

Incidence, prevalence and mortality of anorexia nervosa and other eating disorders

Hans Wijbrand Hoek^{a,b,c}

Purpose of review

The purpose of this review is to evaluate the recent literature on the incidence and prevalence of and mortality associated with eating disorders.

Recent findings

General-practice studies show that the overall incidence rates of anorexia nervosa remained stable during the 1990s, compared with the 1980s. Some evidence suggests that the occurrence of bulimia nervosa is decreasing. Anorexia nervosa is a common disorder among young white females, but is extremely rare among black females. Recent studies confirm previous findings of the high mortality rate within the anorexia nervosa population.

Summary

The incidence of anorexia nervosa is around eight per 100 000 persons per year. An upward trend has been observed in the incidence of anorexia nervosa in the past century till the 1970s. The most substantial increase was among females aged 15–24 years, for whom a significant increase was observed from 1935 to 1999. The average prevalence rates for anorexia nervosa and bulimia nervosa among young females are 0.3 and 1%, respectively. Only a minority of people with eating disorders, especially with bulimia nervosa, are treated in mental healthcare.

Keywords

anorexia nervosa, eating disorder, epidemiology, mortality

Introduction

Incidence and prevalence rates are the basic measures of disease frequency. Incidence is the number of new cases in the population over a specified period. The incidence of eating disorders is commonly expressed in terms of per 100 000 persons of the population per year. Incidence rate differences between groups are better clues to the etiology than are prevalence rate differences because they relate to fairly new cases of an eating disorder.

Prevalence is the total number of cases in the population. The point prevalence is the prevalence at a specific point of time. The 1-year period prevalence rate is the point prevalence rate plus the annual incidence rate. The prevalence rate is the most useful rate for planning facilities as it indicates the demand for care.

Mortality rates are often used as an indicator of the severity of anorexia nervosa. In a meta-analysis of excess mortality in the 1990s, anorexia nervosa was associated with the highest rate of mortality among all mental disorders [1]. The standard measures for mortality are the crude mortality rate (CMR) and the standardized mortality rate (SMR). The CMR is the proportion of deaths within the study population. The SMR is the fraction of the observed mortality rate (CMR) compared with the expected mortality rate in the population of origin, for example, all young females.

This article is based on a selection from the literature, especially pertaining to the last year, on the epidemiology of eating disorders and updates and incorporates our previous reviews [2–4].

Methodology

The validity of many epidemiological studies of eating disorders is called into question because of a number of methodological problems related to the selection of populations under study and the identification of cases [3,5]. Problems that are specific to eating disorders are their low prevalence in the general population and the tendency of the people with eating disorders to conceal their illness and to avoid professional help.

Most incidence studies of anorexia nervosa have used psychiatric case registers or medical records of hospitals in a circumscribed area. All record-based studies will grossly underestimate the incidence in the community

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^aParnassia Psychiatric Institute, The Hague, The Netherlands, ^bDepartment of Epidemiology, Columbia University, New York, USA and ^cDepartment of Psychiatry, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Correspondence to Professor Hans Wijbrand Hoek MD PhD, Parnassia Psychiatric Institute, Mangostraat 15, 2552 KS The Hague, The Netherlands
Tel: +31 70 391 7344; fax: +31 70 391 7088; e-mail: w.hoek@parnassiaagroep.nl

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Abbreviations

BED	binge-eating disorder
CI	confidence interval
CMR	crude mortality rate
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDNOS	Eating Disorder Not Otherwise Specified
SMR	standardized mortality rate

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because not all cases will be referred to (mental) healthcare or become hospitalized. Therefore, it is unclear whether the reported increase in the number of cases in healthcare facilities reflects an actual increase in the incidence in the community; the increase might also be due to improved methods of case detection or the wider availability of services. Findings from case registers and hospital records are of restricted value for generating hypotheses on the etiology of the disease because there is no direct access to the patients and the additional information that is available is usually limited and of a demographic nature only.

At present, a two-stage screening approach is the most widely accepted procedure for the identification of prevalent cases. First, a large population is screened for the likelihood of an eating disorder by means of a screening questionnaire that identifies an at-risk population (first stage). Then definite cases are established on the basis of a personal interview of both the persons from this at-risk population and those from a randomly selected sample of people not at risk (second stage). Methodological problems associated with two-stage studies are poor response rates, sensitivity and specificity of the screening instrument and often the restricted size of the groups interviewed, particularly of those not at risk.

Incidence of anorexia nervosa

The highest reported age-adjusted and sex-adjusted incidence rate of anorexia nervosa was 8.3 per 100 000 person years in Rochester, MN, USA, during 1935–1989 [6]. Lucas and colleagues used an extensive case-finding method, which included all medical records of healthcare providers, general practitioners and specialists in the community of Rochester. They screened records that mentioned diagnostic terms that could refer to non-detected cases. They included probable as well as possible cases, and definite cases constituted only 39% (82 out of 208) of all incident cases identified during 1935–1989.

Incidence rates derived from general practices generally represent eating disorders that started more recently than those based on other medical records. Two recent studies of this type examined the incidence of anorexia nervosa in primary care in the UK and the Netherlands during the second half of the 1990s. Currin and colleagues [7**] searched the *General Practice Research Database* in the UK for new cases of anorexia nervosa between 1994 and 2000. They compared their data with the findings of a similar study for 1988–1993 [8]. The incidence of anorexia nervosa remained remarkably consistent over the two study periods. The age-adjusted and sex-adjusted incidence rate of anorexia nervosa in 2000 was 4.7 [95% confidence interval (CI): 3.6–5.8] compared with 4.2 (95% CI: 3.4–5.0) per 100 000 persons in 1993.

In two studies in the Netherlands [9,10], general practitioners studied the incidence of eating disorders in a large representative sample of the Dutch population. The overall incidence of anorexia nervosa was 7.7 (95% CI: 5.9–10.0) per 100 000 persons per year during 1995–1999. It was comparable to the rate of 7.4 during 1985–1989 [10]. Incidence rates for anorexia nervosa are highest for females aged 15–19 years. They constitute approximately 40% of all identified cases [3]. In Rochester, MN, USA, the incidence rate was 74 per 100 000 person years for 15–19-year-old females during 1935–1989 [6]. In Switzerland the incidence rate of cases admitted for anorexia nervosa was 20 per 100 000 person years for females between 12 and 25 years of age during 1993–1995 [11].

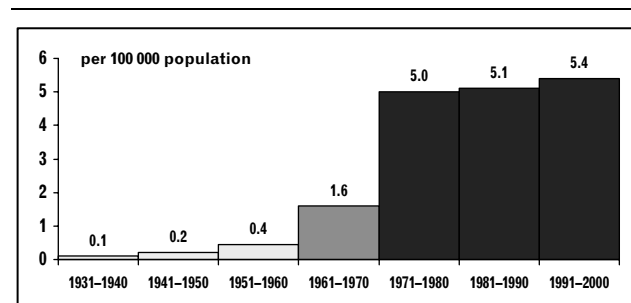
Time trends

The question of whether the incidence of anorexia nervosa is on the rise has been considerably debated. Long-term epidemiological studies are sensitive to minor changes in the absolute incidence numbers and in the methods used, for example, variations in registration policy, demographic differences between the populations, faulty inclusion of readmissions, the specific methods of detection used or the availability of services [12,13].

In a meta-analysis [3] of the incidence of anorexia nervosa in mental healthcare, various studies in northern Europe were combined: Sweden, 1930–1959 [14]; north-east Scotland, 1960–1969 [15]; and the Netherlands, 1970–1999 [9,10,16] (Fig. 1). Until the 1970s, there was an increase of the registered incidence of anorexia nervosa in Europe. Since 1970, the incidence of anorexia nervosa in Europe seems to have been rather stable [3].

Only two studies have used the same methods during a prolonged study period, in the United States from 1935 to 1989 [6] and in Switzerland from 1956 to 1995 [11]. In Rochester, MN, USA the age-adjusted incidence rates of

Figure 1 Registered yearly incidence of anorexia nervosa in mental healthcare in northern Europe in the 20th century



□ Hospital records, Sweden; ▒ case register, north-east Scotland; ■ mental healthcare, the Netherlands.

anorexia nervosa showed a significant linear increasing trend only in females aged 15–24 years from 1935 to 1989. This increase in young females continued probably during the 1990s according to the findings in the Netherlands (G.E. van Son, D. van Hoeken, A.I.M. Bartelds *et al.*, unpublished data).

In Switzerland, the development of the incidence of severe anorexia nervosa was studied in a geographically defined region by means of five sampling periods and the same methodology from 1956 to 1995. The medical records of all hospitals of the canton of Zurich were screened for first-time hospitalizations of female anorexia nervosa patients. The incidence of severe anorexia nervosa in the canton of Zurich rose significantly during the 1960s and 1970s. Since then the incidence of severe anorexia nervosa appears to have reached a plateau of around 1.2 per 100 000 persons per year [11].

Males

Although anorexia nervosa occurs in males as well as in females, few studies report incidence rates for males. From incidence studies that report on males, one can conclude that the incidence of anorexia nervosa among males is below 1.0 per 100 000 persons per year [6, 7^{••},8,10].

Prevalence of anorexia nervosa

The current standard for the assessment of the prevalence of eating disorders is the process employing a two-stage selection of cases. Prevalence rates of anorexia nervosa varied between 0 and 0.9%, with an average point prevalence rate of 0.29% in young females, according to Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria [3]. Most studies found higher prevalence rates for partial syndromes of anorexia nervosa.

In a recent nationwide study in Portugal, the point prevalence of anorexia nervosa among adolescent girls was 0.39% [17].

In Sweden, the lifetime prevalence was 1.2% for rigorously diagnosed anorexia nervosa in the largest twin study of women from the 1935–1958 birth cohorts [18^{••}]. In an Australian study of female twins, aged 28–39 years, the lifetime prevalence of anorexia nervosa was 1.9% with an additional 2.4% for partial anorexia nervosa (absence of amenorrhea) [19[•]]. The lifetime prevalence was 2.2% for anorexia nervosa according to DSM-IV criteria in a large sample of women from the 1975–1979 birth cohorts of Finnish twins [20,21]; half of these cases were previously undetected.

In a meta-analysis [3], the 1-year prevalence rates per 100 000 young females were computed by point preva-

lence plus annual incidence rate at different levels of care (Table 1). Using two-stage studies of community samples and estimates of the incidence, the 1-year prevalence rate of anorexia nervosa in the community was calculated as 370 per 100 000 young females. One can conclude from Table 1 that the majority of the patients with anorexia nervosa in the community do not enter the mental healthcare system.

Mortality associated with anorexia nervosa

The few very long-term follow-up studies indicate a high mortality associated with anorexia nervosa. In an oldest long-term follow-up study in Sweden, a CMR of 18% was found among 94 patients with anorexia nervosa, 24 years after onset [14]. In a meta-analysis in 1995 of 42 published studies [22], the CMR was 5.9% (178 deaths in 3006 patients), translating into 0.56% per year or 5.6% per decade. In the studies specifying the cause of death, 54% of the patients died as a result of eating-disorder complications, 27% committed suicide and the remaining 19% died of unknown or other causes. In a meta-analysis of SMRs in 2001, the overall aggregate SMR of anorexia nervosa in studies with 6–12 years of follow-up was 9.6 (95% CI: 7.8–11.5) and in studies with 20–40 years of follow-up 3.7 (95% CI: 2.8–4.7) [23]. Only one study suggested that the overall mortality of anorexia nervosa was not increased among the spectrum of cases representative of the community; the long-term survival rate of 208 patients with anorexia nervosa in Rochester from 1935 to 1989 did not differ from the expected rate [24].

Recent studies confirm the high mortality rate within the anorexia nervosa population, for example, in Canada [25^{••}], northeast Scotland [26^{••}] and Germany [27[•]]. In Canada, 326 patients diagnosed with anorexia nervosa completed an assessment over a 20-year period; the SMR was 10.5 (95% CI: 5.5–15.5) [25^{••}]. In northeast Scotland, 23 of 524 patients with anorexia nervosa seen in specialist services died; the median length of time between diagnosis and death was 11 years [26^{••}]. The CMR in this study was 4.4% and the SMR 3.3 (95% CI: 2.2–4.9). In only one-third of the cases, anorexia nervosa was mentioned in the death certificate, but an eating disorder or other psychiatric pathology probably contributed to several of the other deaths. In a 12-year follow-up study of 103 patients with anorexia nervosa in Germany, the CMR was 7.7% and another 40% had a poor outcome [27[•]].

Table 1 One-year period prevalence rates per 100 000 young females at different levels of care

Level of morbidity	Anorexia nervosa	Bulimia nervosa
Community	370	1500
Primary care	160	170
Mental healthcare	127	87

Anorexia nervosa in Blacks and Asians

Hardly any epidemiological studies of anorexia nervosa were conducted outside Western countries. Transcultural studies conducted in the 1970s and 1980s showed that anorexia nervosa was rare in non-Western countries [28–31], but some studies conducted later demonstrated that anorexia nervosa does occur in non-Western countries [32,33]. Abnormal eating attitudes and behavior do occur frequently in traditional as well as in developing countries and among Whites as well as among Blacks and Asians [34–38,39•–41•].

In a recent comprehensive study [42••] conducted on the Caribbean island Curaçao, the full spectrum of community health and service providers was contacted. Persons constituting probable incident cases were interviewed. The overall incidence of anorexia nervosa of 1.82 (95% CI: 0.74–2.89) per 100 000 persons per year on Curaçao is much lower than in the United States and Western Europe. No cases were found among the majority black population. The incidence of 9.1 (95% CI: 3.71–14.45) among the minority mixed and white population on Curaçao, however, was similar to the incidence in the Netherlands and the United States. The results obtained on Curaçao are consistent with findings in a US prevalence study, in which anorexia nervosa was not found in black women, in contrast to a lifetime prevalence rate of 1.5% for anorexia nervosa among white women. Bulimia nervosa and binge-eating disorder (BED) occur frequently among black women, but might be also more common among white women [40•,43].

Epidemiology of other eating disorders

Bulimia nervosa was first distinguished as a disorder separate from anorexia nervosa by Russell in 1979 [44] and Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III) in 1980. Before 1980, the term ‘bulimia’ in medical records denoted symptoms of heterogeneous conditions manifested by overeating, but not the syndrome as it is known today. Only a few incidence studies of bulimia nervosa have been conducted. An annual incidence of bulimia nervosa of 13.5 per 100 000 person years was found in Rochester, MN, USA, during 1980–1990 [45] and of 11.5 in the Netherlands during 1985–1989 [10]. In a study of the *General Practice Research Database* in the UK for new cases of bulimia nervosa, the age-adjusted and sex-adjusted incidence of bulimia nervosa decreased during the second half of the 1990s to 6.6 per 100 000 persons in 2000 (95% CI: 5.3–7.9) [7••]. This possible decrease in the occurrence of bulimia nervosa is supported by some recent evidence provided by a US study, suggesting that the prevalence of bulimia nervosa has decreased during 1982–2002 [46•]. The generally accepted prevalence rate of bulimia nervosa from two-stage studies is about 1%

among young females [3,47]. Table 1 shows a meta-analysis of the 1-year prevalence rates of bulimia nervosa per 100 000 young females at different levels of care [3]. One can conclude from this table that only a very small minority (6%) of the patients with bulimia nervosa in the community enters the mental healthcare system. Mortality associated with bulimia nervosa is considerably lower than that associated with anorexia nervosa [48] but has been less examined. A meta-analysis encompassing 43 follow-up studies of bulimia nervosa cohorts gave an overall aggregate SMR of 1.6 (95% CI: 0.8–2.7) for bulimia nervosa [49].

Nowadays the majority of cases suffering from an eating disorder can only be classified in the DSM-IV category Eating Disorder Not Otherwise Specified (EDNOS), including partial syndromes of anorexia nervosa or bulimia nervosa and BED, a proposed new category in DSM-IV for research purposes. BED is often seen in obese individuals, but in a recent study [50•], BED aggregated strongly in families independently of obesity. Using DSM-IV criteria, the prevalence of BED was 1% in a large general population sample in Australia; using a broader definition, the prevalence was estimated to be 2.5% [51]. In the United States, a rate of 2.6% was found among a large sample of 18–40-year-old white women for recurrent binge eating (two episodes per week during the previous 3 months) and a higher rate of 4.5% in black women of the same age group [52,53].

In outpatient settings, EDNOS cases account for an average of 60% of all cases, compared with 14.5% for anorexia nervosa and 25.5% for bulimia nervosa [54•]. Although these patients are characterized by similar core cognitive psychopathology, they represent the least studied group of patients with eating disorders.

Conclusion

The registered incidence rates of anorexia nervosa and bulimia nervosa are up to 8 per 100 000 persons per year and 13 per 100 000 persons per year, respectively. It must be assumed that even the studies with the most complete case-finding methods yield an underestimate of the true incidence. The incidence rate of anorexia nervosa, particularly in females 15–24 years old, increased during the past century, until the 1970s. Although eating disorders are rare in the general population, they are relatively common among adolescent girls and young women. For anorexia nervosa and bulimia nervosa average prevalence rates of 0.3 and 1%, respectively were found for young females. One-third of the people who meet stringent diagnostic criteria for anorexia nervosa and only 6% of those with bulimia nervosa are treated in mental healthcare.

Future epidemiological research should move toward identification of risk factors for eating disorders. Childhood

characteristics of negative self-evaluation and perfectionism have been found to be risk factors for anorexia nervosa [55]. As in the case of other psychiatric disorders, genetic predisposition [18^{••},56] and prenatal and perinatal circumstances [57,58^{••}] are probably important in the development of anorexia nervosa. The challenge for the future will be to identify risk factors specific for eating disorders and to make an effort to control them.

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Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 453–454).

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