DSM-5 EATING DISORDERS AMONG ADOLESCENTS AND YOUNG ADULTS IN FINLAND: A PUBLIC HEALTH CONCERN

The running title: Prevalence and Incidence of Eating Disorders

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Disclosure of Conflicts

The authors declare that they have no conflict of interests.

Data availability statement

The data are not publicly available due to privacy or ethical restrictions. We encourage interested researchers to contact us about arrangements for secondary analyses.

ABSTRACT

Objective

We aimed to assess the lifetime prevalence, 10-year incidence, and peak periods of onset for eating disorders as defined by the Fifth Diagnostic and Statistical Manual of Mental Disorders (DSM-5) among adolescents and young adults born in the 1980s in Finland.

Method

Virtually all Finnish twins born in 1983–87 (n = 5,600) were followed prospectively from the age of 12 years. A subsample of participants (n = 1,347) was interviewed using a semi-structured diagnostic interview in their early twenties.

Results

The prevalence of lifetime DSM-5 eating disorders was 17.9% for females and 2.4% for males (pooled across genders, 10.5%). The estimated lifetime prevalences for females and males, respectively, were 6.2% and 0.3% for anorexia nervosa (AN), 2.4% and 0.16% for bulimia nervosa (BN), 0.6% and 0.3% for binge eating disorder (BED), 4.5% and 0.16% for other specified feeding or eating disorder (OSFED), and 4.5% and 1.6% for unspecified feeding or eating disorder (UFED). Among females, the prevalence of OSFED subcategories was as follows: atypical AN 2.1%, purging disorder 1.3%, BED of low frequency/limited duration 0.7%, and BN of low frequency/limited duration 0.4%. The 10-

year incidence rate of eating disorders was 1,700 per 100,000 person-years among females (peak age of onset 16-19 years) and 220 per 100,000 person-years among males.

Discussion

Eating disorders are a common public health concern among youth and young adults, affecting one in six females and one in forty males. Adequate screening efforts, prevention, and interventions are urgently needed.

Keywords: Eating Disorders; Epidemiology; Prevalence; Incidence; Classification; Diagnosis

INTRODUCTION

Many individuals with eating disorders do not receive the help they need. Few are detected in healthcare, and even fewer get adequate treatment (Cachelin & Striegel-Moore, 2006; Hart, Granillo, Jorm, & Paxton, 2011). The foundation for improving prevention, detection, and treatment of eating disorders is understanding the magnitude of the problem, the spectrum of symptoms, and the age at which the risk in population is the greatest.

Reliable community-based estimates of the occurrence of eating disorders are needed because the diagnostic definitions of eating disorders have changed. The Fifth Diagnostic and Statistical Manual of Mental Disorders (DSM-5) addressed several shortcomings observed in the previous editions by expanding the diagnostic definitions of anorexia nervosa (AN) and bulimia nervosa (BN) and by increasing the number of diagnostic categories. First, binge eating disorder (BED) is included as an independent diagnostic entity. A second new category, other specified feeding or eating disorders (OSFED), comprises atypical anorexia nervosa, purging disorder, night eating syndrome, and bulimia nervosa and binge eating disorder of low frequency and/or limited duration. A third new category, unspecified feeding or eating disorder (UFED), is for eating disorders that do not fulfill the criteria of any other eating disorder. In addition, the DSM-IV diagnosis of feeding disorder of infancy or early childhood (FDIEC) was reformulated as avoidant/restrictive food intake disorder (ARFID) and included with pica and rumination

disorder to the Feeding and Eating disorder category in DSM-5. The principal aim of these additions was to increase the clinical utility of the diagnostic system and to ensure that more people with clinically significant eating problems would receive a specific eating disorder diagnosis (American Psychiatric Association, 2013).

Studies in the DSM-5 era have shown that the ability of the current classification to capture the clinical features of eating disorders has indeed improved compared to its predecessors (Flament et al., 2015; Mustelin, Lehtokari, & Keski-Rahkonen, 2016a; Stice, Marti, & Rohde, 2013). Since the introduction of DSM-5, many community-based studies have assessed the occurrence of DSM-5 defined eating disorders (Galmiche, Dechelotte, Lambert, & Tavolacci, 2019; Glazer et al., 2019; Lindvall Dahlgren, Wisting, & Ro, 2017; Mitchison et al., 2019; Udo & Grilo, 2018; Wagner et al., 2017). Still, gaps in knowledge remain.

Discrepancies exist in the prevalence estimates for individual diagnoses and all eating disorders, likely due to methodological differences such as varying sample characteristics, study designs, and assessment methods (Lindvall Dahlgren & Wisting, 2016; Lindvall Dahlgren et al., 2017; Mitchison & Hay, 2014). This highlights the need for well-conducted population-based studies with large sample sizes that use diagnostic interviews (Udo & Grilo, 2018). Less attention has also been paid to the prevalence of eating disorders among males (Javaras & Hudson, 2015; Murray et al., 2017). Few studies have assessed the prevalence of OSFED, and even fewer have investigated the prevalence and manifestations of UFED (Javaras & Hudson, 2015). Finally, information about the

occurrence of new cases, the incidence and age of onset, is vital to the appropriate allocation of resources for the prevention, detection, and treatment of eating disorders. Nonetheless, only a few studies in DSM-5 era have addressed these factors, and those who have, have mostly focused on females (Allen, Byrne, Oddy, & Crosby, 2013; Micali et al., 2017; Mustelin, Raevuori, Hoek, Kaprio, & Keski-Rahkonen, 2015; Mustelin et al., 2016a; Mustelin et al., 2016b; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Stice et al., 2013; Udo & Grilo, 2018).

To address these needs, we utilized data from a large Finnish nationwide longitudinal twin study that consists of five consecutive birth cohorts born in 1983-87. Using a rigorous protocol, we estimated the lifetime prevalence, 10-year incidence, and peak period of onset for the total number of eating disorders and for the individual diagnostic categories.

METHODS

FinnTwin12 Birth Cohorts

Participants were part of a population-based longitudinal twin study, FinnTwin12. The study consisted of five consecutive birth cohorts of twins who were born between the years 1983 and 1987 and identified through Finland's central population registry (n = 5,600 twins). Follow-up started just before each participant's 12th birthday and occurred at ages 14, 17.5, and 22 years. Depending on the data collection wave, information was gathered by questionnaires from twins, parents, and teachers. Response rates were 85-90% across all waves (Kaprio, 2013; Rose et al., 2019). Figure 1 shows the study participation flowchart.

Intensively-studied sample

A nested subset of twins was selected from the epidemiological sample for a more intensive assessment. For inclusion in the intensively-studied sample, at least one parent had to be Finnish speaking, and parents had to return the family questionnaire and had to permit school contact. The intensively-studied sample consisted of 1,035 families, the majority of whom were selected at random (72.3%, 748 families). Because major funding for the FinnTwin12 Study was obtained from the National Institute on Alcohol Abuse and Alcoholism (NIAAA) in the US, the rest of the subsample (27.7%, 287 families) were selected based on parental self-reports (elevated scores on the Malmö-modified Michigan Alcoholism Screening Test, Mm-MAST), indicating a risk of alcohol problems. This was done to enrich the sample with families who could inform on familial factors and origins

of alcohol use. The study protocol has been described more thoroughly previously (Rose, Dick, Viken, Pulkkinen, & Kaprio, 2004).

Data collection and analysis were carried out in accordance with the Declaration of Helsinki. It was approved by the ethics committee of the Department of Public Health at the University of Helsinki and the Institutional Review Board of Indiana University. Written informed consent was provided by all participants.

Measurements and diagnostic interview for eating disorders

In the fourth follow-up, in 2006-2009, when the twins were approximately 22 years old (range 21-26 years, mean age 22.4 years, standard deviation 0.7), 638 men and 709 women from the intensively studied sample (total n=1,347, 73% of the target sample, 620 complete twin pairs) attended a clinical interview. The interview was conducted by trained interviewers who had a degree in healthcare (registered nurses, advanced graduate students in psychology, and masters of health care). The interview staff was initially trained at the Indiana University Medical School with follow-up training in Finland. Most of the interviews were conducted face-to-face (n = 709) and the rest by phone using Structured Clinical Interview for DSM-IV (SCID) (First, M. B., Spitzer, R. L., Gibbon, M., & Williams, J. B, 2002) which has been used previously for eating disorders with an excellent interrater agreement (Mustelin et al., 2016b). During the interview, participants were questioned in detail about their eating behaviors, compensatory habits,

and potential cognitive distortions related to food, weight, and body image, applying the DSM-IV criteria. Further, participants were asked to elaborate on the time course of symptoms, detection in healthcare, and any treatment they had received. Interviewers wrote a narrative based on the answers. Also, participants' height and weight were measured or self-reported in interviews conducted by phone. Based on this information, the body mass index was calculated as body mass (kg) divided by height (m) squared. Participants were also asked in detail about their weight history. Based on this information, a weight history diagram was drawn, which included a narrative explanation of the participant's weight status over time.

Validation of DSM-5 eating disorder diagnoses

Based on the answers, interviewers categorized participants into three groups. The first group fulfilled the DSM-IV criteria for AN or BN. The second group showed signs of eating disorder symptoms or attitudes (i.e. cognitive distortions about weight or body image, fear of weight gain, dieting, fasting, purging, laxative or other misuses of drugs to control weight, excessive exercise, unhealthy behaviors related to drive for muscularity, bingeing, and weight loss). The third group did not report such behaviors. Three medical doctors (YS, AR, AK), highly experienced in the diagnosis and treatment of eating disorders, established consensus DSM-5 diagnoses for all participants in the first and second groups (n=196). The recoding was made using all the relevant data in the case notes and by examining the weight history diagram. Table 1 summarizes the diagnostic criteria that we used to diagnose eating disorders.

Diagnoses were given in a hierarchic order: AN trumped BN; AN, BN, and BED trumped OSFED, and all other specified eating disorders trumped UFED. A diagnosis of OSFED or UFED was given only to those who had never had AN, BN, or BED. The diagnostic crossover was challenging to interpret, and we identified only three participants with AN who progressed to BN.

As the interview questions were based on DSM-IV classifications, to which substantial changes have been made in the DSM-5, some key questions were missing. For example, questions for binge eating specifiers such as disgust or eating alone or marked distress were not available. However, in most cases, the interviewers had written detailed additional information about each individual's symptoms in the case notes and weight diagram, and these were used when we sought consensus for DSM-5 diagnoses. Nevertheless, we were not able to assess pica, rumination, avoidant/restrictive food intake disorder, or night eating syndrome, because the diagnostic interview lacked specific questions for these. Further, we did not have the tools to assess the impairment related to the diagnosis.

The residual diagnosis UFED was given to participants reporting eating disorder symptoms that caused distress comparable to levels we have observed clinically but did not meet the criteria for any specified diagnosis. To investigate the whole spectrum of eating disorders in the community and to better understand constituents of the residual UFED category, we divided it into four subcategories. We named the subcategories as

follows: UFED restrictive syndrome, UFED BN/BED, UFED other, and UFED insufficient information. The symptom criteria for each subcategory are described in detail in Table 1.

Statistical analysis

We assessed the lifetime prevalence and ten-year incidence rate for specified and unspecified DSM-5 eating disorders. Incidence rates were calculated from the age of 10 to 20. We conducted Pearson chi-squared tests for cross-tabulations. All confidence intervals and p-values were adjusted for the sampling of twins within twin pairs. All analyses were performed using statistical software Stata 13.

RESULTS

DISTRIBUTION

Of the 1,347 participants (709 females, 638 males), 142 (10.5%) were diagnosed with a DSM-5 eating disorder. Eating disorders were more common in females with a sex ratio of 8:1. Of the 709 females, 127 (17.9%) were diagnosed with a DSM-5 eating disorder, but of the 638 males, only 15 (2.4%) were diagnosed with a DSM-5 eating disorder. Three participants (two females, one male) gained two diagnoses. In 15 twin pairs (9 monozygotic), both twins were diagnosed with a DSM-5 eating disorder. One pair was males, and the rest were females. Figure 2 shows the diagnostic distributions of eating disorders among females and males.

LIFETIME PREVALENCE

Females

The combined lifetime eating disorder prevalence was 17.9% for females. The lifetime prevalence estimates of specified eating disorders were 6.2% for AN, 2.4% for BN, and 0.6% for BED. When the analyses were restricted to those whose minimum body mass index (BMI) was 17.5 kg/m^2 or lower, the lifetime prevalence of AN fell to 4.7%. In terms of severity (American Psychiatric Association, 2013), 11% of those with anorexia nervosa had extreme AN (BMI < 15 kg/m^2), 20% severe AN (BMI 15–15.99 kg/m^2), 11% moderate AN (BMI 16–16.99 kg/m^2) and most (57%) had a mild form of the disorder (BMI 17.00–18.5 kg/m^2).

Among females, the total lifetime prevalence for OSFED was 4.5% and, more specifically, 2.1% for atypical AN, 1.3% for purging disorder, 0.4% for BN (low frequency/limited duration), and 0.7% for BED (low frequency/limited duration). The total lifetime prevalence for UFED was 4.5% and, more specifically, 1.4% for the restrictive syndrome, 1.7% for subthreshold BN/BED, 1.1% for other, and 0.3% for insufficient information (Table 2).

Males

The combined lifetime eating disorder prevalence was 2.4% for males. The lifetime prevalence estimates of AN was 0.3%, BN 0.16%, and BED 0.3% among men. When the analyses were restricted to those whose minimum BMI was 17.5 kg/m^2 or lower, the prevalence of AN fell to 0.16%.

Among males, the total lifetime prevalence for atypical AN based on one diagnosed case was 0.16%, and no other cases of any other specified feeding or eating disorder subtype were found. The total lifetime prevalence for UFED was 1.6%, more specifically, 0.5% for the restrictive syndrome, 0.5% for subthreshold BN/BED, and 0.6% for other, while no cases with insufficient information were seen (Table 2).

Prevalences in the enriched and randomly selected groups

In sensitivity analyses, we compared the lifetime prevalence of eating disorders between the sample enriched for families with a high risk of alcohol problems and the randomly

selected sample. The total eating disorder prevalence was similar among females in the enriched sample (15.6% [95% CI 10.8-22]) and the randomly selected sample (18.7% [95% CI 15.4-22.5]), p for difference <0.37. The same was true among males in the enriched sample (3.8% [95% CI 1.6-8.5]) and the randomly selected sample (1.8% [95% CI 0.9-3.5], p for difference <0.16. The supplement table 1 shows the lifetime prevalence for each diagnosis in enriched and in randomly selected samples.

INCIDENCE

The incidence rate of eating disorders between 10 and 20 years of age was 1,700 (95% CI 1,400-2,060) per 100,000 person-years among females and 220 (95% CI 130-410) per 100,000 person-years among males. The 10-year incidence rate for each diagnosis for both genders is shown in Table 3.

PEAK AGE OF ONSET

For females, there was a steady increase in the onset of DSM-5 eating disorders from age 12 onwards, and the peak period dated to ages 16–19 years. Figure 3 shows the peak age of onset for the total number of eating disorders, each specific eating disorder, and OSFED and UFED.

For males, there were two apparent peaks around early and late adolescence. Because of the small number of cases, only the peak age of onset for overall eating disorders is shown in Figure 3.

DISCUSSION

Our results show that eating disorders, as defined by DSM-5, are highly prevalent. More than 1 in 6 females received a lifetime diagnosis of an eating disorder. In particular, anorexia nervosa (AN) and other forms of restrictive eating disorders were more common than previously reported: 1 in 10 females had suffered from them by the time they reached young adulthood. As expected, we observed significant gender differences in eating disorder presentations: 2.4% of males received a lifetime diagnosis of an eating disorder (male-female ratio 1:8). Among males, the most common diagnosis was unspecified feeding or eating disorder (UFED). This indicates that the specified diagnostic categories in DSM-5 still do not fully capture the nature of disordered eating in males.

Unexpectedly high prevalence of AN among females

We found that 6.2% of females in this study fulfilled diagnostic criteria for DSM-5 AN. We compared this prevalence estimate to a previously studied Finnish twin cohort of young women (Mustelin et al., 2016b). The study used a two-stage sampling design, and the screen missed some cases. To approximate the prevalence we would have obtained if all individuals in the cohort had been interviewed, we used sampling weights for the randomly sampled screen-negative women to account for the false negatives missed by the symptom screening. Consequently, the AN prevalence among women in the FinnTwin 16 study rose from 3.6% to 6.3%, which is almost identical to our current results.

What could explain the high prevalence of AN? First, we studied twins. Previously, multiple births (twins and triplets) have been shown to be an independent risk factor for AN with a hazard ratio of 1.33, but not for other eating disorders (Goodman, Heshmati, Malki, & Koupil, 2014). Taking this into account, the resulting lifetime prevalence of AN among females in our sample would be 4.7%, which is still high. Moreover, when we excluded those females from our analyses whose co-twin also had an eating disorder, the AN prevalence remained 5.1%.

A second factor that could explain the high prevalence of AN is that almost one-third of all females in our sample had a minimum BMI under 18.5 kg/m^2. As notable variations in body weight have been observed across developed countries (Lazzeri et al., 2014), it might be that the BMI threshold of 18.5 kg/m^2 recommended to the diagnosis of DSM-5 AN may be too high for our population. However, when the analyses were restricted to those females whose minimum BMI was 17.5 kg/m^2 or less, our observed lifetime prevalence of 4.7% for AN was still higher than previously reported lifetime prevalences (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 et al., 2014; Stice et al., 2013; Udo & Grilo, 2018).

Third, our research might have over-diagnosed AN, as diagnoses in community studies do not automatically result in clinical cases in real life. We did not have specific tools to

assess impairment relating to eating disorders, but we had some indirect indicators of illness severity. Of females diagnosed with AN in our study, 55% reported that healthcare professionals had also diagnosed them with an eating disorder in real life. If we only included detected females to the analyses, the lifetime prevalence of AN would still be 3.4%.

As eating disorder expressions differ by continent (Hoek, 2016), the socio-cultural climate in Finland may partially explain our high prevalence of AN and atypical AN. Drive to thinness, restrictive eating, and excessive exercise may be culturally favored over bingeing. Indeed, a previous Finnish study conducted in the DSM-IV era showed that anorexia-type eating disorders were common among adolescent females as the lifetime prevalence was 2.6% for AN and 7.7% for AN not otherwise specified (Isomaa, Isomaa, Marttunen, Kaltiala-Heino, & Björkqvist 2009).

Further, prevalence estimates are influenced by study setting, methods of case detection (screening, self-report, diagnostic interviews), and even by factors related to the type of interview, interview instrument, and experience of the interviewer (Davis, Couper, Janz, Caldwell, & Resnicow, 2010; Hoek, 2016; Lindvall Dahlgren et al., 2017; Mitchison & Hay, 2014; Thornton, Russell, & Hudson, 1998). Sometimes methodological issues, such as the low sensitivity of the screening instrument, may lead to underestimation of AN occurrence (Solmi, Hotopf, Hatch, Treasure, & Micali, 2016). Our research setup was probably good for detecting AN as a large number of individuals were interviewed by

health-care professionals without relying on screens. More, additional information was gained from detailed weight histories collected through the interviews, and diagnoses were validated by medical doctors.

Recently, two studies based on the same UK cohort used a rigorous eating disorder assessment protocol that yielded a higher AN estimate than previously reported (Micali et al., 2015; Micali et al., 2017). Among middle-aged women, the lifetime prevalence of DSM-5 defined AN was 3.6%, and among 14- and 16-year-old girls, the point prevalence of AN was 3.2% and 2.4%, respectively. In these studies, health-care professionals interviewed a large sample of women, and self-reports and parental questionnaires were used to identify their children's eating disorders. Half of the adolescents diagnosed with AN at the age of 14 were identified solely based on parental reporting. Further, among middle-aged women, no interview skip rules were used, and the study´s two-phase sampling procedure was taken account by using sampling weights. Together, with our research, these results emphasize the importance of a thorough AN assessment in community-based studies.

Distribution of other eating disorders

Only 0.6% of females and 0.3% of males were diagnosed with BED, which is modest compared to previously found lifetime prevalence estimates (Cossrow et al., 2016; Fairweather-Schmidt & Wade, 2014; Glazer et al., 2019; Hudson, Coit, Lalonde, & Pope,

2012; Micali et al., 2017; Smink et al., 2014; Stice et al., 2013; Udo & Grilo, 2018). Due to the absence of interview questions concerning the distress criterion and binge eating specifiers, we depended on the narrative case notes made by the interviewers. We were conservative in giving the BED diagnosis, and if the information was insufficient for the specific diagnosis, we gave UFED BN/BED diagnosis or no diagnosis at all. Perhaps if diagnostically specific questions had been asked, more of those in the UFED BN/BED group might have received a BED diagnosis.

We also found that many individuals in the population experience eating disorders that do not fit the specified diagnostic criteria, as almost two-thirds of all eating disorders detected in males and one-quarter in females belonged to the residual UFED category. Further, our division of UFED into subcategories emphasized the heterogeneous representations of residual eating disorders in the population, adding to previous studies (Hay et al., 2017; Mitchison et al., 2019; Mustelin et al., 2016a; Wade & O'Shea, 2015). Notably, the definition for UFED is, in many ways, problematic and leaves a lot of room for clinical judgment. We diagnosed UFED when we observed disordered eating that caused distress or impairment that was comparable to levels we have observed clinically, excluding individuals qualifying for another specific eating disorder diagnosis. In practice, the line between normal and pathological eating behavior is challenging to draw as we still do not have an agreed-on definition of what minimally constitutes an eating disorder. Moreover, the evidence regarding the severity of UFED is still mixed (Ekeroth, Clinton, Norring, & Birgegard, 2013; Hay et al., 2017; Mitchison et al., 2019; Mustelin et al., 2016a;

Wade & O'Shea, 2015). Nevertheless, the size of the residual category in the population demands that more emphasis should be placed on its identification, research, and targeted treatments.

UFED was the most common diagnosis among males in our study. This indicates that the specified diagnostic categories in DSM-5 still do not fully capture the nature of disordered eating in males. Overall, men are more muscular, and weight gain accumulates to different parts of the body than among women, reflecting different genetic predispositions by sex. Thus, weight and shape concerns tend to differ by gender as a simultaneous desire for weight loss (to decrease fat mass) and weight gain (to increase lean muscle mass), and extremely excessive exercise are common features among men (Limbers, Cohen, & Gray, 2018; Raevuori, Keski-Rahkonen, & Hoek, 2014). In our sample, approximately one-third of males diagnosed with an eating disorder engaged in bingeing, and more than two-fifths reported excessive exercise, concerns in muscularity, or sports-related weight-control behaviors. Therefore, in clinical settings and future studies among boys and men, these behaviors should be recognized to avoid gender-biased under- or misdiagnosis.

Total occurrence of eating disorders

The sum of different eating disorders in our sample amounted to a prevalence of 17.9% among females. The incidence rate of DSM-5 eating disorders among females aged 10 to 20 was also high in our setting, 1,700 per 100,000 person-years, and the risk of eating

disorders started to increase from age 12 onwards. Our prevalence estimate is consistent with other well-conducted community-based studies that have diagnostically interviewed a large sample of females. Approximately 13% of US-based adolescents and young women (Stice et al., 2013), 15% of Australian adolescent twins (Fairweather-Schmidt & Wade, 2014; Wade & O'Shea, 2015), and 15% among middle-aged British women (Micali et al., 2017) had suffered from eating disorder during their lifetime. In addition, when we summed up previously published lifetime prevalence estimates from our other cohort (FinnTwin 16) using sampling weights, the total lifetime prevalence for females rose to 14.2% (Mustelin et al., 2015; Mustelin et al., 2016a; Mustelin et al., 2016b, our calculations). Further, a number of studies have reported high point prevalences of DSM-5 defined eating disorders (10.1% to 32.9%) for females (Allen et al., 2013; Flament et al., 2015; Micali et al., 2015; Mitchison et al., 2019; Solmi et al., 2016).

Among males, our combined eating disorder lifetime prevalence of 2.4% was at the high end of previously published lifetime estimates. Yet, four studies among male adolescents and young adults have reported even higher point prevalences of full-threshold and subthreshold eating disorders (2.9% to 12.8%) in DSM-5 era (Allen et al., 2013; Flament et al., 2015; Micali et al., 2015; Mitchison et al., 2019). This means that our estimates of period prevalence may be conservative. Further, some studies that have assessed point prevalence for both genders either using interviews or self-reports, have detected high prevalences up to 22.2% (Flament et al., 2015; Hammerle, Huss, Ernst, & Burger, 2016; Hay, Girosi, & Mond, 2015; Micali et al., 2015; Mitchison et al., 2019; Solmi et al., 2016).

Our study also offers the first estimate of the incidence of eating disorders among males in the DSM-5 era; the incidence rate was 220 per 100,000 person-years from the age of 10 to 20. As the risk of eating disorders started to increase in early adolescence, also among males, our study strengthens the evidence that primary prevention efforts should occur at pre-adolescence (Javaras et al., 2015).

In contrast to the many studies supporting our findings, three thorough studies using diagnostic interviews have reported more modest lifetime prevalence estimates for eating disorders. In a large national sample of US adults, the lifetime prevalence of specified eating disorders (sum of AN, BN, BED) was 3.1% for women and 0.62% for men (Udo & Grilo, 2018). Further, in Netherlands and Austria, the lifetime prevalence of eating disorders was 5.7% and 5.5% for adolescent girls and 1.2% and 0.6% for adolescent boys, respectively (Smink et al., 2014; Wagner et al., 2017). The differences to our results may be partly explained by the different ages of the samples, the different methods of case detection, and factors related to the type and implementation of the diagnostic interviews.

Strengths and limitations

Our study has some limitations that should be considered when interpreting our results. First, twins may share genetic and environmental influences that predispose them to eating disorders, potentially leading to an overestimation of eating disorders in our sample. Yet, when we excluded those twins whose co-twin also had an eating disorder, the total lifetime prevalence stayed at 14% among females and 2% among males. Second, a

subsample (27.7%) of those interviewed were from families at high risk for alcohol problems. Still, our sensitivity analyses showed that the effect of the enrichment was not statistically significant. Nevertheless, both of these factors may have some effect on the representativeness of our sample. Third, the participants were asked about their eating disorder symptoms and weight changes retrospectively, and therefore, recall bias may have affected the responses. Fourth, the diagnostic interviews were conducted both face-to-face and by phone. We did not find differences in eating disorder presentations by interview type, but this does not necessarily mean that no differences exist, as we were not able to interview the same individuals by both interview types (Muskens et al., 2014; Rohde, Lewinsohn, & Seeley, 1997). Fifth, the SCID interview used was designed to detect DSM-IV diagnoses and has not yet been validated for DSM-5. However, when establishing the DSM-5 diagnoses, we used additional information from the case notes and clear definitions of DSM-5. Last, as the interview data were collected a decade ago, our results do not reflect the latest trends of eating disorder occurrence.

The major strength of our study was that we interviewed a large community-based sample of females and males, mostly face-to-face, without relying on a preceding screening stage that would miss some eating disorder cases. Our eating disorder diagnoses were based on a widely used structured diagnostic interview, and all interviewers were healthcare professionals. Finally, all diagnoses were confirmed by a consensus of medical doctors highly experienced in the detection and treatment of eating disorders. These factors increase the rigor of our assessment. Lastly, participation rates have been low in some

previous prevalence studies (Galmiche et al., 2019). Our rate of 73% of the target sample was reasonably good.

Implications and conclusion

In line with other recent community-based studies, our results from females and males born in the 1980s show that eating disorders, as defined by DSM-5, are a significant public health problem in adolescence and early adulthood. Eating disorder symptoms in the community are diverse and are not fully captured by the present diagnostic categories. In particular, individuals with atypical symptoms need more clinical attention, and their symptoms need more research. Timely prevention, detection, and treatment efforts are essential, and their scale should meet the unmet demand.

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Table 1. *Diagnostic criteria for DSM-5 eating disorders*

DIAGNOSIS	DSM-5 DIAGNOSTIC CRITERIA
SPECIFIED EATING OR FEEDING DISORDER	
Anorexia Nervosa (AN)	A) Restriction of energy intake that resulted in a minimum BMI of ≤ 18.5 kg/m^2 (Brown, Holland, & Keel, 2014; Sysko et al., 2015) B) Fear of weight gain or of becoming fat, or persistent behavior that interferes with weight gain even though at a low weight C) Disturbance in the way body weight or shape is experienced or denial of the seriousness of the current low body weight A, B, C criteria need to be fulfilled
Bulimia Nervosa (BN)	Recurrent episodes of binge eating and compensatory behaviors in order to prevent weight gain at least once a week for more than three months. With a sense of lack of control over eating during the episode and self-evaluation is influenced by body shape and weight
Binge Eating Disorder (BED)	Recurrent episodes of binge-eating at least once a week for more than three months with a sense of lack of control over eating, no recurrent compensatory behaviors and marked distress, disgust or embarrassment present regarding binge eating
OTHER SPECIFIED EATING OR FEEDING DISORDER (OSFED)	
Atypical Anorexia Nervosa (OSFED-Atypical AN)	All the criteria for AN met, expect despite weight loss minimum BMI is more than 18.5 kg/m^2

DIAGNOSIS	DSM-5 DIAGNOSTIC CRITERIA
Bulimia Nervosa of low frequency and/or limited duration (OSFED-BN)	All the criteria for BN met, but binge-eating and compensatory behaviors occur less frequently than once a week and/or less than three months
Binge Eating Disorder of low frequency and/or limited duration (OSFED-BED)	Same criteria as in BED, but binge-eating occurs less frequently than once week or/and less than three months
Purging Disorder (OSFED-PD)	Recurrent purging behavior to influence weight or shape in the absence of binge eating
UNSPECIFIED FEEDING OR EATING DISORDER (UFED) 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 (UFED-Restrictive)	Excessive exercise or fasting or significant weight loss but the criteria for AN or atypical AN not fulfilled, or weight loss leading to amenorrhea, or orthorexia
Subthreshold BN/BED (UFED-BN/BED)	Objective bingeing behavior 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

DIAGNOSIS	DSM-5 DIAGNOSTIC CRITERIA
Other (UFED-Other)	Eating problems related to depression, or temporary purging, or high concern and unhealthy behaviors related to a high drive for muscularity
Insufficient information (UFED-Insuf)	Insufficient information to make a specific diagnosis

Table 2. *The lifetime prevalence of DSM-5 eating disorders (n=1,347 comprising 709 females and 638 males)*

	FEMALES % (n)	95%CI %	MALES % (n)	95%CI %	TOTAL % (n)	95%CI %
SPECIFIED EATING OR FEEDING DISORDER						
Anorexia Nervosa	6.2% (44)	4.6–8.3	0.3% (2)	0.08-1.3	3.4% (46)	2.5–4.6
Anorexia Nervosa (BMI ≤ 17.5)†	4.7% (33)	3.3–6.6	0.16% (1)	0.02-1.1	2.5% (34)	1.8-3.6
Bulimia Nervosa	2.4% (17)	1.5-3.9	0.16% (1)	0.02-1.1	1.3% (18)	0.8-2.2
Binge Eating Disorder	0.6% (4)	0.2-1.5	0.3% (2)	0.08-1.25	0.4% (6)	0.2-1.0
OTHER SPECIFIED EATING OR FEEDING DISORDER (OSFED)						
OSFED-Atypical AN	2.1% (15)	1.3-3.5	0.16% (1)	0.02-1.1	1.2% (16)	0.7-2.0
OSFED-BN	0.4% (3)	0.1–1.3	0% (0)	--‡	0.2% (3)	0.07-0.7

Table 2. *The lifetime prevalence of DSM-5 eating disorders (n=1,347 comprising 709 females and 638 males)*

	FEMALES % (n)	95%CI %	MALES % (n)	95%CI %	TOTAL % (n)	95%CI %
OSFED-BED	0.7% (5)	0.3–1.7	0% (0)	--‡	0.4% (5)	0.2–0.9
Purging Disorder	1.3% (9)	0.7-2.4	0% (0)	--‡	0.7% (9)	0.3–1.3
Any OSFED	4.5% (32)	3.2-6.3	0.16% (1)	0.02-1.1	2.4% (33)	1.8-3.4
UNSPECIFIED FEEDING OR EATING DISORDER (UFED)						
Restrictive syndrome	1.4% (10)	0.8-2.6	0.5% (3)	0.2-1.5	1.0% (13)	0.6-1.7
Subthreshold BN/BED	1.7% (12)	1.0-3.0	0.5% (3)	0.2-1.5	1.1% (15)	0.7-1.8
Other	1.1% (8)	0.6-2.2	0.6% (4)	0.2-1.7	0.9% (12)	0.5-1.6
Insufficient information	0.3% (2)	0.07-1.1	0% (0)	--‡	0.15% (2)	0.04-0.6
Any UFED	4.5% (32)	3.2-6.3	1.6% (10)	0.8-2.9	3.1% (42)	2.3-4.2
ANY EATING OR FEEDING DISORDER	17.9% (127)	15.1-21.1	2.4% (15)	1.4-4.0	10.5% (142)	8.9-12.4

CI=confidence interval

n=number of cases

OSFED-Atypical AN = Atypical Anorexia Nervosa

OSFED-BN = Bulimia Nervosa of low frequency and/or limited duration

OSFED-BED = Binge Eating Disorder of low frequency and/or limited duration

†Restricted to those with minimum BMI (Body mass index) ≤17.5

‡ Confidence interval missing due to no eating disorder cases in the category

Table 3. *The incidence rate of DSM-5 eating disorders between 10 and 20 years of age per 100,000 person-years*

	FEMALES	95%CI	MALES	95%CI	TOTAL	95%CI
SPECIFIED EATING OR FEEDING DISORDER						
Anorexia Nervosa	580	430-810	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 OR FEEDING DISORDER (OSFED)						
OSFED-Atypical AN	210	130-370	20	-‡	120	80-200
OSFED-BN	30	10-280	-‡	-‡	15	3-150
OSFED-BED	70	30-210	-‡	-‡	40	20-110
Purging Disorder	130	70-270	-‡	-‡	70	40-140
Any OSFED	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 BN/BED	130	70-270	30	10-310	80	50-160
Other	100	50-240	60	20-220	80	50-160

Table 3. *The incidence rate of DSM-5 eating disorders between 10 and 20 years of age per 100,000 person-years*

	FEMALES	95%CI	MALES	95%CI	TOTAL	95%CI
Insufficient information	10	-‡	-‡	-‡	7	-‡
Any UFED	370	260-550	140	80-300	260	190-370
ANY EATING OR FEEDING DISORDER	1700	1400-2060	220	130-410	980	820-1180

CI=confidence interval

n=number of cases

OSFED-Atypical AN = Atypical Anorexia Nervosa

OSFED-BN = Bulimia Nervosa of low frequency and/or limited duration

OSFED-BED = Binge Eating Disorder of low frequency and/or limited duration

‡ missing confidence interval missing due to no eating disorder cases in the category value

Figure 1. *Flowchart of data collection as adapted from (Kaprio, 2013). The intensively studied sample was nested within the epidemiological sample and, therefore, participated in all four questionnaire-based data collection waves. In waves 1, 2, and 4, participants in the intensive study sample took part in additional interviews and tests, as indicated on the right-hand column of the flowchart.*

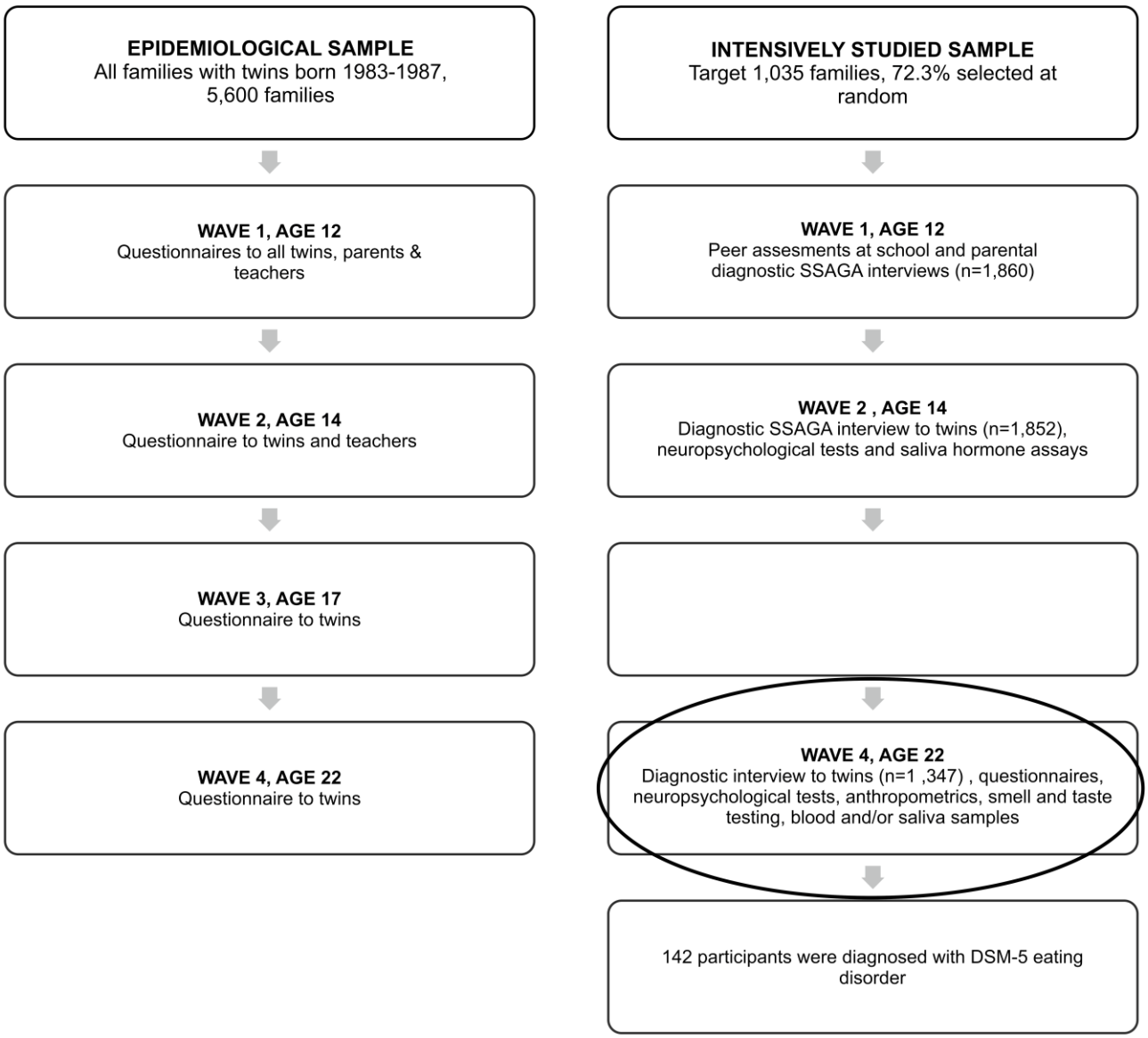

Figure 2. *The diagnostic distribution of DSM-5 eating disorders for males and females (% of all eating disorders in that gender).*

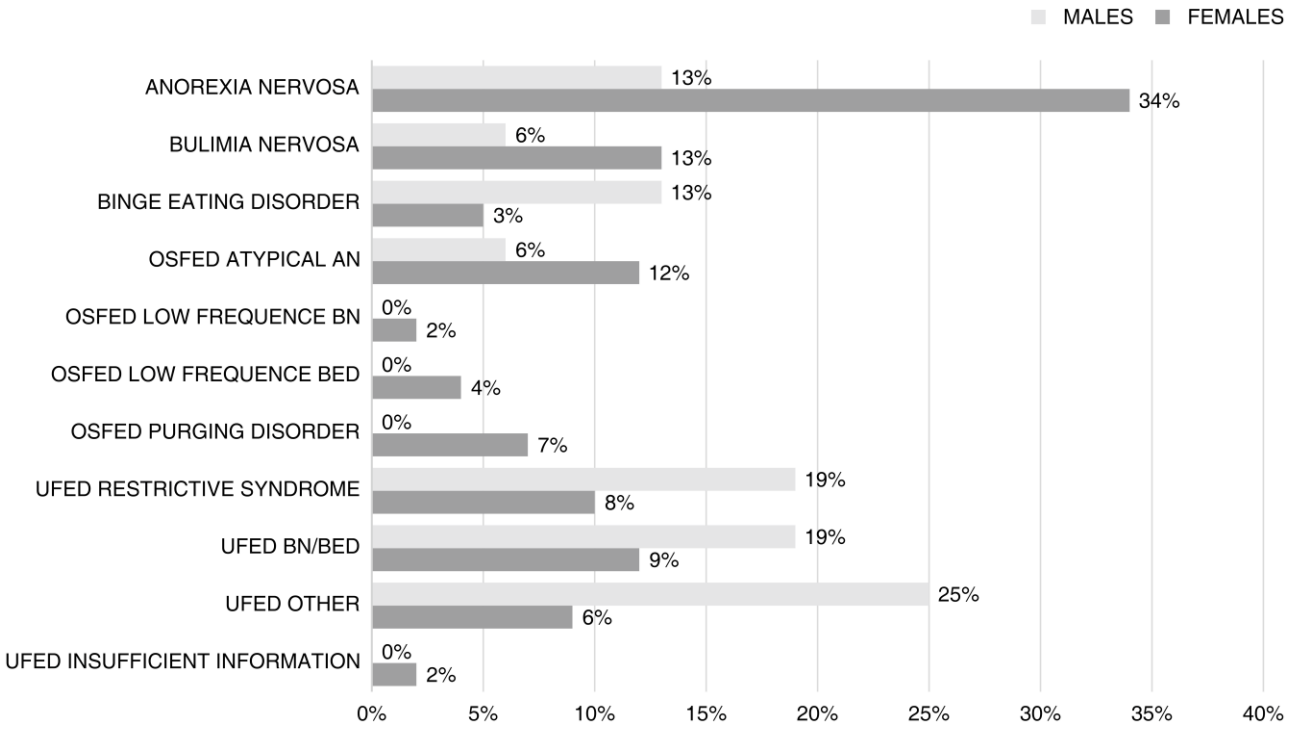

Figure 3. *The peak period of onset for DSM-5 eating disorders among the 709 female and 638 male participants*