapy service or directly to a specialist service (Currin, Schmidt, Yeomans, & Waller, 2006). The pattern may in part be driven by the local availability of specialist services. Augmentation strategies given pre (Muir, et al., 2017) or postspecialist assessment (Cardi et al., 2020) have so far only shown limited benefit although a service which fast tracked those with a short duration of illness improved outcomes (Flynn et al 2021).

### 6 | SPECIALIST ASSESSMENT

There is a wide diversity between presentations of anorexia nervosa to adult services. These include duration of illness, severity, level of risk, diagnostic subtype (restricting vs. binge purge), medical (e.g., diabetes) and psychological comorbidity (such as ASD, ADHD, obsessive compulsive disorder, depression, borderline personality, substance use disorders) and psychosocial functioning. The biopsychosocial aspects that may maintain the illness include isolation, stress, and aspects of neuroprogression (Treasure Willmott 2020). Ideally these should be considered in the assessment so that the

**Table recent policy documents for eating disorder service in UK**

2017	Ignoring the alarms: How NHS eating disorder services are failing patients (2017) Parliamentary and Health Service ombudsman.
2018	Welsh Government. Eating disorder service review
2019	Adult eating disorders: community, inpatient and intensive day patient care. Guidance for commissioners and providers Publishing approval number: 000957. Version number: 1 First published: August 2019. Prepared by NHS England with NICE and the National Collaborating centre for mental health
2020	QED quality standards for adult community eating disorder services. Second Edition. Publication number: CCQI344. Royal College of Psychiatrists. Editor: Hannah Lucas
2020	Health Education England: Cognitive behavioural therapy for severe mental health problems eating disorder pathway and adult eating disorders wholeTeam training Specification Published: 2020 Prepared by: Health Education England
2020	Community mental health planning. Transformation NHS England health improvement
2020	Community eating disorder programme (Pan London & others) Mental health Transformation Board. NHS England

**TABLE 1** Policy documents relating to eating disorder services in the UK

treatment can be personalised with a precision approach (Kan, Cardi, Stahl, & Treasure, 2019; Kan & Treasure, 2019).

The baseline profile of cases enrolled into a recent multicentre study (in the UK from adult eating disorder community services found that 13% had severe weight loss (BMI < 15), 67% with moderate weight loss (BMI 15–17) and 20% with mild weight loss (BMI 17–18.5; Cardi et al., 2020). In terms of illness duration, 30% had less than 3 years of illness, 50% had an established illness (3–7 years) and 20% had an illness that had persisted for over 7 years (Cardi et al., 2020).

The baseline data from one of the biggest adults ED Units in Spain is similar. We found that 15.7% had severe weight loss (BMI < 15), 38.9% with moderate weight loss (BMI 15–17) and 42.6% with mild weight loss (BMI 17–18.5). In Spain, following the COVID pandemic, more severe weight loss and higher symptomatology has been observed in several Spanish services (Baenas et al., 2020; Fernández-Aranda et al., 2020; Graell et al., 2020).

## 7 | PROGNOSTIC OR STAGING MARKERS OF ANOREXIA NERVOSA

The form and severity of the illness may lead to a plan to deliver treatment in the community or in a more intensive specialist setting (day or inpatient care).

Delay in access to specialised care, longer duration of the ED, a lower BMI, higher comorbidity, associated personality traits and lower motivation at discharge have been found to be associated with poorer prognosis in

several Spanish studies (Andres-Perpiña, 2020; Beato-Fernandez et al., 2020; Castro-Fornieles et al., 2007; Fernández-Aranda et al., 2020; Riesco et al., 2018). These align with the findings from an earlier systematic review (Vall & Wade, 2016).

There has been interest in the possibility of using a precision psychiatry strategy for staging the illness. Proxy markers such as duration and severity have been considered and the term severe and enduring stage of illness has been used. However, this simplified model is controversial, and the parameters are uncertain (Broomfield, Stedal, Touyz, & Rhodes, 2017; Fernández-Aranda et al., 2020; Treasure & Schmidt, 2013; Wonderlich, Bulik, Schmidt, Steiger, & Hoek, 2020).

BMI has been used by the DSM 5 as a marker of severity (APA, 2013). It is a surrogate marker of medical risk approximating to the need to access more intensive forms of treatment but there is uncertainty about its role as a prognostic or stage marker. Duration also has not always been found to be associated with a negative prognosis (Fernández-Aranda et al., 2020; Radunz, Keegan, Osenk, & Wade, 2020). However, in SHARED (multicentre OPD trial in UK) depression in combination with duration was associated with a worse outcome whereas duration alone did not (Ambwani et al., 2020). Thus, more complex models for staging and precision psychiatry using data from many variables, larger studies and machine learning may be needed.

Weight gain during the early phase of treatment is also a prognostic marker (Nazar et al., 2017; Vall & Wade, 2016) especially if this is combined with a BMI above 17 at baseline. This suggests that early monitoring

of the progression of therapy and augmenting care for those with a suboptimal response may be of benefit rather than basing treatment decisions on parameters measured at baseline.

## 8 | MATCHING PATIENTS TO SERVICES WITHIN THE CARE PATHWAY

As seen from the discussion above matching patients to the form of service within the care pathways is an imprecise art. There are many factors that impact on how service users respond to treatment and flow through the system. A recent development in the UK has been the introduction of early intervention services for people with a duration of anorexia nervosa of less than 3 years (FREED) to reduce delays post-help seeking. These have been found to improve retention and outcomes. For example, weight recovery at 12 months in the FREED group was 56%–59% in comparison to the treatment as usual group (19%–30%) and the need for intensive (in/day patient) treatment 6.6%–8.9% compared with treatment as usual 12.4%–14.1% (Fukutomi, Austin, & McClelland, 2020; McClelland, Kekic, Bozhilova, Nestler, & Dew, 2016). However, there is less certainty about the group with a longer illness, which may have not responded to earlier treatment.

## 9 | SPECIALISED OUTPATIENT TREATMENTS

A variety of specialist outpatient treatments have been developed for the management of adult outpatients with anorexia nervosa, but most are time limited interventions (20–60 sessions usually spanning less than a year). Most of these have some degree of multidisciplinary integration with sessions for families/carers or for nutritional advice.

Systematic reviews synthesising the evidence have failed to find differences between models of treatment in terms of clinical outcomes, which are on the whole disappointing with high dropout rates (Riesco et al., 2018; Van den Berg, Houtzager, & de Vos, 2019). Only a third of cases were classified as recovered at 2 years (Murray, Quintana, Loeb, Griffiths, & Le Grange, 2019; Zeeck et al., 2018). The proportion of outpatients switched to inpatient “rescue” treatment ranges from 8% to 41.0% with variation between studies and between treatments. The highest levels (41%) of rescue treatment reported were in the optimised treatment as usual arm from a high quality randomised control trial conducted in Germany

(Zipfel, Wild, & Groß, 2014). The lower need for rescue treatment in both the cognitive behavioural treatment arm and the focal psychodynamic therapy arm contributed to the higher cost-effectiveness of the latter form of treatment (Egger et al., 2016).

A similar pattern of lower admissions (by over 50%) was found with specialist interventions (MANTRA and SSCM) in the MOSAIC RCT study ( $n = 142$ ; MANTRA and SSCM; Schmidt, Magill, & Renwick, 2015) when compared with treatment as usual from UK clinics in the SHARED ( $n = 187$ ) multicentre study (Cardi et al., 2020; Figure 1). The level of rescue treatment is thus of relevance for service planning however this is not often explicitly reported in trials and the clinical decision-making underpinning it may vary.

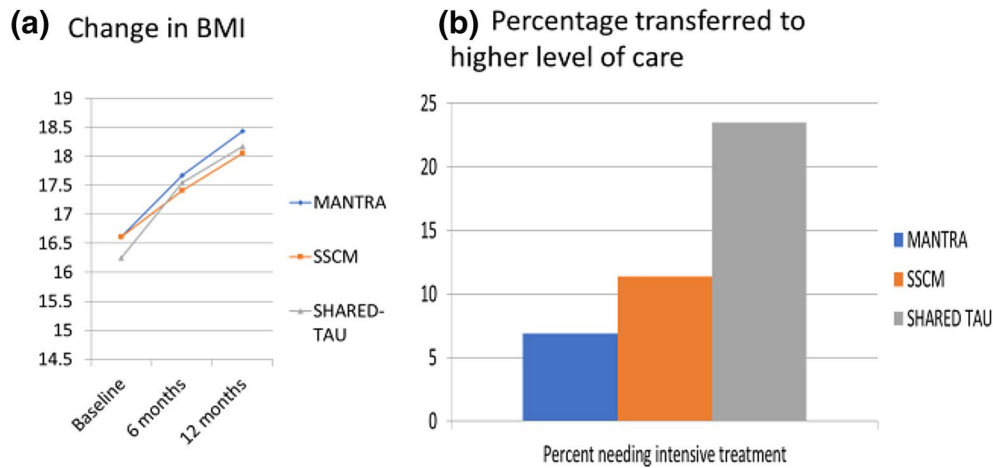
The presence of bingeing/purging behaviours and longer duration of illness were associated with higher outpatient costs in the German ANTOP study, as was the presence of additional mental health problems (Stuhldreher et al., 2015).

## 10 | THE MANAGEMENT OF HIGH-RISK ANOREXIA NERVOSA: INPATIENT AND DAY PATIENT CARE

More intensive services (day care and inpatient settings) are used to manage risk (medical and psychological). In the UK, the admission BMI for inpatient care in a multicentre study was approximately 15 kg/m<sup>2</sup> (Hibbs et al., 2015). Nutritional restoration is the main target to manage risk. The average weekly inpatient weight gain for adults was 0.537 kg compared to weight gain of 0.1 week in outpatients; Zeeck, et al., 2018). However, there is very little empirical evidence to guide the parameters of inpatient care (see systematic review of length of stay Cribben kan treasure european eating review 2020 this is in this addition I cannot find it though which shows cultural differences. For example, admissions in Europe were longer than for other countries. LOS, in turn, is impacted by weight on admission (lower in Europe). A German study found that a lower BMI at admission, a purging AN-subtype as well as higher EDI-2 asceticism were associated with longer admissions (Kästner, et al., 2018).

Transition into and out of inpatient, care can be challenging. Relapse after discharge lies between 20% and 50% (Hibbs, et al., 2015). A variety of strategies to reduce relapse have been tested in feasibility studies (transition systematic review).

Guided self-help approaches linking with community support using a variety of digital approaches hold promise. Several large, randomised trials which provide



**FIGURE 1** Outcomes (a) change in BMI (b) percentage transferred into a higher level of care “rescue treatment” from two UK multicentre randomised trials. MANTRA Maudsley model of anorexia nervosa treatment for adults. SSCM (specialised supportive clinical management; Schmidt et al., 2015) and SHARED self-help and recovery guide for eating disorders (Cardi et al., 2020) in which TAU treatment as usual (informed by the NICE guidelines) was delivered

augmented psychological support for patients and families (TRIANGLE; Cardi et al., 2017) and SUSTSAIN are in progress.

## 11 | DAY PATIENT AND HOME TREATMENT

Less intensive treatment such as day care is more variable in terms of number and length of each day and hence the number of supported meals and the admission BMI is usually higher than that of patients for inpatient stay.

In a Spanish study, an average baseline BMI was 16.7 in ANR and of 17.2 in ANBP (Agüera, et al., 2015) Full-partial or remission of symptoms was found in 55.7% and 70.9%, in AN-R and ANBP in the short term. The likelihood of partial or full remission was higher for patients who were older and had high baseline BMI.

A variety of alternative forms of specialised intensive care have been introduced (home treatments, day and residential care, specialised group therapies for ED subtypes/gender, etc.; Agüera et al., 2017; Anastasiadou et al., 2020; Peckmezian & Paxton, 2020; Reilly, Rockwell, & Ramirez, 2020; Serrano-Troncoso et al., 2020).

## 12 | NEW TREATMENTS

Services for eating disorders were early adopters of guided self-management approaches and were poised to innovate and reset services in the post COVID world. The specialised skills that can support people with anorexia nervosa have been manualised and digitised and can be

delivered with online support of various forms (group/individual/family). The concerns that this form of management might be problematic given the risk and ambivalence about treatment (Wilson & Zandberg, 2012) does not seem to be a barrier. Indeed dropout is lower in this form of management (Albano, Hodsoll, Kan, Lo Coco, & Cardi, 2019).

Of course, there needs to be a secure system to measure medical risk possibly recruiting help from the family or primary care. Thus digital systems are of promise in a variety of forms to augment treatment such as virtual reality to target food or body image fears and training approaches to improve food and social approach behaviours. Also given the long course of the illness, a recovery approach with peer support may enhance hope (Ranzenhofer et al., 2020). Social support provided from family, friends and people with lived experience in connection with a consultative and tailored service approach might allow a more optimised, personalised approach to care (Treasure, Willmott, et al., 2020).

Work is in progress developing new forms of treatment for the group of patients who are resistant to standard treatment. Thus, neuromodulation using either deep brain stimulation (Lipsman et al., 2017; Villalba Martinez et al., 2020) or repetitive transcranial magnetic stimulation may have a role (Dalton et al., 2020).

## 13 | CONCLUSION

High-quality services for adult eating disorders involve an admixture of community-focused care supported with a step up to higher intensity day and/or inpatient provision

as needed. Specialist interventions should be delivered in a timely manner. Reducing treatment delays for those in the early stage of illness (defined as either duration or severity of weight loss) can improve outcome and reduce the need for more intense levels of care.

Nevertheless, the outcomes of treatment for adult anorexia nervosa are disappointing. Therefore, various strategies to augment care are being tested. Specialised structured treatments produce better outcomes than treatment at usual in terms of the need for rescue beds. Intensive treatments (in and day patient care) remediate symptoms but relapse post discharge is common. Psychological interventions to bridge the transfer to home hold promise as a means of sustaining the benefit from inpatient care. The expertise from a multidisciplinary team is needed for the functional remediation needed in later stages of illness.

The pathways into and through these services need to be carefully delineated and yet be personalised and flexible. There are several pinch points that may warrant further attention. These include reducing delays in help seeking and accessing specialised care. A precision approach matching care to the profile of the patient with continuous monitoring of the response to treatment and augmenting care as needed is warranted. For those who require intensive care the transition home needs to be carefully managed. Community support is of benefit to sustain the gains made during treatment and the role of peers and wider support systems is under review.

## ACKNOWLEDGEMENTS

This study was supported by the European Brain Council (EBC) and the European Psychiatric Association (EPA). Janet Treasure receives financial support from the National Institute for Health Research (NIHR) Specialist Biomedical Research Centre for Mental Health award to the South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, King's College London. F. Fernandez-Aranda would like to thank CERCA Programme/Generalitat de Catalunya for institutional support and his research was partially funded by FIS-Instituto de Salud Carlos III (ISCIII; FIS INT19/00046 and PI17/01167; PI20/132) and co-funded by FEDER funds /European Regional Development Fund (ERDF), a way to build Europe. CIBRobn is an initiative of ISCIII. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

## CONFLICT OF INTERESTS

Janet Treasure gets royalties from self-treatment books. The other authors declare that there are no conflict of interests.

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**How to cite this article:** Treasure J, Oyeleye O, Bonin EM, Zipfel S, Fernandez-Aranda F. Optimising care pathways for adult anorexia nervosa. What is the evidence to guide the provision of high-quality, cost-effective services? *Eur Eat Disorders Rev*. 2021;1–10. <https://doi.org/10.1002/erv.2821>