

## REVIEW

# Can you find the right support for children, adolescents and young adults with anorexia nervosa: Access to age-appropriate care systems in various healthcare systems

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## Abstract

**Objective:** Anorexia nervosa (AN) often has its onset in childhood or adolescence. However, there is insufficient knowledge regarding access to and utilisation of age-specific clinical diagnostics and treatment.

**Methods:** A literature review covering the last 10 years was conducted to provide a narrative review of the current state of research on the detection and treatment of young patients with AN in primary and secondary care.

**Results:** Most articles were of Western European or US origin. Timely diagnosis of the eating disorder (ED) and treatment options more often depend on the structure and quality of the national health care system than on scientific evidence. Regular paediatric health check-ups and age-appropriate eating disorder services appear to facilitate early diagnosis. Age-specific treatment that also involves the carers is often associated with a higher continuity of care and a better outcome. Although many adolescents require an extension of treatment into young adulthood, individual and health care system-related obstacles in many countries prevent a smooth transition.

**Conclusion:** To improve outcomes in childhood and adolescent AN, age-specific and timely diagnostic and therapeutic procedures are urgently needed.

## KEYWORDS

adolescence, anorexia nervosa, childhood, mental health service, transition, young adulthood

**Abbreviations:** AEDS, adult service for eating disorders; AN, Anorexia nervosa; BEAT, beating eating disorders (parent advocacy); BMI, body mass index; BN, bulimia nervosa; CAEDS, child and adolescent eating disorder service; CAMHS, child and adolescent mental health service; CBT-E, enhanced cognitive behavioural psychotherapy; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders Fourth Edition; EAT-40, Eating Attitudes Test-40; EBC, European Brain Council; ED, eating disorder; EDNOS, eating disorders not otherwise specified; EPA, European Psychiatric Association; FBT, family-based treatment; FEAST-ED, Families Empowered and Supporting Treatment of Eating Disorders (parent advocacy); ICD-10, Tenth Revision of the International Classification of Diseases; NHS, National Health Service; UK, United Kingdom; US, United States of America

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## 1 | INTRODUCTION

Eating disorders (EDs) are one of the most common chronic illnesses in adolescence and young adulthood (Gonzales, Kohn & Clarke, 2007). Anorexia nervosa (AN) and bulimia nervosa (BN) combined are the 12th leading cause of disability-adjusted life years in 15-to-19-year-old females in high-income countries (Hoek, 2016), and mortality rates, specifically for AN, are high, even among young individuals (Arcelus, 2011). Thus, EDs at a young age have become an important issue for health care systems, at least in the Western world.

This article tries to give an overview of access to and utilisation of care in different age groups of youth, mostly in European countries and North America. In childhood, EDs are often underdiagnosed, resulting in delayed treatment (for a review, see Herpertz-Dahlmann & Dahmen, 2019; Nicholls et al., 2011; Walker, Watson, Leach, McCormack, Tobias, Hamilton & Forbes, 2014). In adolescence, many individuals do not seek treatment because of shame or insufficient insight into the illness (Guarda et al., 2007; Laporta-Herrero & Latorre, 2020). During the transition from adolescence to young adulthood, gaps in medical and psychological care frequently result in treatment dropouts with a high risk of progression into a chronic illness (Lockertsen et al., 2020). Thus, an important aim of this article is to describe current treatment services for this age group. In addition, we wish to highlight requirements and recommendations for more age-specific health care for young individuals with EDs, including the need to support a smoother transition from adolescence to adulthood. Because most available data refer to AN, AN is the focus of this paper.

The following narrative review summarises the research conducted between February and April 2020. It is based on the body of literature produced between 2010 and 2020 that includes the keywords “eating disorders”, “anorexia nervosa”, “detection”, “treatment”, “transition”, “eating disorder service”, “mental health service”, “child” and “childhood”, “adolescent” and “adolescence”, “young adult” and “young adulthood” in PubMed and Web of Science. We are well aware that the literature selection is biased by a preponderance of studies from English-speaking and Western European countries.

## 2 | IS THERE A CHANGE IN AGE OF ONSET?

There are conflicting results regarding whether the true incidence of EDs has changed. While Dutch researchers could not find any difference in 10-year assessment periods in primary care (Smink et al., 2016), Scandinavian

### Highlights

- Access to early diagnosis and selection of treatment setting in AN often depend on the country in which a young patient resides.
- Regular health check-ups, age-appropriate specific ED services and involvement of carers seem to be associated with earlier diagnosis and less admissions to hospital.
- Transition from adolescent to adult ED services has to be improved by eliminating health care system-related obstacles.

groups found a significant increase in AN in adolescence between the years 2000 and 2009 (Javaras et al., 2015; for a more detailed overview, see Keski-Rahkonen & Silén, 2019). In an epidemiological study from the UK, incidence rates in primary care were stable for AN and BN but increased for eating disorders not otherwise specified according to Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV; Micali, Hagberg, Petersen, & Treasure, 2013). In more recent studies, there is broad agreement that EDs and specifically AN are increasing in childhood. In a Norwegian health care register study, the age and gender stratification revealed a significant average annual increase in the incidence of narrowly and broadly defined AN according to ICD-10 (narrow: typical AN [F 50.0] and broad: typical and atypical AN [F 50.0 and F 50.1]) among 10-to-14-year-old girls over a 7-year period, while an increase in 15-to-19 year olds was only found between 2010 and 2012 (Reas & Rø, 2018). A clinical practice research datalink study from England covering the 2004–2014 period did not find an increase in incidence in patients aged 11–15 years (Wood et al., 2019). In an investigation by Steinhausen and Jensen (2015) based on the Danish psychiatric registry, the most prevalent age of onset ranged from 12 to 15 years in 2010, while the peak age of onset averaged between 16 and 19 years at the beginning of the millennium. In a German large-scale community study with more than 3000 participants, 40% of subjects with symptomatic AN (fulfilling the weight criterion plus one other DSM-IV criterion) reported an onset of symptoms prior to age 13 (Nagl et al., 2016, see also below). Another large Italian epidemiological study on the local recourse population by Favaro, Caregato, Tenconi, Bosello, and Santonastaso (2009) included approximately 3000 participants with an age range between 12 and 66 years for AN and between 14 and 61 years for BN. There was an obvious decrease in age of onset according to year of

birth; in younger generations there was an earlier onset of the ED.

A similar trend was found in admission rates to hospital treatment for children in several European countries (e.g., German Federal Statistics, 2019; Holland, Hall, Yeates, & Goldacre, 2016; also see below).

There is evidence from population-based studies that most adolescents and young adults who meet classification criteria for an ED do not seek treatment (e.g., Solmi, Hotopf, Hatch, Treasure, & Micali, 2016). In a nationally representative sample of 280 adolescents who fulfilled lifetime criteria for an ED in the US, only 20% of girls and less than 10% of boys had ever sought treatment for their ED (Forrest, Smith, & Swanson, 2017). In a Swedish long-term 30-year follow-up study in AN by Dobrescu et al. (2019), nearly 25% of the sample had never received professional treatment.

Figure 1 delineates schematic pathways of care for subjects with AN in European health care systems.

### 3 | DETECTION OF CASES AND TREATMENT IN PRIMARY CARE

Detection of an ED in children is often difficult because many children do not exhibit typical symptoms, particularly in the case of AN. Body weight and shape concerns are less frequent symptoms in children. They often do not overestimate their body size but want to stay “as thin” as they are (for a review, see Herpertz-Dahlmann & Dahmen, 2019). However, diagnosis and treatment also seem to depend on the cultural environment and health care system of the respective country. In studies that compared patients with childhood and adolescent AN, children from Australia (Walker et al., 2014) and Singapore (Kwok, Kwok, Lee, & Tan, 2020) had a longer illness duration than adolescents at first presentation, while Peebles, Wilson, and Lock (2006) reported a shorter illness duration in children compared to adolescents in the US. In a recent review of 14 studies from seven countries, younger age at first treatment was also associated with shorter illness duration (Austin et al., 2020). In our own registry study, which included all children and adolescents referred to 14 university clinics and major hospitals across Germany, children had a significantly shorter illness duration and a higher body mass index (BMI) percentile at admission than adolescents (Bühren et al., 2017; Jaite et al., 2019). This finding is likely the result of the regular paediatric health check-up for 12–15 year olds established in Germany since 1998, which involves a complete physical examination, including weight measurement. In another study comprising more than 150

children and adolescents admitted between 2001 and 2010, there was a small but significant increase in the age-adjusted BMI score and absolute BMI at admission during the 10-year observation period (Bühren et al., 2013). In the large German community study with more than 3000 participants mentioned above, nearly half of the subjects with full-blown AN reported the onset of symptoms prior to age 13 (Nagl et al., 2016). Thus, preventative medical check-ups for children and younger adolescents might help clinicians detect early stages of AN.

Most clinicians understand that adolescents try to hide their eating disorder symptoms. In an investigation of 62 adolescents with AN, it was striking that nearly half of the patients diagnosed with AN by experienced clinicians did not report a sufficient number of food symptoms to exceed the cutoff point of the EAT-40, a special screening instrument for EDs (Laporta-Herrero & Latorre, 2020). Additionally, a large proportion of parents did not detect AN symptoms in their children (Laporta-Herrero & Latorre, 2020). In Germany, 6 months elapse on average between the first symptoms of the ED and first presentation at any primary care setting (Bühren et al., 2017).

Studies on the detection and treatment of EDs in primary care are scarce. In a new scoping review comprising all English publications on primary care-based detection and treatment of paediatric EDs in patients  $\leq 24$  years between 1980 and 2015, most of the retrieved articles were secondary sources that highlight potential roles for primary care physicians. Only three original contributions could be identified (Lenton-Bryme, Rodrigues, Johnson, Couturier, & Toulany, 2020). In another study from the US, 160 physicians primarily active in family care were recruited online to determine their ability to detect early manifestations of AN. Videotaped vignettes of an appointment were shown to participants, who were asked to diagnose the patient's problem. Nearly 40% of the participants failed to make a diagnosis of AN, and only 40% of those who made a correct diagnosis recommended referring the patient to treatment (Higgins & Cahn, 2018).

In sum, patients and parents often delay—intentionally or unintentionally—an early diagnosis. Moreover, in many countries, the screening and detection of eating disorders in young individuals in primary care remains to be improved, and referral to specialist treatment should be accelerated (Cadwallader, Godart, Chastang, Falissard, & Huas, 2016; see also below). There is some evidence that an early referral to treatment is associated with a better outcome (e.g., Javaras et al., 2015, for a review, see; Austin et al., 2020). However, studies on this topic are rare.

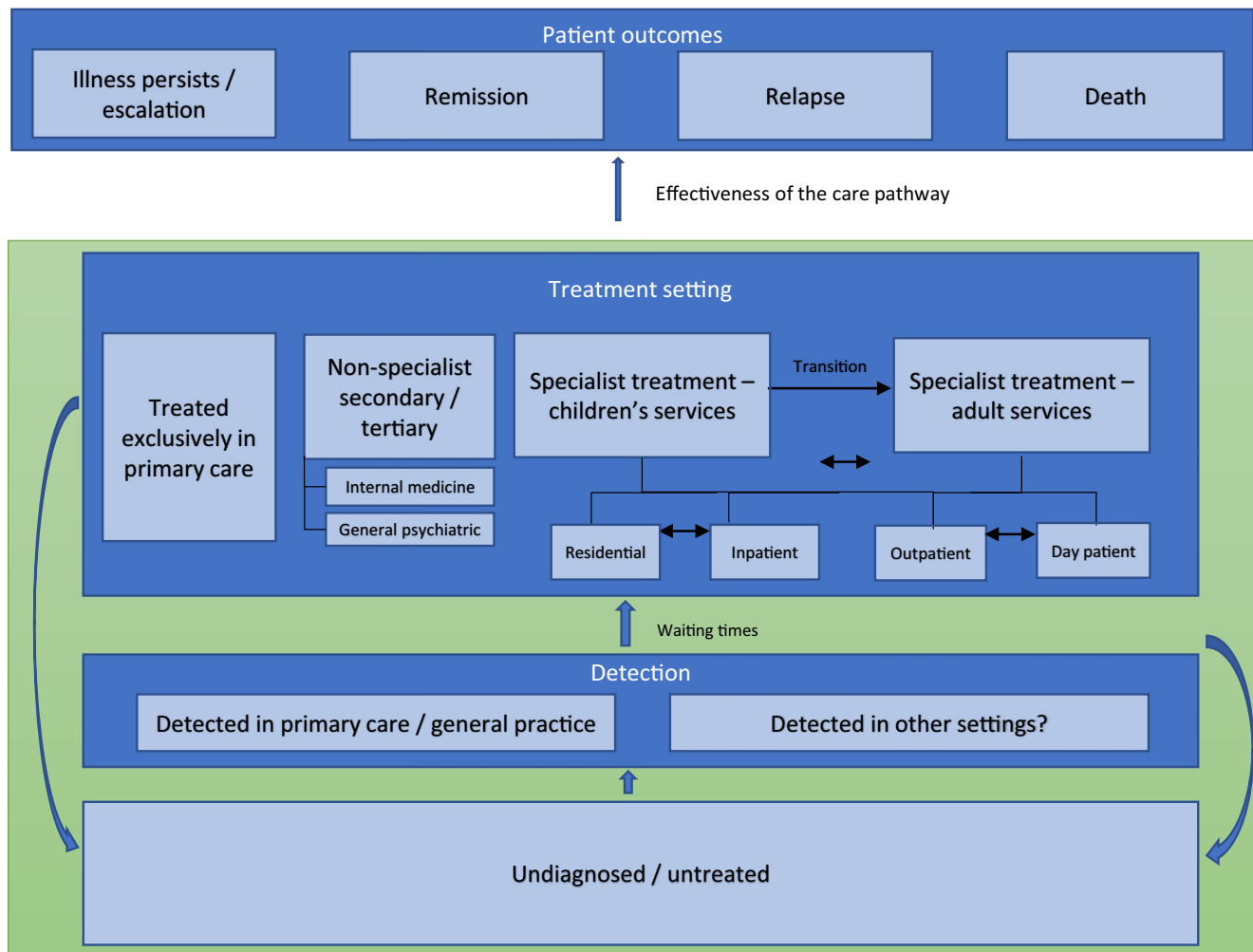


FIGURE 1 Pathways of care in childhood and adolescence

#### 4 | ACCESS TO TREATMENT AND TREATMENT SETTING

Access to treatment and the selection of a treatment setting heavily depend on the country in which a young patient resides. Inpatient treatment is often preferred in central European countries in contrast to outpatient services in the UK or the US (Brockmeyer, Friedrich, & Schmidt, 2018). However, there is insufficient evidence regarding which treatment setting is superior for treating children and adolescents when the patients do not need intensive medical care (Hay et al., 2019)

##### 4.1 | Outpatient service

The variety in outpatient services is large and depends on the national health care system, making comparisons difficult. While, for example, young patients with ED symptoms are seen by a general practitioner of the National Health Service (NHS) in the UK first, these

individuals are normally seen by a paediatrician or directly by a child and adolescent psychiatrist in Germany (Bühren et al., 2017). According to the authors of a recent national data linkage study in Wales, a general practitioner will see between one and three new cases of ED per year (Demmler, Brophy, Marchant, John, & Tan, 2020), which does not generate sufficient experience in diagnosing or treating EDs. In addition, across countries, outpatient ED specialist treatment is practiced very differently. Depending on the respective health care system, it may be delivered by a multidisciplinary team or by a single psychologist/psychiatrist, by specialists in general mental health or specialists in EDs, whereby in all cases the frequency of treatment sessions varies.

In addition, the availability of outpatient services and even more specialised ED services for children and adolescents is highly heterogeneous from country to country.

The question arises whether a general mental health service is more effective than a specialist ED service. In the so-called TOuCAN study in adolescents with AN, a specialist child and adolescent ED service (CAEDS) was

not more advantageous than a general child and adolescent mental health service (CAMHS). However, the results of this trial must be judged rather critically. Many of those who were randomised to CAEDS opted out of CAMHS because the distance to a provider of the latter was too far, and a high proportion of those randomised for CAMHS were in fact treated as inpatients; additionally, the duration of outpatient sessions was very short (Gowers et al., 2007). In a more recent study to analyse outpatient specialist versus nonspecialist eating disorder services for adolescents (House et al., 2012), areas of London with good CAEDS availability were compared to others with more comfortable access to a CAMHS. The authors note three major advantages of CAEDS: (a) a higher rate of case identification in the areas provided with the specialist service; (b) a significantly lower rate of referral to inpatient treatment in these areas; (c) a higher continuity of care; for example, significantly more patients stayed with their original therapeutic treatment service (House et al., 2012).

In 2015, the NHS Service in England set standards for children and adolescents below 18 years and invested in the development of CAEDS. The result was a very short wait time for routine treatment of EDs of less than 4 weeks at the end of 2019 in more than 80% of the treatment-seeking population (<https://www.england.nhs.uk/statistics/statistical-work-areas/cyped-waiting-times/>, accessed August 2020), which is rather unusual for Europe. As previously mentioned, shorter illness duration prior to admission to treatment is likely associated with a better outcome (Austin et al., 2020).

## 4.2 | Partial hospitalisation or day patient treatment

Adolescents often experience hospital treatment as coercive, and they delay or refuse hospitalisation (Guarda et al., 2007). For children with AN, separation from their parents is even more burdensome.

Thus, day patient treatment might be an effective alternative for adolescents and children with moderate forms of AN. However, it does not seem to be a frequently offered treatment option, at least in Europe.

Generally, day patient treatment providers operate 4–7 days/week; however, the number of offered treatment hours can vary considerably, as can the length of stay, which has been reported as between 3 and 18 weeks (Friedman et al., 2016; Simic et al., 2018).

In a systematic review, Friedman et al. (2016) assessed six open studies investigating the effect of partial hospital treatment/day patient treatment for adolescent EDs, mostly AN. All of the studies reported significant improvements in ED behaviour and weight at discharge.

However, none of them was conducted in Europe. A study by Abbate-Daga et al. (2015) performed in Italy only included adolescents aged 16 years or older. A recent study from Spain reported significant weight gain and weight stabilisation at the one-year follow-up in an intensive day patient program lasting 11 h per day (Serrano-Troncoso et al., 2020). Eighteen percent of the patients had to be readmitted to the hospital during the following 2 years. Simic et al. (2018) retrospectively analysed the charts of 105 adolescent patients who had participated in an intensive day patient program, after outpatient family-based treatment (FBT) had not achieved the desired success. After an average of 28.5 days of participation in this program, patients improved in a range of domains, including weight, ED behaviour, motivation to change and quality of life.

To the best of our knowledge, only our own randomised controlled trial, which included 172 adolescents, compares step-down treatment (i.e., short inpatient followed by day patient treatment) to continued inpatient treatment. At the 1-year follow-up, the step-down treatment was less costly. However, the outcome was equivalent to continued inpatient treatment with similar improvements in BMI and ED behaviour. In addition, participants in the day patient group described better mental well-being and psychosexual adjustment (Herpertz-Dahlmann et al., 2014).

Although studies on partial or day patient ED programs in adolescence and childhood remain rare, reports of successful management of this treatment option are increasing, making day patient treatment a promising alternative to inpatient or outpatient treatment.

## 4.3 | Inpatient treatment

Rates of admission to the hospital for those below 15 years increased from 7/100,000 to 13/100,000 between 2000 and 2017 in Germany (German Federal Statistics, 2019). For the same period, admission rates for those between 15 and 45 increased from 10/100,000 to 15/100,000. A similar trend was found for other European countries. In the UK, admission rates for AN in 10–14 year olds increased from 2.5/100,000 to approximately 7.8/100,000 between 1963–1971 and 2007–2011 and in adolescents from 6.5/100,000 to approximately 15.8/100,000, respectively (Oxford Record Linkage Study, Holland et al., 2016). In young adults (20–24 years), admission rates only increased from approximately 4.2 to 6.4. A more recent study from England reported a similar trend. Interestingly, younger age groups were much more likely to be admitted to inpatient treatment than older age groups ((14.7% in 11–15 year olds compared to 8.7%

in 16–20 year olds (Wood et al., 2019)). According to an analysis of NHS data by the English newspaper “The Guardian”, there were also increasing hospital admission rates for minorities in England, especially from black African background; however, no data for minors were given (<https://www.theguardian.com/society/2020/oct/18/nhs-hospital-admissions-eating-disorders-rise-among-ethnic-minorities>). A recent study from Portugal also demonstrated a sharp increase in hospital admission rates between 2000 and 2014. However, only adults with a mean age of 25.7 years were assessed (Cruz et al., 2018).

We are unsure why admission rates for young individuals are increasing in several European countries. Possible causes could be increasing incidence and prevalence rates of AN in this age group (see above) or better-informed medical professionals, resulting in earlier diagnosis.

Controversy remains regarding whether a child or adolescent should be treated in a special ED ward or a general psychiatric ward. Most clinical guidelines recommend a child and adolescent psychiatric or paediatric unit with a “developmentally aware and sensitive staff” experienced in the treatment of EDs (Hay et al., 2014; Herpertz et al., 2019; Lock, La Via, & AACAP, 2015; NICE guidelines, 2017). To our knowledge, there is only one early (*trans-European*) study that reported a better outcome in young adults with AN from a specialised ED ward compared to a general mental health ward 2.5 years after discharge (Richard, Bauer, Kordy, & COST Action B6, 2005).

However, in several countries, particularly in the US, specialised ED units for young individuals have closed because of cost considerations and poor insurance coverage (Derenne, 2019). There are also controversies in the ED literature regarding whether inpatient treatment for AN should serve the purpose of only medical stabilisation or provide support and management of ED behaviour and weight restoration. Madden et al. (2015) compared the effectiveness of prolonged hospitalisation for weight restoration with that of a shorter stay for medical stabilisation both followed by FBT. Because of a shorter time in hospital the latter was more cost-effective. In addition, the authors could not find any difference between further hospital bed use. However, the difference between both hospital stays was only 15 days, and there was little information regarding the therapeutic components of both options.

In some European countries (e.g., Germany, France, Italy) and Japan, specialised inpatient psychiatric or behavioural programs with longer admission times and a more holistic and individualised therapeutic goal apart from medical and weight stabilisation are still a central element in the treatment of adolescent AN. Interestingly,

in a recent survey adolescents with ED's—in contrast to their carers—preferred a more gradual weight gain and longer admission periods (O'Brien et al., 2018). Unfortunately, there are scarcely any studies in adolescent AN that compare the mid- or long-term outcome of more psychotherapeutically oriented hospital admissions to those limited to medical stabilisation.

Most likely due to a decrease in inpatient bed availability and as an insurance-financed alternative to hospitalisation, residential treatment programs in the US have strongly increased during the last 10 years (Attia, Blackwood, Guarda, Marcus, & Rothman, 2016). Unfortunately, access to these treatments is biased by selection criteria, such as very high treatment costs, and most providers do not furnish systematic outcome data (Lock, 2019).

## 5 | PSYCHOLOGICAL INTERVENTIONS

### 5.1 | Children

While in adolescence a family-based approach is the best studied treatment method for AN (see ahead), there is no evidence-based study on treatment for children. There are only a few randomised controlled trials that include children 12 years of age and older in their samples, such as those on FBT (Lock et al., 2010), systemic family therapy (Agras et al., 2014) and parent-focused treatment (Le Grange et al., 2016), as well as on enhanced cognitive behavioural psychotherapy (CBT-E) from 11 years on (Dalle Grave et al., 2019). However, age was not considered a possible prognostic factor. That is, we cannot be sure whether children benefit in a similar way as adolescents. As far as we know, there is only one early case study on FBT, by Lock, Le Grange, Forsberg and Hewell, (2006), which included 32 children aged 12 years or younger which demonstrated a statistically and clinically significant weight gain and reduction of ED symptoms. In our own study on day patient treatment in youth with AN, children had a worse outcome than adolescents (Herpertz-Dahlmann et al., 2014). In addition, previous long-term follow-up studies in children and adolescents concluded that children with AN followed a more chronic course than adolescents (Dobrescu et al., 2019; Herpertz-Dahlmann et al., 2018).

### 5.2 | Adolescents

In adolescence, there is broad evidence for the effectiveness of family-based approaches, mostly FBT (Gorrell, Loeb, & Le Grange, 2019).

While FBT is widely practiced in Anglo-Saxon countries and the Netherlands, it is not accepted by the health care insurance system in Germany and other European countries. The main reason is that only very few child and adolescent psychiatrists or psychologists have been trained in FBT. Instead, many adolescents receive CBT or CBT-E with regular involvement of the parents. In Switzerland and Italy, many adolescents receive psychoanalytic or systemic family treatment (Michael Kaess and Angela Favaro, personal communication) or CBT-E (Dalle Grave, Calugi, Doll, & Fairburn, 2013); in France, systemic family therapy and/or individual psychodynamic therapy is practiced (Nathalie Godart, personal communication). However, because there have not been enough controlled studies that compare FBT with other treatment methods, including CBT-E, a final conclusion regarding which approach is best, is impossible. Several studies have shown that individual interventions may also be effective in the long term (Dalle Grave et al., 2019; Le Grange et al., 2014). In a very recent nonrandomised effectiveness trial patients treated with FBT only achieved a higher weight gain at the end of treatment, but not at the 6- and 12-month follow-up. The authors concluded that CBT-E is a viable treatment for adolescents with an ED (Le Grange et al., 2020).

In sum, we only have preliminary evidence regarding which treatment program works best for whom. Because the relapse rate in AN is high in adolescents and even higher in childhood, there is an urgent need for intensive research.

### 5.3 | Role of the carers

With the introduction of FBT, carers have become increasingly important as cotherapists in treating childhood and adolescent EDs. In the “cognitive interpersonal maintenance model of eating disorders” developed by Schmidt and Treasure (2006), the interpersonal component implies that the responses of carers to their child’s disorder may unintentionally contribute to perpetuating the illness. Conversely, the impact of the child’s or adolescent’s ED on her/his carers seems to be more impairing than that of an adult patient on his/her family (Priestley & Mc Pherson, 2016). Thus, interventions that enhance the caregiver’s coping strategies as well as her/his skills are helpful to improve the outcome of adolescent AN. For this reason, many specialist outpatient and inpatient treatment programs include psychoeducation programs for parents (e.g., Holtkamp, Herpertz-Dahlmann, Vloet, & Hagenah, 2005; for a review, see Nicholls & Yi, 2012). In a treatment survey in adolescent AN at German maximum care hospitals, approximately 40% of

the departments offered a group psychoeducation program for parents (Foecker et al., 2017). Treasure and her group developed a program for carers of adolescents with AN by mailing a book and/or providing information to them by telephone with the help of carers who had also experienced caring for someone with an ED (Hodsoll et al., 2017). However, engagement with this intervention was poor. Only slightly more than one-third of the participants read more than 50% of the book, and telephone calls by experienced carers did not have any significant effect. According to our experience, carers best accept practical support and a direct exchange with a professional. In our home treatment study in adolescent AN, a multidisciplinary team visited patients and their parents at home after a shortened inpatient treatment period. At the 1-year follow-up, carers were significantly less depressed and had acquired more coping strategies and skills in handling their eating disordered child than at the beginning of the study. Moreover, very few patients had to be readmitted to the hospital (Herpertz-Dahlmann et al., 2020). In sum, there are few studies on specific interventions for carers. However, several trials on such interventions have been initiated. Therefore, there is reason to hope that support for carers might contribute to a better outcome in childhood and adolescent AN (e.g., Cardi et al., 2017; Franta et al., 2018; Spencer, Potterton, Allen, Musiat, & Schmidt, 2019).

In addition, parent advocacies such as “Beating Eating Disorders” (BEAT) and “Maudsley Parents” (engaging for FBT) in the UK and “Families Empowered and Supporting Treatment of Eating Disorders” in various Anglo-Saxon countries and Israel should not be ignored. These patient and parent support groups have an important political impact to establish evidence-based, but also new and promising treatment options for children and adolescents with ED. As an example, BEAT has called on the British National Health Service to develop new models of “intensive day and home-based treatment” (Beat eating disorders, 2019).

## 6 | TRANSITION TO ADULT CARE

Generally, transition is defined as a “planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-centred health care systems” (Blum et al., 1993). Long-term follow-up studies on adolescents with AN demonstrate that approximately one-third suffer from a persistent illness with a median duration of 5–10 years (Dobrescu et al., 2019; Fichter, Quadflieg, Crosby, & Koch, 2017). Thus, it can be expected that a considerable proportion of adolescents with AN would require adult ED services.

However, there is a paucity of research on the proportion of patients who use adult mental health care after ED treatment in childhood and/or adolescence and which disorder-specific characteristics lead to continuity in care.

In an earlier study by Arcelus, Bouman, and Morgan (2008), approximately one-fourth of the patients supported by an adult service for EDs (AEDS) had been cared for by a CAEDS during the previous 5 years. Fifty-eight percent of those transferred to an AEDS had been treated in an inpatient service before. These individuals presented more maturity fears and lower self-esteem than those who started treatment as adults. In a new study from the UK by McClelland, Simic, Schmidt, Koskina, and Stewart (2020), the transition between CAEDS and AEDS was described from the CAEDS perspective. One-third of the sample ( $n = 322$ ) seen at the CAEDS between the ages of 13 and 17 years required further mental health treatment, and 23% received the help of a more specialised AEDS. Approximately 11% of the CAEDS patients were directly transferred to AEDS, and approximately 8% were discharged from CAEDS and then readmitted to AEDS. Again, a rather high number (30%) of those transferred to AEDS had received inpatient treatment as a child or adolescent. Older age and more severe ED symptoms at admission/discharge to CAEDS, including a diagnosis of AN and low body weight, predicted ED treatment in young adulthood. Because of a relatively short follow-up period of 5 years, no patients with childhood ED (<13 years) could be included in this study, although the outcome of children with EDs, particularly AN, seems to be worse than that of adolescents (see above). Studies that investigate the factors underlying the transition from CAEDS to AEDS might help us understand the development of a chronic ED, such as severe and enduring AN.

The high proportion of patients who require a continuity of specialist treatment highlights the necessity of a smooth transition from paediatric/child and adolescent psychiatric services to adult programs. However, there are several obstacles that may prevent securing continuity of care, including (a) individual age-related reasons; (b) differences in therapeutic approach between child and adolescent and adult services; and (c) health care system-related reasons.

## 6.1 | Individual age-related reasons

In late adolescence, many ED patients display a lack of insight into their illness and use their newly acquired autonomy to renew weight loss and practice unhealthy eating behaviour. They feel overprotected and controlled and insist on self-determination in protest against their

parents. Others living independently for the first time do not intentionally start weight loss but are unable to provide themselves with sufficient food or skip meals. Others exaggerate physical activity or binge with or without vomiting because they have unlimited access to sweets or “comfort food” (for a review, see Derenne, 2019). Adolescents and young adults often feel intense pressure to be thin to be attractive to peers, although several patients with an ED do not find access to a peer group at their college or university because of high levels of social phobia, self-doubt or timidity (Derenne, 2013; Dimitropoulos, Herschman, Toulany, & Steinegger, 2016). Additionally, relapse is facilitated by moving away from home and from one’s long-term therapist.

## 6.2 | Differences in therapeutic approach between child and adolescent and adult services

The approach to patients of paediatric and adult services is often based on different “treatment philosophies”. While paediatric services often represent a more supportive and educational style, teams for adults expect more autonomy and independence. Moreover, in adult services, parents are often excluded from the treatment despite having cared for their eating disordered child for many years. Both parents and young adults experience a sudden interruption of the family’s connection to the health care service. ED patients, who are often shy and insecure, might be overstrained by having to navigate an unknown care system (Dimitropoulos, Freeman, Bellai, & Olmsted, 2013). In addition, there is often a large gap between the treatment strategies in both services: while family-based intervention is the primary approach in the treatment of child and adolescent EDs, individual treatment, such as CBT, is often used in adult psychotherapy. In FBT and other forms of family-oriented therapy, parents are asked to take charge of their child’s ED, while in adult therapy, individuals are required to take control by themselves. In addition, in many family-oriented therapies, the ED is externalised to relieve the patient and her/his parents from guilt, whereas in adult therapy, the ED is often viewed as an “integral part” of the person (Winston, Paul, & Juanola-Borrat, 2012).

## 6.3 | Health care system-related obstacles

In many countries, such as in the UK, a transition between CAED and AEDS is strictly required at the age



of 18 years, irrespective of the stage of illness. However, not every patient and his/her family are ready to leave the familiar treatment setting. Additionally, changing the therapeutic environment might be detrimental during an acute eating disorder crisis. In Germany, there is an overlap of both services between 18 and 21 years, although most child and adolescent psychiatric hospitals no longer treat 18-year olds, particularly when the illness is taking a chronic course. In France, certain services also accept ED patients in their early twenties (Nathalie Godart, personal communication). In Italy, a transition from adolescent to adult psychiatric care is normally required at the age of 18, but this rule is often not followed in the field of eating disorders (Angela Favaro, personal communication). In the Netherlands, several eating disorder treatment centres treat both adolescents and adults, and transition is dependent on the needs and maturity status of the individual patient (Annemarie van Elburg, personal communication).

The provision of specialist AEDS varies widely between and within countries. In certain countries, child and adolescent psychiatrists view the treatment of EDs as part of their typical occupational activity, while many adult mental health services often lack experience in the care of ED patients, and patients must struggle to obtain adequate treatment. In addition, there are often organisational obstacles that delay or complicate the transition between CAEDS and AEDS, such as long waiting times.

In sum, there is often no clear procedure for managing the transfer from CAEDS to AEDS. Rigid health care system rules may not be in the patient's best interest. To facilitate the transition from protected care in adolescence to adult patient service with more self-responsiveness, individual solutions with good communication and cooperation between services are urgently required. While the status of adulthood is defined by law as commencing with the age of 18 years, many researchers—based on an increasing knowledge of brain development—argue that adulthood is not achieved until the mid-twenties. The concept of “emerging adulthood” could include addressing these problems in 18–25 year olds (Potterton, Richards, Allen, & Schmidt, 2020). Recently, a special ED service for this age group was developed in England with short wait times. The result was a higher BMI in patients with AN, less ED behaviour and a reduction of depressive and anxious symptoms at a 2-year follow-up (Fukutomi et al., 2020). Other researchers refer to FBT treatment in transition-aged youth and report an improvement in ED behaviour and BMI (Chen et al., 2016). However, these positive results must be replicated in larger studies.

## 7 | CONCLUSION

A timely diagnosis of an ED and age-appropriate access to care seem to depend much more on the respective national health care system than on scientific evidence. In many countries, screening and detection of EDs in young individuals in primary care continue to require improvement. Therefore, training and continuing education of physicians in childhood and adolescent EDs should be intensified. To improve the outcome of early onset AN, specialised age-appropriate ED services should be established. The transition from child and adolescent to adult ED services must be facilitated by improving the collaboration between these service types and eliminating health care system-related obstacles. Because AN often entails a delay in the child's or adolescent's physical, psychological and social development, possibly resulting in a chronic course, there is no time to waste.

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## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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