

# Focus on anorexia nervosa: modern psychological treatment and guidelines for the adolescent patient

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**Abstract:** Anorexia nervosa is a serious condition associated with high mortality. Incidence is highest for female adolescents, and prevalence data highlight a pressing unmet need for treatment. While there is evidence that adolescent-onset anorexia has relatively high rates of eventual recovery, the illness is often protracted, and even after recovery from the eating disorder there is an ongoing vulnerability to psychosocial problems in later life. Family therapy for anorexia in adolescence has evolved from a generic systemic treatment into an eating disorder-specific format (family therapy for anorexia nervosa), and this approach has been evidenced as an effective treatment. Individual treatments, including cognitive behavioral therapy, also have some evidence of effectiveness. Most adolescents can be effectively and safely managed as outpatients. Day-patient treatment holds promise as an alternative to inpatient treatment or as an intensive program following a brief medical admission. Evidence is emerging of advantages in detecting and treating adolescent anorexia nervosa in specialist community-based child and adolescent eating-disorder services accessible directly from primary care. Limitations and future directions for modern treatment are considered.

**Keywords:** AN, evidence, family, therapy, FT-AN, inpatient, outpatient, day patient, specialist

## Introduction

Anorexia nervosa (AN) is a severe disorder affecting every bodily system. It is characterized by a restriction in energy intake, body-image disturbance, undue influence of body image on self-evaluation, and an intense fear of weight gain. Anorexia can involve a failure to recognize the seriousness of low body weight and a difficulty in acting to correct this. The condition involves extremely high rates of mortality.<sup>1</sup> Even in adolescent onset, brain function and cognitive processing are affected.<sup>2</sup> Incidence rates peak between the ages of 15 and 19 years in females,<sup>1</sup> highlighting the need for effective, age-appropriate treatments for this age-group. The focus of the current review is on treatment for AN, and will therefore not consider other eating disorders. Although medication is sometimes useful in the treatment of young people with AN, the empirical evidence for the efficacy of pharmacotherapy is relatively limited, and a review of medication practice will not be provided here. Guidelines<sup>3</sup> and updates covering medication<sup>4</sup> are available elsewhere. The current review has a focus on psychological treatment, and does not aim to examine other important aspects of a multidimensional approach, such as medical care.

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## Incidence and prevalence

Past studies have suggested that the incidence (ie, the rate of new cases of AN) in the population is eight per 100,000 people/year.<sup>5</sup> Prevalence estimates using the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV suggested that 0.29% of young females met criteria for AN. Considerably more females are found in prevalence studies compared to males. One large birth-cohort study examining Finnish twins found lifetime prevalence for AN in women of 2.2% and 0.24% in men.<sup>6</sup> The prevalence of eating disorders in non-Western groups has been found to be generally lower than in Western populations, but may be rising.<sup>7</sup> The advent of broader criteria for the diagnosis of AN in the DSM-V means that previous estimates of prevalence are likely to become underestimates.<sup>8</sup>

Until the 1970s, in Europe there was evidence of an increase in the registered prevalence of AN.<sup>1</sup> Overall prevalence appears to have reached a plateau thereafter, and incidence rates detected in primary care seem to have stabilized.<sup>9,10</sup> Incidence rates are highest for females between the ages of 15 and 19 years. There is some evidence of an increase in incidence rate in females in this age-group. It is unclear if this is due to earlier detection or a change in the age of onset of the illness.<sup>10</sup>

Prevalence data highlight a great unmet need for treatment in eating disorders. A review by Hart et al<sup>11</sup> found that considerably fewer than half of the diagnosable cases of eating disorder in the community seek or receive any treatment whatsoever. Wentz et al<sup>12</sup> found that 20% of people living with adolescent-onset AN had never consulted anyone about their condition. This was found to be the case 18 years after the onset of AN (and by a mean age of 32 years). A recent study<sup>13</sup> found that in areas of London where specialist outpatient services could be accessed directly from primary care, referral rates were approximately at the level predicted by epidemiological research. In other areas where referrals went to generic Child and Adolescent Mental Health Service (CAMHS) services, the rates were two to three times lower.

## Mortality

AN is often reported to have the highest mortality rate among all psychiatric disorders.<sup>14</sup> One meta-analysis estimated the mortality rate (deaths per 1,000 members of the population per year) at 5.1,<sup>15</sup> of which 1.3 was due to suicide. This study calculated a striking standardized mortality ratio across studies of 5.86 (a ratio of 1 would equal the expected number of deaths in the general population). Standardized mortality ratios appear similar between males and females.<sup>16</sup>

Arcelus et al<sup>15</sup> described a clear pattern in his meta-analysis with age at first presentation affecting standardized mortality ratio. Age at presentation is often used as a proxy variable for age at illness onset, as the latter is difficult to determine accurately in retrospect. This meta-analysis reported a standardized mortality ratio of approximately 10 in people aged 15–19 years at first presentation, whereas the ratio was close to 18 for 20–29 years. The ratio was lower again for younger and older groups.

Follow-up studies for AN with onset in adolescence also find lower mortality rates than those concerning AN in early adulthood. This is the case for studies following participants over time using both community<sup>12</sup> and clinical<sup>17</sup> samples.

## Prognosis

AN typically first occurs during adolescence. This is a sensitive period of development, and it differs from adulthood in many ways. The physical impact of starvation in adolescence is different to its impact in adulthood. There are risks of potentially irreversible effects on growth and development in the adolescent body. There are also risks to long-term psychosocial functioning following adolescent-onset AN. One community-based study examined prognosis with a lengthy follow-up.<sup>12</sup> Fifty-one adolescents were detected with a diagnosis of AN by community screening in Sweden. High rates of recovery meant that only three individuals met criteria for AN after 18 years (a further three had other eating disorders). However, 39% had a psychiatric disorder other than an eating disorder. One in four people who had experienced adolescent-onset AN had no paid employment as a result of psychiatric problems at a mean age of 32 years. All participants with ongoing eating disorders were unemployed. Many people continued to show over awareness of body shape and weight. Tension at mealtimes could still be problematic. Strober et al<sup>18</sup> followed up a clinical sample for 10–15 years. The young people in this study had received specialist inpatient treatment for severe AN in adolescence. Time to full recovery was protracted (57–79 months), but 76% of the cohort recovered by the end of the follow-up period. The majority of recovered patients also had good psychosocial adjustment, as measured by ratings of school/work outcome, interpersonal relating, and life satisfaction. In the community, the average duration of AN has been measured at 3.4 years.<sup>12</sup>

Community-based research relating to more common mental health problems suggests that a longer duration of mental health disorders in adolescence is a strong predictor of adult disorders.<sup>19</sup> Treasure and Russell<sup>20</sup> suggest that unless

effective treatment is delivered early (within 3 years of the first onset of AN in adolescence), outcome is poor.

## Psychological treatments

Reviews informing best practice rely heavily on findings from randomized controlled trials (RCTs). This experimental model can be difficult to apply in the study of psychological treatments of AN, as the relatively low prevalence of AN in the general population makes recruitment for studies challenging. In trials of treatment for adults with AN, a wide range of approaches have been examined. No clear primacy of one approach has been identified, and outcome differences are generally nil to small.<sup>21</sup> However, the picture for treatment of AN with adolescents is a brighter one. The key treatment studies highlighted by review of the literature concern systemic family-based treatment.

Systemic family therapy (FT) has evolved into a distinct approach in its application to AN in adolescence. The approach is rooted in a general family-systems approach,<sup>22–24</sup> and has incorporated more recent ideas from the family-systems field focusing on family strengths and family narratives.<sup>25,26</sup> The distinctiveness of the treatment when applied to AN is shaped by the need to manage a potentially life-threatening illness and the way in which the family has become organized around the illness. Mobilizing the family as the primary resource in feeding an undernourished child is a central focus in early phases, before moving on to broader issues of individual and family development that have been affected by the illness. Specific eating disorder-focused FT has been well described in the literature.<sup>27–32</sup> The treatment approach has been given a variety of labels that have included FT for AN (FT-AN), systemic FT for AN (SFT-AN), the Maudsley FT approach, and family-based treatment (FBT). The term FBT is increasingly used within the eating-disorder field sometimes to refer specifically to the Lock/Le Grange manual,<sup>33</sup> which operationalizes SFT-AN. This manual has more of an emphasis on the detail of early stages of treatment, and differentiates three rather than four phases of treatment, but does not differ conceptually from the manual of the treatment used in the Maudsley team.<sup>34</sup>

FBT is also used as a generic term for this approach. The term has two disadvantages: 1) outside the eating-disorder field, the term has a different meaning, and is often used (eg, in addictions) to denote general, family-oriented counseling approaches or treatments that work not just with the family but also wider systems, and 2) the term FBT can be (mis) understood as describing an atheoretical treatment, disconnecting it from the theoretical and conceptual developments

in the FT field. We therefore prefer the term FT-AN (or SFT-AN) to emphasize both the general theoretical framework and the specificity of its application to AN. SFT-AN and FT-AN refer to the same treatment, and the terms might be used interchangeably. For consistency, we will use FT-AN.

Using a set of inclusion and exclusion criteria defined a priori, Watson and Bulik identified six RCTs in their systematic review of the literature of treatment for acute AN in youth.<sup>21</sup> One identified study compared behavioral systems FT (in keeping with FT-AN) and ego-oriented individual therapy.<sup>35</sup> Both were effective treatments, but the behavioral systems FT (which involved adolescents and their families being seen conjointly) produced a faster return to health (greater weight gain and higher rates of resumption of menstrual periods). Lock et al further investigated the effectiveness of individual and family approaches in their study comparing adolescent-focused individual therapy and FT (FT-AN).<sup>36</sup> The sample was recruited from referrals to university-based treatment centers, and thus may not be representative of the community population. Nonetheless, a number of methodological strengths are present in this particular RCT. A robust design included allocation concealment, blinding, and use of intent-to-treat analysis. Both FT-AN and the individual therapy treatments were delivered in 24 therapy hours over 12 months. The primary outcome measure was ambitious: full remission from AN. Full remission was defined as weight greater than 95% of median body mass index and a score on the Eating Disorder Examination<sup>37</sup> less than one standard deviation above community norms. There was no difference in remission rate at completion of therapy between the two treatments, although a large effect size was found concerning weight, which favored FT-AN. Although there were no statistically significant differences in weight between the two treatments at 6- and 12-month follow-up points, FT-AN was significantly superior to individual treatment in achieving full remission from AN at both time points in follow-up.

As well as comparing FT-AN to alternative treatments, RCTs have also investigated the mode in which FT-AN is delivered. Le Grange et al<sup>38</sup> compared FT-AN delivered with child and family present with a similar approach in which parents and child were seen separately. This pilot study reported large effect sizes on weight and eating-disorder pathology across both treatment groups. Another study trialed the two forms of FT-AN (conjoint and separated), and found improvement in nutritional and psychological state across both groups.<sup>39</sup> Lock et al<sup>40</sup> compared short-term (ten sessions over 6 months) and long-term (20 sessions over 12 months)

FT-AN. Both treatments were found to be effective, with no significant difference between the treatment groups.

One further RCT met the criteria set out by Watson and Bulik.<sup>21</sup> Geist et al<sup>41</sup> reported that FT and family group psychoeducation were both effective in achieving weight restoration in an inpatient setting. Treatment was delivered in both treatment streams every 2 weeks for 4 months. Both treatments were effective, with psychoeducation the cheaper option. However, it is difficult to develop recommendations from this study, as both treatments took place in the context of inpatient weight restoration. Such a process inevitably involves many treatment components. This means it becomes problematic to infer which specific treatment components are most active in fostering improvements.

Despite the limitations of studies such as those just described, taken in combination they provide a considerable weight of evidence. A number of systematic reviews now substantiate the claim that with some further caveats (considered later), FT-AN is an effective treatment for AN in adolescence. Recommendations for involvement of the family in treatment are made in several current practice guidelines.<sup>3,42,43</sup> Such guidelines incorporate the best-available published data with expert consensus. Perusal of independent treatment guidelines reveals an acknowledgment of the importance of working with families in recovery from AN in adolescence. The National Institute for Health and Care Excellence in the UK, for example, stipulates that family interventions directly addressing the eating disorder should be offered.<sup>43</sup> The American Psychiatric Association (APA) guidelines state that for children and adolescents with AN, family treatment is the most effective psychosocial intervention.<sup>3</sup> Furthermore, the APA guidelines mention the “Maudsley approach” in which families become actively involved, in a blame-free atmosphere, in helping patients eat more.

While a recent update to the APA practice guidelines stated that results continue to provide support for the value of FT, the caveat was given that the overall quality of the evidence remains poor.<sup>4</sup> It is not the case that all adolescents recover with a family approach alone, and it is therefore necessary to consider alternatives when this treatment is not effective or when constructive family involvement is not possible.

Studies by Lock et al<sup>36</sup> and Robin et al<sup>35</sup> showed that individual therapy (while less effective than family-based therapy at follow-up) can lead to significant improvement for many adolescents with AN. For adults with AN, the research literature suggests that individual cognitive behavioral therapy (CBT) can be a moderately effective treatment<sup>44</sup> and may reduce relapse risk.<sup>45</sup> Although several RCTs have compared FT to

therapy delivered individually or focused on the adolescent, until now the individual treatment has rarely been CBT.

In one exception to this, individual manualized CBT was compared with behavioral FT.<sup>46</sup> An RCT design was used with a sample of adolescents and young adults living with their families. Improvements in outcome did not differ significantly between approaches at the end of treatment or at follow-up. Another RCT for separate inpatient and outpatient groups compared a general family-based approach (although this was not FT-AN) and a specialist manualized CBT approach for the outpatient adolescents.<sup>47</sup> No differences in outcomes were found between family-based and CBT treatments. Both groups made improvements.

A recent study of the use of enhanced CBT for adolescents with AN showed some promise.<sup>48</sup> Almost two-thirds of the recruited Italian cohort completed 40 weekly individual CBT for eating disorders sessions. Improvements in both weight and eating-disorder psychopathology were maintained at the 60-week follow-up. It seems then that while evidence for the effectiveness of treatment may be strongest for FT-AN, it is not the only evidenced treatment, and such alternatives as CBT might be useful when FT-AN is not applicable.

Further understanding about the impact of moderators in the treatment for adolescence could aid clinical decisions about the particular emphases in treatments within and across modalities. Work has begun on understanding moderating influences on recovery, and the maintenance of progress following FT-AN. Le Grange et al<sup>49</sup> found that remission status was negatively impacted by (older) age and (longer) duration of illness. Prior hospitalization as an inpatient also had a negative impact on remission status.

## Inpatient and day-patient treatment

Alongside the type and content of treatment delivered, the setting of treatment warrants consideration. One study explored this using random allocation to inpatient treatment, two outpatient-treatment settings, and a no-treatment group.<sup>50</sup> Results showed that inpatient treatment did not lead to better outcomes than outpatient alternatives. One other study concluded that inpatient treatment presented no advantage over outpatient CAMHS treatment.<sup>47</sup> However, these studies highlighted adherence problems in inpatient-treatment streams. Several other studies showed high relapse rates following initial admission (25%–30%) and higher relapse rates (50%–75%) after subsequent admissions.<sup>51</sup> Such findings suggest a “first-line” role for outpatient treatment in most cases. Expert guidelines confirm that the majority of children and adolescents can be effectively and safely managed as outpatients,<sup>43</sup> with

the caveat that outpatient psychological treatment should be of at least 6 months' duration.<sup>3</sup> Despite this, rates of inpatient admission for AN in adolescence appear to be high, perhaps rising over time.<sup>52</sup> In the UK, admission rates of 40% have been found in nonspecialist treatment services.<sup>13</sup>

Although outpatient treatment is indicated for the majority of teenagers with AN, a small proportion will require more intensive treatment. Such cases might include patients at immediate risk or for whom previous treatments have failed. Further indicators for hospital admission include rapid or persistent decline in oral intake and decline in weight despite maximally intensive outpatient intervention. Assessment of physical parameters, such as hemodynamic instability, cardiovascular risk, and electrolyte abnormalities, will inform decisions about location of care,<sup>53</sup> as will psychiatric assessment of such factors as risk of harm to self and others. Options for increased support include brief medical pediatric admissions, day treatment, and psychiatric or specialist eating-disorder inpatient care.

For those needing more intensive intervention, day-patient programs have some advantages over (solely) inpatient programs in allowing some continued engagement with the patient's educational, occupational, and social contexts. Day-patient settings are also more conducive to the active involvement of family members (including siblings) in treatment. A European multicenter randomized trial<sup>54</sup> has potentially wide-ranging treatment implications for cases where a more intensive approach is required. The participants in this study were anorexic adolescents with no previous history of hospitalization. All participants received 3 weeks of inpatient care, and were then randomly assigned to either continued inpatient treatment or day-patient treatment. Both treatment streams were multimodal and multidisciplinary, and involved nutritional counseling, CBT, and FT. Therapists had expertise in eating disorders, and an identical manualized treatment protocol was used across inpatient and day-patient provisions. This meant the study evaluated only specialist treatments for AN. The participants were then followed up 12 months after the admission. The findings of this large study show that continued inpatient treatment is no more effective and no safer than a short inpatient stay followed by day-patient treatment.

## Specialist and nonspecialist treatment providers

As well looking as at the content of psychological treatments for AN in adolescence, we have also considered the setting for treatment. There is also research available about

the nature of services providing treatment. In particular, a question has arisen about whether a difference in outcome is found between specialist eating-disorder services and nonspecialist provision. Following the TOuCAN trial,<sup>47</sup> it was suggested that a specialist outpatient CAMHS did not provide advantages in terms of outcome over nonspecialist CAMHS treatment, although specialist treatment was the least costly.<sup>55</sup> However, the researchers point out that the manualized specialist outpatient treatment in TOuCAN was a relatively brief (mainly CBT) treatment, and was devised before the publication of convincing data about FT-AN.<sup>36</sup> Therefore, results leave us unable to draw a comparison involving a specialist family-based treatment versus nonspecialist CAMHS.

House et al<sup>13</sup> also considered the merits of specialist versus nonspecialist services. They compared areas of London where there was access to specialist outpatient services directly from primary care with areas where more initial referrals were to a generic CAMHS. The study had three key findings: first, the rate of case identification was two to three times higher in specialist areas than in nonspecialist areas; second, the rate of admission to inpatient care during the first 12 months following referral was 2.5 times higher for young people who started their treatment in a nonspecialist team than those starting treatment in a specialist team; third, in areas without a specialist service, "care pathways" were more complex, with 20% being referred on immediately following initial assessment, and of those being offered treatment, only 40% receiving care from the same team over time; in comparison, less than 20% of those starting treatment in a specialist service were referred on elsewhere. The study's authors argued that specialist child and adolescent eating-disorder services (with direct access from primary care) could lead to improved treatment outcomes and reduced overall service costs. This is particularly pertinent, given that most people do not access specialist treatment services.<sup>56</sup> The higher rates of case identification in areas with child and adolescent eating-disorder services compared to areas with generic CAMHS further highlight community rates of unmet need, missed opportunities for early intervention, and therefore potential overall savings in health care systems.

## Limitations and future directions

In practice, treatment is often individualized to fit the circumstances of each presentation. A limitation of the gold-standard methodology of RCT research is that much of routine good practice can be difficult to evaluate.

Comorbidity is common in adolescent AN and may persist into adulthood,<sup>12</sup> but there is little research to show that treating these comorbid problems makes a difference to outcomes. A lack of understanding of the role of comorbidity is a key limitation of the current evidence base and a future direction for study.

The effectiveness of FT-AN might be enhanced. For example, there is emerging RCT evidence that the efficacy of FT-AN can be improved when combined with treatment in multi-family therapy (MFT-AN).<sup>57,58</sup> MFT-AN draws on FT-AN principles, and is considered an extension of FT-AN. More information about the background and practicalities of MFT-AN treatment is available elsewhere.<sup>59</sup> The addition of multiple families working together toward recovery is one example of how FT-AN has continued to evolve. Future research on mediators and moderators of FT-AN could elucidate the factors to consider in maximizing the effectiveness of treatment in producing sustained recovery. Further data on neuropsychological functioning of adolescents experiencing AN might also guide clinicians in targeting additional individual or group therapies helpful in recovery from AN in adolescence.<sup>60</sup>

Cost pressures on health care systems worldwide mean that a health economics perspective becomes essential in evaluating the contribution of additional therapies, mediating and moderating factors, and intensity and setting of treatment provided. It is hoped that the most efficacious and efficient treatments and treatment modifications will be those experienced as effective and beneficial by adolescents with AN and the families caring for them.

## Conclusion

AN has a prevalence of one in 50 for women, and this may rise with the application of the DSM-V. Prevalence is stable, and is highest in the 15- to 19-year age-group. Many people with AN in adolescence do not access treatment. Mortality is high for AN, and is highest between the ages of 15 and 29 years. Effective and early intervention is required. With caveats, FT-AN has become accepted as an effective treatment in adolescence. It is not effective for all, and some positive findings have been found for alternative treatments, such as CBT. Treatment mediators and moderators are important. Better outcomes tend to be found following outpatient treatment, but rates of inpatient referrals may be increasing. Treatments with a greater intensity than outpatient care are sometimes required. Day-patient care might provide a safe and effective alternative to inpatient care. Specialist

services for adolescent AN incorporating FT-AN could lead to improved outcomes and reduced overall service costs.

## Disclosure

The authors report no conflicts of interest in this work.

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