EATING DISORDERS IN ADOLESCENTS AND YOUNG ADULTS: DIAGNOSIS, OCCURRENCE, TREATMENT, AND OUTCOME

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ACADEMIC DISSERTATION

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Doctoral dissertation, to be presented for public discussion with the permission of the Faculty of Medicine of the University of Helsinki, in lecture hall PIII (70), Porthania, Yliopistonkatu 3, on 18 December, 2021 at 10 o'clock.

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The Faculty of Medicine uses the Urkund system (plagiarism recognition) to examine all doctoral dissertations.

ISBN 978-951-51-7668-4 (print)
ISBN 978-951-51-7669-1 (PDF)

Unigrafia, Helsinki 2021

ABSTRACT

Background: Eating disorders are severe mental health issues that undermine psychological and physical health and quality of life. The latest changes to the psychiatric disorder classifications have tried to improve the diagnosis of eating disorders. These changes may affect the occurrence and natural course of eating disorders because a wider variety of experiences is covered. Yet, the impact of these changes remains poorly understood, and little is known about how eating disorders are detected and treated in Finland.

Aims: This thesis aimed to investigate the occurrence of eating disorders in a community sample of adolescents and young adults. Eating disorders were defined using the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). A second major aim was to describe how often individuals with eating disorders were detected and received treatment and what kind of treatment was offered. Finally, the natural course and outcome of different subcategories of eating disorders were also examined.

Methods: The study used two population-based Finnish twin datasets and one clinical dataset. FinnTwin12 followed all twins born in Finland between 1983 and 1987, whereas FinnTwin16 followed all twins born between 1975 and 1979, from adolescence to adulthood. From the FinnTwin12 data, we studied the occurrence, detection and treatment of eating disorders in health care and the natural course of these diseases (study I & II). From the FinnTwin16 data, we examined the effects of diagnostic changes on the occurrence and prognosis of anorexia nervosa (study III). From the clinical data of the Helsinki and Uusimaa Hospital District (HUS) Adolescent Psychiatry Eating Disorders Unit, we examined the treatment and prognosis of adolescents with typical and atypical anorexia nervosa (study IV). In all studies, we analysed the outcome of eating disorders using survival analysis.

Results: Eating disorders were common. Up to one in 6 females and 1 in 40 males had suffered from an eating disorder during their development towards adulthood. Changes in diagnostic criteria increased the lifetime prevalence of anorexia nervosa by more than half and increased diagnostic heterogeneity. Overall, anorexia nervosa and related subthreshold symptoms were prevalent among females: One in 10 young women had suffered from a restrictive eating disorder by early adulthood. We also found that eating disorder symptoms in a community setting were diverse, and many reported eating disorder symptoms

that could not be clearly labelled. This was particularly true among boys and men. Many individuals with eating disorders also described an unmet need for care; healthcare professionals diagnosed only one-third and even fewer received treatment. In addition, eating disorder symptoms were highly persistent: Five years after disease onset, less than two-fifths of the females and two-thirds of the males had recovered. The likelihood of recovery was similar between those who had and who had not received treatment, but more severe cases were more likely to receive treatment.

Conclusions: Overall, this thesis showed that eating disorders are common, and their symptoms are highly diverse among Finnish adolescents and young adults. Considering the magnitude of the problem, detection and treatment approaches for eating disorders are still inadequate and mainly focused on typical presentations of eating disorders. In addition, eating disorder symptoms often persisted for years. Future research should determine how the prevention and detection of eating disorders could be improved in Finland. The threshold for access to treatment should also be lowered, and additional interventions should be developed. Future studies should investigate whether these actions could eventually lead to better outcomes.

TIIVISTELMÄ

Tausta: Syömishäiriöt ovat vakavia psyykkistä ja fyysistä terveyttä sekä elämänlaatua uhkaavia mielenterveyden häiriöitä. Syömishäiriöiden diagnostiikkaan on liittynyt puutteita, joita on pyritty korjaamaan uusimmissa mielenterveyshäiriöiden tautiluokituksissa. Diagnoosimuutosten myötä on tarvetta syömishäiriöiden yleisyyttä ja luonnollista sairaudenkulkua selvittäville tutkimuksille. Myös syömishäiriöiden tunnistamista ja hoitoa on tutkittu niukasti Suomessa.

Tavoitteet: Tämän väitöstutkimuksen tavoitteena oli selvittää Amerikan psykiatriyhdistyksen DSM-5 (the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders) tautiluokituksen mukaisten syömishäiriöiden yleisyyttä suomalaisilla nuorilla ja nuorilla aikuisilla. Lisäksi tutkimuksessa kartoitettiin syömishäiriöiden tunnistamista terveydenhuollossa ja saatua hoitoa, sekä tutkittiin syömishäiriöiden luonnollista kulkua ja diagnooseihin liittyvää ennustetta.

Menetelmät: Tutkimuksessa hyödynnettiin kahta väestöpohjaista kaksosaineistoa ja yhtä kliinistä potilasaineistoa. Kaksosten kehitys ja terveys- tutkimuksessa (FinnTwin12) pyrittiin seuraamaan kaikkia Suomessa vuosina 1983–1987 ja Nuorten kaksosten terveystutkimuksessa (FinnTwin 16) kaikkia vuosina 1975 – 1979 syntyneitä kaksosia nuoruudesta aikuisuuteen saakka. FinnTwin12 aineistosta kartoitettiin DSM-5 tautiluokituksen mukaisten syömishäiriöiden yleisyyttä, tunnistamista ja hoitoa terveydenhuollossa sekä sairauden kestoa ja toipumista (osatyöt I & II). FinnTwin16 aineistosta tarkasteltiin diagnoosimuutosten vaikutusta laihuushäiriön yleisyyteen ja ennusteeseen (osatyö III). Helsingin ja Uudenmaan sairaanhoitopiirin (HUS) nuorisopsykiatrian syömishäiriöyksikön aineistosta selvitettiin laihuushäiriötä ja epätyypillistä laihuushäiriötä sairastavien nuorten hoitoa ja ennustetta sekä kartoitettiin diagnoosin merkitystä ennusteeseen (osatyö IV). Tutkimusten analyyseissä hyödynnettiin eloonjäämismalleja.

Tulokset: Tämän väitöstutkimuksen tulokset osoittivat, että syömishäiriöt ovat Suomessa yleisiä. Varhaisaikuisuuteen mennessä jopa joka kuudes nainen ja joka neljäskymmenes mies oli sairastanut syömishäiriön. DSM-tautiluokitukseen liittyvien diagnoosimuutosten todettiin lisäävän laihuushäiriön esiintyvyyttä yli puolella. Kokonaisuudessaan tytöillä ja nuorilla naisilla laihuushäiriö ja sen taudinkuvaa muistuttavat syömishäiriöt olivat yleisiä, sillä joka kymmenes

nuori nainen oli kärsinyt restriktiivisestä syömishäiriöstä varhaisaikuisuuteen mennessä. Lisäksi väestössä esiintyvien syömishäiriöiden havaittiin olevan oirekuvaltaan monimuotoisia. Diagnoosimuutoksista huolimatta määrittämättömät syömishäiriöt olivat yhä yleisiä ja muodostivat pojilla ja miehillä yleisimmän syömishäiriöluokan. Lisäksi monen syömishäiriöön sairastuneen todettiin jäävän ilman apua, sillä vain kolmasosa tunnistettiin terveydenhuollossa, ja vielä harvempi sai hoitoa. Erityisen huonosti hoidon piiriin pääsivät epätyypillisistä syömishäiriöistä kärsivät. Syömishäiriöoireiden havaittiin myös olevan pitkäaikaisia, sillä viisi vuotta taudin puhkeamisen jälkeen alle kaksi viidesosaa naisista ja kaksi kolmasosaa miehistä oli toipunut. Hoitoa saaneiden toipumisen todennäköisyys ei eronnut hoitoa vaille jääneiden toipumisen todennäköisyydestä, mutta hoitoa saaviin valikoitui mahdollisesti vaikeammin oireilevia.

Johtopäätökset: Kokonaisuudessaan tämä väitöstutkimus osoittaa, että suomalaisilla nuorilla ja nuorilla aikuisilla syömishäiriöt ovat yleisiä ja oirekuviltaan monimuotoisia. Syömishäiriöiden tunnistaminen ja hoito ovat vielä puutteellisia ongelman suuruusluokka huomioiden ja keskittyneet lähinnä tyypillisiin oirekuviin. Lisäksi syömishäiriöoireista kärsitään usein vuosia. Tulevissa tutkimuksissa tulisikin selvittää, miten syömishäiriöiden ehkäisyä ja tunnistamista voitaisiin parantaa Suomessa. Hoitoon pääsemisen kynnystä tulisi myös madaltaa sekä kehittää hoitoja, ja tutkia näiden toimien vaikutusta syömishäiriöiden ennusteeseen.

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LIST OF ABBREVIATIONS

AN Anorexia nervosa
ARFID Avoidant/Restrictive Food Intake Disorder
BED Binge Eating Disorder
BMI Body Mass Index
BN Bulimia Nervosa
CI confidence interval
DSM-IV Diagnostic and Statistical Manual of Mental Disorders 4th Edition
DSM-5 Diagnostic and Statistical Manual of Mental Disorders 5th Edition
ED Eating disorder
EDNOS Eating Disorders not otherwise specified
ICD-10 International Classification of Diseases 10th revision
ICD-11 International Classification of Diseases 11th revision
N Number of participants
SCID Structured Clinical Interview for DSM-IV
SD standard deviation
OSFED Other specified feeding and eating disorders
UFED Unspecified specified feeding and eating disorders
WHO World Health Organization

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following articles that are referred by Roman numbers.

I. Silén, Y., Sipilä, P. N., Raevuori, A., Mustelin, L., Marttunen, M., Kaprio, J., & Keski-Rahkonen, A. (2020). DSM-5 eating disorders among adolescents and young adults in Finland: A public health concern. The International Journal of Eating Disorders, 53(5), 520–531. https://doi.org/10.1002/eat.23236

II. Silén, Y., Sipilä, P. N., Raevuori, A., Mustelin, L., Marttunen, M., Kaprio, J., & Keski-Rahkonen, A. (2021). Detection, treatment, and course of eating disorders in Finland: A population-based study of adolescent and young adult females and males. European Eating Disorders Review: The Journal of the Eating Disorders Association, 29(5), 720–732. https://doi.org/10.1002/erv.2838

III. Mustelin, L., Silén, Y., Raevuori, A., Hoek, H. W., Kaprio, J., & Keski-Rahkonen, A. (2016). The DSM-5 diagnostic criteria for anorexia nervosa may change its population prevalence and prognostic value. Journal of Psychiatric Research, 77, 85–91. https://doi.org/10.1016/j.jpsychires.2016.03.003

IV. Silén, Y., Raevuori, A., Jüriloo, E., Tainio, V. M., Marttunen, M., & Keski-Rahkonen, A. (2015). Typical Versus Atypical Anorexia Nervosa Among Adolescents: Clinical Characteristics and Implications for ICD-11. European Eating Disorders Review: The Journal of the Eating Disorders Association, 23(5), 345–351. https://doi.org/10.1002/erv.2370

INTRODUCTION

Although the first descriptions of behaviour resembling eating disorders date back hundreds of years, even to the thirteenth century, the terms *anorexia nervosa* and *l'anorexie hysterique* were first used in the 1870s to describe adolescent females who were self-starving (Soh, Walter, Robertson, & Malhi, 2010). A hundred years later, *bulimia nervosa* was described in a clinical sample that mostly consisted of normal-weight women who binged and purged (Russell, 1979). These classical case reports served as a basis for establishing an eating disorder classification. Thus, the classification was not based on systematic studies on the types of eating disorders appearing in the population but rather on the description of specific and severe symptoms (Blashfield, Keeley, Flanagan, & Miles, 2014; Wilfley, Bishop, Wilson, & Agras, 2007). This was reflected in the kinds of perceptions and presuppositions we have had about eating disorders. For a long time, eating disorders were thought of as being relatively rare diseases that mainly affected young women. Research mainly concentrated on anorexia and bulimia nervosa, and generally, young adult women were the subjects included in these studies (Mitchison, & Hay, 2014; Schaumberg et al., 2017). In particular, the study of treatments was limited to these typical manifestations (Bardone-Cone, Hunt, & Watson, 2018).

The assumption that only certain eating disorder profiles exist in a single set of people was in many ways problematic because, in health care, there is a tendency to detect what has already been defined, leaving a gap between problems that people have and what is detected and treated. Consequently, many people in need of evidence-based care were left without it. Furthermore, these limitations led to a very one-sided picture of the eating disorder prognosis and its natural course (Schaumberg et al., 2017).

In recent years, significant changes have been made to improve the diagnosis of eating disorders to reflect more on the symptoms found in the population, as exemplified by the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). In this study, I try to bridge some of the information gaps left by the biases and myths associated with eating disorders. We investigated what kinds of eating disorder manifestations appear among Finnish adolescents and young adults. Further, we studied how frequent these eating disorders are, how often they are detected and treated in health care and what their outcomes are.

In the next section, I review the relevant literature regarding the diagnosis of eating disorders. I then address the occurrence, detection and treatment of eating disorders in the new diagnostic definition era. Finally, I discuss outcomes related to eating disorders.

REVIEW OF THE LITERATURE

2.1 THE DIAGNOSTIC ASSESSMENT OF EATING DISORDERS

2.1.1 Psychiatric diagnoses

A diagnosis, which simply means identifying a problem and giving it a name, is a cornerstone of modern medicine. Ideally, a diagnosis should provide some information about the aetiology of a disease. Establishing an exact diagnosis is the first step in choosing and determining a treatment plan. Diagnosis should also say something about the prognosis of a disease; in other words, it should give information about a disease's course and its symptoms (Fairburn & Cooper, 2011).

Perhaps not surprisingly, when comparing psychiatric to somatic diagnoses, certain difficulties arise. In physical conditions, clinicians may, for example, take blood tests or use imaging tests to make a correct diagnosis. However, we do not yet have reliable biomarkers or scan findings for psychiatric diseases. Psychiatric diagnoses are merely based on specific criteria of symptoms and clinical features (Burger & Neeleman, 2007). Moreover, the symptom criteria change over time, and each change reflects the time in which it emerges.

In psychiatry, the line between health and sickness is not easily defined. The main question is, who is a case? The two nosological systems that are commonly used for classifying psychiatric disorders—the DSM-5 (American Psychiatric Association, 2013) and the International Classification of Diseases, 10th edition (ICD-10; World Health Organization, 2003)—both use categorical approaches. This means that the psychiatric diagnoses are described as discrete entities that differ from each other and normality (Luo, Donnellan, Burt, & Klump, 2016).

In particular, when we study psychiatric illnesses in the population, the way we conceptualise and measure psychiatric disorders is of primary importance. Exact diagnostic criteria and the accuracy of diagnostic methods are critical to enable the investigation of comparable and well-defined groups. In turn, this can lead to results that are generalisable and transferable (Kessler, 2000).

2.1.2 Eating disorder diagnosis

Eating disorders are mental disorders in which the core symptoms centre on a troubled relationship with food, weight and body image. They can impair the sufferer's psychological and physical well-being, quality of life, social function-

ing and ability to work (Herpertz-Dahlmann, 2015; Steinhausen, 2009). Eating disorder diagnoses present the same difficulties as other psychiatric diagnoses. The main problem is that we have not yet been able to identify where an eating disorder starts and where it ends. Where should we draw the line between an eating disorder, disturbed eating and normality (Luo et al., 2016)? Furthermore, although eating disorders' longitudinal stability is more common than the crossover to another eating disorder, diagnostic crossover still occurs in a considerable proportion of cases. Crossover seems to be especially common among adolescents with eating disorders (Agras, Crow, Mitchell, Halmi, & Bryson, 2009; Allen, Byrne, Oddy, & Crosby, 2013a; Eddy et al., 2008; Stice, Marti, & Rohde, 2013).

Some eating disorder-related behaviours frequently occur in the general population. Short-term dieting, binge eating at the buffet table or Christmas and children's picky eating are examples of these behaviours. The question is how to differentiate behaviours that are neither pathological nor developmentally inappropriate from those that cause suffering and impairment.

2.1.3 Different eating disorder classifications

There are two separate diagnostical classifications for categorizing eating disorders: The American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) and the World Health Organization's (WHO) International Classification of Diseases (ICD). In addition, problematically, the criteria for eating disorders have differed between these two diagnostic classifications. In the following paragraphs, I summarise the main characteristics and problems of both diagnostic systems.

2.1.4 Diagnostic and Statistical Manual of Mental Disorders

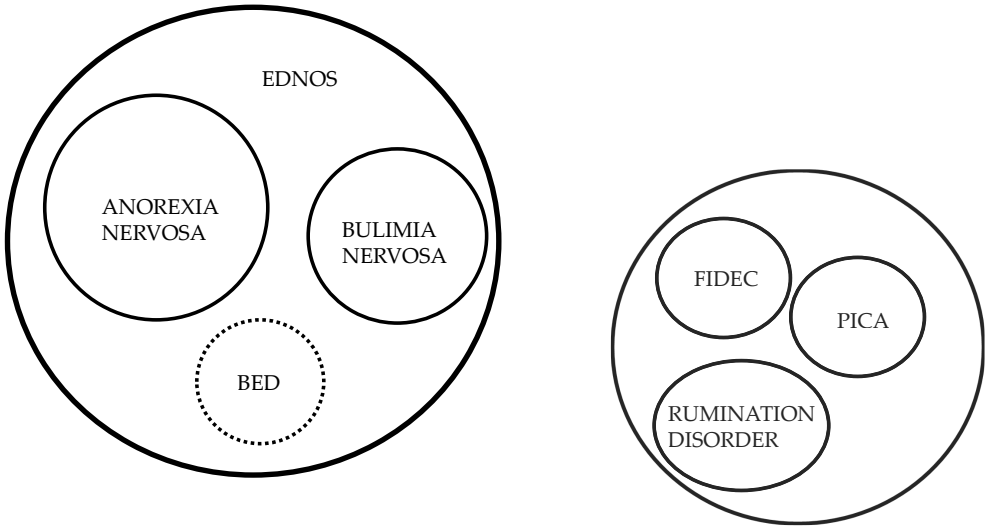
The American Psychiatric Association first introduced the Diagnostic and Statistical Manual of Mental Disorders, DSM I, in 1952 (American Psychiatric Association, 1952). The first version only included 60 disorders. The major criticism it faced was that the diagnoses were not based on systematic studies, and therefore the validity and reliability of the diagnoses were questionable (Blashfield et al., 2014). The second version (DSM II) was published in 1968 (American Psychiatric Association, 1968), the third version (DSM III) in 1980 (American Psychiatric Association, 1980), and its revision DSM-III-R in 1987 (American Psychiatric Association, 1987).

Eating disorders first appeared in the DSM III when anorexia nervosa was included in the classification, and 7 years later, bulimia nervosa was included in the DSM-III-R. The DSM-IV was published in 1994 and a revision of it, DSM-IV-TR, in 2000 (American Psychiatric Association, 1994; American Psychiatric Association, 2000). With each new volume, the research base for diagnostic criteria was increased (Blashfield et al., 2014). The fifth and the most current edition of the DSM was published in 2013 (American Psychiatric Association, 2013). This time, it was developed in cooperation with the WHO, the National Institute of Mental Health and the World Psychiatric Association. Below, I discuss the fourth and fifth versions of the diagnostic classification of eating disorders in more detail.

Eating and feeding disorder classification in DSM-IV

In the fourth version of the DSM, eating and feeding disorders were described as two separate groups—namely, the *Eating Disorders* and *Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence* categories. Figure 1 illustrates the categorisation of these disorders. The eating disorder category consisted of only two diagnoses with exact criteria—anorexia nervosa and bulimia nervosa. The third diagnosis was called an eating disorder not otherwise specified (EDNOS). This residual diagnosis had no specific, explicit criteria. The only definition was that there was an eating disorder and the criteria for anorexia nervosa or bulimia nervosa were not fulfilled. As the borderline between eating disorder, distorted eating and normality was not well defined, the residual diagnosis contained heterogeneous representations with varying severity (Fairburn & Bohn, 2005). The criteria for binge eating disorder (BED) were only described in the appendix for research purposes.

Figure 1. DSM-IV-TR Diagnostic classification of eating disorders. Anorexia Nervosa, Bulimia Nervosa and Eating Disorder Not Otherwise Specified (EDNOS) were included in the eating disorder category. Pica, Rumination Disorder and Feeding Disorder of Infancy or Early Childhood (FDIEC) were placed in the category Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence. The criteria for Binge Eating Disorder (BED) were described for research purposes.



The DSM-IV classification for eating disorders also faced criticism for its poor reflection of clinical reality because the most common eating disorder diagnosis given in clinics was eating disorder not otherwise specified (Fairburn & Bohn, 2005). This issue was pronounced among adolescents, of whom up to 80% received this residual diagnosis (Le Grange, Swanson, Crow, & Merikangas, 2012). This was problematic because in some instances, patients with highly disabling eating disorders did not receive the needed treatment because their symptom features did not fulfil the strict criteria of a specific diagnosis for anorexia or bulimia nervosa required for insurance reimbursement or treatment.

Since the not otherwise specified category was so heterogeneous, it significantly hampered the research base of eating disorders. Different studies used different definitions for the residual diagnosis, making comparison difficult. Eating disorders not otherwise specified were also under-researched, especially in relation to its treatment. This hampered the types of treatments that were offered in real-world clinical settings (Fairburn & Bohn, 2005).

The DSM-IV criteria for anorexia and bulimia nervosa were viewed as impractically strict, and the empirical basis of the criteria was critiqued (Wilfley et al., 2007). First, the term 'refusal' used in the A criterion of anorexia nervosa was problematic because many patients reported that they could not control their eating. Therefore, wording that describes the 'inability' to eat rather than a voluntary decision not to eat was seen as more suitable (Knoll, Bulik, & Hebebrand, 2011). Further, the weight criterion of 85% of normal weight for height and age was intended as a guideline, but in many situations became a necessity for treatment and insurance reimbursement (Hebebrand & Bulik, 2011). Besides, the criterion did not consider gender, age, body composition or ethnicity (Wilfley et al., 2007).

Second, the B criterion, 'an intense fear of gaining weight or becoming fat', was also problematic, as some individuals could not verbalise the fear of weight gain or fat, although their actions strongly suggested this. This was more common with younger individuals and with those who objected to treatment. Therefore, a criterion that would instead describe the action rather than the psychological aspect would be a better fit (Hebebrand, Casper, Treasure, & Schweiger, 2004).

Third, the C criterion in anorexia nervosa described the 'disturbance in the way body weight or shape is experienced'. This criterion again required that individuals with anorexia nervosa can verbalise how they see and feel about their bodies (Hebebrand et al., 2004).

The D criterion of anorexia nervosa, amenorrhea, was also problematic. Some studies have indicated that amenorrhea originates from the primary disturbance of hypothalamic function. Others suggested that amenorrhea was only a reflection of weight loss. Several studies found that there was a negligible difference between those individuals who met all the criteria of DSM-IV anorexia nervosa and those individuals who met all the criteria except amenorrhea (Dalle Grave, Calugi, & Marchesini, 2008; Roberto, Steinglass, Mayer, Attia, & Walsh, 2008). Further, the D criterion could not be used among males and prepubertal children.

In terms of bulimia nervosa, the DSM-IV criterion of the frequency of binges and compensatory behaviour was criticised for being arbitrary. Research indicated that changing the criteria from twice a week to once per week over three months would have little impact on the prevalence of bulimia nervosa and help identify those with clinically significant eating disorder pathology. The same was

suggested for binge eating disorder, (Trace, Thornton, Root, Mazzeo, Lichtenstein, Pedersen, & Bulik, 2012; Wilson & Sysko, 2009). The diagnosis of bulimia nervosa was also accompanied by a more detailed subdivision of purging and non-purging subtypes that reflected the individual's compensatory behaviour. Still, studies had found that many patients had both of these compensatory behaviours, and therefore, the specifier was not diagnostically relevant (Ekeroth, Clinton, Norring, & Birgegard, 2013; Vaz, Peñas, Ramos, López-Ibor, & Guisado, 2001)

The DSM-IV-TR category of Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence included three eating disorders: pica, rumination disorder, and feeding disorder of infancy or early childhood (FDIEC). The summary for the diagnosis of feeding disorder of infancy or early childhood was: "restrictive intake with malnutrition but no body image disturbance or fear of weight gain." The age of onset was restricted to children 6 years or younger, and thus, the diagnosis was rarely used or studied (Bryant-Waugh, Markham, Kreipe, & Walsh, 2010; Zimmerman & Fisher, 2017). Further, the placement of eating and feeding disorders in two different sections of the DSM classification was seen as problematic. Therefore, it was suggested that these disorders should be merged into a single group without age restriction (Uher & Rutter, 2012).

Table 1 describes the diagnostic criteria for DSM-IV eating disorders, and Table 2 describes the diagnostic criteria of DSM-IV-defined feeding disorders. The DSM-IV criteria of binge eating disorder for research purposes are described in Table 3. In each diagnosis, all the criteria have to be fulfilled.

Table 1. Diagnostic criteria for DSM-IV Eating Disorders.

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR DSM-IV EATING DISORDERS
Anorexia Nervosa (AN)	A. Refusal to maintain bodyweight at or above minimally normal weight for height/age (less than 85th percentile). B. Intense fear of gaining weight or becoming obese, even though underweight. C. Disturbed by one's body weight or shape, self-worth influenced by body weight or shape, or persistent lack of recognition of seriousness of low bodyweight. D. In menstruating females, absence of at least 3 consecutive non-synthetically induced menstrual cycles. Type: *Restricting type:* During the current episode, has not regularly engaged in binge-eating or purging *Binge-eating/purging type:* During the current episode, has regularly engaged in binge-eating or purging.
Bulimia Nervosa (BN)	A. Recurrent episodes of binge eating, as characterized by both: 1. Eating, within any 2-hour period, an amount of food that is definitively larger than what most individuals would eat in a similar period of time under similar circumstances. 2. A feeling that one cannot stop eating or control what or how much one is eating. B. Recurrent inappropriate compensatory behaviors in order to prevent weight gain such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting or excessive exercise. C. The binge eating and inappropriate compensatory behaviors occur, on average, at least twice a week for 3 months. D. Self-evaluation is unjustifiability influenced by body shape and weight. E. The disturbance does not occur exclusively during episodes of anorexia nervosa. Type: Purging type: During the current episode, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas. Non-purging Type: During the current episode, the person has used inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.
The Eating Disorder Not Otherwise Specified (EDNOS)	Disorders of eating that do not meet the criteria for any specific Eating Disorder.

Table 2. Diagnostic criteria for DSM-IV Feeding Disorders.

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR DSM-IV DEFINED FEEDING DISORDERS
Feeding Disorder of Infancy or Early Childhood (FDIEC)	A. Feeding disturbance as manifested by persistent failure to eat adequately with significant failure to gain weight or significant loss of weight over at least one month. B. The disturbance is not due to an associated gastrointestinal or other general medical condition (e.g., esophageal reflux). C. The disturbance is not better accounted for by another mental disorder (e.g., Rumination Disorder) or by lack of available food. D. The onset is before the age of 6.
Rumination Disorder	A. Repeated regurgitation and/or rechewing of food for a period of at least one month following a period of normal functioning. B. The behavior is not due to an associated gastrointestinal or other medical condition (e.g., esophageal reflux). C. The behavior does not occur exclusively during the course of Anorexia Nervosa or Bulimia Nervosa. If the symptoms occur exclusively during the course of Mental Retardation or a Pervasive Developmental Disorder, they are sufficiently severe to warrant independent clinical attention.
Pica	A. Persistent eating of nonfood/ nonnutritive substances for a period of at least one month. B. The eating of nonnutritive substances is inappropriate to the developmental level. C. The eating behavior is not part of a culturally sanctioned practice. D. If the eating behavior occurs exclusively during the course of another mental disorder (e.g., Mental Retardation, Pervasive Developmental Disorder, Schizophrenia), it is sufficiently severe to warrant independent clinical attention.

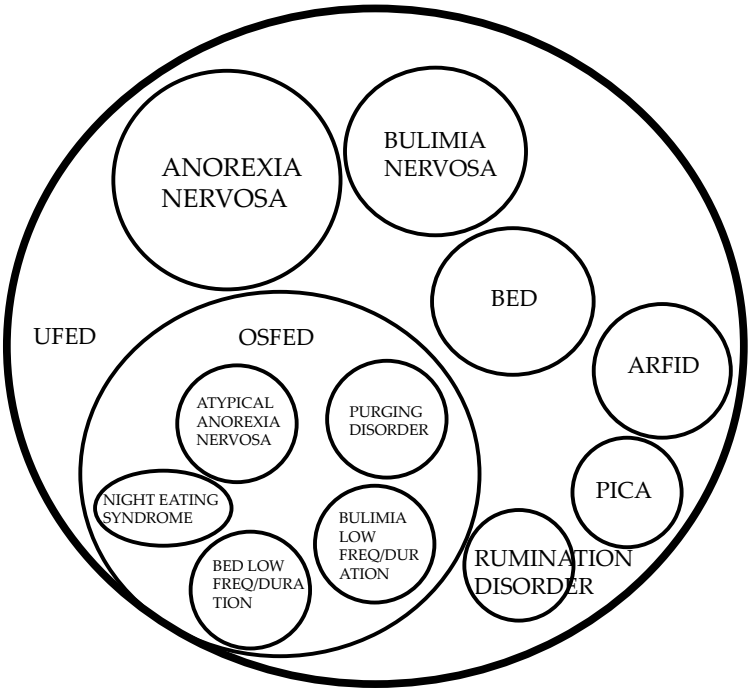
Table 3. Diagnostic criteria for DSM-IV defined binge eating disorder.

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR DSM-IV DEFINED BINGE EATING DISORDER
Binge Eating Disorder (BED)	A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: 1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat in a similar period of time under similar circumstances 2. A sense of lack of control over eating during the episode (e.g, a feeling that one cannot stop eating or control what or how much one is eating) B. The binge-eating episodes are associated with three (or more) of the following: 1. Eating much more rapidly than normal 2. Eating until feeling uncomfortably full 3. Eating large amounts of food when not feeling physically hungry 4. Eating alone because of feeling embarrassed by how much one is eating 5. Feeling disgusted with oneself, depressed, or very guilty after overeating C. Marked distress regarding binge eating is present D. The binge eating occurs, on average, at least 2 days a week for 6 months. E. The binge eating is not associated with the regular use of inappropriate compensatory behaviors (e.g., purging, fasting, excessive exercise) and does not occur exclusively during the course of Anorexia Nervosa or Bulimia Nervosa.

Eating and feeding disorder classification in the DSM-5

Because of the previously described difficulties, three significant changes were made to the DSM-5 classification. First, the criteria for existing eating disorders anorexia and bulimia nervosa were relaxed. Second, many new categories were added. The primary goal of these changes was to reduce the number of individuals in the residual eating disorder category. Third, feeding disorders that usually emerge in childhood were relocated to the same chapter with the other eating disorders, and the whole group was labelled 'Feeding and Eating Disorders'. The aim of this change was to make the review and comparison of diagnoses more straightforward (American Psychiatric Association, 2013). Figure 2 illustrates the categorisation of DSM-5 Feeding and Eating Disorders.

Figure 2. DSM-5 Diagnostic classification of eating and feeding disorders. Specific eating disorders Anorexia Nervosa, Bulimia Nervosa, Binge-Eating Disorder (BED), Other Specified Feeding or Eating Disorder (OSFED), Unspecified Feeding or Eating Disorder (UFED), Pica, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder (ARFID).



*Bulimia Nervosa of low frequency and/or limited duration (Bulimia low freq/duration), Binge Eating Disorder of low frequency and/or limited duration (BED low freq/duration)

The diagnosis of anorexia nervosa faced some significant changes in this version of the DSM. First, the weight loss criterion was redefined to allow more subjectivity to consider individuals' weight history and growth trajectory. Second, the explicit verbalisation of fear of weight gain was no longer required, making an anorexia nervosa diagnosis possible with those who were not cognitively capable of verbalising this fear. Finally, the diagnosis could also be made in the absence of amenorrhea (American Psychiatric Association, 2013). Still, the implications of the revision are not known. One possible unintentional result of the revised criteria for anorexia nervosa might be that it could lead to a more heterogeneous patient group, diluting the diagnosis' predictive value.

The diagnosis of bulimia nervosa was changed in the DSM-5 so that bingeing and compensatory behaviour only have to occur once a week for 3 months. In addition, the subtypes were abandoned. Further, the binge eating disorder was raised to a distinct specific eating disorder diagnosis, and the requirement for binge eating frequency was changed again from twice a week to once a week for 3 months (American Psychiatric Association, 2013).

The DSM-5 classification created an entirely new diagnostic category called other specified feeding and eating disorder (OSFED). This category consisted of five different diagnoses: atypical anorexia nervosa, bulimia nervosa of low frequency and/or limited duration, BED of low frequency and/or limited duration, purging disorder and night eating syndrome (American Psychiatric Association, 2013).

The new classification included a residual diagnostic category called unspecified feeding and eating disorders. The criteria for the diagnosis was that there had to be an eating disorder causing clinically significant distress or impairment, but no other criteria for an eating disorder could be fulfilled (American Psychiatric Association, 2013).

The DSM-5 eating and feeding disorder category also includes avoidant/restrictive food intake disorder (ARFID), reformulated from the DSM-IV diagnosis of feeding disorder of infancy or early childhood (FDIEC). This also includes pica and rumination disorder, where relatively minor changes were made to their definitions. These diagnoses were recategorised to emphasise that ARFID, rumination disorder and pica can affect individuals in all age ranges (American Psychiatric Association, 2013; Hartmann, 2015).

The exact diagnostic criteria for DSM-5 Feeding and Eating Disorders are described in Table 4. In each diagnosis, all the criteria have to be fulfilled.

Table 4. Diagnostic criteria for DSM-5 Feeding and Eating Disorders.

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR DSM-5 FEEDING AND EATING DISORDERS
SPECIFIED EATING OR FEEDING DISORDER	
Anorexia Nervosa (AN)	A. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than minimally expected. B. Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight. C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight. Type *Restricting type*: During the last three months, the individual has not engaged in recurrent episodes of binge eating or purging behaviour (i.e. self-induced vomiting, or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting and/or excessive exercise. *Binge-eating/purging type*: During the last three months the individual has engaged in recurrent episodes of binge eating or purging behaviour (i.e. self-induced vomiting, or the misuse of laxatives, diuretics, or enemas).
Bulimia Nervosa (BN)	A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: 1. Eating in a discrete period of time (e.g. within any 2 hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances. 2. A sense of lack of control over eating during the episodes (e.g. a feeling that one cannot stop eating or control what or how much one is eating. B. Recurrent inappropriate compensatory behaviors to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise. C. The binge eating and inappropriate compensatory behaviors both occur, on average, at least once a week for 3 months. D. Self-evaluation is unduly influenced by body shape and weight. E. The disturbance does not occur exclusively during episodes of anorexia nervosa.

Binge Eating Disorder (BED)	A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: 1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat in a similar period of time under similar circumstances 2. The sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating) B. Binge-eating episodes are associated with three (or more) of the following: 1. Eating much more rapidly than normal 2. Eating until feeling uncomfortably full 3. Eating large amounts of food when not feeling physically hungry 4. Eating alone because of being embarrassed by how much one is eating 5. Feeling disgusted with oneself, depressed, or very guilty afterward C. Marked distress regarding binge eating is present. D. The binge eating occurs, on average, at least 1 day a week for 3 months E. The binge eating is not associated with the regular use of inappropriate compensatory behavior as in bulimia nervosa and does not occur exclusively during the course of anorexia nervosa or bulimia nervosa.

OTHER SPECIFIED EATING OR FEEDING DISORDER (OSFED)

Symptoms characteristic of a feeding or eating disorder that cause clinical distress or impairment in social, occupational, or other important areas of functioning predominate. However, do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class.

Atypical Anorexia Nervosa (OSFED-AN)	All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual's weight is within or above the normal range.
Bulimia Nervosa of low frequency and/ or limited duration (OSFED-BN)	All of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory behaviors occur, on average, less than once a week and/ or for less than 3 months.
Binge Eating Disorder of low frequency and/ or limited duration (OSFED-BED)	All of the criteria for binge-eating disorder are met, except that the binge occurs, on average, less than once a week and/ or for less than 3 months.
Purging Disorder (OSFED-PD)	Recurrent purging behavior to influence weight or shape (e.g. self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
Night eating syndrome	Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness of recall of the eating. The night eating is not better explained by external influences such as changes in the individual's sleep-wake cycle or by local social norms. The night eating causes significant distress and/ or impairment in functioning. The disordered pattern of eating is not better explained by binge-eating disorder and or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

UNSPECIFIED FEEDING OR EATING DISORDER (UFED)

Symptoms characteristic of a feeding and eating disorder & cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate. However, do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. Used when the clinician chooses not to specify the reason that criteria are not met for a specific feeding and eating disorder. This includes times when there is insufficient information to make a more specific diagnosis (e.g., in an emergency room setting).

Avoidant/Restrictive Food Intake Disorder (ARFID)	A. An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: 1. Significant loss of weight (or failure to achieve expected weight gain or faltering growth in children). 2. Significant nutritional deficiency 3. Dependence on enteral feeding or oral nutritional supplements 4. Marked interference with psychosocial functioning B. The behavior is not better explained by lack of available food or by an associated culturally sanctioned practice. C. The behavior does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is experienced. D. The eating disturbance is not attributed to a medical condition, or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behavior exceeds what is usually associated, and warrants additional clinical attention.
Rumination Disorder	A. Repeated regurgitation of food for a period of at least one month. Regurgitated food may be re-chewed, re-swallowed, or spit out. B. The repeated regurgitation is not due to an associated gastrointestinal condition or other medication condition (e.g., gastroesophageal reflux, pyloric stenosis). C. The eating disturbance does not occur exclusively in the course of anorexia nervosa, bulimia nervosa, binge eating disorder, or avoidant/restrictive Food Intake disorder. D. If the symptoms occur in the presence of another mental disorder (e.g., intellectual developmental disorder or another neurodevelopmental disorder), they are severe enough to warrant independent clinical attention.
Pica	A. Persistent eating of non-nutritive substances for a period of at least one month. B. The eating of non-nutritive, nonfood substances is inappropriate to the developmental level of the individual. C. The eating behaviour is not part of a culturally supported or socially normative practice. D. If occurring in the presence of another mental disorder (e.g. intellectual disability, autistic spectrum disorder, schizophrenia), or during a medical condition (including pregnancy), it is sufficiently severe to warrant additional clinical attention.

In addition, for the first time, DSM-5 included a severity grading for anorexia nervosa, bulimia nervosa, and binge eating disorder, although knowledge regarding how the severity indicators indicate the outcome is still limited (Smith, Ellison, Crosby, Engel, Mitchell, Crow, Peterson, Le Grange, & Wonderlich, 2017). Table 5 describes the severity criteria for each eating disorder.

Table 5. The severity criteria for DSM-5 defined eating disorders

DIAGNOSIS	THE SEVERITY CRITERIA FOR DSM-5 DEFINED EATING DISORDERS
Anorexia nervosa	Mild: BMI more than 17 kg/m2 Moderate: BMI 16- 16.99 kg/m2 Severe: BMI 15-15.99 kg/m2 Extreme: BMI less than 15 kg/m2
Bulimia nervosa	Mild: An average of 1-3 episodes of inappropriate compensatory behaviours per week. Moderate: An average of 4-7 episodes of inappropriate compensatory behaviours per week. Severe: An average of 8-13 episodes of inappropriate compensatory behaviours per week. Extreme: An average of 14 or more episodes of inappropriate compensatory behaviours per week.
Binge eating disorder	Mild: 1 to 3 episodes per week, Moderate: 4 to 7 episodes per week, Severe: 8 to 13 episodes per week, Extreme: 14 or more episodes per week

2.1.5 International Classification of Diseases

The WHO's International Statistical Classification of Diseases and Related Health Problems (ICD) was developed to provide clinical diagnoses that can be used in clinical and reimbursement settings and for gathering public health data. Psychiatric diagnoses were added to the ICD-6 classification in 1949 (World Health Organization, 1949). Eating disorders were described for the first time in ICD-9 in 1977 (World Health Organization, 1977).

Eating and feeding disorder classification in ICD-10

The International Classification of Diseases 10th revision was released in 1992, and it is used in over 190 countries around the world (World Health Organization, 2003). It includes specific descriptions for anorexia nervosa (F50.0) and bulimia nervosa (F50.2). It also includes atypical anorexia nervosa (F50.1) and atypical bulimia nervosa diagnoses (F50.3), which are defined as 'disorders that

fulfill some of the features of the disorder but in which the overall clinical picture does not support that diagnosis'. For instance, in anorexia nervosa, a key symptom, such as amenorrhea or 'fear of being fat', may be absent in the presence of marked weight loss and weight-reducing behavior. The category of behavioural and emotional disorders with onset usually occurring in childhood and adolescence (F90-F98), also included the two following feeding disorder diagnoses: feeding disorder of infancy and childhood (F98.2) and pica of infancy and childhood (F98.3).

The major criticism of ICD-10 is that it does not recognise or offer a specific code for binge eating disorder (Walsh, 2019); symptoms fitting binge eating disorder receive diagnostic code F50.8, other eating disorders. Another issue is that ICD-10 is criticised for separating eating and feeding disorders into different categories and ignoring cultural differences (Uher & Rutter, 2012). Many patients also receive atypical or non-specific diagnoses that are not as clinically informative or usable (Claudino et al., 2019; Uher & Rutter, 2012). Table 6 describes the diagnostic criteria for ICD-10 eating disorders in detail, whereas Table 7 gives criteria for ICD-10 behavioural and emotional disorders with onset usually occurring in childhood and adolescence. In each diagnosis, all the criteria have to be fulfilled.

Table 6. Diagnostic criteria for ICD-10 eating disorders

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR ICD-10 EATING DISORDERS
Anorexia nervosa (F50.0)	A. Body weight is maintained at least 15% below that expected (either lost or never achieved), or Quetelet's body-mass index is 17.5 or less. Prepubertal patients may show failure to make the expected weight gain during the period of growth. B. The weight loss is self-induced, and one or more of the following may be present: self-induced vomiting; self-induced purging; excessive exercise; use of appetite suppressants and/or diuretics. C. There is body-image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, overvalued idea and the patient imposes a low weight threshold on himself or herself. D. A widespread endocrine disorder involving the hypothalamic-pituitary - gonadal axis is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency. If onset is prepubertal, the sequence of pubertal events is delayed or even arrested (growth ceases; in girls the breasts do not develop and there is a primary amenorrhoea; in boys the genitals remain juvenile).
Bulimia nervosa (F50.2)	A. Patient succumbs to episodes of overeating in which large amounts of food are consumed in short periods of time (at least twice a week for 3 months). B. There is a persistent preoccupation with eating, and craving for food; C. The patient attempts to counteract the effects of food by one or more of the following: self-induced vomiting; purging, alternating periods of starvation; use of drugs such as appetite suppressants, thyroid preparations or diuretics. When bulimia occurs in diabetic patients they may choose to neglect their insulin treatment. D. The psychopathology consists of a morbid dread of fatness and the patient sets herself or himself a sharply defined weight threshold, well below the premorbid weight that constitutes the optimum or healthy weight.
Atypical anorexia nervosa (F50.1)	Disorders that fulfil some of the features of anorexia nervosa but in which the overall clinical picture does not justify that diagnosis. For instance, one of the key symptoms, such as amenorrhoea or significant weight loss, is absent, but who otherwise present a fairly typical clinical picture. This diagnosis should not be made in the presence of known physical disorders associated with weight loss.
Atypical bulimia nervosa (F50.3)	Disorders that fulfil some of the features of bulimia nervosa, but in which the overall clinical picture does not justify that diagnosis. For instance, there may be recurrent bouts of overeating and overuse of purgatives without significant weight change, or the typical overconcern about body shape and weight may be absent.
Overeating associated with other psychological disturbances (F50.4)	Overeating due to stressful events, such as bereavement, accident, childbirth, etc.
Vomiting associated with other psychological disturbances (F50.5)	Repeated vomiting that occurs in dissociative disorders (F44.-) and hypochondriacal disorder (F45.2), and that is not solely due to conditions classified outside this chapter. This subcategory may also be used in addition to O21. (excessive vomiting in pregnancy) when emotional factors are predominant in the causation of recurrent nausea and vomiting in pregnancy.

Other eating disorders (F50.8)	Includes: pica of nonorganic origin in adults, psychogenic loss of appetite.
Eating disorder, unspecified (F50.9)	No description

Table 7. Diagnostic criteria for ICD-10 behavioural and emotional disorders with onset usually occurring in childhood and adolescence

DIAGNOSIS	BEHAVIOURAL AND EMOTIONAL DISORDERS WITH ONSET USUALLY OCCURRING IN CHILDHOOD AND ADOLESCENCE (F90-F98)
F98.2 Feeding disorder of infancy and childhood	A feeding disorder of varying manifestations usually specific to infancy and early childhood. It generally involves food refusal and extreme faddiness in the presence of an adequate food supply, a reasonably competent caregiver, and the absence of organic disease. There may or may not be associated rumination (repeated regurgitation without nausea or gastrointestinal illness).
F98.3 Pica of infancy and childhood	Persistent eating of non-nutritive substances (such as soil, paint chippings, etc.). It may occur as one of many symptoms that are part of a more widespread psychiatric disorder (such as autism), or as a relatively isolated psychopathological behaviour; only the latter is classified here. The phenomenon is most common in mentally retarded children and, if mental retardation is also present, F70-F79 should be selected as the main diagnosis.

Eating and feeding disorder classification in ICD-11

It has been nearly 30 years since the introduction of ICD-10, and in this time, research evidence on the prevalence, symptoms and treatment of eating disorders has increased considerably. The next revision, ICD-11, was first presented in May 2019 in advance to allow countries to have sufficient time to prepare translations, see how the new version would be used and train clinicians. This version will be officially launched in January 2022 (World Health Organization, 2018). One of the major goals of the DSM-5 and ICD-11 classifications was to better align them. Many of the same individuals participated in the workgroups for both manuals, allowing parallel development (Blashfield et al., 2014). Further, the ICD-11 classification of eating disorders aimed to be scientifically valid, clinically useful and globally applicable. The goal was that the new diagnostic definitions would enable clinicians to exercise their discretion when making the diagnosis (Reed et al., 2019).

Eating disorder diagnoses exhibited significant changes in ICD-11. The diagnostic criteria for in anorexia nervosa were relaxed. The amenorrhea criterion was removed, and as a whole, the criteria were made to resemble those of DSM-5. For bulimia nervosa, the new criteria include subjective binge eating, whereas ICD-

10 previously required objective binge eating. This change was made because of studies finding that individuals who subjectively experienced binge eating, but whose food intake was within normal limits, had as much psychopathology as individuals with actual objective binge eating (Fitzsimmons-Craft et al., 2014; Palavras, Morgan, Borges, Claudino, & Hay, 2013). Therefore, it appears that the sense of loss of control of eating, not the amount of food consumed, is the central psychopathological aspect. Moreover, an essential difference from the definition of bulimia nervosa in the DSM-5 is that instead of 3 months, a period of about 1 month during which binge eating and compensation behaviour occurs is sufficient for the diagnosis. In addition, binge eating disorder was recognised for the first time as a diagnostic entity in ICD-11. This version also included diagnostic numbers for other specified and unspecified eating disorders and similar diagnostic criteria to the DSM-5 for ARFID, rumination-regurgitation disorder and pica. So far, research indicates that the ICD-11 classification of eating disorders is more clinically useful and improves the accuracy of eating disorder diagnoses (Claudino et al., 2019).

Table 8. Diagnostic criteria for ICD-11 Feeding and Eating disorders

DIAGNOSIS	DIAGNOSTIC CRITERIA FOR ICD-11 EATING DISORDERS
Anorexia Nervosa	Is characterised by significantly low body weight for the individual's height, age and developmental stage that is not due to another health condition or to the unavailability of food. A commonly used threshold is body mass index (BMI) less than 18.5 kg/m2 in adults and BMI-for-age under 5th percentile in children and adolescents. Rapid weight loss (e.g. more than 20% of total body weight within 6 months) may replace the low body weight guideline as long as other diagnostic requirements are met. Children and adolescents may exhibit failure to gain weight as expected based on the individual developmental trajectory rather than weight loss. Low body weight is accompanied by a persistent pattern of behaviours to prevent restoration of normal weight, which may include behaviours aimed at reducing energy intake (restricted eating), purging behaviours (e.g. self-induced vomiting, misuse of laxatives), and behaviours aimed at increasing energy expenditure (e.g. excessive exercise), typically associated with a fear of weight gain. Low body weight or shape is central to the person's self-evaluation or is inaccurately perceived to be normal or even excessive.
Bulimia Nervosa	Is characterised by frequent, recurrent episodes of binge eating (e.g. once a week or more over a period of at least one month). A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eating notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten. Binge eating is accompanied by repeated inappropriate compensatory behaviours aimed at preventing weight gain (e.g. self-induced vomiting, misuse of laxatives or enemas, strenuous exercise). The individual is preoccupied with body shape or weight, which strongly influences self-evaluation. There is marked distress about the pattern of binge eating and inappropriate compensatory behaviour or significant impairment in personal, family, social, educational, occupational or other important areas of functioning. The individual does not meet the diagnostic requirements of Anorexia Nervosa.
Binge eating disorder	Is characterised by frequent, recurrent episodes of binge eating (e.g. once a week or more over a period of several months). A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eating notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten. Binge eating is experienced as very distressing, and is often accompanied by negative emotions such as guilt or disgust. However, unlike in Bulimia Nervosa, binge eating episodes are not regularly followed by inappropriate compensatory behaviours aimed at preventing weight gain (e.g. self-induced vomiting, misuse of laxatives or enemas, strenuous exercise). There is marked distress about the pattern of binge eating or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.
Other specified feeding or eating disorders	No description currently available
Feeding or eating disorders, unspecified	No description currently available

Avoidant-restrictive food intake disorder (ARFID)	Is characterised by avoidance or restriction of food intake that results in: 1) the intake of an insufficient quantity or variety of food to meet adequate energy or nutritional requirements that has resulted in significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or has otherwise negatively affected the physical health of the individual; or 2) significant impairment in personal, family, social, educational, occupational or other important areas of functioning (e.g.,due to avoidance or distress related to participating in social experiences involving eating). The pattern of eating behaviour is not motivated by preoccupation with body weight or shape. Restricted food intake and its effects on weight, other aspects of health, or functioning is not due to unavailability of food, not a manifestation of another medical condition (e.g. food allergies, hyperthyroidism) or mental disorder, and are not due to the effect of a substance or medication on the central nervous system including withdrawal effects.
Pica	Is characterised by the regular consumption of non-nutritive substances, such as non-food objects and materials (e.g., clay, soil, chalk, plaster, plastic, metal and paper) or raw food ingredients (e.g., large quantities of salt or corn flour) that is persistent or severe enough to require clinical attention in an individual who has reached a developmental age at which they would be expected to distinguish between edible and non-edible substances (approximately 2 years). That is, the behaviour causes damage to health, impairment in functioning, or significant risk due to the frequency, amount or nature of the substances or objects ingested.
Rumination-regurgitation disorder	Is characterised by the intentional and repeated bringing up of previously swallowed food back to the mouth (i.e., regurgitation), which may be re-chewed and re-swallowed (i.e. rumination), or may be deliberately spat out (but not as in vomiting). The regurgitation behaviour is frequent (at least several times per week) and sustained over a period of at least several weeks. The regurgitation behaviour is not fully accounted for by another medical condition that directly causes regurgitation (e.g., oesophageal strictures or neuromuscular disorders affecting oesophageal functioning) or causes nausea or vomiting (e.g. pyloric stenosis). Rumination-regurgitation disorder should only be diagnosed in individuals who have reached a developmental age of at least 2 years.

2.2 OCCURRENCE OF EATING DISORDERS

2.2.1 Aetiology of eating disorders

Despite numerous studies, we do not yet know why one person falls ill with an eating disorder and another does not. Rather than a single cause, the aetiology of eating disorders seems to be complex and multifactorial, including biological, environmental, psychosocial and developmental factors. The presence of any single predisposing factor does not mean that an eating disorder will occur; however, when a person has enough predisposing features, one cause can trigger an eating disorder (Schaumberg et al., 2017; Treasure, Duarte, & Schmidt, 2020). Below, some of the key recognised risk factors are briefly discussed.

The current understanding emphasises the role of genes in the development of eating disorders. Although the findings from genetic studies are still preliminary, it seems that many genes act together with environmental factors to increase the risk of eating disorders (Baker, Schaumberg, & Munn-Chernoff, 2017; Schaumberg et al., 2017; Trace, Baker, Peñas-Lledó, & Bulik, 2013). Perinatal factors may also play a role in the development of eating disorders. Studies have indicated that the risk of anorexia is threefold among very premature compared with full-term babies (Cnattingius, Hultman, Dahl, & Sparén, 1999). Multiple births also increase the risk of anorexia but not that of other eating disorders (Goodman, Heshmati, Malki, & Koupil, 2014).

Although eating disorders affect individuals of all ages, adolescence is a well-established risk time for the onset of eating disorders (Herpertz-Dahlmann, 2015; Schaumberg et al., 2017). Adolescence is defined as the period between childhood and adulthood, and often, the exact age is set at 12–18. However, research on brain development suggests that adolescence continues for several years after the legal age of adulthood (Jaworska & MacQueen, 2015). In adolescence, the individual undergoes a process of biological, psychological and social change. This evolution begins with the physical changes of puberty and challenges the integrity that the adolescent has achieved thus far. Difficulties in adjusting to developmental challenges, such as accepting the changing body, the new kind of relationship with parents and friends and the individual identity, can disturb the development process (Jaworska & MacQueen, 2015).

Girls have a higher eating disorder risk than boys, and in girls, an early onset of puberty is associated with an increased risk of eating disorders (Klump, 2013; Striegel-Moore et al., 2009; Weissman, 2019). One theory is that the increased adiposity and relative weight increases in puberty move girls' bodies farther from the socio-cultural ideals, and experiences of these changes earlier than peers may increase body dissatisfaction and subsequently eating disorder risk (Bulik, 2002; Klump, 2013; Treasure et al., 2020). It is also hypothesised that an increase in oestrogen levels during adolescence can activate genes that contribute to an eating disorder's development among girls (Klump, 2013; Treasure et al., 2020). In boys, early or late onset of adolescence also increases dissatisfaction with the own body and the risk of an eating disorder. Testosterone may be a protective factor, but evidence on this point is still scarce (Culbert, Burt, Sisk, Nigg, & Klump, 2014).

Socio-cultural factors that perpetuate the stigmatisation of obesity and the glorification of disordered eating behaviour can increase the probability of eating disorders (Grabe, Ward, & Hyde, 2008; Izydorczyk & Sitnik-Warchulska, 2018). Overall, the country and cultural context affect the occurrence of eating disorders to some extent, but eating disorders still occur across different races and ethnicities (Kolar, Rodriguez, Chams, & Hoek, 2016; Mitchison & Hay, 2014; van Hoeken, Burns, & Hoek, 2016). Moreover, the history of dieting, participation in aesthetic or weight-oriented sports, and body dissatisfaction have all been associated with eating disorders (Hilbert et al., 2014; Mitchison & Hay, 2014). Traumatic events and challenges in family and peer relationships can contribute to the onset of an eating disorder, although no single family dynamics can be blamed (Schaumberg et al., 2017). Last, numerous psychological factors have been linked to eating disorders like alexithymia, emotional regulation problems, a reduced theory of mind, cognitive rigidity, difficulty interpreting social situations, body image disturbances and such personality traits as perfectionism, impulsivity and neuroticism (Treasure et al., 2020).

Despite extensive studies, several questions still remain to be answered regarding the aetiology of eating disorders. For studying the variables that predict the development of eating disorders, precise information about the onset of different eating disorders is needed. This information is also vital for prevention efforts and treatment development.

2.2.2 Descriptive psychiatric epidemiology

Descriptive psychiatric epidemiology strives to determine the distribution and occurrence of psychiatric diseases in a population. The key measures are prevalence and incidence.

The term *prevalence* reflects the number of individuals affected by the disease in question at any given moment. Often, such terms as lifetime, point and period prevalence are used. *Lifetime prevalence*, also known as cumulative incidence, refers to the proportion of individuals who have been affected by the disease by a given time point. The term *lifetime* can sometimes be misleading because those assessed may have not yet reached the maximum age of risk to develop the disease. *Point* and *period* prevalence reflect the proportion of individuals who are affected by the disease over various timeframes. These often include the current time, the 3-month and 12-month point prevalence (Javaras & Hudson, 2015; Keski-Rahkonen & Silén, 2019).

The term *incidence* reflects the number of individuals who have become sick over a particular time. Disease prevalence is affected by the incidence, recovery and mortality of the disease. For example, in a disease with high incidence and high mortality, the disease's point prevalence can be low. For a disease with a medium incidence but a very persistent course and low mortality, the point prevalence at a given time can be high (Javaras & Hudson, 2015; Keski-Rahkonen & Silén, 2019).

Acknowledging the prevalence and incidence of a particular disease is a cornerstone for improving the prevention, detection and treatment of that disease. However, the true prevalence and incidence of disease can never really be known for a population. The best we can do is to estimate these factors as closely as possible. Community-based studies, where individuals are selected from the general population, are vital to these close estimates: Only a minority of patients with mental illness seek treatment; therefore, looking only at those who are detected in primary, secondary or tertiary care would significantly underestimate the number of patients affected by the disease (Henderson, Evans-Lacko, & Thornicroft, 2013).

2.2.3 Prevalence of eating disorders based on the DSM-5 diagnostic criteria

Since significant changes to the eating disorder classification were made, the new estimates of its prevalence and incidence are crucial. Because epidemiological studies of eating disorders mainly use the DSM classification and no epidemiological studies using ICD-11 criteria have been conducted to date, the prevalence and incidence of the DSM-5 eating disorders are discussed below.

Until now, many community-based studies have tried to disentangle the prevalence and incidence of DSM-5 eating disorders, but the information is still missing in many parts. One of the key reasons for this is that the reliable assessment of eating disorder occurrence in the community is costly and time consuming. In particular, using structured diagnostic interviews rather than self-reports to make accurate diagnoses requires access to many resources. The information gap is more prevalent in males, and there is less information on specified and unspecified eating disorders than there is on typical eating disorders (Javaras & Hudson, 2015).Regionally, little information has been collected on Nordic eating disorder prevalence (Dahlgren, Stedal, & Wisting, 2018).

The prevalence rates for specified eating disorders seem to be higher in the DSM-5 era than in the DSM-IV era (Flament, Buchholz et al., 2015a; Lindvall Dahlgren, Wisting, & Ro, 2017). However, the estimates of occurrence show wide discrepancies. In community samples of females, the DSM-5 lifetime prevalence has ranged from 0.8% to 3.6% for anorexia nervosa (Fairweather-Schmidt & Wade, 2014; Glazer et al., 2019; Micali et al., 2017; Mohler-Kuo, Schnyder, Dermota, Wei, & Milos, 2016; Munn-Chernoff et al., 2015; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Stice et al., 2013; Udo & Grilo, 2018), 0.46% to 2.6% for bulimia nervosa (Bagaric, Touyz, Heriseanu, Conti, & Hay, 2020; Fairweather-Schmidt & Wade, 2014; Glazer et al., 2019; Micali et al., 2017; Smink et al., 2014; Stice et al., 2013; Trace et al. 2012; Udo & Grilo, 2018) and 0.4% to 6.1% for binge eating disorder (Bagaric et al. 2020; Cossrow et al., 2016; Fairweather-Schmidt & Wade, 2014; Glazer et al., 2019; Hudson, Coit, Lalonde, & Pope, 2012; Micali et al., 2017; Mustelin, Raevuori, Hoek, Kaprio, & Keski-Rahkonen, 2015a; Smink et al., 2014; Stice et al., 2013; Trace et al., 2012; Udo & Grilo, 2018).Furthermore, estimates for other specified and unspecified feeding or eating disorders have been even more mixed, with lifetime prevalence ranges among females of 0.6%–11.5% (Fairweather-Schmidt & Wade, 2014; Micali et al., 2017; Mustelin, Lehtokari, & Keski-Rahkonen, 2016a; Smink et al., 2014; Stice et al., 2013) and 0.09%–4.7% (Micali et al., 2017; Mustelin et al., 2016a; Smink et al., 2014; Wade & O'Shea, 2015), respectively.

Additionally, the ranges for point and period prevalence has been identified as 0.0%–3.19% for anorexia nervosa (Allen et. al, 2013a; Flament et al., 2015a; Flament et al., 2015b; Machado, Goncalves, & Hoek, 2013; Masheb et al., 2021; Micali et al., 2015; Micali et al., 2017; Mitchison et al., 2019; Mohler-Kuo et al., 2016; Smink et al., 2014; Solmi, Hotopf, Hatch, Treasure, & Micali, 2016; Udo & Grilo, 2018), 0.22%-7.9% for bulimia nervosa (Allen et al., 2013a; Bagaric et al. 2020; Flament et al., 2015a; Flament et al., 2015b; Machado et al., 2013; Masheb et al., 2021; Micali et al., 2015; Micali et al., 2017; Mitchison et al., 2019; Smink et al., 2014; Solmi et al., 2016; Udo & Grilo, 2018) and 0.54%-4.4% for binge eating disorder (Allen et al., 2013a; Bagaric et al., 2020; Cossrow et al., 2016; Flament et al., 2015a; Flament et al., 2015b; Hudson et al., 2012; Machado et al., 2013; Masheb et al., 2021; Micali et al., 2015; Micali et al., 2017; Mitchison et al., 2019; Olsen, Koch, Skovgaard & Strandberg-Larsen, 2021; Smink et al., 2014; Solmi et al., 2016; Udo & Grilo, 2018).

The few studies conducted among males show lifetime ranges of 0.1%-0.2% for anorexia nervosa (Mohler-Kuo et al., 2016; Smink et al., 2014; Udo & Grilo, 2018), 0.08–1.21% for bulimia nervosa (Bacaric et al. 2020; Smink et al., 2014; Udo & Grilo, 2018) and 0.42–2.1% for binge eating disorder (Bacaric et al. 2020; Cossrow et al., 2016; Hudson et al., 2012; Smink et al., 2014; Udo & Grilo, 2018).

The ranges for point prevalence have been identified as 0%–1.6% for anorexia nervosa (Allen et al., 2013a; Flament et al., 2015a; Flament et al., 2015b; Masheb et al., 2021; Micali et al., 2015; Mitchison et al., 2019; Mohler-Kuo et al., 2016; Smink et al., 2014; Solmi et al., 2016; Udo & Grilo, 2018), 0.00%-3.5% for bulimia nervosa (Allen et al., 2013a; Bacaric et al. 2020; Flament et al., 2015a; Flament et al., 2015b; Masheb et al., 2021; Micali et al., 2015; Mitchison et al., 2019; Smink et al., 2014; Solmi et al., 2016; Udo & Grilo, 2018), and 0.2%-2.9% for binge eating disorder (Allen et al., 2013a; Bagaric et al., 2020; Cossrow et al., 2016; Flament et al., 2015a; Flament et al., 2015b; Hudson et al., 2012; Masheb et al., 2021; Micali et al., 2015; Mitchison et al., 2019; Olsen et al. 2021; Smink et al., 2014; Solmi et al., 2016; Udo & Grilo, 2018)

Tables 10, 11, 12 and 13 include details about the previously conducted community-based prevalence studies in the DSM-5 era. For clarity and simplicity, no confidence intervals or fastidious information about the studies are included. Further, some information was missing in individual studies, and there were some inconsistencies in the reported numbers. The data are described as accurately as possible.

Table 10. Previous lifetime prevalence estimates of eating disorders in DSM-5 era among females

AUTHORS	SAMPLE N, COUNTRY	AGE (RANGE, MEAN AGE)	ASSESSMENT INSTRUMENT	TOTAL PREVALENCE	
Stice et al. 2013	496 USA	Baseline 12-15, followed 8 yrs	One stage sampling. EDDI-Interview, in person. Professional interviewers.	13.1%	
Fairweather-Schmidt et al. 2014, Wade & O'Shea 2015	699 Australia	12.7-19.84 yrs, mean age each wave 13.96, 15.1,16.9yrs	One stage sampling. EDE-interview, by telephone. Professional interviewers.	15.1%	
Smink et al. 2014	861 Netherland	Mean 19.1 yrs	Two-stage sampling. First stage: Screen included self-report questionnaires + WHO-CIDI Interview, by lay-interviewers. Second stage: SCID-I -interview and part of EDE, by professional interviewers, by telephone.	5.7%	
Mohler Kuo et al. 2016	5220 Switzerland	15-60yrs	Two-stage sampling. First stage: questions about household structures Second stage WHO-CIDI, by telephone.		
Munn-Chernoff et al. 2015	3230 USA	18-25 yrs, mean 21.5 yrs	One stage sampling. Adapted version SSAGA, by telephone.		
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered.	3.1%	
Micali et al. 2017	5658 United Kingdom	mean 47.8 yrs	Two-stage sampling. First stage: EDDS questionnaire, Second stage revised, SCID-I interview, in person	15.33%	
Hudson et al. 2012	888 (66.4% females) USA	Mean age 46.7 yrs	SCID-interview for a sample, and then application of the prevalence estimates for the increase National Comorbidity Survey Replication. Interview by telephone or in person. Professional interviewers.		
Wagner et al. 2017	3615 (boys and girls) Austrian	10-18 yrs	Two-stage sampling. First stage: screen for mental health: The Youth Self-Report + SCOFF. Second stage CDI-MD-interview, by telephone. Professional interviewers.	5.47%	
Glazer et. al 2019	9031 USA	mean 12.0 yrs, followed aged 9-28+	MRFS-questionnaire	26.7%*	
Cossrow et. al 2016	12182, USA	Adults of 18 yeas and older, Mean age 51.1 yrs	Internet survey, questions representing DSM-5 or DSM-IV-TR BED symptom criteria 3-month, 12-month prevalence		
Trace et al. 2012	13,295 Sweden	20-47yrs	Web-based questionnaire/ SCID-interview, by telephone		
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 years old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person		

	AN	BN	BED	OSFED TOTAL	ATYPI-CAL AN	BN LOW	BED LOW	PURGING DISORDER	UFED
	0.8%	2.6%	3.0%	11.5%	2.8%	4.4%	3.6%	3.4%	
	2.0%	1.0%	2.4%	5.0%	1.9%	2.6%		0.6%	4.7%
	1.7%	0.8%	2.3%	0.6%					0.2%
	1.9%								
	1.37%							3.77%	
	1.42%	0.46%	1.25%						
	3.64%	2.15%	1.96%	7.64%; (includes other-OSFED 2.14%)	1.7%	1.42%	0.9%	1.28%	0.09%
			3.6%						
	1.6%	2.1%	6.1%			3.6%	12.2%	6.2%	
			2.61%						
		1.6%	0.4%						
		2.59%	1.85% (Broad)						

n, number; yrs, years; EDDI, The Eating Disorder Diagnostic Interview; EDE, The Eating Disorder Examination; SCID, Structured clinical Interview; WHO-CIDI, World Health Organization Composite International Diagnostic Interview; EDI-2, Eating Disorder Inventory-2; OSFED-NES, Night eating syndrome; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; EDDS, Eating Disorders Diagnostic Schedule; SSAGA, Semi-Structured Assessment on the Genetics of Alcoholism; MRFS, McKnight Risk Factor Survey; CDI-MD, Children's Diagnostic Interview for Mental Disorders

**Prevalence of any full or subthreshold eating or feeding disorder among those who participated at least three consecutive surveys. As the study assessed transition between eating disorder diagnoses in follow-up, the full prevalence cannot be directly assessed.*

Table 11. Previous lifetime prevalence estimates of eating disorders in DSM-5 era among males

AUTHORS	SAMPLE N, COUNTRY	AGE (RANGE, MEAN AGE)	ASSESSMENT INSTRUMENT	TOTAL PREVA-LENCE	
Smink et al. 2014	736, Netherlands	Mean 19.1 yrs	Two-stage sampling. First stage: Screen included self-report questionnaires + WHO-CIDI Interview, by lay-interviewers. Second stage: SCID-I -interview and part of EDE, by professional interviewers, by telephone	1.2%	
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered	0.6%	
Mohler-Kuo et al. 2016	4818 Switzerland	15-60yrs	Two-stage sampling. First stage: questions about household structures Second stage WHO-CIDI, by phone.		
Hudson et al. 2012	888 (66.4% females) USA	Mean age 46.7 yrs	SCID-interview, for a sample of and then application to prevalence estimates for the increase National Co-morbidity Survey Replication. Interview by telephone or in person. Professional interviewers.		
Wagner et al. 2017	3615 Austrian	10-18 yrs	Two-stage sampling. First stage: screen for mental health: The Youth Self-Report + SCOFF. Second stage CDI-MD-interview, by phone. Professional interviewers.	0.64%	
Cossrow et al 2016	10215 USA	Adults of 18 yeas and older, Mean age 51.1 yrs	Internet survey, questions representing DSM-5 or DSM-IV-TR BED symptom criteria 3-month, 12-month prevalence		
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 years old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person		

n, number; yrs, years; EDE, The Eating Disorder Examination; SCID, Structured clinical Interview; WHO-CIDI, World Health Organization Composite International Diagnostic Interview; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; CDI-MD, Children's Diagnostic Interview for Mental Disorders

	AN	BN	BED	OSFED TOTAL	ATYPI-CAL AN	BN LOW	BED LOW	PURGING	UFED
	0.1%	0.1%	0.7%	0.3%					0.0%
	0.12%	0.08%	0.42%						
	0.2%								
			2.1%						
			1.41%						
		1.21%	0.74% broad						

Table 12. Lifetime prevalence of DSM-5 defined eating disorders among all genders

AUTHORS	SAMPLE n, country	AGE (range, mean age)	ASSESSMENT INSTRUMENT	TOTAL PREVALENCE	
Cossrow et al 2016	22 397 USA	Adults of 18 yeas and older, Mean age 51.1 yrs	Internet survey, questions representing DSM-5 or DSM-IV-TR BED symptom criteria 3-month, 12-month prevalence		
Wagner et al. 2017	3615 (boys and girls) Austrian	10-18 yrs	Two-stage sampling. First stage: screen for mental health: The Youth Self-Report + SCOFF. Second stage CDI-MD-interview, by phone. Professional interviewers.	3.73% includes pica, rumination ARFID	
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered	1.9%	
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 years old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person		

n, number; yrs, years; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; CDI-MD, Children's Diagnostic Interview for Mental Disorders; EDE, The Eating Disorder Examination

	AN	BN	BED	OSFED TOTAL	ATYP-ICAL AN	BN LOW	BED LOW	PURGING	UFED
			2.03%						
	1.44%	0.32%	0.2%	0.59%					
	0.8%	0.28%	0.85%						
		3.80%	2.59% broad						

Table 13. Previous point and period prevalence estimates of eating disorders in DSM-5 era among females

AUTHORS	SAMPLE n, country	AGE (range, mean age)	ASSESSMENT INSTRUMENT; Prevalence time-frame	TOTAL PREVA-LENCE	
Smink et al. 2014	861 Netherland	Mean 19.1 yrs	Two-stage sampling. First stage: Screen included self-report questionnaires + WHO-CIDI Interview, by lay-interviewers. Second stage: SCID-I -interview and part of EDE, by professional interviewers, by telephone Point prevalence at the time of the interview	3.7%	
Flament et al. 2015a and 2015b	1789 Canada	Range 11-20 yrs Mean 14.19 yrs	Self-report questionnaire the EDDS	10.1%	
Allen et al. 2013a	703 Australia	Follow up 14, 17, and 20 yrs	Self-report questionnaires adapted from ChEDE and EDE-Q 1 month	15.2% at (20yrs)	
Machado et al. 2013	3048 Portugal	two samples: 1) students 12-23 yrs 2) university students 18-58 yrs	Screening EDE-Q, Interview EDE, in person	3.87%	
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered 12-month prevalence	0.9%	
Solmi et al. 2016	1698 (66% females) United Kingdom	16-90 yrs, mean age 36.4 yrs	Two-stage sampling. First stage: SCOFF, second stage SCID interview 12-month prevalence	10.1%	
Micali et al. 2017	5658 United Kingdom	mean 47.78 yrs	Two-stage sampling. First stage: EDDS questionnaire, Second stage revised, SCID-I interview, in person 12-month prevalence	3.61%	
Mohler-Kuo et al. 2016	5615 Switzerland	15-60yrs	Two-stage sampling. First stage: questions about household structures Second stage WHO-CIDI, by phone. 12-month prevalence		
Hudson et al. 2012	888 (66.4% females) USA	Mean age 46.7 yrs	SCID-interview, for a sample of and then application to prevalence estimates for the increase National Comorbidity Survey Replication. Interview by telephone or in person. Professional interviewers. 12-month prevalence		
Cossrow et al 2016	12182 USA	Adults of 18 yeas and older, Mean age 51.1 yrs	Internet survey, questions representing DSM-5 or DSM-IV-TR BED symptom criteria 3-month, 12-month prevalence		
Mitchison et al. 2019	2455 females Australia	11-19 yrs, mean 14yrs 11months	An online survey including EDE-Q, questions from NEQ, K10, PedsQL SF-15, and additional questions by researchers, 1-month prevalence	32.9%*	

	AN	BN	BED	OSFED TOTAL	ATYP-ICAL AN	BN LOW	BED LOW	PURGING	UFED
	1.2%	0.6%	1.6%	0.3%					0.0%
	0.1%	2.0%	0.7%	6.6%	1.35%	3.69%		1.5%	
	0.6% (20yrs)	7.9% (20yrs)	4.1% (20yrs)	2.7% (20yrs)	0.1% (20yrs)			1.6% (20yrs)	
	0.69%	0.59%	0.62%	1.97% named EDNOS					
	0.08%	0.22%	0.60%						
	0%	1.2%	4.7%	4.2%				0.8%	
	0.23%	0.41%	1.03%	1.65% Includes other-osfed 0.29%	0.35%	0.44%	0.38%	0.23%	
	0.07%								
			1.7%						
			1.6% 3-month 2.0% 12-month						
	1.3%	7.7%	1.8%	14.5% (includes also OS-FED-NES 3.6%)	4.8%	2.7%	0.5%	4.8%	6.3%

Micali et al. 2015	Wave 14+, 3,416 girls, Wave 16+ 3,059 girls United Kingdom	Wave 14+ mean 14.0 Wave 16+ mean 16.7	Adapted questions from Youth Risk Behavior Surveillance System questionnaire. Parental report of AN symptoms based on DAWBA Previous year prevalence	6.55% (14yrs) 12.88% (16yrs)	
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 yrs old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person, current prevalence		
Masheb et al. 2021	1121 veterans, (51,2% women) USA	Mean age of 43.8 yrs	EDDS-5 questionnaire and other validated measures of eating pathology and mental health. 3-month prevalence	32.8%	
Olsen et al. 2021	1,404 Denmark	mean age 16.5 yrs	Web-based questionnaire that included items of eating cognitions and behaviors adapted from the McKnight Risk Factor Survey and the Avon Longitudinal Study of Parents and Children. 1,511 also participated in a subsequent face-to-face examination The 1-year prevalence		

* *without a criterion for clinical significance;*

n, number; yrs, years; OSFED-NES, Night eating syndrome; EDE-Q, Eating Disorder Examination Questionnaire; NEQ, Night Eating Questionnaire; K10, K10 Psychological Distress Scale; PedsQL SF-15, Pediatric Quality of Life Scale SF-15; EDDS, Eating Disorder Diagnostic Scale; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; WHO-CIDI, World Health Organization Composite International Diagnostic Interview; SCID, Structured clinical Interview, ChEDE, Child Eating Disorder Examination; EDDS-5, The Eating Disorder Diagnostic Scale-5; EDE, The Eating Disorder Examination; DAWBA, Development and Wellbeing Assessment

	3.19% (14yrs) 2.35% (16yrs)	0.41% (14yrs) 1.34% (16yrs)	0.61% (14yrs) 1.54% (16yrs)			1.7% (14yrs) 4.48% (16yrs)	0.03% (14yrs) 0.72% (16yrs)	0.61% (14yrs) 2.45% (16yrs)	
		0.81%	0.54% broad						
	0.0%	6.1%	4.4%	22.3% including 5.2% for night eating syndrome	13.6%	0.0%	1.4%	2.1%	
			3.6%						

Table 14. Previous point and period prevalence estimates of eating disorders in DSM-5 era among males

AUTHORS	SAMPLE n, country	AGE (range, mean age)	ASSESSMENT INSTRUMENT Prevalence time-frame	TOTAL PREVALENCE	
Smink et al. 2014	736, Netherland	Mean 19.1 yrs	Two-stage sampling. First stage: Screen included self-report questionnaires + WHO-CIDI Interview, by lay-interviewers. Second stage: SCID-I -interview and part of EDE, by professional interviewers, by telephone Point prevalence at the time of the interview	0.5%	
Flament et al. 2015a and 2015b	1233 Canada	Range 11-20 yrs 14.19 yrs	Self-report questionnaire the EDDS	3.4%	
Allen et al. 2013a	680 Australia	Follow up 14, 17, and 20 yrs	Self-report questionnaires adapted from ChEDE and EDE-Q 1-month	2.9% (20yrs)	
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered 12-month prevalence	0.32%	
Solmi et al. 2016	1698 (66% females) United Kingdom	16-90 yrs, mean age 36.4 yrs	Two-stage sampling. First stage: SCOFF, second stage SCID interview 12-month prevalence	0.9%	
Mohler-Kuo et al. 2016	4423 Switzerland	15-60 yrs	Two-stage sampling. First stage: questions about household structures Second stage WHO-CIDI, by phone. 12-month prevalence		
Hudson et al. 2012	888 (66.4% females) USA	Mean age 46.7yrs	SCID-interview, for a sample of and then application to prevalence estimates for the increase National Co-morbidity Survey Replication. Interview by telephone or in person. Professional interviewers. 12-month prevalence		
Cossrow et al 2016	10215 USA	Adults of 18 years and older, Mean age 51.1yrs	Internet survey, questions representing *DSM-5* or *DSM-IV-TR* BED symptom criteria 3-month, 12-month prevalence		
Mitchison et al. 2019	2495 Australia	11-19 years, mean 14yrs 11months	An online survey including EDE-Q, questions from NEQ, K10, PedsQL SF-15, and additional questions by researchers, 1-month prevalence	12.8*	
Micali et al. 2015	Wave 14+, 2,742 Wave 16+ 2,154 United Kingdom	Wave 14+ mean 14.0 Wave 16+ mean 16.7	Adapted questions from Youth Risk Behavior Surveillance System questionnaire. Parental report of AN symptoms based on DAWBA Previous year prevalence	3.09% (14yrs) 3.20% (16yrs)	
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 years old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person, current prevalence		

	AN	BN	BED	OSFED TOTAL	ATYPI-CAL AN	BN LOW	BED LOW	PURGING	UFED
	0.1%	0.1%	0.3%	0.0%					0.0%
	0%	1.3%	0.2%	1.9%	0.41%	0.73%		0.74%	
	0.0% (20yrs	1.6% (20yrs)	0.7% (20yrs)	0.6% (20yrs)	0.3% (20yrs)			0.3% (20yrs)	
	0.01%	0.05%	0.26%						
	0.0%	0%	0.9%	0%					
	0.03%								
			0.8%						
			0.76% 3-month 1.24% 12-month						
	0.0%	1.8%	0.2%	8.5% (includes OSFED-NES 4.9%)	1.2%	1.2%	0.0%	1.6%	1.3%
	1.60% (14yrs) 0.88% (16yrs)	0.07% (14yrs) 0.05% (16yrs)	0.33% (14yrs) 0.60% (16yrs)			0.88% (14yrs) 1.44% (16yrs)	0.04% (14yrs) 0% (16yrs)	0.18% (14yrs) 0.23% (16yrs)	
		0.4%	0.30% broad						

Masheb et al. 2021	1121 veterans, (51,2% women) USA	Mean age of 43.8 yrs	EDDS-5 questionnaire and other validated measures of eating pathology and mental health. 3-month prevalence	18.8%	
Olsen et al 2021	1,105 Denmark	mean age 16.5 years	Web-based questionnaire that included items of eating cognitions and behaviors adapted from the McKnight Risk Factor Survey and the Avon Longitudinal Study of Parents and Children. 1,511 also participated in a subsequent face-to-face examination The 1-year prevalence		

* *without a criterion for clinical significance*

n, number; yrs, years; OSFED-NES, Night eating syndrome; EDE-Q, Eating Disorder Examination Questionnaire; NEQ, Night Eating Questionnaire, K10, K10 Psychological Distress Scale; PedsQL SF-15, Pediatric Quality of Life Scale SF-15; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; WHO-CIDI, World Health Organization Composite International Diagnostic Interview; SCID, Structured clinical Interview; ChEDE, Child Eating Disorder Examination; EDDS, Eating Disorder Diagnostic Scale; EDDS-5, The Eating Disorder Diagnostic Scale-5; EDE, The Eating Disorder Examination; DAWBA, Development and Wellbeing Assessment

	0.0%	3.5%	2.9%	12.4% including 6.0% for night eating syndrome	4.9%	0.2%	0.6%	0.7%	
			1.2%						

Table 15. Point and period prevalence of DSM-5 defined eating disorders among all genders

AUTHORS	SAMPLE n, country	AGE (range, mean age)	ASSESSMENT INSTRUMENT Prevalence time-frame	
Hay et al. 2015a	6041 (51% females) Australia	Range 15-96 yrs	Non-diagnostical interview but eating disorder assessment was based on diagnostic questions in EDE-interview, lay-interviewers, in person 3-month prevalence	
Hay et al. 2017	2014 (n = 2732) and 2015 (n =3005) Australia	15 yrs or older	Interview based on diagnostic questions from EDE, in person 3-month prevalence: assessment years 2014 and 2015	
Solmi et al. 2016	1698 (66% females) United Kingdom	16-90 yrs, mean age 36.4 yrs	Two-stage sampling. First stage: SCOFF, second stage SCID interview 12-month prevalence	
Hammerle et al. 2016	1654 (873 females, 781 males) Germany	Mean age 13.4 yrs	SIAB-S in questionnaire form and EDI-2, objective measures of height/weigh	
Wagner et al. 2017	3653 (boys and girls) Austria	10-18 yrs	Two-stage sampling. First stage:screen for mental health: The Youth Self-Report + SCOFF. Second stage CDI-MD-interview, by phone. Professional interviewers. Current point prevalence	
Udo & Grilo 2018	36 306 men and women USA	18-60 yrs	One-stage AUDADIS-5, in person, Lay-administered 12-month prevalence	
Flament et al. 2015a and 2015b	3022 Canada	Range 11-20 yrs mean age 14.19 yrs	Self-report questionnaire the EDDS	
Cossrow et al 2016	22,397 USA	Adults of 18 yeas and older, Mean age 51.1 yrs	Internet survey, questions representing DSM-5 or DSM-IV-TR BED symptom criteria 3-month, 12-month prevalence	
Mitchison et al. 2019	5072 (49.2% identified as males, 48.4% as females and 2.4% as others) Australia	11-19 years, mean 14yrs 11months	An online survey including EDE-Q, questions from NEQ, K10, PedsQL SF-15, and additional questions by researchers, 1-month prevalence	
Micali et al. 2015	Wave 14+, 6,140 (55.5% females) Wave 16+ 5,069 (58.7 females) United Kingdom	Wave 14+ mean 14.0yrs Wave 16+ mean 16.7 yrs	Adapted questions from Youth Risk Behavior Surveillance System questionnaire Previous year prevalence	
Bagaric et al. 2020	2977 (51.2% females) Australia	Over 15 years old, mean age 53.9 yrs	Questions modelling EDE -interview, Lay interviewers, in person, current prevalence	
Olsen et al. 2021	2509 (1404 girls) Denmark	mean age 16.5 yrs	Web-based questionnaire that included items of eating cognitions and behaviors adapted from the McKnight Risk Factor Survey and the Avon Longitudinal Study of Parents and Children. 1,511 also participated in a subsequent face-to-face examination The 1-year prevalence	

	TOTAL PREVALENCE	AN	BN	BED	OSFED TOTAL	ATYPICAL AN	BN LOW	BED LOW	PURGING	UFED
	16.3% for eating disorder or disordered eating	0.46%	0.66%	5.58%			0.7%	6.92%	0.58%	1.41%
	16.8% (year 2015) (17.1% including ARFID)	0.4% (year 2014) 0.5% (year 2015)	1.1% (year 2014) 1.2% (year 2015)	1.5% (year 2015)	3.2% (year 2015)	2.5% (year 2015)	0.5% (year 2015)	0.4% (year 2015)	0.3% (year 2015)	10.4% (year 2015)
	7.4%	0.0%	0.8%	3.6%	3%				0.6%	
	6.7%	0.3%	0.4%	0.5%	5,5%	3.6%	0%	0%	1.9%	
	1.56% includes also pica, rumination, ARFID	1.01%	0.17%	0.12%	0.3%					
	0.63%	0.05%	0.14%	0.44%						
	7.4%	0.1%	1.6%	0.5%	4.8%				1.4%	
				1.19 % 3-month 1.64% 12-month						
	22.2%* 13.6%**	0.7%* 0.5%**	4.6%* 3.3%**	1.0%* 0.8%**	11.2%* (includes OSFED-NES 4.1%) 6.6%** (includes OSFED-NES 2.7%)	2.9%* 2.2%**	2.1%* 1.2%**	0.3%* 0.2%**	3.2%* 1.5%**	3.8%* 2.3%**
	5.03% (14yrs) 9.13% (16yrs)	2.48% (14yrs) 1.75% (16yrs)	0.26% (14yrs) 0.81% (16yrs)	0.50% (14yrs) 1.15% (16yrs)			1.33% (14yrs) 3.22% (16yrs)	0.03% (14yrs) 0.42% (16yrs)	0.42% (14yrs) 1.53% (16yrs)	
			1.21%	0.84% Broad						
				2.6%						

** without a criterion for clinical significance, ** with a criterion for clinical significance*

n, number; yrs, years; OSFED-NES, Night eating syndrome; EDE-Q, Eating Disorder Examination Questionnaire; NEQ, Night Eating Questionnaire; K10, K10 Psychological Distress Scale; PedsQL SF-15, Pediatric Quality of Life Scale SF-15; AUDADIS-5, National Institute on Alcohol Abuse and Alcoholism Alcohol Use Disorder and Associated Disabilities Interview Schedule-5; SCID, Structured clinical Interview; SIAB-S, The structured interview for anorexia and bulimia nervosa—self report (SIAB-S) was used in questionnaire form; EDI-2, Eating Disorder Inventory 2; CDI-MD, Children's Diagnostic Interview for Mental Disorders; EDE, The Eating Disorder Examination, EDDS, Eating Disorder Diagnostic Scale

2.2.4 Incidence of eating disorders based on the DSM-5 diagnostic criteria

Knowing the incidence and the peak onset of eating disorders is essential because it helps to allocate prevention and detection of eating disorders. There are indications that the incidence is highest among 15-to 19-year-olds as 40 % of new cases emerge in this age group (Herpertz-Dahlmann, 2015). The incidence of eating disorders has been studied in only one previous community sample using DSM-5 criteria: Among American adolescent females and young women, the incidence over eight years was 104 per 100 000 person-years for anorexia nervosa, 289 per 100 000 person-years for bulimia nervosa, 343 per 100 000 person-years for binge eating disorder, 366 per 100 000 person-years for atypical anorexia nervosa, 504 per 100 000 person-years for subthreshold bulimia nervosa, 447 per 100 000 person-years for subthreshold bulimia nervosa and 447 per 100 000 person-years for purging disorder (Stice et al., 2013). In addition, no healthcare register–based studies on the incidence of eating disorders in the DSM-5 era have yet been conducted. Nevertheless, register-based studies would underestimate the true incidence because of the help-seeking bias.

The incidence of eating disorders in Finland was assessed in a few previous studies during the DSM-IV era. Among adolescent girls aged 15–18 years, the total incidence rate for anorexia nervosa, bulimia nervosa, anorexia nervosa not otherwise specified and bulimia nervosa not otherwise specified was 1641 per 100 000 person-years (95% confidence interval [CI]: 980–2724). Further, the combined incidence rate for anorexia nervosa and anorexia nervosa not otherwise specified was 1204 per 100 000 person-years (95% CI: 652–2181), and the combined incidence rate for bulimia nervosa and bulimia nervosa not otherwise specified was 438 per 100 000 person-years (95% CI: 132–1175). The study did not identify any boys with DSM-IV eating disorders, and only two boys

had subclinical eating disorders (Isomaa, Isomaa, Marttunen, Kaltiala-Heino, & Bjorkqvist, 2009). Further, among female twins born in the 1970s, the incidence for DSM-IV anorexia nervosa was 270 per 100 000 person-years between 15 and 19 years of age. For bulimia nervosa, the rate was 300 per 100 000 person-years in the peak age of 16 and 20 years of age and 150 per 100 000 between 10 and 24 years of age. (Keski-Rahkonen al., 2007; Keski-Rahkonen et al., 2009). Among males in the same cohort, the incidence rate of anorexia nervosa was 15.7 per 100,000 person-years at presumed risk-age between 10 and 24 years (Raevuori, Hoek, Susser, E., Kaprio, J., Rissanen, & Keski-Rahkonen, 2009).

2.2.5 Psychiatric comorbidity

Comorbidity simply refers to the presence of two or more physical or psychiatric disorders in an individual. The overall consensus is that ´psychiatric comorbidities are the norm in people with eating disorders' (Treasure et al. 2020), although comorbidity estimates vary somewhat by studies, eating disorder diagnosis and whether population or those at treatment are studied. For example, Swedish research based on an extensive clinical database with almost 12 000 men and women with eating disorders showed that 71% had been diagnosed with at least one other psychiatric disorder (Ulfvebrand, Birgegård, Norring, Högdahl, & von Hausswolff-Juhlin, 2015). Further, a nationally representative US population-based study with 9300 men and women reported psychiatric comorbidity up to 56% among individuals with anorexia nervosa, 95% of individuals with bulimia nervosa, 79% of individuals with binge eating disorder and 64% with subthreshold binge eating disorder (Hudson, Hiripi, Pope, & Kessler, 2007). In addition, among clinically treated adolescents with anorexia nervosa, psychiatric comorbidity has reached up to 77% (Salbach-Andrae et al., 2008). In Finland, among young females with a diagnosed lifetime eating disorder, 68% had at least one other psychiatric diagnosis (Lähteenmäki et al., 2014). The most common psychiatric comorbidities related to eating disorders are mood and anxiety, substance use, neurodevelopmental, impulse control and personality disorders (Hudson et al., 2007; Hughes, 2012; Lähteenmäki et al., 2014; Treasure et al., 2020).

2.2.6 Methodological considerations

The previous eating disorder occurrence estimates have differed substantially, and several factors can explain the variation (Lindvall Dahlgren et al., 2017). In the next subsections, a few of the most important are discussed in detail.

Sample characteristics

The gender and age distribution of the sample affect the occurrence estimates in eating disorder studies. Eating disorders are more prevalent among females than males (Mitchison & Hay, 2014). Thus, pooling genders together tends to lead to lower estimates than if only females were accounted for in the analysis. Further, although adolescence is a risk time for eating disorder onset, some eating disorders like binge eating disorder and purging disorder tend to peak slightly later compared with others (Mitchison & Hay, 2014; Striegel-Moore & Franko, 2003). Therefore, if eating disorders are assessed at early or middle adolescence, the lifetime prevalence of binge eating disorder or purging disorder tends to be lower. Further, although eating disorders occur globally, the country and cultural context of the sample affect the occurrence estimates. For example, anorexia nervosa seems rare in Africa and Latin America (Hoek, 2016). Differences may be explained by different genetic backgrounds, eating behaviours and cultural factors (Galmiche, Dechelotte, Lambert, & Tavolacci, 2019).

Study design

The occurrence of eating disorders is usually studied either using self-reported questionnaires or two-stage or one-stage study designs. Each has advantages and disadvantages. With self-report questionnaires, it is possible to survey the occurrence of eating disorders among many people at a relatively low cost. Moreover, for some individuals, reporting sensitive health information is easier in anonymous questionnaires than it is in interviews (Fairburn & Beglin, 1994). However, some survey questions may be confusing (Decaluwe & Braet, 2004). Therefore, establishing diagnoses based on self-report surveys alone can lead to several source errors.

In two-stage studies, eating disorder symptoms are first screened by a questionnaire; then, a diagnostic interview is performed. Screening reduces the need for research resources, as it enables focusing the time-consuming psychiatric interview on the high-risk population. The screening tool's sensitivity and specificity are central; if the screen misses positive cases, it underestimates the occurrence of eating disorders. Therefore, some studies with rigorous protocols also diagnostically interview a sample of screen negatives and account for possible false negatives by using sampling weights in the analysis (Hoek, Hans Wijbrand & van Hoeken, 2003).

Finally, in one-stage studies, a sample of participants is directly interviewed without screening. This eliminates the problem of missing cases during screening. However, interviewing a large sample is costly and time consuming. To reduce interview time, many studies use gatekeeping questions. These are questions about the key symptoms of the given disease, and if the participant answers these questions negatively, no further questions are asked. Sometimes the initial gatekeeping questions may be difficult to understand or age inappropriate, leading to underestimations (Breton et al., 1995).

Assessment methods

There are no uniform assessment methods for identifying eating disorders. Different studies use different self-report questionnaires, screens and diagnostic interviews, which affect the gained estimates and hamper the comparison between studies. The interview type used, skip rules and even small wording differences can significantly affect the prevalence estimates (Swanson, Brown, Crosby, & Keel, 2014; Thornton, Russell, & Hudson, 1998). Therefore, some researchers have decided, for example, not to include skip rules in their studies because these can minimise the estimates (Micali et al., 2017). The interviewer's experience may also influence estimates because specifying the interview questions and processing the information may be easier for experienced and more educated interviewers (Davis, Couper, Janz, Caldwell, & Resnicow, 2010). Furthermore, the impact of the interview modes (telephone interviews vs face-to-face interaction) has been debated (Evans, Kessler, Lewis, Peters, & Sharp, 2004; Rohde, Lewinsohn, & Seeley, 1997). Last, among children and adolescents, it is often emphasised that information should be collected from multiple sources because their ability to understand questions and willingness of self-closure is questioned (Kessler, 2000). In eating disorder studies, up to half of cases may be identified based on parental reporting (Micali et al., 2015).

In conclusion, gaining an accurate reflection of the big picture of eating disorder occurrence, one that best serves clinical needs and healthcare planning, will require well-conducted population-based studies with large sample sizes. These studies should include all genders and use diagnostic interviews to make eating disorder diagnoses rather than relying on self-reports (Decaluwe & Braet, 2004) or physician diagnoses, which depend on access to high-quality health care; use of the latter information may lead to imprecise estimates (Javaras & Hudson, 2015; Smink, van Hoeken, & Hoek, 2012).

2.3 EATING DISORDER DETECTION AND TREATMENT

2.3.1 Eating disorder detection

There is a lack of detection and treatment of all psychiatric illnesses in health care (Wang et al., 2007), and eating disorders are no exception. The reasons for the phenomenon of eating disorders are multifactorial. Both mental disorders and eating disorders are associated with stigma, prejudice and misunderstanding; thus, eating disorder sufferers may fear that their symptoms will be dismissed (Cachelin & Striegel-Moore, 2006). They may also have difficulty acknowledging or admitting the seriousness of their symptoms and the need for treatment, or they may feel that suitable treatment options are not available (Cachelin & Striegel-Moore, 2006; Grillot & Keel, 2018). A healthy weight and appearance can also make it difficult for loved ones or health care professionals to identify an eating disorder (Duncan, Ziobrowski, & Nicol, 2017). Moreover, a lack of understanding of the diversity of eating disorders can make identification difficult, and indeed, non-stereotypical eating disorders are less readily identified in primary care (Waller, Micali, & James, 2014). Males' and older people's eating disorders are also less often detected (Mangweth-Matzek, & Hoek, 2017). In addition, physicians may be unwilling to identify eating disorders if there are no known treatment sites to refer patients to (Waller et al., 2014).

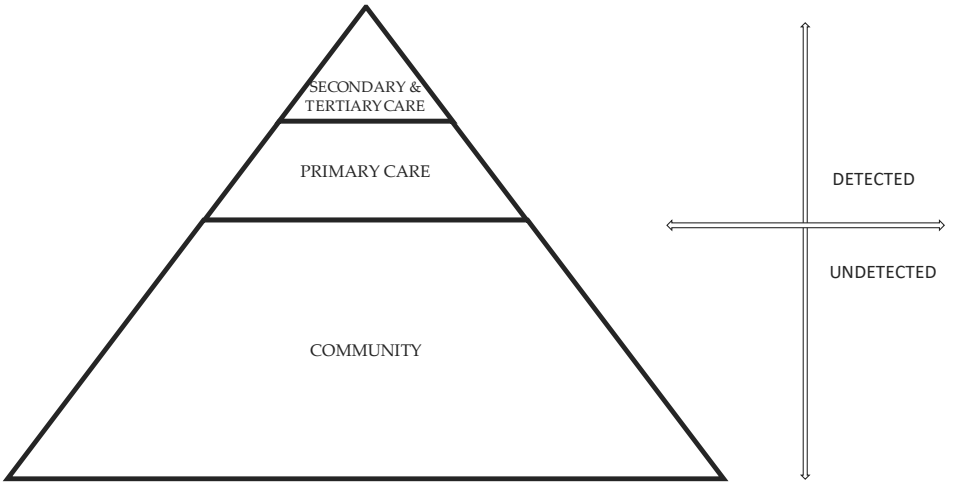
2.3.2 Eating disorder treatment

Eating disorders can be treated at primary, secondary or tertiary care levels (Figure 3). The level attributes describe how specialised care is provided at each level offered, and at times, reflect the medical complexity of the sufferers. Usually, individuals with eating disorders are identified and possibly treated at primary care, and if needed, referred to secondary or tertiary care, which indicates highly specialised treatment. The levels of care can also be compartmentalised to outpatient care and higher levels of care, indicating intensive outpatient treatment, partial hospitalisation and inpatient care (Anderson et al., 2017).

Because of the severity and complexity of eating disorders, several treatments have been developed. Still, there are controversies regarding treatment indications and the superiority of specific treatments over others (Hay et al., 2019; Herpertz-Dahlmann, 2015; Steinhausen, 2009). Current international and Finnish recommendations for eating disorder treatment advocate various approaches, including somatic care, psychiatric and psychosocial care and nutritional rehabilitation (Hay et al., 2014; Käypä hoitosuositus, 2014; National Guideline Alliance (UK), 2017). Further, little is known about how treatment affects the course of the disease (Steinhausen, 2002), although there is some indication that early

detection and treatment of eating disorders may lead to an improved course (Steinhausen, 2002; Treasure & Russell, 2011). Research on eating disorder treatments is also plagued with biases in that research has focused on stereotypical eating disorders with female sufferers. Below, the core research evidence related to the various treatments is briefly described.

Figure 3. Individuals with eating disorders identified in health care represent a small minority. After the initial identification, assessment, support and possible treatment in primary care, referrals to secondary and tertiary care can be made. The referral protocols and thresholds and the availability of secondary and tertiary care services often vary in different areas.



Psychological therapies and nutritional rehabilitation

There is little evidence of any difference in effect between the distinct psychological treatments for anorexia nervosa (Hay, Claudino, Touyz, & Abd Elbaky, 2015b). Further, although family therapy is often suggested, especially for children and adolescents who suffer from eating disorders, the evidence for the recommendation is limited (Fisher, Skocic, Rutherford, & Hetrick, 2019). In contrast, cognitive behaviour therapy for bulimia and binge eating disorder might be effective (Hay, Bacaltchuk, Stefano, & Kashyap, 2009). The psychological treatments of other specified and unspecified eating disorders have been less studied. It is often suggested that the treatment of these disorders should be similar to the diagnostic grouping they most closely match. Conventional

cognitive behavioural therapy seems to be well suited for patients with other specified eating disorders, although treatment adherence appears challenging (Riesco et al., 2018).

Patients with eating disorders often have unhealthy dietary restrictions, eating patterns and eating behaviours that may lead to changes in nutritional status and somatic complications. Thus, nutritional counselling and rehabilitation are essential elements in treating eating disorders (Marzola, Nasser, Hashim, Shih, & Kaye, 2013; Reiter & Graves, 2010). The aim of treatment is to restore a healthy body weight, reverse medical complications because of impaired nutritional status and enhance eating behaviour. Nutritional counselling should not be a standalone treatment for eating disorders, but it is a valuable adjunctive therapy with other treatments at all levels of care (National Institute for Health and Care Excellence, 2004; Reiter & Graves, 2010).

Pharmacological agents

Psychiatric medication may be considered for eating disorder patients to support nutrition, promote weight gain and treat comorbid anxiety and depression (Frank & Shott, 2016). The lack of qualitatively good research has prevented recommendations for using antidepressants like selective serotonin reuptake inhibitors in the treatment of anorexia nervosa (Claudino et al., 2006). Overall, studies have not shown robust improvements in weight gain or recovery (Frank & Shott, 2016). In bulimia nervosa, antidepressant use has proven to be more clinically effective than placebo (Bacaltchuk & Hay, 2003).

Second-generation antipsychotics, such as quetiapine and olanzapine, may reduce anxiety, obsessive symptoms and psychotic-like thinking associated with eating disorders. They can also potentially increase appetite. The evidence for antipsychotic use is scarce and mixed. Some have not found benefits (Kafantaris et al., 2011), whereas others have reported indications of higher and faster weight gain and reduced eating disorder ruminations (Attia et al., 2011; Bissada, Tasca, Barber, & Bradwejn, 2008; Mondraty et al., 2005). Individual case reports have also illustrated harmful effects related to antipsychotic use, such as hyperglycaemia or neuroleptic malignant syndrome (Ayyıldız et al., 2016; Yasuhara, Nakahara, Harada, & Inui, 2007).

Little is known about how commonly medication is used among young eating disorder patients. One previous study in a UK specialist service showed that about a quarter of children and adolescents with an eating disorder used medication (Gowers et al., 2010). Another community study in Austria found that 1 in 15 adolescents diagnosed with an eating disorder had received medication (Wagner et al., 2017).

Hospitalization and specialized units for eating disorders

Patients with eating disorders sometimes require intensive treatment approaches in inpatient or day-patient units because of somatic and psychiatric complications (Derenne, 2019). Some previous naturalistic and randomised studies have found less favourable outcomes among eating disorder patients requiring inpatient treatment (Gowers, Weetman, Shore, Hossain, & Elvins, 2000; Gowers et al., 2007), while others have found that hospitalisation has no effect on prognosis (Halvorsen, Andersen, & Heyerdahl, 2004). Yet, an excessively short length of inpatient treatment has been shown to have a detrimental effect on care among anorexia nervosa patients (Wiseman, Sunday, Klapper, Harris, & Halmi, 2001), and a longer duration of the first hospital stay has been associated with lower mortality (Papadopoulos, Ekbom, Brandt, & Ekselius, 2009). Moreover, two randomised studies comparing the efficacy of inpatient care to day treatment and to outpatient treatment after short hospitalisation among anorexia nervosa patients found similar treatment results in different settings (Herpertz-Dahlmann al., 2014; Madden et al., 2015). Thus, a recent Cochrane review concluded that evidence is too elusive to support that any treatment setting is better than others for the treatment of eating disorders (Hay et al., 2019).

Current clinical treatment recommendations suggest that hospitalisation should be restricted to eating disorder patients whose psychological or physical health is severely compromised. It is emphasised that the decisions regarding inpatient care should not be based solely on weight thresholds but should instead consider the overall psychological and physical risk (Hay et al., 2014; Käypä hoitosuositus, 2014; National Guideline Alliance (UK), 2017).

2.3.3 Detection and treatment rates in the community in the DSM-5 era

The few community studies that have been conducted to date according to DSM-5 criteria show that only a small percentage of individuals with eating disorders are detected and receive treatment for their condition (Cossrow et al., 2016; Micali et al., 2017; Smink et al., 2014; Solmi et al., 2016). In a study conduct-

ed among middle-aged British women, one-fourth of those with a lifetime eating disorder had sought help or received treatment for an eating disorder at any point in their life (5% had received individual psychological treatment for eating disorders, 4% psychological treatment for another disorder and 1% had received inpatient care, 1% had seen a psychiatrist for their eating disorder and 8 % general practitioner) (Micali et al., 2017). Among Austrian adolescents with feeding or eating disorders, less than one in five had used mental healthcare services. Overall, 33% had received inpatient care, 33% outpatient care, 6% medication and 33% had unknown treatment. The ego-syntonic nature of eating disorders was evident in that those who had not used mental health services expressed no wish to have treatment (Wagner et al., 2017).

The detection and treatment of eating disorders seem to be concentrated on individuals with a typical presentation, such as anorexia or bulimia nervosa. Among adolescent girls with anorexia nervosa, the rate has been as high as 69% (Smink et al., 2014) compared with the 3% found among individuals with BED (Cossrow et al., 2016). Furthermore, there are indications that people with eating disorders seek treatment for reasons other than an eating disorder. For example, 30% of participants with an eating disorder had sought help from healthcare providers for their mental health problems in the year before assessment (Solmi et al., 2016).

Despite the findings listed above, there is a need for more comprehensive information at the population level on how DSM-5-defined eating disorders are identified and treated. In particular, there is a lack of knowledge about males, and no previous study has addressed how DSM-5-defined eating disorders are identified or treated in Finland.

2.4 THE COURSE OF EATING DISORDERS

Information about the course and outcome of eating disorders is vital. Understanding the prognosis related to eating disorders helps make adequate treatment plans and set realistic expectations for recovery time (Keel, 2018). The course of eating disorders seems to be variable. For some sufferers, the illness is mild, lasts for a short while and is ultimately cured. For others, the illness lasts for years and sometimes leads to chronic illness or even death (Keel, 2018; Steinhausen, 2009).

Community samples are essential for the estimates of the course of eating disorders because they most closely represent the natural course of eating disorders, including both treated and untreated groups. Still, creating an overall picture is challenging because research on the subject has been very different concerning study samples, designs, follow-up time and definitions of recovery.

2.4.1 Definition of recovery in eating disorders

Historically, the most used criteria for recovery from eating disorders is the Morgan–Russell categories of general outcome introduced in 1975 to define recovery from anorexia nervosa (Morgan & Russell, 1975). When the Morgan–Russell criteria were first introduced, they included physical, psychological and social dimensions of recovery. However, in research use, a more reduced form was often used, which mainly included the criterion of correction of underweight and menstruation recovery, leading to three outcomes—good, intermediate and poor (Morgan & Hayward, 1988). Similar methods to assess recovery from other eating disorders have yet to be developed.

The recovery from an eating disorder is a gradual process that often includes a reduction in symptoms at different stages (Clausen, 2004). Most studies have used solely eating disorder symptom remission as a base for recovery, although more and more information about the importance of psychological well-being has emerged (Vall & Wade, 2015). In particular, eating disorder sufferers seem to emphasise psychological, emotional, social and appearance-related dimensions (de Vos et al., 2017; Emanuelli, Waller, Jones-Chester, & Ostuzzi, 2012). The consensus about recovery components has included physical, behavioural and psychological/cognitive criteria (Bachner-Melman, Lev-Ari, Zohar, & Lev, 2018; Bardone-Cone et al., 2018).

The lack of a standardised definition of recovery has severely hampered the assessment and comparison of the course of eating disorders (Bardone-Cone et al., 2018; Vall & Wade, 2015). Depending on the criteria, the recovery estimates can vary from 3% to 96% (Couturier & Lock, 2006).

2.4.2 Clinical recovery in studies based on the DSM-IV criteria

For comparison purposes and to offer an overview, key findings of eating disorder recovery based on DSM-IV assessment are briefly discussed, emphasising community-based studies with long-term follow-up.

Anorexia nervosa The crude estimation of the course of DSM-IV-defined anorexia nervosa has been that approximately 1 in 10 achieve remission over the short term. When the follow-up increases to intermediate to long-term, about 50%–70% achieve recovery, and up to one-fifth remain chronically ill (Brown, Klein, & Keel, 2015). In detail, among Finnish twins born in the 1970s, the 5-year clinical recovery rate was 67% (Keski-Rahkonen et al., 2007), and 10 years after baseline diagnostic assessment, 88% were weight-recovered (BMI above 18.5 kg/m2; Mustelin al., 2015b). In a Swedish sample of adolescents with DSM-IV-defined anorexia nervosa, 18 years after disorder onset, 12% of the sufferers still had an eating disorder (Wentz, Gillberg, Anckarsater, Gillberg, & Rastam, 2009). At the 30-year follow-up, one in five had a chronic eating disorder, and two-thirds had fully recovered (Dobrescu et al., 2020). This increase in eating disorder occurrence during the follow-up emphasises that relapse can occur in a substantial minority of anorexia nervosa patients and can happen years after remission. There is some indication that adolescent-onset anorexia nervosa has a better outcome than eating disorders starting later in life (Steinhausen, 2002). In addition, psychiatric comorbidity and a long period from the onset of illness to first treatment have been related to poorer outcomes (Salbach-Andrae et al., 2008; Steinhausen, 2002).

Bulimia nervosa A rule of thumb based on DSM-IV-based studies of recovery from bulimia nervosa has been that approximately one-third of sufferers achieve remission in the short or intermediate-term and that long-term remission occurs in 50% to 70% of cases (Brown et al., 2015). For instance, the 5-year clinical recovery rate was 55% among Finnish twins born in the 1970s (Keski-Rahkonen et al., 2009). In addition, in a mixed community and clinical sample in the United States, the 4-year follow-up remission rate was 47% (Agras, Crow, Mitchell, Halmi, & Bryson, 2009). Furthermore, a study conducted across 14 countries found that duration is slightly higher for bulimia nervosa (6.5 years; 2.2–15.4) than it is for binge eating disorder (4.3 years; 1.0–11.7; Kessler et al., 2013).

It seems that the course of bulimia nervosa is often episodic, with periods of symptoms and periods of remission. For example, a community-based study that followed adolescent and adult females for 5 years found that for each follow-up year of those diagnosed with bulimia nervosa, about one-third of the subjects remitted and a third relapsed (Fairburn, Cooper, Doll, Norman, & O'Connor, 2000). Notably, the likelihood of relapse is highly dependent on the definition of relapse, with lower relapse rates reported with strict definitions of relapse (Brown et al., 2015; Herzog et al., 1999; Olmsted, Kaplan, & Rockert, 2005). Among other things, comorbid substance use, self-injurious behaviour

and personality disorder pathologies have been associated with the worst course of bulimia nervosa (Keel, Mitchell, Miller, Davis, & Crow, 1999; Steinhausen & Weber, 2009).

Binge eating disorder A rule of thumb for clinicians has been that 50% of binge eating disorder sufferers achieve short-term remission, whereas the intermediate and long-term likelihood of recovery is 75% (Brown et al., 2015). It seems that individuals suffering from binge eating disorder tend to recover more quickly than those with anorexia nervosa and bulimia nervosa (Agras et al., 2009; Fairburn et al., 2000). A study assessing the short-term outcomes of binge eating disorder among a community sample of adult women found that 48% of those who stayed in the study were in partial remission after six months. However, the drop-out rate was high (10/31 of the initial sample; Cachelin et al., 1999). In an Australian population-based sample where 14-year-olds were followed until they turned 20, 44% of those initially diagnosed with binge eating disorder or purging disorder did not meet the criteria of an eating disorder at 17–20 years of age (Allen, Byrne, Oddy, & Crosby, 2013b). In another community-based sample of adolescent and adult females diagnosed with binge eating disorder, 80% of the subjects did not have any form of clinical eating disorder after 5 years (Fairburn et al., 2000).

Eating disorders not otherwise specified The residual category of eating disorder not otherwise specified led to heterogeneous eating disorder representations with varying severity, representing a challenge for outcome studies. In a US-based study conducted among adult women and men with bulimia nervosa or eating disorder not otherwise specified, roughly 74% of patients with bulimia nervosa and 83% of patients with eating disorder not otherwise specified achieved remission in a 5-year follow-up. The proportions of those who relapsed within the 5-year follow-up were 47% and 42%, respectively (Grilo, Pagano, Skodol, Sanislow, McGlashan, Gunderson, & Stout, 2007). Further, a study assessing eating disorder sufferers who were recruited from community and speciality clinics and assessed every 6 months over a 4-year period found that remission from eating disorder not otherwise specified together with binge eating disorder was more likely than remission from anorexia nervosa or bulimia nervosa. At the end of follow-up, nearly 80% of those diagnosed with eating disorder not otherwise specified had recovered (Agras et al., 2009).

2.4.3 Clinical recovery in studies based on the DSM-5 criteria

Only a few community-based studies to date have examined the course of eating disorders based on DSM-5 definitions (Glazer et al., 2019; Mustelin et al., 2016a; Stice et al., 2013; Udo & Grilo, 2018; Wade & O'Shea, 2015). In the US adult sample, the mean times per episode when both genders were pooled were 11.4 years for anorexia nervosa, 12.2 years for bulimia nervosa and 15.9 years for binge eating disorder (Udo & Grilo, 2018). In contrast, some studies have reported a shorter duration of eating disorders. Among US adolescent females the duration were 8 months for anorexia nervosa, 2.9 months for bulimia nervosa, 3.3 months for binge eating disorder, 11.6 months for atypical anorexia nervosa, 3.5 months for sub-threshold bulimia nervosa, 3.0 months for sub-threshold binge eating disorder and 5 months for purging disorder (Stice et al., 2013). Further, in a US adolescent and young adult female sample, the symptom remission rate was as high as 1–3 years after detection; more than 60% no longer met the criteria for eating disorders (Glazer et al., 2019). Previously, in the Finnish FinnTwin16 study, the 5-year likelihood of recovery among women with other specified and unspecified feeding and eating disorders was 60%, and the median duration of illness was 2 years (Mustelin et al., 2016a). In Australia, the mean duration for unspecified feeding and eating disorders was also 2 years (Wade & O'Shea, 2015). Overall, the variation in estimates is significant.

Data on the course of different eating disorders enables the assessment of the predictive validity of diagnoses. Understanding the natural course of eating disorders is a foundation for developing adequate services for those affected. Thus, there is a considerable need for more community-based studies to understand the natural courses of DSM-5 eating disorders (Brown et al., 2015). In particular, there is a need for studies that include large populations, all genders and well-recorded outcomes. In addition, as major changes were made to the diagnosis of anorexia nervosa in DSM-5, it is vital to assess whether the resulting inclusion of milder forms of the illness is clinically and prognostically meaningful. Furthermore, it is unclear how the DSM-5 severity indicator prognosticates the outcome of anorexia nervosa. The courses of other specified feeding and eating disorder subclasses and unspecified feeding and eating disorders are also poorly understood (Keel, 2018). Last, little is known about how gender influences the course and outcome of eating disorders, especially in the DSM 5-era (Strobel, Quadflieg, Voderholzer, Naab, & Fichter, 2018; Strobel, Quadflieg, Naab, Voderholzer, & Fichter, 2019; Strober, Freeman, Lampert, Diamond, & Teplinsky, 2006).

AIMS OF THE STUDY

This study aims to better understand the occurrence and course of eating disorders among adolescents and young adults in Finland. A further aim is to assess how eating disorders are detected and treated.

The specific questions of this study are as follows:

1. What are the lifetime prevalence, incidence and peak periods of onset of eating disorders defined by the DSM-5 among a community sample of youths and young adults?

2. How often are DSM-5-defined eating disorders detected and treated in the community by healthcare providers?

3. How do different subcategories of eating disorders affect the course and outcome of eating disorders?

METHODS

4.1 ETHICAL CONSIDERATIONS

All the researches in this study were conducted according to the Helsinki Declaration. Data was gathered and handled as required by the Finnish data protection legislation and Helsinki University Central Hospital rules.

Both the FinnTwin 12 and FinnTwin 16 study received approval for the data collection and analysis from the Institutional Review Board of Indiana University and the Department of Public Health's ethics committee at the University of Helsinki. More, all participants in the FinnTwin 12 and 16 studies provided written informed consent. Lastly, The Hospital District of Helsinki and Uusimaa (HUS) granted ethical approval to study adolescents' treatment in the Helsinki University Central Hospital (Dnro 715/13/002012).

4.2 FINNTWIN 12

4.2.1 Study cohort

The FinnTwin 12 is a population-based ongoing longitudinal study that aims to assess genetic and environmental factors relating to health-related behaviours with a particular focus on alcohol use and abuse. The study cohort consists of twins who were born in five subsequent years in 1983-1987 as identified from the Finnish Central Population Registry. All in all, 5,600 twins and their families were invited to participate in the study. The epidemiological sample of the FinnTwin 12 study included all these participants. The response rate was 85-90% in waves 1-4 (Kaprio, 2013).

The study also has an intensively studied sample taken from the epidemiological sample, and the target number of families in this intensively studied sample was 1035. This sample was mostly constituted by randomly selected families from the epidemiological sample (72.3%). The rest were enriched from the families who had gained high points from the Malmö-modified Michigan Alcoholism Screening Test (Mm-MAST) (Seppä, Sillanaukee, & Koivula, 1990) that has been designed to survey alcohol use and alcohol dependency.

The first information gathering wave happened just before the twins' 12th birthday. Information was gathered by sending questionnaires to all twins, their parents and teachers. The questionnaire included items surveying alcohol and tobacco use, lifestyle, and health status. The teachers and parents were also asked

about twins' behavior, and parents also answered questions relating to twins' pregnancy and early childhood. At the first wave, parents from the intensively studied sample were also interviewed by using a semi-structured psychiatric assessment interview (SSAGA) (Bucholz et al., 1994) (n=1860).

At the second information gathering wave, when the twins were 14 years old, information was again gathered from twins and teachers from the whole epidemiological sample by questionnaires. All twins in the intensively studied sample (n=1852) were interviewed using a semi-structured psychiatric assessment interview (SSAGA). The intensively studied sample also participated in neuropsychological tests and additional saliva hormone assays.

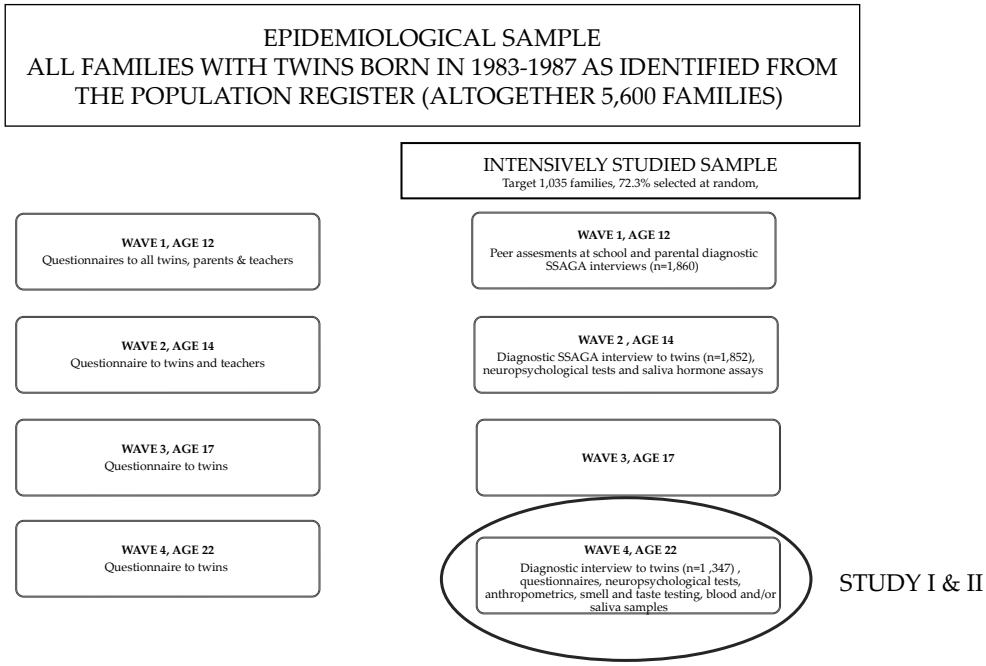
At the third wave, when the twins were 17 years old, information was gathered solely by questionnaires to all participating twins.

At the fourth information gathering wave, when the twins were around 22 years old in 2006-2009 (range 21-26 years), information was gathered from the whole epidemiological sample by questionnaires. Besides, 1347 individuals (709 women and 638 men) from the intensively studied sample participated in semi-structured psychiatric interviews (a Structured Clinical Interview for DSM-IV, SCID (First, Spitzer, Gibbon & Williams, 2002)) and neuropsychological tests, anthropometrics, smell, and taste testing, blood and/or saliva samples. Figure 4 shows the data collection.

Slightly more than half of the diagnostic interviews were done face-to-face (n = 709) and the rest by phone. The interview staff—13 Finnish women—all had a degree in health care. They were masters of health care, advanced graduate students in psychology, and registered nurses. Before conducting the interviews, they had received intensive training in the interview instrument at the Indiana University Medical School in the USA.

The interviewers asked the participants about eating disorder symptoms according to DSM-IV criteria. Participants were also asked about the onset and duration of eating disorder symptoms, possible identification of an eating disorder in health care, and received treatment. The interviewees were also asked in detail about weight development from late youth to adulthood, and a weight curve was drawn based on the information. For those participants who participated in the face-to-face interview, weight and height were also measured, and those interviewed by telephone reported their height and weight themselves.

Figure 4. The flow-chart of the FinnTwin 12 study including aspects relevant to study



4.2.2 Diagnostic definitions

Based on all collected data, three medical doctors who had a lot of expertise in treating and studying eating disorders made consensus DSM-5 diagnoses. Because the interviewers had asked the interviewees in detail about their eating disorder symptoms and had written a detailed description, it was possible to make DSM-5 diagnoses. The criteria are described in detail in table 16. Those individuals who did not fulfill the diagnostic criteria of specified or other specified feeding and eating disorders but still had an eating disorder that caused impairment or distress were classified in the residual unspecified feeding and eating disorder group. To analyze the different phenotypes of eating disorders in the population, unspecified feeding and eating disorders were divided into four subcategories that are also described in table 16. Hierarch order was implemented when diagnoses were given: anorexia nervosa outdid bulimia nervosa; anorexia nervosa, bulimia nervosa and binge eating disorder outdid other specified feeding and eating disorders, and all specified eating disorders outdid unspecified feeding and eating disorders. To gain a diagnosis of 'other specified eating disorder' or 'unspecified feeding and eating disorder', no previous diagnosis of specified eating disorder diagnosis could not be fulfilled.

Table 16. The diagnostic criteria for DSM-5 feeding and eating disorders (used in study I & II)

DIAGNOSIS	DSM-5 DIAGNOSTIC CRITERIA
Specified Eating/Feeding Disorder	
Anorexia Nervosa	Restriction of energy that resulted in a minimum BMI of ≤ 18.5 kg/m^2 (Brown, Holland, & Keel, 2014; Sysko et al., 2015) Fear of weight gain or of becoming fat or persistent behavior that interferes with weight gain even though at a low weight Disturbance in way body weight or shape is experienced or denial of seriousness of the current low body weight
Bulimia Nervosa	Recurrent binge eating and compensatory behaviors in order to prevent weight gain once a week for more than 3 months. With sense of lack of control and self-evaluation is influenced by shape and weight
Binge Eating Disorder	Recurrent binge-eating episodes once a week for more than 3 months with sense of lack of control, no recurrent compensatory behaviors, marked distress, disgust or embarrassment present regarding to binge eating
Other Specified Eating/Feeding Disorder	
Atypical Anorexia Nervosa	All the criteria for AN met, expect despite restriction of energy min. BMI is more than 18.5 kg/m^2
Bulimia Nervosa of low frequency and/or limited duration	All the criteria for BN met, but binge-eating and compensatory behaviors occur less frequently than once week or/and less than 3 months
Binge Eating Disorder of low frequency and/or limited duration	All the criteria for BED met, but binge-eating behaviors occur less frequently than once week or/and less than 3 months
Purging Disorder	Recurrent purging behavior to influence weight or shape in the absence of binge eating
Unspecified Feeding or Eating Disorder	Clinically significant eating disorder symptoms but do not meet criteria for other specified disorders or insufficient information to make a more specific diagnosis
Restrictive Syndrome	Restrictive behavior concerning excessive exercise, significant weight lost but A criteria and B or C criteria of AN not fulfilled, weight lost leading to amenorrhea, orthorexia
Subthreshold BN/BED	Objective bingeing with or without compensatory behaviors that did not include loss of control, or bingeing that was not restricted to a limited time period or some binge eating specifiers were missing
Other	Eating problems related to depression, social difficulties, temporary purging, high concern and unhealthy behaviors related to drive for muscularity
Insufficient Information	Insufficient information to make a specific diagnosis

4.2.3 Measures

Occurrence The lifetime prevalence of eating disorders was assessed when interviewees were, on average, 22 years old (range 21-26 years, standard deviation 0.7). Further, incidence rates were calculated from the ages of 10 to 20. The peak onset of eating disorders was assessed for females and males separately. Because of the small number of males suffering from an eating disorder, it was only possible to evaluate peak periods for the total number of eating disorders.

Detection and treatment of eating disorders in health care During the diagnostic interview, participants were asked if their eating disorders had been detected in health care. In addition, participants were asked if they had received treatment for an eating disorder, and if so, what kind of treatment it had been. There was a lack of information on the time between eating disorder onset and the start of detection and subsequent treatment. Further, the sufficiency of the treatment could not be assessed as there were limited data on the intensity and delivery of care.

Eating Disorder recovery During the interview, participants were also asked how long their eating disorder symptoms had lasted and whether they were still suffering from eating disorder symptoms. If the participants thought that they had recovered, they were asked what had helped them to improve. The recovery was assessed using the criteria described in table 17.

Table 17. The criteria for eating disorder recovery in study II.

THE CRITERIA FOR RECOVERY	
1)	No significant eating disorder behavior (restrictive or binge eating, compensatory behaviors, excessive exercise) or psychological symptoms (persistent body image concerns, fear of weight gain, fat phobia) at least one year before the interview.
2)	Own expression that they no longer suffered from an eating disorder and the recovery seemed clinically meaningful.
3)	The current BMI was 18.5 kg/m2 or higher.

4.3 FINNTWIN 16

4.3.1 Study cohort

The FinnTwin 16 study is a longitudinal population-based study of twins and their families to study health behaviors (Kaidesoja et al., 2019). The research aimed to include all the twins born in 1975-1979 as identified from the central

population register in Finland. The study consists of five information gathering waves. The first information gathering wave happened when the twins were 16 years old. At that time, data was collected by baseline questionnaires that were sent to both the twins and their parents. Follow-up questionnaires were also sent to twins at wave 2 when the twins were 17 years old, at wave 3 when twins were 18.5 years old, at wave 4 when twins were 22-27 years old (mean age 24.4, SD 0.9), and at wave 5 when twins were 31-37 years old.

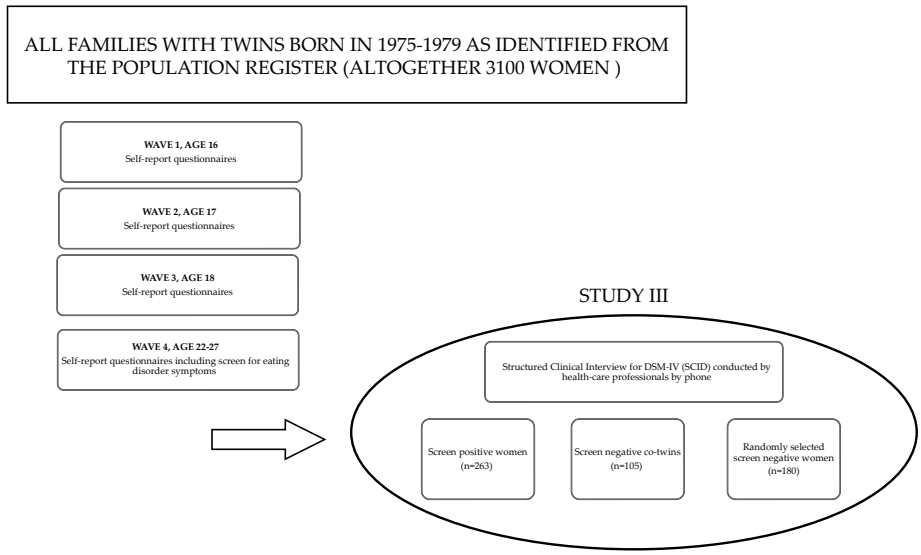
The study utilized a two-stage study design. At the fourth information gathering wave, 2825 women (87% of the original cohort) answered a self-report questionnaire that included a screen for eating disorder symptoms. The screen positivity was based on questions about self-report of eating disorders or if anyone else had suspected eating disorders, current and past minimum BMIs, and subscales of Eating Disorder Inventory-2 (Garner, 1991; Keski-Rahkonen et al., 2006). The screening process of men's eating disorders and the occurrence have been described in more detail previously (Raevuori et al., 2009).

All those women who were screen positive (n=292) were invited to participate in a telephone interview. Also, screen-positive women's screen-negative female co-twins (n=130), and 210, randomly selected screen-negative women were asked to take part in the interview. Together, 263 screen-positive women, 105 female co-twins of screen-positive women, and 180 randomly chosen women participated in the interview. This made up 86.7% of those invited. Figure 5 shows the data collection, including aspects relevant to study.

The women were interviewed by health care professionals using a Structured Clinical Interview for DSM-IV (SCID) (First et al, 2002) to obtain a lifetime and a current diagnosis of anorexia nervosa, bulimia nervosa, binge eating disorder, and major depressive disorder. Four of the interviewers were medical doctors and one registered nurse. The interrater agreement was excellent (mean k=0.87, range 0.64-1.00).

During the interview, participants were asked in detail about eating disorder symptoms, the time course of symptoms. Also, interviewers collected information on self-reported minimum, maximum, and current weight and reasons for weight status.

Figure 5. The flow-chart of the FinnTwin 16 study including aspects relevant to study



4.3.2 Diagnostic definitions

Eating disorder symptoms were examined using the Structured Clinical Interview for DSM-IV. Because the interviewers had written down narrative details about each participant's course of symptoms and weight status, it was possible to derive DSM-5 eating disorder diagnoses based on the interviews. Four medical doctors who had a lot of expertise in treating and studying eating disorders made consensus DSM-5 diagnoses. The used criteria for DSM-IV and DSM-5 criteria for anorexia nervosa are described in table 18. In each diagnosis, all the criteria have to be fulfilled.

Table 18. The diagnostic criteria for DSM-IV and DSM-5 defined anorexia nervosa (used in study III)

DIAGNOSIS	CRITERIA
DSM-IV Anorexia Nervosa	A weight loss had resulted to a BMI of 17.5 kg/m2 or less. Intense fear of gaining weight or becoming fat, even though underweight. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body shape on self-evaluation, or denial of the seriousness of the current low body weight. In postmenarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles.
DSM-5 Anorexia Nervosa	Restriction of energy intake that resulted in a minimum BMI of ≤ 18.5 kg/m2 (Brown et al., 2014; Sysko et al., 2015) Fear of weight gain or of becoming fat, or persistent behavior that interferes with weight gain even though at a low weight Disturbance in way body weight or shape is experienced or denial of seriousness of the current low body weight.

4.3.3 Measures

Occurrence The lifetime prevalence of DSM-IV and DSM-5 anorexia nervosa was assessed at the age of 22-27-years. The fifteen-year incidence rate of DSM-IV and DSM-5 anorexia nervosa was assessed at age intervals of 10-24 years.

Detection of eating disorders in health care At the time of the interview, participants were also sent a questionnaire that included a question about had any doctor or other health care professional diagnosed them with an eating disorder.

Eating Disorder Outcome Based on the information gathered in the interview, the interviewers had established the age at when the participant had last had eating disorder symptoms. The criteria for clinical recovery are reported in Table 19.

Table 19. The criteria for anorexia nervosa recovery in study III.

THE CRITERIA FOR RECOVERY	
1)	Absence of eating disorder behavior (bingeing, purging) at least one year before the interview.
2)	Weight restoration (was interpreted as a return to pre-disease or normal weight).
3)	Menstrual restoration if relevant.

4.4 CLINICAL ADOLESCENTS SAMPLE

4.4.1 Study setting and offered treatment

The Helsinki and Uusimaa Hospital District (HUS) adolescent eating disorder unit was Finland's largest unit specialized in treating adolescent eating disorders and providing treatment for patients aged 13-17 years with severe eating disorder symptoms. The clinic offered treatment at their inpatient and day ward, as well as the outpatient clinic. All adolescents' treatment included individual and family meetings and visits to the pediatric unit, a nutritionist, and a physiotherapist. Also, there was a peer support group for parents. The primary aim was to offer outpatient treatment, but the adolescent could be referred to the specialized eating disorder ward, compulsory treatment, or pediatric ward if necessary. During inpatient and day and ward treatment, adolescents at primary school age attended hospital school. On 30 April 2013, the unit merged with the Adult Psychiatry Eating Disorder Unit.

4.4.2 Sample and inclusion criteria

We reviewed adolescents' medical records retrospectively. To be included in the study sample, two terms had to be fulfilled. The adolescent had to be in treatment at the unit on 12 March 2012, and his/her treatment had to be ended by 30 April 2013. Further, adolescents' main diagnosis, as recorded by the attending physician, had to be ICD-10 F50.0 anorexia nervosa or F50.1 atypical anorexia nervosa. All in all, 47 adolescents, of which 43 were girls and four were boys, fulfilled the criteria. Of those, 34 adolescents had typical anorexia nervosa and 13 atypical anorexia nervosa. Table 20 describes the core descriptives of the sample.

Table 20. General descriptive statics of the boys and girls in the clinical adolescent sample.

	F50.0 TYPICAL ANOREXIA NERVOSA (N=34)	F50.1 ATYPICAL ANOREXIA NERVOSA (N=13)	TOTAL (N=47)
Girls, n (%)	32 (94)	11 (85)	43 (91)
Age at admission, years (SD)	14.3 (1.0)	15.2 (1.5)	14.6 (1.2)
BMI at admission (SD)	15.1 (1.2)	16.7 (2.0)	15.6 (1.6)
BMI at end of treatment (SD)	18.7 (2.3)	18.9 (1.8)	18.8 (2.2)
Amenorrhoea at the end of treatment, n (%)	11 (32)	3 (23)	14 (30)

** SD standard deviation, BMI body mass index, n number*

In detail, the unit had no internal criteria for treatment conclusion: each clinician made the decision individually with the adolescent and her/his family. Treatments were ended because:

1. The treating physicians saw no need for further psychiatric treatment (n=23, 49%).
2. The adolescent was referred to a general psychiatric clinic due to the treatment of another psychiatric disorder or because anorexic symptoms no longer required tertiary care (n=12, 26%).
3. The adolescent was referred to the adult eating disorder unit (n=6, 13%).
4. The adolescents had dropped out of treatment (n=6, 13%).

4.4.3 Diagnostic definitions

ICD-10 - The treating physicians had initialized psychiatric diagnoses for each treated adolescent. Information on typical anorexia (F50.0), atypical anorexia (F50.1), and other psychiatric diagnoses were gathered from the patient records.

DSM-5 - Based on the information that was collected from patient records, DSM-5 diagnoses were reconstructed by three medical doctors. The criteria for ICD-10 and DSM-5 anorexia nervosa are described in table 21.

Table 21. The diagnostic criteria for ICD-10 and DSM-5 defined anorexia nervosa (used in study IV)

DIAGNOSIS	CRITERIA
ICD-10 Anorexia Nervosa (F50.0)	Body weight is maintained at least 15% below that expected or BMI is 17.5 or less. The weight loss is self-induced by avoidance of "fattening foods" and one or more: self-induced vomiting, self-induced purging, excessive exercise or use of appetite suppressants and/or diuretics. There is self-perception of being too fat, with an intrusive dread of fatness, which led to a self-imposed low weight threshold A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis that is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency, or if onset was prebupertal the sequence of pubertal events was delayed.
ICD-10 Atypical Anorexia Nervosa (F50.1)	Some of the features in AN are fulfilled but key symptoms as amenorrhoea or marked dread of fat are absent, but who otherwise present a fairly typical clinical picture.
DSM-5 Anorexia Nervosa	Restriction of energy intake that resulted in a minimum BMI of ≤ 18.5 kg/m2 or equivalent in ISO-BMI (Saari et all. 2011). Fear of weight gain or of becoming fat, or persistent behavior that interferes with weight gain even though at a low weight Disturbance in way body weight or shape is experienced or denial of seriousness of the current low body weight

4.4.4 Measures

Anorexia nervosa outcome The outcome of anorexia nervosa at the end of treatment was classified using modified Morgan-Russell criteria as described in table 22 (Grewal, 2011; Morgan & Hayward, 1988).

Table 22. The criteria for anorexia nervosa recovery based on Modified Morgan-Russell criteria in study IV.

RECOVERY BASED ON MODIFIED MORGAN-RUSSELL CRITERIA	
Good outcome*	Regular menstrual cycles, weight maintained many consecutive months at BMI ≥ 17.5 kg/m^2 indicating 'weight within 15 % ideal body weight' (Couturier & Lock 2006).
The intermediate outcome	Bodyweight had risen to BMI 17.5 kg/m2, but the bodyweight had not been constantly maintained and/or menstrual disturbances continued.
Poor outcome	BMI 17.5 kg/m2 was not reached during treatment and menstruation had not started.

*For boys and those girls who were premenarcheal at time of initial admission, only weight criterion was used.

4.5 DATA ANALYSIS

In the FinnTwin 12 sample, we calculated the lifetime prevalence of the total number and individual eating disorders by dividing the number of prevalent cases by the total number of those interviewed. In the FinnTwin 16 sample, the same was applied. Furthermore, we calculated the incidence by dividing the detected incident cases at the given age interval with the number of person-years at risk.

In the FinnTwin 12 sample, prevalence and incidence were calculated separately for females and males. We also assessed the prevalence estimates in enriched and randomly selected groups and compared them using Pearson chi-squared tests for cross-tabulations. In the FinnTwin 16 sample, we also used sampling weights to correct false negatives missed by symptom screening: We attempted to approximate the prevalence to what we had obtained by interviewing all individuals in the cohort.

We adjusted for twin sampling within twin pairs when calculating the prevalence and incidence of eating disorders and p-values.

In both of the population samples, we analyzed the outcome of eating disorders by using Kaplan-Meier survival analysis. The follow-up started at the onset of the eating disorder. Censoring happened at the end of the follow-up if recovery had not occurred. There were no drop outs or lost in the follow-up in the Fin-

nTwin 12 or FinnTwin 16 sample, because the analytic sample was defined by participation in the interview at the end of the follow-up. We also analyzed five-year recovery rates defined as the proportion of eating disorder sufferers who fulfilled the clinical recovery criteria five years from disease onset. Further, we used descriptive statistics for continuous variables.

We compared recovery rates between different diagnoses, genders, and detection/treatment status using log-rank tests. In both population samples, we also stratified individuals with anorexia nervosa by the minimum BMI to evaluate how the severity rating is associated with recovery.

In the FinnTwin 12 sample, the information about the time onset of eating disorder symptoms was missing for two people, and therefore we did not include these individuals in the analysis.

In the clinical adolescent sample, we also analyzed recovery rates using Kaplan-Meier analysis. We assessed differences in recovery rates between the different definitions of anorexia nervosa using log-rank tests. Two patients were excluded from the analyses because of the missing data.

We used a p-value of 0.05 as a cut-off for statistical significance. Last we used Stata Statistical Software, version 14, for all analyses.

RESULTS

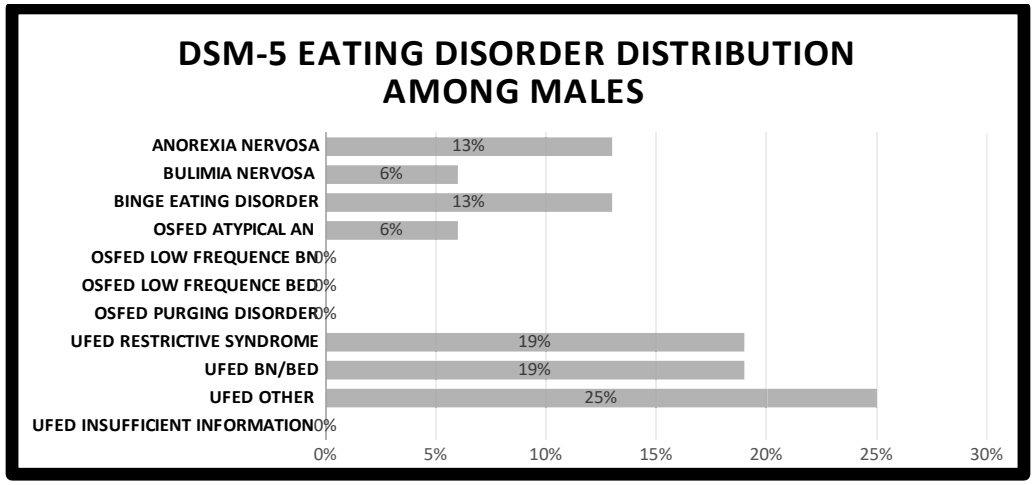
5.1 EATING DISORDER OCCURRENCE IN COMMUNITY (STUDY I, III)

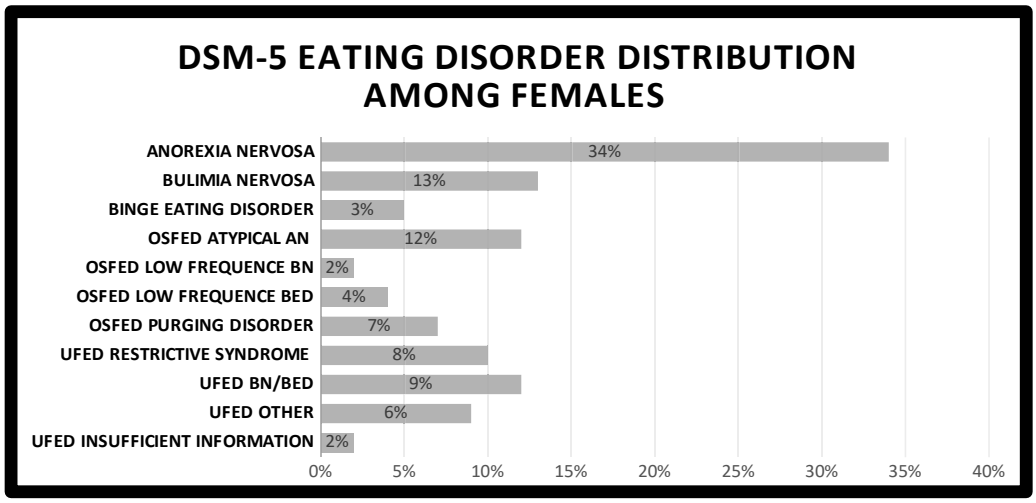
5.1.1 Distribution

We assessed the distribution of DSM-5 eating disorders in the population from the FinnTwin 12 sample in study I. We diagnosed DSM-5 eating disorders in 142 individuals from the 1,347 females and males interviewed. The sex ratio was 8:1. Of the total, 709 females interviewed, 127 were diagnosed with DSM-5 eating disorders compared to 15 of 638 in males. Two females and one male received two diagnoses.

The distribution of different diagnoses among females and males is shown in figure 6. Among females, anorexia nervosa was the most common diagnosis. Over 50% of eating disorders among females were restrictive (anorexia nervosa, atypical anorexia nervosa, unspecified eating disorders restrictive syndrome). Among males, unspecified eating disorders were most common, comprising 63% of all eating disorders diagnosed among males.

Figure 6. Distribution of DSM-5 defined eating disorders among females and males from the FinnTwin 12 sample (study I).





5.1.2 Lifetime prevalence

We assessed the lifetime prevalence of DSM-5 eating disorders from FinnTwin 12 and FinnTwin 16 population samples in studies I & III. The results are described in detail in table 23.

In study I (FinnTwin 12), lifetime prevalent eating disorders were found in 17.9% of the female participants. In detail, the lifetime prevalence for typical eating disorders was: 6.2% for anorexia nervosa, 2.4% for bulimia nervosa, and 0.6% for binge eating disorder, making the total prevalence 9.2%. For other specified eating disorders, the prevalences were: 2.1% for atypical anorexia nervosa and 1.3% for a purging disorder, 0.4% for bulimia nervosa (low frequency/lim-

ited duration), and 0.7% for binge eating disorder (low frequency/limited duration), making the total percentage 4.5%. The lifetime prevalence for unspecified eating disorders was: 0.4% for the restrictive syndrome, 1.7% for subthreshold BN/BED, 1.1% for other, and 0.3% for insufficient information, making the total prevalence 4.5%.

Among males, the lifetime prevalence of eating disorders was 2.4%. In detail, the lifetime prevalence for typical eating disorders was: 0.3% for anorexia nervosa, 0.16% for bulimia nervosa, 0.3% for binge eating disorder. The total percentage of other specified eating disorders was 0.16%, as only one male was identified as having atypical anorexia nervosa. The lifetime prevalence for unspecified eating disorders was: 0.5% for the restrictive syndrome, 0.5% for subthreshold BN/BED, and 0.6% for other, making the total prevalence 1.6%.

The sensitivity analysis showed no significant difference between the lifetime prevalence estimates of eating disorders between the randomly selected sample and sample enriched for families with a high risk of alcohol problems. Among females, in the randomly selected sample, the lifetime prevalence was 18.7% (95% CI 15.4-22.5), and in the enriched sample, 15.6% (95% CI 10.8-22), p for difference 0.37. Among males in the randomly selected sample, the lifetime prevalence was 1.8% (95% CI 0.9-3.5), and in the enriched sample 3.8% (95% CI 1.6-8.5), p for difference = 0.16.

In study III (FinnTwin 16 sample), the lifetime prevalence of anorexia nervosa increased by 60% when the criteria were changed from DSM-IV to DSM-5. When the analyses focused only on those with actual detected cases, the lifetime prevalence among women was 3.6%. We also used sampling weights to correct for false negatives missed by symptom screening, and the lifetime prevalence estimate increased to 6.3%.

Further, we analysed the lifetime prevalence of the total number of eating disorders, including anorexia nervosa, bulimia nervosa, binge eating disorder, other specified and unspecified eating and feeding disorders, using sampling weights, making the total prevalence 14.2% among females.

Table 23. The lifetime prevalence of DSM-5 eating disorders from the FinnTwin 12 sample. From the FinnTwin 16 sample, only a lifetime estimate for anorexia nervosa is described with and without using sampling weights.

	FE-MALES% ♀	95 % CI	MALES % ♂	95 % CI	TOTAL %	95 % CI
Specified Eating or Feeding Disorder						
Anorexia nervosa						
FT12	6.2	4.6–8.3	0.3	0.08-1.3	3.4	2.5–4.6
FT16	3.6	2.7 - 4.2	-	-	-	-
FT 16 *	6.3					
Bulimia Nervosa	2.4	1.5-3.9	0.16	0.02-1.1	1.3	0.8-2.2
Binge Eating Disorder	0.6	0.2-1.5	0.3	0.08-1.25	0.4	0.2-1.0
Other Specified Eating or Feeding Disorder (OSFED)						
Atypical Anorexia Nervosa	2.1	1.3-3.5	0.16	0.02-1.1	1.2	0.7-2.0
Bulimia Nervosa of low frequency and/ or limited duration	0.4	0.1–1.3	0	-	0.2	0.07-0.7
Binge Eating Disorder of low frequency and/or limited duration)	0.7	0.3–1.7	0	-	0.4	0.2–0.9
Purging Disorder	1.3	0.7-2.4	0	-	0.7	0.3–1.3
OSFED all	4.5	3.2-6.3	0.16	0.02-1.1	2.4	1.8-3.4
Unspecified Feeding or Eating Disorder (UFED)						
Restrictive syndrome	1.4	0.8-2.6	0.5	0.2-1.5	1.0	0.6-1.7
Subthreshold bulimia/BED	1.7	1.0-3.0	0.5	0.2-1.5	1.1	0.7-1.8
Other	1.1	0.6-2.2	0.6	0.2-1.7	0.9	0.5-1.6
Insufficient information	0.3	0.07-1.1	0	-	0.15	0.04-0.6
UFED all	4.5	3.2-6.3	1.6	0.8-2.9	3.1	2.3-4.2
Any Eating or Feeding Disorder						
	17.9	15.1-21.1	2.4	1.4-4.0	10.5	8.9-12.4

**with sampling weights,* CI, confidence interval

5.1.3 Incidence

We assessed the incidence of different DSM-5 eating disorders among males and females from the FinnTwin 12 sample in study I, and the incidence of anorexia nervosa among females from the FinnTwin 16 sample in study III. The results are described in detail in table 24. Briefly, in the FinnTwin 12 sample, the total 10-year incidence rate of eating disorders among females was 1,700 per 100,000 person-years between 10 and 20 years of age (95% CI 1,400-2,060). Among males, the rate was 220 (95% CI 130-410) per 100,000 person-years. The 15-year incidence of DSM-5 anorexia nervosa among women in the FinnTwin 16 sample was 230 per 100,000 person-years between 10 and 24 years of age (95% CI 180-280).

Table 24. The incidence of DSM-5 eating disorders from the FinnTwin 12 sample. From the FinnTwin 16 sample, only incidence rate for anorexia nervosa is described.

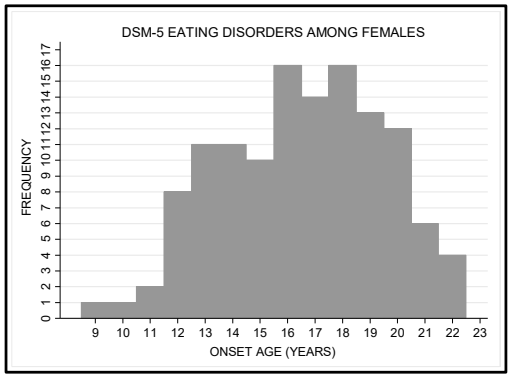
	FEMALES ♀	95% CI	MALES ♂	95% CI	TOTAL	95% CI
Specified Eating/Feeding Disorder						
Anorexia nervosa **FT12** **FT 16***	 580 230	 430-810 180-280	 30	 10-310	 320	 230-440
Bulimia Nervosa	180	110-340	20	-‡	100	60-190
Binge Eating Disorder	60	20-200	30	10-310	40	20-120
Other specified Eating/Feeding Disorder (OSFED)						
Atypical Anorexia Nervosa	210	130-370	20	-‡	120	80-200
Bulimia Nervosa of low frequency and/ or limited duration	30	10-280	-‡	-‡	15	3-150
Binge Eating Disorder of low frequency and/or limited duration	70	30-210	-‡	-‡	40	20-110
Purging Disorder	130	70-270	-‡	-‡	70	40-140
OSFED all	440	320-640	20	-‡	240	170-340
Unspecified Feeding or Eating Disorder (UFED)						
Restrictive syndrome	130	70-270	50	10-230	90	50-170
Subthreshold bulimia/BED	130	70-270	30	10-310	80	50-160
Other	100	50-240	60	20-220	80	50-160
Insufficient information	10	-‡	-‡	-‡	7	-‡
UFED all	370	260-550	140	80-300	260	190-370
Any Eating or Feeding Disorder						
	1700	1400-2060	220	130-410	980	820-1180

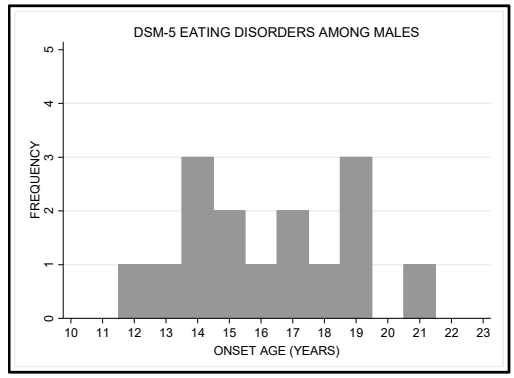
**without sampling weights,* CI, confidence interval; ‡ Confidence interval missing because no eating disorder cases in the category value.

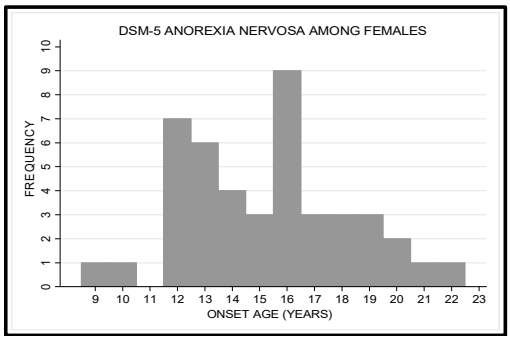
5.1.4 Peak period of onset

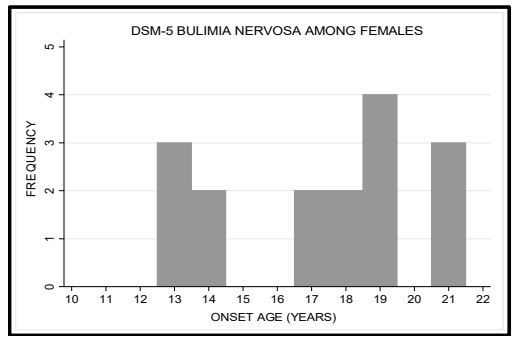
Among females, the onset of eating disorders peaked at 16–19 years of age, and among males, it peaked at 14 and 19 years. Figure 7 shows the total onset of eating disorders in males and females. More, the figure shows the onset of women's eating disorders in each of the diagnosis categories. Because there were so few eating disorders in males, only an overall picture of the onset of eating disorders is shown.

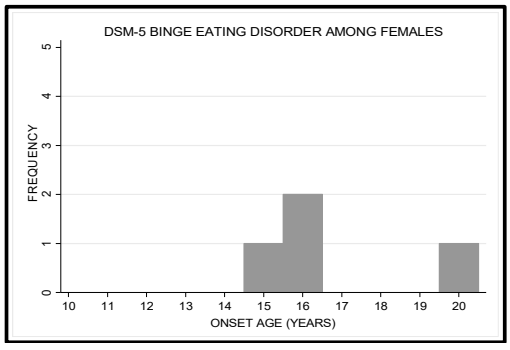
Figure 7. Peak onset of DSM-5 defined eating disorders among females and males from the FinnTwin 12 (study I).

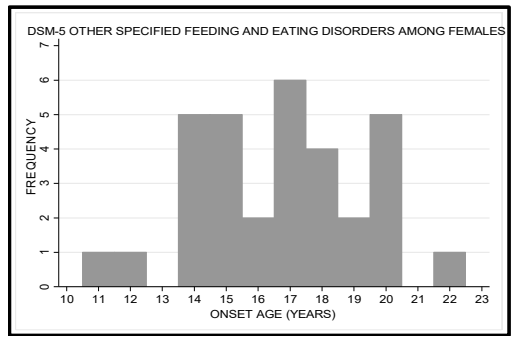


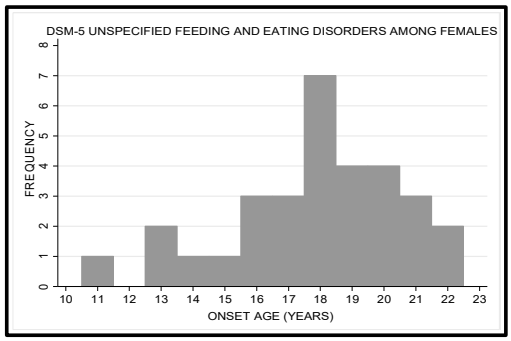












5.2 EATING DISORDER DETECTION AND TREATMENT IN COMMUNITY (STUDY II, III)

5.2.1 Detection

In the FinnTwin 12 sample in study II, one-third of the participants diagnosed with an eating disorder were identified by health care services. There was no difference between females and males (41/127 [32%] vs. (4/15 [27%], p for difference 0.7). Anorexia nervosa (57%), bulimia nervosa (50%), and atypical anorexia nervosa (44%) were identified more often than other eating disorders (binge eating disorder 33%, other specified feeding and eating disorders 12%, unspecified eating disorders 5%).

In the FinnTwin 16 sample, 42% (39/92) of all women diagnosed with a lifetime DSM-5 anorexia nervosa were detected in health care.

5.2.2 Treatment

Not all those identified by health care services in the FinnTwin 12 sample received treatment. The percentage of receiving treatment for those identified was 89% (40/45). In detail, of the diagnosed females, 30% (38/127) and males 13% (2/15) had received treatment. The difference was not statistically significant (p=0.19).

Of the forty participants who had received treatment, everyone had outpatient treatment. More specifically, nine participants had individual psychotherapy, and one family therapy (7%).Eight participants reported having received inpatient treatment (5.6%), and six participants told that they had been treated at a specialized eating disorder unit (*4%*). Psychiatric medication had been offered to twelve participants (8.5%).

Participants who suffered from anorexia nervosa (52%), bulimia nervosa (50%), or atypical anorexia nervosa (38%) received treatment more often than those who were diagnosed with binge eating disorder (17%), other specified eating disorders (12%) or unspecified eating disorders (2%) (p=0.0001).

5.3 THE COURSE OF EATING DISORDERS (STUDY II, III, IV)

5.3.1 The natural course of eating disorders

The natural course of eating disorders was assessed in study II. At the time of the interview, of the 127 females with a lifetime diagnosis of a DSM-5 eating disorder, 66 % (84/127) were still suffering from eating disorder symptoms during the past year. The corresponding percentage for males was 27% (4/15).

Because of the small number of males, both sexes were analyzed together. The mean duration of anorexia nervosa among males and females was 4.6 years (SD 3.4, range 0.5-13), 4.2 years for bulimia nervosa (SD 2.9, range 0.5-9), binge eating disorder 4.0 years (SD 2.4, range 1-7), other specified feeding and eating disorder 3.9 years (SD 2.6, range 0.5-11), unspecified feeding and eating disorder 3.2 years (SD 2.5, 0.5-9). This led to a mean duration of all eating disorders of 4.0 years (SD 2.9, range 0.5-13).

The five-year recovery rate of all eating disorders in both sexes was 40.7%. The course of eating disorders did not significantly differ by the diagnosis, as shown in figure 8 (all eating disorders log-rank p=0.66, other specified feeding and eating disorder subgroups log-rank p=0.60). In detail, five years after disease onset, 41.5% of individuals with anorexia nervosa, 23.1% with bulimia nervosa, 40.0% with binge eating disorder, 43.1% with other specified feeding and eating disorder, and 42.6% with unspecified feeding and eating disorders had recovered.

Figure 8. Recovery from DSM-5 eating disorders: Anorexia nervosa, Bulimia Nervosa, Binge Eating Disorder, Other Specified Feeding and Eating Disorders (OSFED), Unspecified Feeding and Eating Disorders (UFED)

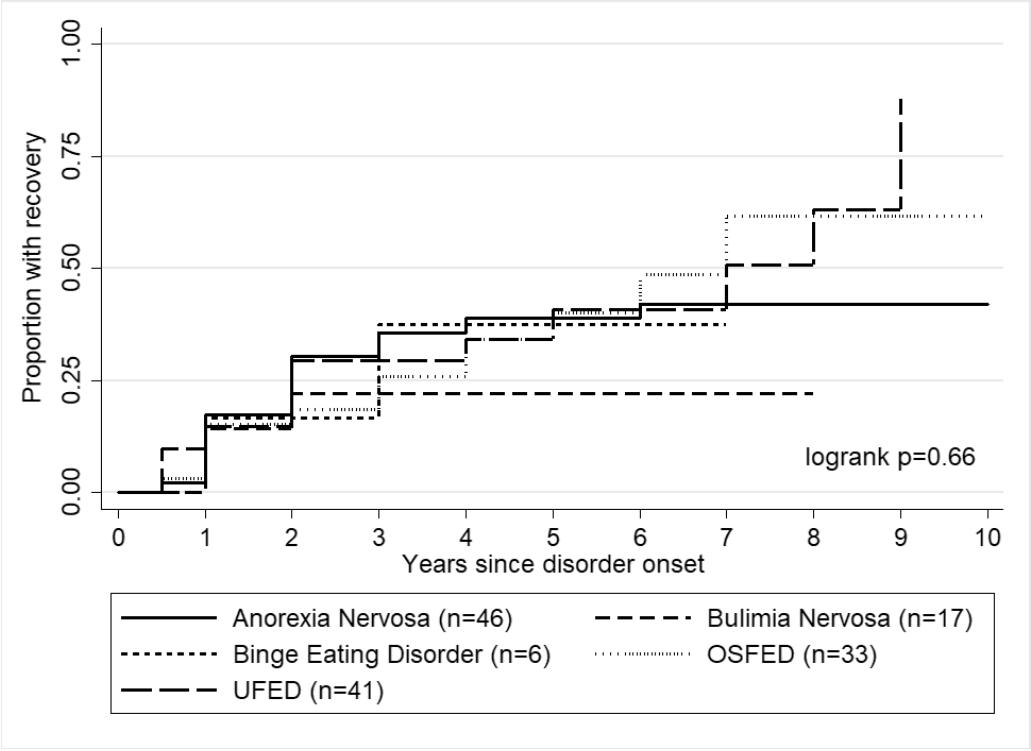
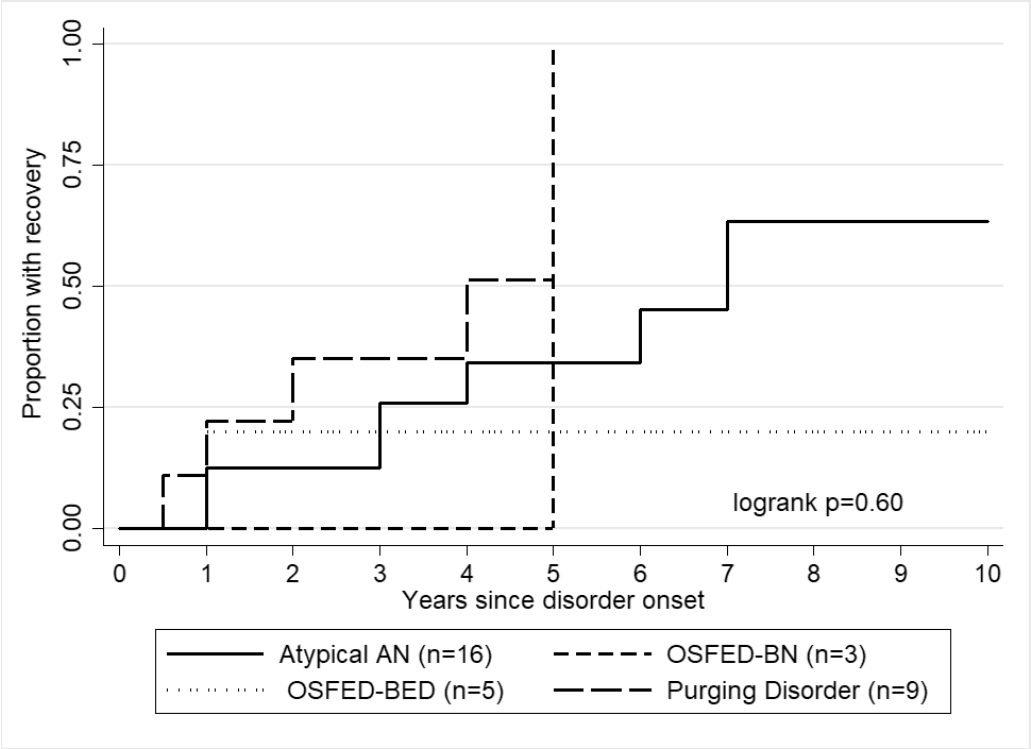


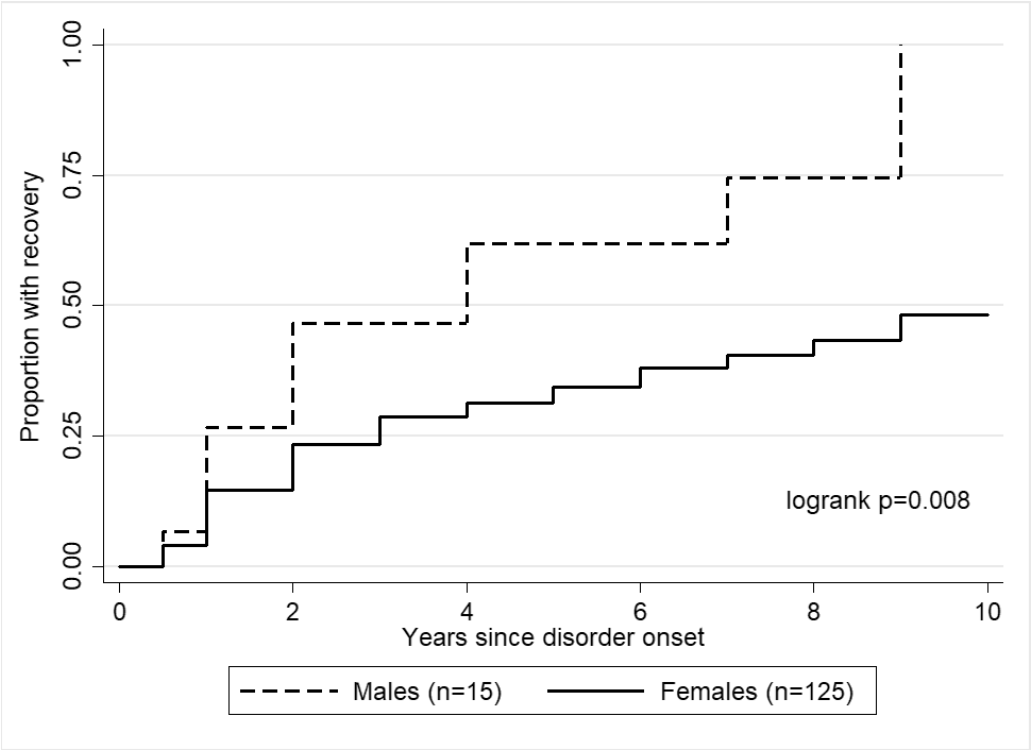
Figure 9. Recovery from the DSM-5 other specified feeding and eating disorder (OSFED) subgroups: Atypical Anorexia Nervosa (Atypical AN), Bulimia Nervosa of low frequency and/or limited duration (OSFED-BN), Binge Eating Disorder of low frequency and/or limited duration (OSFED-BED), Purging Disorder.



Gender differences

The five-year recovery rate among males and females differed. Males suffered from eating disorder symptoms for less time and recovered more often than their female counterparts (five-year recovery rate 64% vs. 37%, log-rank p=0.008).

Figure 10. The difference of recovery from the DSM-5 eating disorders among females (n=125) and males (n=15).



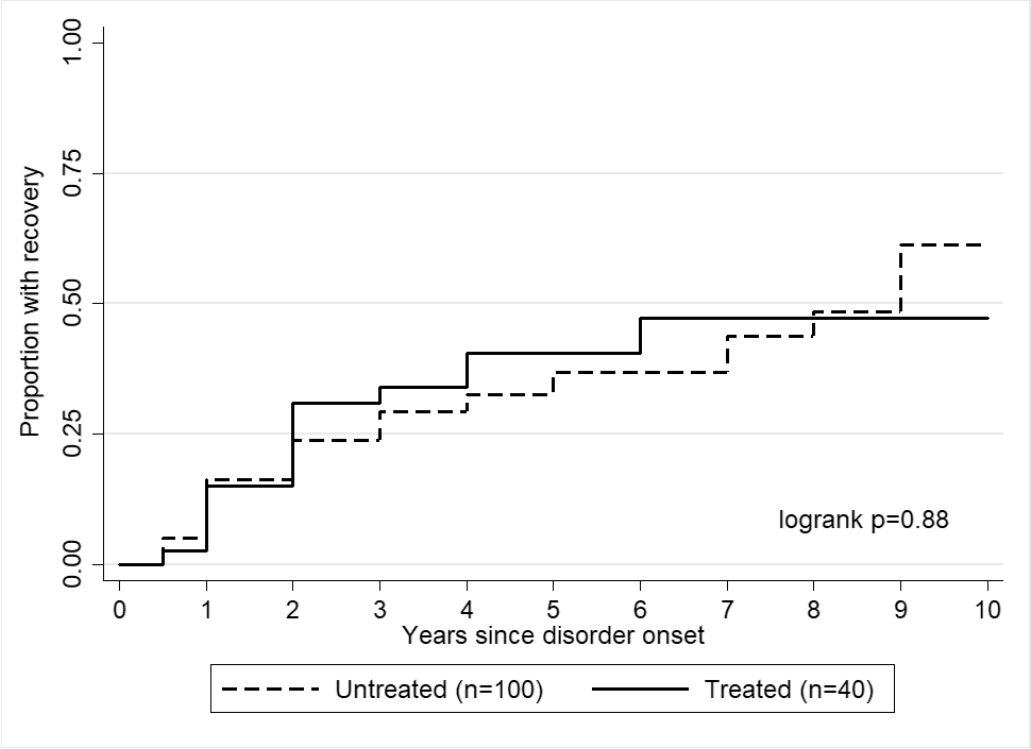
5.3.2 Impact of detection and treatment in naturalistic setting

The detection of eating disorders did not significantly affect the recovery rate of DSM-5 anorexia nervosa among women in the FinnTwin 16 sample in study III.

Similarly, the outcome of DSM-5 eating disorders among those who had received and who had not received treatment did not differ in the FinnTwin 12 sample in STUDY II (figure 11). Five years after disease onset, 41% of those who had received treatment and 40.5% of those who had not had recovered (p=0.66).

There was no difference in the recovery of different eating disorders between treated and untreated individuals (anorexia nervosa, log-rank p=0.86; bulimia nervosa, log-rank p=0.52; binge eating disorder, log-rank p=0.47; other specified feeding and eating disorders, log-rank p=0.28; unspecified feeding and eating disorders, log-rank p=0.54). Those who had received treatment were younger (15.35 years vs. 16.96 years, p=0.0026). Further, treated individuals had lower minimum BMI than untreated (17.90 kg/m2 vs. 19.96 kg/m2, p=0.0001).

Figure 11. The difference of recovery from the DSM-5 eating disorders among those who received treatment versus those who did not receive treatment.



5.3.3 Diagnostic definitions of Anorexia Nervosa and outcome

Diagnostic definitions and duration of illness

Studies III and IV investigated in the community (FinnTwin 16) and the clinical adolescent sample how different diagnostic definitions in the DSM and ICD classifications affect the course and prognostic value of the anorexia nervosa diagnosis.

All females in the community sample in study III who were diagnosed as having DSM-IV anorexia nervosa (n=55) fulfilled the criteria for DSM-5 anorexia nervosa. Further, additional 37 females were identified who fulfilled the criteria for DSM-5 anorexia nervosa.

All adolescents in the clinical sample in study IV who were diagnosed as having ICD-10 typical anorexia nervosa and 92% of those diagnosed as having ICD-10 atypical anorexia nervosa filled the criteria of DSM-5 anorexia nervosa.

In the community sample in study III, the median illness duration significantly differed depending on the DSM-IV or DSM-5 criteria used. The median duration of illness was three years among those who fulfilled the criteria for DSM-IV anorexia nervosa and one year among those who were new DSM-5 anorexia nervosa cases ($p = 0.002$).

The likelihood of recovery from Anorexia Nervosa

In the community sample in study III, the outcome of anorexia nervosa was different among DSM-5 and DSM-IV cases. Five-years after disease onset, 67% of those diagnosed with DSM-IV anorexia nervosa had recovered compared to 81% of all those who were newly diagnosed with DSM-5 anorexia nervosa (log-rank $p=0.008$). When the new DSM-5 and DSM-IV cases were pooled together, the five-year recovery rate was 72%.

In the clinical adolescent sample in study IV, at the end of the treatment in the adolescent eating disorder unit, of those with ICD-10 typical anorexia nervosa, 56% (n=19) achieved good outcome according to the modified Morgan-Russell measure, 15% (n=5) intermediate outcome and 26% (n=9) poor outcome. Of those who were diagnosed with atypical anorexia nervosa, 69% (n=9) achieved good outcome, 8% (n=3) intermediate outcome, and 23% (n=5) poor outcome.

Further, when the time to recovery was taken into account, the likelihood of recovery differed significantly (log-rank $p<0.00001$). When treatment had lasted for one year, 46% of adolescents with atypical anorexia nervosa and 3% of adolescents with typical anorexia nervosa had recovered.

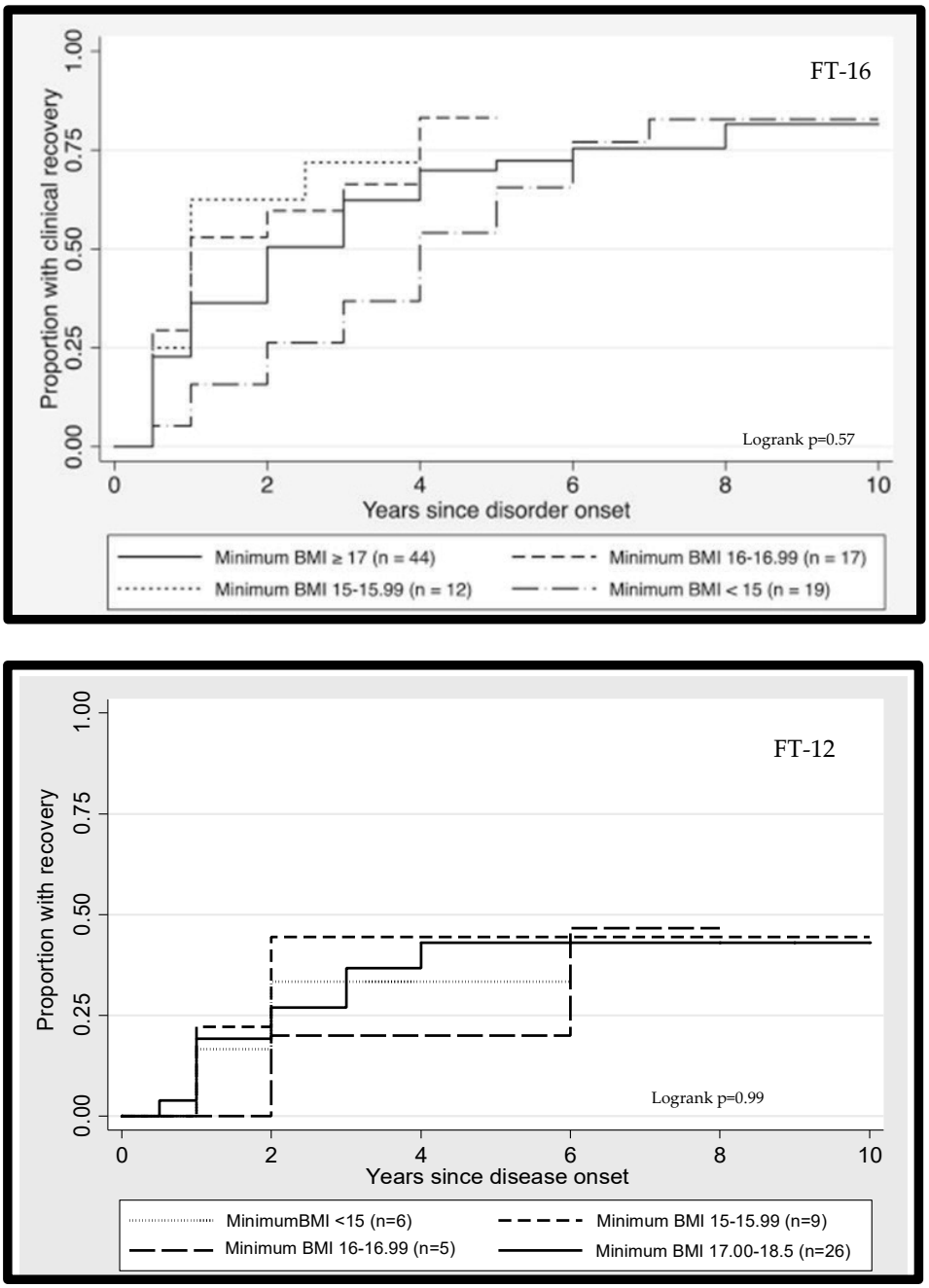
In addition, the mean duration of treatment significantly differed between those diagnosed with ICD-10 typical anorexia nervosa and atypical anorexia nervosa ($p<0.00001$). The mean duration of treatment with adolescents with anorexia nervosa was 2.2 years (95% confidence interval [1.9, 2.6], range 0.8-6.3 years). The mean duration of treatment with adolescents with atypical anorexia nervosa was 1.1 years (95% confidence interval [0.8, 1.3], range 0.3-1.7 years).

DSM-5 BMI-based clinical severity marker for anorexia nervosa

DSM-5 characterizes the severity of anorexia nervosa by weight status: BMI 17.00–18.5 kg/m2 refers to mild, BMI 16.00–16.99 to moderate, BMI 15.00–15.99 to severe, and BMI < 15 to extreme form of the disorder (American Psychiatric Association 2013).Figure 12 shows that this severity marker was not associated with recovery in follow-up at FinnTwin 12 sample in study II (log-rank p=0.99) nor in the FinnTwin 16 sample III (log-rank p=0.57).

Figure 12. Recovery from anorexia nervosa by the DSM-5 severity criterion based on body mass index (BMI). In the FinnTwin 16 sample, only females were included in the analysis, and in the FinnTwin 12 sample, all genders were analyzed together.

DSM-5 SEVERITY SPECIFIER FOR ANOREXIA NERVOSA



DISCUSSION

6.1 SUMMARY OF MAIN FINDINGS

Eating disorder diagnoses have undergone significant changes in the DSM-5 and the ICD-11. When such substantial changes to the diagnostic system arise, there is a need for well-conducted community-based studies on the occurrence and the natural course of these disorders. This study showed that DSM-5-defined eating disorders were common in Finland among young people. Approximately 1 in 6 females and 1 in 40 males had suffered from an eating disorder during their development towards adulthood.

We found that along with the change from DSM-IV to the DSM-5 criteria, the lifetime prevalence of anorexia nervosa increased by more than half, and studies I and III reported the highest lifetime prevalence for anorexia nervosa to date among females. Overall, restrictive eating disorders were common among Finnish girls, and 1 in 10 had suffered from these disorders by the time they reached young adulthood. We noted varying symptom profiles, suggesting that the symptoms of eating disorders are diverse in the population. Moreover, unspecified eating disorders were frequent in males and females, but they formed the most common eating disorder category in males.

Despite the commonness of eating disorders in the population, their detection in health care was modest: Only one-third of cases were detected in real life. Moreover, the detection and treatment of eating disorders was focused on typical eating disorder representations.

Our study showed that for many individuals, eating disorder symptoms were longstanding. Five years after the disease onset, less than two-fifths of females and two-thirds of males had recovered. Symptoms were also longstanding for those diagnosed with other specified and unspecified eating disorders, emphasising the significance of these disorders. Moreover, our study indicated that loosening the diagnostic criteria for anorexia nervosa reduces the predictability of the diagnosis. We found that individuals who met the strict diagnostic criteria for anorexia nervosa in the DSM-IV or ICD-10 recovered less often and had a longer disease duration than those who met the broader DSM-5 criteria for anorexia nervosa.

Finally, in our naturalistic setting, the likelihood of recovery among treated and untreated individuals was similar. However, this result should be interpreted with caution because our recall-based study design was not optimal for assessing treatment differences. One possible explanation for our result is that those suffering from more severe forms of eating disorders were detected and treated more frequently: Without treatment, their outcome could have been worse. Further, we could not evaluate whether the treatment was sufficient, delivered at the optimal time or delivered with the right intensity. Moreover, we were unable to address the impact of comorbidity on prognosis. At the same time, our results imply that treatments delivered in the real world may still be suboptimal for many sufferers. Thus, future studies should focus on early intervention and implementation research using carefully planned designs to address outcomes and their mediators and moderators in greater detail.

Taken together, our results provide further evidence for the clinical and public health impact of eating disorders in Finland among youths and young adults. The symptoms of eating disorders are longstanding, and considering the magnitude of the problem, their detection and treatment are insufficient.

6.2 OCCURRENCE OF EATING DISORDERS

In this section, the total occurrence of eating disorders and the observed eating disorder distribution are discussed in more detail.

Total prevalence of eating disorders

The total prevalence of eating disorders among females was 17.9% in the FinnTwin12 (study I) and 14.2% in the FinnTwin16 (study III) cohorts. Among males, the estimate was 2.4% (FT-12, study I). The risk of eating disorders started to increase from age 12 years onwards among girls and peaked at age 16–19. Among boys, the onset of eating disorders peaked in early and late adolescence.

Previous studies in the DSM-5 era have reported lifetime prevalence in community samples ranging from 3.1% to 15.3% among females (Fairweather-Schmidt & Wade, 2014; Micali et al., 2017; Smink et al., 2014; Stice et al., 2013; Udo & Grilo, 2018; Wade & O'Shea, 2015; Wagner et al. 2017) and 0.6% to 1.2% among males (Smink et al., 2014; Udo & Grilo, 2018; Wagner et al. 2017). In individual

studies, the point and period prevalence rates have been even higher, at up to 33% among females and 18.8% among males (Masheb et al., 2021; Mitchison et al., 2019).

The observed high prevalence estimates have raised a concern that the DSM-5 classification leads to the overdiagnosis of eating disorders. Indeed, the diagnostic changes aimed to diminish the number of individuals with residual diagnosis rather than increase the number of those who gain an eating disorder diagnosis per se. The reasons for this phenomenon are still unknown. The lack of strict frequency criteria in some of the diagnostic categories may contribute to the high rates, emphasising the need to weigh distress and impairment rigorously (Lindvall Dahlgren et al., 2017). Indeed, a study assessing the point prevalence of eating disorders among adolescents found that applying a criterion for clinical significance (severe distress and/or functional impairment) decreased the prevalence estimates by 40% (Mitchison et al., 2019). However, the study used online survey data to attain the eating disorder diagnosis, and using self-reports rather than diagnostic interviews to gain a diagnosis may lead to higher estimates (Lindvall Dahlgren et al., 2017). Therefore, the results are not directly comparable to those of studies using diagnostic interviews.

The high reported prevalence of eating disorders has raised the question of whether eating disorders have become more common in recent years. However, the different eating disorder classifications, assessment tools, samples and methodological issues challenge the comparison over time. Overall, the results of major studies and reviews are ambiguous: A systematic review assessing the prevalence of eating disorders during 2000–2018 found some indications of a global increase of the point prevalence of eating disorders (Galmiche et al., 2019). In addition, a large study of a nationally representative sample of US women and men identified that the lifetime prevalence of eating disorders was higher in younger compared with older age groups (Udo & Grilo, 2018). Less recent reviews have indicated that the incidence of anorexia nervosa increased until the 1970s. After that, the overall incidence remained stable in the population, but an increase among adolescents was still noted (Hoek & van Hoeken, 2003; Smink et al., 2012). Lately, a meta-analysis assessing the incidence of anorexia nervosa from 1980 to 2019 found that the incidence of anorexia nervosa has increased regardless of the age range or the record type used (Martínez-González, Fernández-Villa, Molina, Delgado-Rodríguez, & Martín, 2020).

There are some data suggesting that the incidence of bulimia nervosa may have fallen since the 1990s (Smink et al., 2012). A recent analysis of the lifetime prevalence by age in Australia indicated that previously noted rises in the prevalence rates of bulimia nervosa and binge eating disorder may be slowing down (Bagaric et al., 2020). There is no comprehensive information on changes in the occurrence of other eating disorders.

In Finland, no changes in the prevalence of anorexia or bulimia nervosa were observed among adolescents between 2002–2003 and 2012–2013 (Litmanen, Fröjd, Marttunen, Isomaa, & Kaltiala-Heino, 2017). Moreover, the total incidence of eating disorders among females in our study (1700 per 100 000 person-years) reflects the previously reported incidence of DSM-IV-defined typical and atypical eating disorders among adolescent girls (1641 per 100 000 person-years; Isomaa et al., 2009). In studies I and III, we looked at eating disorders in those born in the 1970s and 1980s. From the results, it can be concluded that eating disorders were common in these age groups at the stages of teenagerhood or young adulthood, suggesting that eating disorders have already been a public health issue in Finland for a while.

Eating disorder distribution

Anorexia nervosa - One of the unexpected results of our studies (I, III) was the high prevalence of DSM-5-defined anorexia nervosa. The lifetime prevalence of anorexia nervosa among females was around 6% in both our twin samples, representing the highest estimate to date (Fairweather-Schmidt & Wade, 2014; Glazer et al., 2019; Micali et al., 2017; Mohler-Kuo et al., 2016; Munn-Chernoff et al., 2015; Smink et al., 2014; Stice et al. 2013; Udo & Grilo, 2018). There are some explanatory factors related to our high prevalence that should be highlighted. First, study III showed that the relaxation of the diagnostic criteria for anorexia nervosa in the DSM classification increased the prevalence of anorexia nervosa by 60% among females. Second, in both samples, we studied twins, and twins may have a slightly higher risk for anorexia nervosa than singletons do (Goodman et al., 2014). Third, socio-cultural factors affect eating disorder prevalence rates and distributions worldwide (Hoek, 2016). Since we were studying eating disorders in Finland, the socio-cultural context may have affected the rate of eating disorders we observed: Restrictive eating disorder behaviours may be typical for Finns. This possibility is strengthened by previous results from a Finnish study that found the total lifetime prevalence of DSM-IV anorexia and anorexia nervosa not otherwise specified to be 10.3% among adolescents (Isomaa et al.,

2009). Fourth, our rigorous one- and two-stage study designs with healthcare professional–led diagnostic interviews may be sensitive to recognising anorexia nervosa.

Bulimia nervosa - The observed lifetime estimates for bulimia nervosa (study I; 2.4% for females and 0.16% for males) exhibited high similarity to those found in other samples in the DSM-5 era (Bagaric et al., 2020; Glazer et al., 2019; Micali et al., 2017; Stice et al., 2013). Moreover, the estimate was similar to that published in the DSM-IV era in the FinnTwin 16 cohorts (2.3%; Keski-Rahkonen et al., 2009). However, when we used sampling weights to determine the false negatives missed by the symptom screening, the prevalence estimates for DSM-5 bulimia nervosa rose to 3.9%. Moreover, the lifetime prevalence of bulimia nervosa was similar to the prevalence rates found in other Finnish samples in the DSM-IV era: Among adults, the prevalence was 2.3% (Lähteenmäki et al., 2014), and among adolescents, the sum of bulimia and bulimia not otherwise specified was 1.7% (Isomaa et al., 2009). Taken together, the results of the studies suggest that the true prevalence of bulimia nervosa among Finnish females is around 2%. Our results also confirm that the relaxation of the frequency of binges and compensatory behaviour criteria evident in the DSM-5 does not significantly change the prevalence of bulimia nervosa (Trace et al., 2012; Wilson & Sysko, 2009).

Binge eating disorder - Only 0.6% of females and 0.3% of males were diagnosed with binge eating disorder (study I). These numbers are somewhat modest compared with the pooled global prevalence of binge eating disorder, which are as follows: 0.9% for all genders, 1.4% for women and 0.4% for men (Erskine, Whiteford, & Pike, 2016). They are also modest compared with some previous lifetime and point prevalence estimates, which have shown lifetime prevalence rates up to 6.1% among women (Glazer et al., 2019) and 2.1% among men (Hudson et al., 2012) and point prevalence rates up to 4.4% among women and 2.8% among men (Masheb et al., 2021).

Our study likely underestimated the prevalence of binge eating disorder because the Structured Clinical Interview was designed for DSM-IV diagnoses and did not include the specific questions concerning binge eating specifiers. Further, binge eating disorder seems to be more common in older ages, and the young age of the participants may explain our modest numbers (Mitchison & Hay, 2014; Striegel-Moore & Franko, 2003). Socio-cultural factors in Finland may have some effect, but little is known about it (Hoek, 2016).

Other specified feeding and eating disorders – The new other specified feeding and eating disorder category in the DSM-5 appeared to be common among females (study I), with a total prevalence of 4.5%; this category mostly comprised atypical anorexia nervosa and purging disorder. However, among males, the diagnosis was rare, as only one male had a diagnosis belonging to the category.

A previous meta-analysis has shown that purging disorder is a valid diagnostic category (Smith, Crowther, & Lavender, 2017). To date, the highest reported prevalence rates have been 6.2% (lifetime prevalence) among women (Glazer et al., 2019) and 1.6% (period prevalence) among men (Mitchison et al., 2019). The diagnostic definition of purging disorder is somewhat problematic. The DSM-5 states that there should be 'recurrent purging behavior to influence weight or shape in the absence of binge eating', but there is no definition of 'recurrent'. In our sample, we noted substantial variation in purging behaviour: Some sufferers had almost daily purging, but for others, purging occurred recurrently only once a month over the years. Indeed, further research should be undertaken to investigate the effect of purging frequency and impairment related to purging disorder.

Unspecified feeding and eating disorder The residual eating disorder category from previous DSM editions was renamed in DSM-5 as unspecified feeding and eating disorder. Based on our study (I), the diagnosis appeared to be frequent in the population. It was the most common eating disorder diagnosis received by males, and one-quarter of females diagnosed with an eating disorder gained this residual diagnosis. Our further subdivision of unspecified feeding and eating disorders highlighted the heterogeneous representations of residual eating disorders in the community. Especially in males, we identified eating disorders where the main symptom characteristics were excessive exercise, sports-related weight-control behaviours and bingeing.

Previously, others have shown that individuals who received an unspecified feeding and eating disorder diagnosis have less severe problems compared with those with specified eating disorders (Ekeroth et al., 2013; Hay et al., 2017), whereas other researchers have found that it is associated with considerable clinical severity and impairment (Mustelin et al., 2016a; Wade & O'Shea, 2015). Overall, our results emphasise that despite the best intentions to reduce the number of individuals in the residual category in the DSM-5, the unspecified feeding and eating disorder is still a significant, sizeable eating disorder category in a population showing heterogeneous representations.

6.3 DETECTION AND TREATMENT OF EATING DISORDERS

Although eating disorders were common, only every third patient in the FinnTwin 12 sample was identified in health care (study II). Moreover, not all detected patients received treatment. For those who did receive some treatment, it is not known whether the treatment was adequate. For example, only a very small proportion of those diagnosed received treatment in a unit specialising in eating disorders (4%). Overall, our rate of detection and treatment was similar to previous studies in the DSM-5 era (Hart, Granillo, Jorm, & Paxton, 2011; Micali et al., 2017; Mohler-Kuo et al., 2016; Mustelin et al., 2016a; Smink et al., 2014; Solmi et al., 2016).

Like in previous studies (Smink et al., 2014), anorexia nervosa, bulimia nervosa and atypical anorexia nervosa were identified more often compared with other eating disorders. The identification of eating disorders was equally common among sexes. Still, 30% of females received treatment compared to 13% of males, and treatment concentrated on typical representations.

The treatment rate in our study was somewhat lower than that observed in a previous Finnish population-based sample of young adults. Of young women with lifetime eating disorders, 79% had had treatment contact at some point in their lives, but only one-third of those currently suffering had present contact (Lähteenmäki et al., 2014). With our findings, the evidence strongly indicates that eating disorders are not sufficiently identified and treated. Importantly, health care's ability to identify eating disorders with atypical representations seems to be severely flawed. As there are indications that those individuals who will eventually be diagnosed with an eating disorder have consulted health care with a variety of psychological and somatic complaints on several occasions without their disorder being detected (Ogg, Millar, Pusztai, & Thom, 1997), there is an urgent need for developing greater awareness of eating disorders among those working in the front line in health care.

6.4 OUTCOME OF EATING DISORDERS

Definition of recovery

The samples, follow-up times, assessment methods and definition of recovery all affect the assessment of the outcome of eating disorders. The definition of recovery in eating disorders has been compared to a broken phone because almost

every study assessing recovery finds it difficult to compare results with those from other studies as a consequence of their different recovery criteria. Therefore, studies have repeatedly emphasised the importance of consistent recovery criteria, but the requirements are unique in almost all studies (Bachner-Melman et al., 2018; Bardone-Cone et al., 2018). This was also a challenge in our studies (II, III, IV) because each had a different definition of recovery. First, in study III, recovery from anorexia nervosa was ascertained with the following criteria: 1) 1 year of no eating disorder symptoms, 2) menstrual recovery and 3) normalisation of weight to BMI 18.5 kg/m^2 or higher. Second, in study II, the focus of the criteria for recovery was on the patients' experience of recovery. Being asymptomatic for 1 year was required (both in terms of psychological and behavioural symptoms), and weight had to be normalised (BMI 18.5 kg/m^2 or higher). The recovery also had to be clinically meaningful. This criterion was relatively strict because psychological symptoms often disappear last and sometimes take years to alleviate (Clausen, 2004). Therefore, many of those who were not classified as recovered might have had some residual symptoms and no longer fulfilled the diagnostic criteria for eating disorders. Finally, the narrow Morgan–Russell criterion used in the clinical study (study IV) did not consider psychological, emotional or social factors, which may have led to the overestimation of recovery.

Outcome at the diagnostic level

The different criteria for recovery in our studies (studies II, III and IV) were reflected in the recovery rates. In the FinnTwin12 sample in study II, the 5-year recovery rate of DSM-5-defined eating disorders was approximately 40% for anorexia nervosa, binge eating disorder and other specified and unspecified feeding and eating disorders, whereas it was slightly lower for bulimia nervosa, with a rate of 20%. In the FinnTwin16 sample, the 5-year recovery rates for DSM-5-defined eating disorders were 72% for anorexia nervosa (study III), 55% for bulimia nervosa and 60% for other specified and unspecified feeding and eating disorders (Keski-Rahkonen et al., 2009; Mustelin et al., 2016a). Further, the disease duration was high in the FinnTwin 12 sample compared with previous studies in the DSM-5 era (Glazer et al., 2019; Mustelin et al., 2016a; Stice et al., 2013; Udo & Grilo, 2018; Wade & O'Shea, 2015). Only one large US study has reported a higher mean time for the diseases (up to 11.4 years for anorexia nervosa, 12.2 years for bulimia nervosa and 15.9 years for binge eating syndrome) than found in the FinnTwin12 sample. This is probably because of the longer follow-up time and older sample (Udo & Grilo, 2018).

Overall, in psychiatry, the prognostic value of a diagnosis is difficult to assess, and eating disorders are no exception (Gordon, Holm-Denoma, Douglas, Crosby, & Wonderlich, 2017). Based on our population-based (III) and clinical study (IV), individuals with strict anorexia nervosa (ICD-10 F50.0 and DSM-IV 307.1 anorexia nervosa) had a worse prognosis in that they recovered less often and had a longer disease duration than individuals with ICD-10 atypical anorexia nervosa (F50.1) or DSM-5 anorexia nervosa (307.1). These results raise questions about the prognostic value of the criteria of DSM-5 anorexia nervosa. The broader criteria may have unintentionally led to a more heterogeneous patient group and diluted the prognostic information value of the diagnostic category.

In our FinnTwin 12 sample in study II, individuals diagnosed with other specified or unspecified eating disorders did not have a significantly better prognosis than those with specified eating disorders. Further, we did not find significant differences in the outcome of different subtypes of other feeding and eating disorders. This finding is in accordance with a previous study finding that patients who had been diagnosed with atypical anorexia nervosa, purging disorder, bulimia nervosa or binge eating disorder of low frequency and/or limited duration did not differ from one another in terms of recovery (Riesco et al., 2018). Based on these results, it seems that the symptoms are often persistent if one develops an eating disorder. This finding highlights the seriousness of other specified and unspecified eating disorders. Still, it is essential to note that we could not assess the impairment associated with an eating disorder or the alleviation of it. We cannot estimate whether the onset of these eating disorders presented as much of a threat to psychological, physical and social well-being as, for example, anorexia nervosa or bulimia nervosa.

An important endpoint—death—was not considered in our study. It appears that anorexia nervosa is differentiated from other eating disorders in terms of higher overall mortality rates (Arcelus, Mitchell, Wales, & Nielsen, 2011; Suokas et al., 2013) and higher suicide rates (Preti, Rocchi, Sisti, Camboni, & Miotto, 2011). Further, mortality rates are often derived from clinical samples. In the two community-based longitudinal studies of anorexia nervosa, the Swedish Gothenburg study and the Finnish FinnTwin16 study, none of the females in the 30-year or 10-year follow-up had died (Mustelin et al., 2015b, Dobrescu et. al., 2020).

DSM-5 eating disorder severity indicators predicting the outcome

Our results from the FinnTwin12 and FinnTwin16 samples showed that the minimum BMI proposed for classification of the severity of anorexia nervosa in the DSM-5 criteria did not predict recovery. Our findings are consistent with previous studies (Dalle Grave, Sartirana, El Ghoch, & Calugi, 2018; Smith et al, 2017). Thus, the BMI-based severity indicator may help clinicians clarify the current situation and guide treatment decisions for the moment. Still, it seems to be an inadequate measure for the long-term prognosis.

The severity indicators in DSM-5 for bulimia nervosa and binge eating disorder are based on several binge and purge episodes. Unfortunately, we could not derive the severity of bulimia nervosa or binge eating disorder because the interview did not assess the frequency of these symptoms in detail. Previously, some studies have found that the severity criteria are not associated with eating disorder pathology or outcome (Gorrell et al., 2019; Grilo, Ivezaj, & White, 2015), and some have had contrary findings (Dakanalis et al., 2018). Thus, it has been suggested that a specifier based on shape and weight concerns would be more clinically meaningful because these concerns are related to greater psychopathology (Grilo et al., 2015). In conclusion, as the severity criterion of anorexia nervosa was not associated with recovery in either of our community samples, and evidence for the severity criterion for bulimia nervosa and binge eating disorder is lacking, we need further studies to assess better severity indicators for eating disorders.

Difference of outcome between genders and heterotypic continuity

Since outcome studies have focused on females, little is known about gender differences and the natural course of eating disorders among males. In individual studies, there have been some indications that the outcome of eating disorders could be better for males than it is for females (Støving, Andries, Brixen, Bilenberg, & Hørder, 2011; Strober et al., 2006). However, overall, the evidence is still considered insufficient to draw any firm conclusions (Strobel et al., 2018; Strobel et al., 2019). In the FinnTwin12 sample in study II, we found that males were more likely to recover from an eating disorder than females were, bringing some additional information to address the lack of knowledge. In the clinical data in study IV, the number of boys was limited, so it was not meaningful to look at gender differences.

Previously, important findings have been established from the FinnTwin16 sample concerning the continuity of eating disorder symptoms among males (Raevuori et al., 2009). The study found that the duration of DSM-IV-defined anorexia nervosa among males was transient, as the average time to recovery was 1.6 years. Still, anorexia nervosa preceded the onset of major depression in four of the five males that were diagnosed in the study. Crossover to bulimia nervosa was also common (Raevuori et al., 2009). These results suggest a substantial heterotypic continuation of psychiatric symptoms among males with anorexia nervosa.

Long-term studies among females have also shown that 10 years after teenage-onset anorexia nervosa, four out of five women have suffered at least one episode of major depression or dysthymia (Ivarsson, Rastam, Wentz, Gillberg, & Gillberg, 2000). Moreover, a 30-year follow-up study of anorexia nervosa patients found that one in five still had a chronic eating disorder, and almost two-fifths had other psychiatric conditions (Dobrescu et al., 2020). Because psychiatric comorbidity is high in eating disorders, it is challenging to assess whether eating disorders simply evolve to another type of psychiatric disorder or whether it is merely a case of a continuation of the comorbidity. Importantly, in the long term, it seems that recovery from the eating disorder is associated with a lower risk for common major comorbidities like major depressive disorder and substance use (Keshishian et al., 2019). In our studies, we were unable to evaluate this change in psychiatric symptoms over time, and therefore, we cannot comment on the long-term psychiatric prognosis.

Impact of detection and treatment in naturalistic settings

The findings on the likelihood of recovery were similar in both the detected/treated and untreated groups in studies II and III. However, it is essential to note that our results do not mean that treatment would be ineffective. Many factors have influenced our results. First, our naturalistic research setting is not the most suitable for assessing treatment differences. The optimal study design for assessing treatment differences would have been a randomised controlled trial in which eating disorder sufferers were allocated to groups undergoing different treatments, with the groups then compared in terms of response. Future research should focus on conducting randomised treatment trials in real-life settings.

Second, our results can be partly explained by confounding by indication, which means that those suffering from a more severe form of an eating disorder were detected—and thus treated—more often. If no treatment had been offered, their outcomes may have been worse.

Third, we could not control for the effect of all potentially affecting factors, such as psychiatric comorbidity. Still, we found that in each eating disorder diagnostic group, the recovery was similar among those who received treatment and those who remained untreated. Moreover, we had an indication that those who received treatment were younger and had a lower minimum BMI than those who remained untreated. Perhaps eating disorders evident in adolescence are detected and treated more often. In addition, those who had early onset eating disorders had more time in the follow-up to be detected than those who got sick later in adulthood. Anorexia nervosa was treated most often of all the eating disorders, which can partly explain the lower BMI among treated individuals. Further, although eating disorders affect people in all BMI categories (Schaumberg et al., 2017), those with stereotypical eating disorder symptoms like underweight are often more easily identified in primary care (Waller et al., 2014).

Fourth, our results cannot indicate whether the actualised treatment was sufficient or delivered at the optimal time. We could not assess the adequacy of treatment because the interviews contained limited data on the intensity and delivery of care. Further, we did not know the time span between the onset of symptoms and the beginning of the treatment. Previous studies have indicated that depending on the eating disorder type, the duration of untreated eating disorder ranges from 2.5 to 6 years, and rapid access to care may improve the prognosis (Austin et al. 2021; McClelland 2018). Thus, it may be that in real-world implementation, eating disorder treatment is still suboptimal for many individuals. Resources for eating disorder treatment have typically been built around the assumption that incident cases are rare and eating disorder treatment will take place in a multidisciplinary specialist setting. However, it may be that in practice, many individuals with eating disorders are treated in school health settings and primary care by just one person or a small team, and the intensity and delivery of care could vary substantially.

The comparison of treated and untreated groups in naturalistic settings is surprisingly rare. Outside our samples, treatment was not associated with the 5-year outcome among treatment-seeking patients who fulfilled the criteria for DSM-IV-defined anorexia nervosa, bulimia nervosa or eating disorder not otherwise

specified (Ben-Tovim, Walker, Gilchrist, Freeman, & Kalucy, 2001). In addition, no association of treatment with the outcome of DSM-IV-defined anorexia nervosa was found in a 30-year follow-up (Dobrescu et al., 2020).

Consideration of the effect of treatment is important when looking at the prognosis of different eating disorder diagnoses. It was found in this study that individuals diagnosed with other specified or unspecified feeding and eating disorders had not received treatment as often as those diagnosed with specified eating disorders. If treatment had been offered at the same rate, the prognosis for these disorders may have been better. To date, no clinical trials have been conducted in which those diagnosed with different DSM-5 eating disorders have been offered treatment and the responses to treatment have then been compared.

6.5 METHODOLOGICAL CONSIDERATIONS

Considerations regarding samples and study designs

The process of conducting, collecting and analysing a rigorous community study requires time and resources. Our prospective community-based studies were based on two nationwide samples that included all twins born in many consecutive years in the 1970s and 1980s. These samples made it possible to study the occurrence of eating disorders in at-risk groups in adolescence and early adulthood over a broad period. These samples also enabled us to assess the natural course of eating disorders, including both treated and untreated groups.

The study designs enabled rigorous data collection. The FinnTwin16 study used a two-stage design where eating disorder symptoms were screened using a questionnaire, followed by a diagnostic interview. To account for the possible cases missed in the screening, a sample of screen negative individuals was also diagnostically interviewed, and sampling weights were used to consider those not caught via screening. In the FinnTwin12 studies, all the participants were interviewed without relying on a preceding screening stage. This eliminated the possibility of missing eating disorder cases during screening.

Importantly, the studies were based on two twin cohorts. Twins are very similar to the rest of the population in terms of psychiatric morbidity (Chitkara, MacDonald, & Reveley, 1988). However, in a single sizeable Swedish dataset, twin and triple pregnancies were associated with a higher risk of anorexia nervosa in the offspring. A similar association was not observed in other eating disorders

(Goodman et al., 2014). Twins may also have a higher concordance of eating disorders because of perinatal factors, genetic influence—about which little is known—or sharing a common family climate. This may have some effect on the generalisability of our results to the general population.

In the FinnTwin12 study's intensively studied sample, a proportion of individuals were enriched from families with a possible risk for an alcohol problem. One-third came from families where the parents had gained elevated scores from a self-reported alcohol-related problems questionnaire. This could potentially affect the obtained results, but overall, the enrichment did not significantly affect the prevalence of eating disorders (p for difference 0.37 for females and 0.16 for males). Moreover, the prevalence estimates in the FinnTwin16 sample among females, which did not include any enrichment, were similar to those in the FinnTwin 12 sample. This strengthens the notion that the effect of enrichment was minimal.

In our clinical study, for the first time, we were able to observe the outcome of typical and atypical anorexia nervosa among adolescents in a real-life setting in a unit specialising in the treatment of eating disorders. Although this was Finland's largest unit specialising in eating disorders, our study was limited by the small sample size.

Notably, the clinical sample and the population-based FinnTwin12 sample included both females and males. The samples allowed additional information on eating disorders in males—historically, a population that, has been poorly studied. Further, the extensively collected data in the FinnTwin12 study allowed analysis of the prevalence and course of various eating disorders from the same data among all genders, which has been lacking in many previous studies.

Considerations regarding assessment methods and diagnoses

In our population-based studies, many participants were interviewed by healthcare professionals using diagnostic interviews. The interviewers had received intensive training of the interview instrument, the Structured Clinical Interview (SCID), a widely used structured diagnostic interview to assess whether the individual fulfils the criteria for eating disorder or any other DSM disorder (Glasofer, Brown, & Riegel, 2015). Still, there were some limitations regarding this interview. The SCID was designed for DSM-IV diagnoses and not yet validated for DSM-5. Therefore, the interview favoured typical eating disorders—anorex-

ia nervosa and bulimia nervosa. However, the interviewers gathered extra information in the interviews, making it possible to make diagnoses as accurate as possible. In addition, the interview was not able to detect ARFID, pica or rumination disorder. Given the opportunity to use the new Pica, Avoidant Restrictive Food Intake Disorder, and Rumination Disorder Interview (PARDI) designed to detect these eating disorders (Bryant-Waugh et al., 2019), the total prevalence of eating disorders would probably have been higher. Moreover, a group of medical doctors highly specialised in eating disorders confirmed all diagnoses, and expert judgement optimises the accuracy of diagnoses.

Unfortunately, we did not have the specific tools to assess the impairment related to diagnosis, which is a common problem in community-based studies. In addition, the assessment of psychiatric comorbidity was not within the scope of our research, so we lack information on comorbidity. Moreover, the participants in both community samples were questioned about eating disorder symptoms and their alleviation, weight changes, detection and treatment retrospectively; recall bias may have affected the responses. The participants were also the sole informants providing the information, which could have led to information bias. These factors are important, especially when considering the onset age for eating disorders: Childhood eating disorders were poorly identified in the study. Recall bias, the lack of parental interviews and the dearth of appropriate questions regarding childhood-type eating disorder manifestations may all have affected the results.

Finally, in our population-based studies, we had a good to excellent interview participation rate (86.7% in the FinnTwin16 sample and 73% of the FinnTwin12 sample) compared with many other studies (Galmiche et al., 2019).

Considerations regarding the definition of recovery and follow-up

As previously discussed, the definition of recovery varied across all three studies. The strength of our definition in the population-based studies was that a 1-year period without eating disorder behaviours was required for recovery; such a criterion has been recommended in previous studies because the risk of relapse is greatest within the first year (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017; Strober, Freeman, & Morrell, 1997). The results of all our studies should be interpreted in light of the duration of follow-up. In the FinnTwin 12 and FinnTwin 16 samples, recovery from an eating disorder was assessed when the interviewees were approximately 22 and 24 years old, respectively,

and many of those interviewed still had eating disorder symptoms. In general, chances of recovery tend to increase with longer follow-up periods (Hjern, Lindberg, & Lindblad, 2006; Lock, Agras, Bryson, & Kraemer, 2005; Nilsson & Hägglöf, 2005; Strober et al., 1997). Also, in our clinical sample, one disadvantage was the lack of longer follow-up. Finally, as discussed above, we had limited possibility to account for how eating disorder diagnoses evolved to other eating disorders over time or to another psychiatric disorder.

6.6 CONCLUSION, IMPLICATIONS AND FUTURE DIRECTIONS

This study set out to investigate the diagnosis, occurrence, detection, treatment and course of eating disorders among adolescents and young adults in Finland. With those of other recent community-based studies, our results show that eating disorders are common, supporting the large effect of eating disorders on mental health in adolescence and the brink of adulthood. Since it is known that psychiatric symptoms in adolescence often persist into adulthood (Kessler et al. 2007), it is urgent for more prevention and detection efforts to be allocated to this age group.

Our results also highlight that, in the population, eating disorder symptoms are diverse. Moreover, despite the best intentions to diminish the number of individuals receiving a residual eating disorder diagnosis in the DSM-5, the proportion of such individuals is still substantial, especially in males. This indicates that further improvements to the eating disorder categorisation that consider symptom expression in males are vital. Still, no matter how the classification is refined, there will always be individuals whose symptom profile does not fit the specified eating disorder diagnoses. Thus, the detection and treatment of eating disorders should not be diagnosis dependent; instead, these measures should cover the full spectrum of eating disorder symptoms.

Importantly, awareness of the diversity of eating disorder symptoms should be raised among those working on the first line in health care, especially those working closely with adolescents and young adults. This is especially important because our study showed that the detection rates of eating disorders were profoundly inadequate considering the magnitude of the problem. These shortcomings were highlighted in the findings related to atypical eating disorders.

Many individuals with eating disorders suffer from their symptoms for a long time. The likelihood of recovery in our naturalistic setting was similar among treated and untreated individuals. One explanation for this may be that treat-

ments delivered in the real world may still be implemented in a suboptimal manner for many sufferers. Since there are indications that early identification and rapid access to eating disorder treatment may improve the prognosis (Fukutomi et al. 2020; McClelland et al. 2018; Isomaa & Isomaa 2016), future studies and clinical efforts should explore ways to increase early help seeking and enhance detection. In addition, referral and acceptance protocols in health care should not apply too narrow diagnostic or time criteria to considering referrals because delays in treatment access may lead to more complex symptom profiles.

In forthcoming studies, it should be determined whether enabling rapid access to early treatment and sufficient treatment administration in Finland could eventually lead to better outcomes. In the future, intervention and implementation research should also focus on forms of treatment that non-specialists can effectively deliver in the primary care context.

At present, the need to monitor and assess the quality and impact of eating disorder treatment in real-world clinical settings is highlighted (Mountford, Allen, Tchanturia, Eilender & Schmidt, 2021; Södersten, Brodin, Sjöberg, Zandian & Bergh, 2019). In Finland, too, the quality and effectiveness of eating disorder treatment in public healthcare should be monitored in the future, for instance, using quality registers or Kela's registers. In addition, to increase the diagnostic categories' clinical utility, we need future studies to assess the course of eating disorders and response to treatment in detail.

Finally, we were not able to assess the role of comorbidity, but previous studies have shown that eating disorders are highly comorbid with numerous psychiatric disorders (Ulfvebrand et al., 2015). This also means that many individuals accessing health care because of different psychiatric problems, such as depression or anxiety, may simultaneously suffer from eating disorder symptoms. Therefore, a comprehensive survey of psychopathology is essential. Previously, it has been indicated that comorbidity complicates eating disorders' prognosis (Kask et al., 2016; Brand-Gothelf, Leor, Apter & Fennig, 2014) and that alleviation of an eating disorder diminishes the subsequent risk of other psychiatric disorders (Keshishian et al., 2019). Thus, comorbidity should be considered during treatment. Moreover, treatment for eating disorders should not be denied because of comorbidity and vice versa because patients cannot simply leave one part of their illness on hold while being treated for the other. Finally, future studies should investigate whether a treatment that focuses on common psychopatho-

logical factors and traits of eating disorders and the most common psychiatric comorbidities, such as emotional regulation problems and perfectionism, helps improve the long-term prognosis.

ACKNOWLEDGEMENTS

At the beginning of my career, I worked in units specialising in treating eating disorders. These years aroused my interest in eating disorders, and I am grateful that I was later offered the opportunity to study them and contribute to the ongoing research on their occurrence, detection, treatment and course.

Conducting this doctoral thesis has been an interesting and inspiring process. During this journey, I have learned about conducting research, writing and teaching, and I have also met many wonderful people. First, I would like to thank my supervisors, Professor Anna Keski-Rahkonen, Adjunct Professor Anu Raevuori and Doctor Pyry Sipilä, who have always supported me with kindness and provided their time and expertise. It is difficult to imagine supervisors more inspiring and warm-hearted. In addition, I would like to thank the other members of our research community, Linda Mustelin, Terhi Lohela, Ulla Kärkkäinen and Joni Lindbohm. Thank you for your company, all the fun we had through the years, your peer support and your expertise. I would also like to thank Professor Jaakko Kaprio, who always had time to answer my questions, and Kauko Heikkilä, who provided invaluable help in processing the data.

Furthermore, I want to express my gratitude to Professor Mauri Marttunen, who always gave me excellent advice and helped me obtain funding for my research. I would like to thank the Yrjö and Tuulikki Ilvonen Foundation for providing the grant that enabled me to work full-time on the thesis. I would also like to acknowledge my colleagues and co-authors, Veli-Matti Tainio and Elisabeth Jüriloo. Thank you for the wonderful collaboration.

I would also like to express my gratitude to Associate Professor Rasmus Isomaa for agreeing to act as the opponent for the public examination of this doctoral thesis. I would further like to thank Adjunct Professor David Gyllenberg and Clinical Associate Professor Else Marie Olsen for serving as pre-examiners. Your important and insightful feedback made the thesis much better.

Furthermore, I would like to thank my parents and my brother for their unconditional love, support and help with the kids. Many thanks to Tuula and Janne as well for all the support provided to our family, which made my accomplishing this project easier. Thanks also to my lovely friends for their empathy, friend-

ship and great parties. Finally, to my caring husband and best friend, Esko, my deepest gratitude. You have supported me every step of the way, and I always know you want the best for me. I am truly thankful for having you in my life.

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