Through the looking glass
Smink, Frédérique Rebecca Esther

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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2016

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

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Download date: 28-06-2020
Chapter 3

Three decades of eating disorders in Dutch primary care: decreasing incidence of bulimia nervosa but not of anorexia nervosa

Frédérique R.E. Smink
Daphne van Hoeken
Gé A. Donker
Ezra S. Susser
Albertine J. Oldehinkel
Hans W. Hoek

Psychological Medicine 2016; 46: 1189-1196
ABSTRACT

Background
Whether the incidence of eating disorders in Western, industrialized countries has changed over time has been the subject of much debate. The purpose of this primary-care study was to examine changes in the incidence of eating disorders in the Netherlands during the 1980s, 1990s and 2000s.

Method
A nationwide network of general practitioners (GPs), serving a representative sample (~1%) of the total Dutch population, recorded newly diagnosed patients with anorexia nervosa (AN) and bulimia nervosa (BN) in their practice during 1985-1989, 1995-1999, and 2005-2009. GPs are key players in the Dutch health care system, as their written referral is mandatory in order to get access to specialized (mental) health care, covered by health insurance. Health insurance is virtually universal in the Netherlands (99% of the population). A substantial number of GPs participated in all three study periods, during which the same case identification criteria were used and the same psychiatrist was responsible for making the final diagnoses. Incidence rates were calculated and for comparison between periods, incidence rate ratios.

Results
The overall incidence rate of BN decreased significantly in the past three decades (from 8.6 per 100,000 person-years in 1985-1989 to 6.1 in 1995-1999, and 3.2 in 2005-2009). The overall incidence of AN remained fairly stable during three decades, i.e. 7.4 per 100,000 person-years in 1985-1989, 7.8 in 1995-1999, and 6.0 in 2005-2009.

Conclusions
The incidence rate of BN decreased significantly over the past three decades, while the overall incidence rate of AN remained stable.
INTRODUCTION

Anorexia nervosa (AN) and bulimia nervosa (BN) are severe mental disorders with high mortality rates.\(^1\,^2\) The etiology is still largely unknown.\(^3\,^4\) Incidence studies examining secular trends enhance our understanding of how eating disorders develop, because changes in incidence over time may uncover risk factors. In developing countries, for example, increasing industrialization, urbanization and globalization are associated with an increase in eating disorders.\(^5\) Whether the incidence of eating disorders in Western, industrialized countries has changed over time has been the subject of much debate.\(^6\,^7\)

For AN, reports of an ‘epidemic’\(^8\) have been downsized to ‘a modest increase in AN incidence over the 20\(^{th}\) century’,\(^9\) by the identification of methodological confounders in long-term incidence studies such as variations in registration policy, diagnostic criteria, detection methods, and the availability of services; demographic differences between the populations; and faulty inclusion of readmissions.\(^7\,^10\)

Less is known about secular trends in BN incidence. The diagnosis ‘bulimia’ was only introduced in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980, and since 1970, few incidence studies have been conducted.\(^7\,^9\) Most studies suggest an increase in BN incidence that reached a peak in the mid-1990s,\(^9\,^{11-13}\) after which in UK primary care the incidence declined and then stabilized since 2000.\(^11\,^{12}\) The observed increase might stem from increased recognition and help-seeking behavior of cases of a previously undefined disorder, instead of a true increase in incidence.\(^14\) In a study comparing incidence rates of BN in Dutch primary care between 1985-1989 and 1995-1999, a decreasing trend was observed.\(^15\) In line with this finding are the results from a prevalence study among college students in three periods,\(^16\) which reported a lower BN point prevalence among women in 1992 and 2002 compared to 1982. In another US study among female students the point prevalence of probable cases of BN remained relatively stable between 1990 and 2004.\(^17\)

In the present study, we want to enhance the limited knowledge on time trends in AN and BN, especially in the 21\(^{st}\) century, by examining the incidence of AN and BN in Dutch primary care in 2005-2009, using the same methodology as our previous studies covering 1985-1989 and 1995-1999.\(^15\,^{18-20}\) Data from general practitioners (GPs), serving a representative sample of the total Dutch population and instructed to detect eating disorders, were used, and diagnoses were established by systematic assessment of DSM-IV criteria. Time trends over three decades are reported.
METHOD

Sample
Since 1970, GPs participating in the sentinel practices of NIVEL Primary Care Database have continuously registered morbidity among their patients. Participating GPs were either recruited or selected (after application) based on the region and population density of their practice in order to ensure national representation. The GPs in the network weekly assessed and delivered data with regard to certain illnesses, events and procedures in general practice. Besides collection of regular weekly data, the participating GPs also provided annual data on relatively uncommon diseases, disorders and occurrences, such as eating disorders. All these activities took about an hour per week for both the GP and the practice assistant. As compensation for their time investment participating GPs received an annual reimbursement.

The GPs had on average 148,326 patients in their practices during 1985-1989; 149,797 patients during 1995-1999, and 135,854 patients during 2005-2009. These patients were representative of the total Dutch population with respect to gender, age, regional distribution and population density, and covered about 1.0% of the Dutch population during 1985-1989 and 1995-1999, and 0.8% during 2005-2009. For example: in 2005-2009, 50.5% of the Dutch population was female; in the same period the total percentage of female patients registered in the sentinel practices was 50.7%. All 5-year age categories in the Dutch population were represented by 0.8% or 0.9% in the population of the sentinel practices in 2005-2009.

GPs in the Netherlands play a central role in the health care system and function as ‘gatekeepers’ to specialized care. Even if an individual contacts a medical specialist directly, the GP is always notified because health care insurers do not compensate for specialized health care costs without a written referral from the GP. Health insurance is virtually universal in the Netherlands: until 2006 health insurance through so-called ‘sickness funds’ was compulsory for low-income groups, while higher-income groups relied on private insurance. Since 2006 basic health insurance is obligatory for all Dutch residents, regardless of income. In 2008, 99% of the Dutch population thus had health insurance.

During three periods, i.e. 1985-1989 (P1), 1995-1999 (P2), and 2005-2009 (P3), the participating GPs (n=82; average per period calculated over the three study periods; total n=164) registered the number of eating disorder patients in their practices. The P1 and P2 samples have been described extensively elsewhere.
Procedure

Every year, the participating GPs received detailed information on eating disorders by means of a circular and at meetings convened for the purpose. With the use of case identification criteria described in Appendix 3.1, the GPs considered whether each patient who consulted them might be suffering from AN or BN. Sometimes the GP was alerted to the possibility of an eating disorder by other health care workers or worried relatives. To ensure consistency, the same case identification criteria were used in all three study periods and the same information on eating disorders was provided to the GPs. For each possible eating disorder patient, the GP completed an information sheet regarding eating disorder symptoms, height, weight, co-morbidity, and information on referral to specialized health care. The date of first detection by a health care professional (including, but not limited to the GP) was also noted. As in previous periods, registration forms of 2 years after the study period (2010 and 2011) were additionally screened for incident cases newly detected between 2005 and 2009, but not reported during that period. The research team made DSM-IV diagnoses of AN and BN on the basis of the information provided by the GPs. If necessary, the GP was contacted to provide additional information. During all three study periods the same psychiatrist (author H.W.H.) was responsible for scrutinizing the records from the GPs and making the final diagnoses, in order to ensure consistency in the systematic assessment of DSM-IV-criteria of AN and BN. There was a change from DSM-III-R to DSM-IV during the study periods, with more stringent criteria for BN in DSM-IV, while criteria for AN remained the same over time. To eliminate bias by this transition, the GP records of all possible cases from the first study period, which had originally been assessed with DSM-III-R criteria, were re-evaluated according to DSM-IV criteria.15,19

Statistical analysis

The incidence rate was defined as the number of new cases in primary care per year. It was based on the time when the eating disorder was detected, because it was unfeasible to assess precisely when the eating disorder began. Only patients with an eating disorder detected during 1985-1989, 1995-1999 and 2005-2009 were considered incident cases. The incidence rate was calculated by dividing the number of detected incident cases by the number of person-years in the Dutch sentinel practices. Person-years and number of cases per age group reported here differ slightly from those previously reported,15 due to post-hoc updated information on the participating GPs and the registered cases. Incidence rates and their Poisson exact 95% confidence intervals (CIs) were calculated for the total population, for
females overall, and for females per 5-year age category. To determine if differences in incidence rates over time were statistically significant, incidence rate ratios (IRRs) were computed by dividing the incidence of P3 by the incidence of P1 (IRR_{P3-P1}), and P2 (IRR_{P3-P2}). We used STATA SE13 for the calculations of incidence rates and IRRs.

**Ethical standards**

The study was carried out according to the precepts of the Helsinki Declaration, Dutch legislation on privacy and the regulations of the Dutch Data Protection Authority. According to Dutch legislation, approval by a Medical Ethics Committee was not obligatory for this study, as the study used only anonymous data. In addition, the participants were not submitted to any medical interventions other than standard practice.

**RESULTS**

**Anorexia nervosa**

During 2005-2009, 41 patients (all female) were first diagnosed with AN, yielding an overall incidence rate of 6.0 per 100,000 person-years (Table 3.1, 95% CI: 4.3–8.1), which did not differ significantly from the overall rate in P1 and in P2 (IRR_{P3-P1}=0.8, 95% CI: 0.5–1.2; IRR_{P3-P2}=0.8, 95% CI: 0.5–1.1). The mean age at detection was 23.4 years (standard deviation (SD)=11.3, median 19.7 years, range 12.7-62.4 years), which did not differ significantly from the mean ages at P1 and P2 (F=0.4, df=2, p=0.7; for P1 and P2 see van Son et al.15).

Considering that the overall incidence rate was stable over time, and that the number of male incident AN cases was small in P1 and P2, it is not surprising that the incidence rate of AN in females remained stable as well (IRR_{P3-P1}=0.9, 95% CI: 0.6–1.3; IRR_{P3-P2}=0.8, 95% CI: 0.5–1.2). In all three study periods, the age-specific incidence was highest in the 15-19 years age group. The incidence rate among females aged 15-19 years initially increased between P1 and P2 (IRR_{P2-P1}=2.0, 95% CI: 1.1-3.7), but remained stable thereafter (IRR_{P3-P2}=0.9, 95% CI: 0.5–1.5).

**Bulimia nervosa**

During 2005-2009, 22 patients (including two men, aged 20 and 22 years, respectively, at detection) were first diagnosed with BN, yielding an overall incidence rate of 3.2 per 100,000 person-years (Table 3.2, 95% CI: 2.0–4.9). This rate differed
significantly from the overall incidence rate in P1 and in P2 (IRR_{P3:P1}=0.4, 95% CI: 0.2–0.6; IRR_{P3:P2}=0.5, 95% CI: 0.3–0.9). The mean age at detection was 24.8 years (SD=7.5, median 21.6 years, range 15.0-42.3 years), which did not differ significantly from the mean ages at P1 and P2 (F=0.9, df=2, p=0.4; for P1 and P2 see van Son et al.15).

The female incidence rate of BN was nearly three times higher in P1 than in P3 (IRR_{P3:P1}=0.3, 95% CI: 0.2–0.6; IRR_{P3:P2}=0.5, 95% CI: 0.3–0.8). During P1, the highest age-specific incidence was in the 25-29 years age group; during both P2 and P3, the age-specific incidences were highest in the 15-19 years age group.

**DISCUSSION**

In this Dutch primary-care study examining the incidence of AN and BN in the 1980s, 1990s and 2000s, the overall incidence of BN decreased significantly over the past three decades, while the incidence of AN remained fairly stable. The notion of the past century that BN is more common than AN is therefore no longer valid. In the first decade of this century, the prominence of BN over AN seems to have disappeared (relative risk BN:AN=0.5, 95% CI: 0.3-0.9). Supporting evidence comes from a Finnish population cohort of female twins born during 1975-1979, in which the lifetime prevalence of AN was higher than that of BN (2.2% vs. 1.7%, respectively), and incidence rates among the high-risk group of females aged 15-19 years were comparable.30,31

AN is considered to be less prone to sociocultural influences than BN.9,20 Historical, cross-cultural and biological evidence indicates that an AN-like syndrome has been existing across time, cultures,9 and species.32,33 Throughout the past centuries and across cultures, different motivations for the restriction of food have been ascribed to the patients, both by themselves and by their environment, such as religious motives (so called holy anorexia or anorexia mirabilis), digestive discomfort and weight concerns.9 These motivations, however, impress more as a culturally meaningful attempt to understand AN than to have causal connotations.9 AN may be seen as the formation of ‘a well-ingrained and maladaptive habit’.4

For BN on the other hand, weight concerns and a desire to be slim seem crucial motivations to develop the disorder;9 cognitive prerequisites impossible to create in animal models.32 No historical or cross-cultural evidence of a binge-purge syndrome resembling BN exists outside the relatively new Western context of a culture that values and promotes the thin-body ideal.9 Gaining more and more clinical
### Table 3.1 Incidence anorexia nervosa per 100,000 person-years

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<td>Overall males + females</td>
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<td>59</td>
<td>752,117</td>
<td>7.8</td>
<td>6.0–10.1</td>
<td>41</td>
<td>684,860</td>
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N=number of cases; PY=person-years; IR=incidence rate; CI=confidence interval
### Table 3.2 Incidence bulimia nervosa per 100,000 person-years

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<tr>
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<tr>
<td>Overall females</td>
<td>62</td>
<td>373,975</td>
<td>16.6</td>
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<tr>
<td>Overall males + females</td>
<td>64</td>
<td>740,091</td>
<td>8.6</td>
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</table>

N=number of cases; PY=person-years; IR=incidence rate; CI=confidence interval
attention in the 1970s,\textsuperscript{8} it was not until 1979 that the term ‘bulimia nervosa’ was coined by Gerard Russell in his influential paper describing several eating disorder cases with the binge-purge syndrome.\textsuperscript{34} Keel & Klump\textsuperscript{9} therefore conclude that BN is a culture-bound syndrome, while AN is not.

Which sociocultural developments in the last three decades might have caused the decreasing incidence of BN? Keel and colleagues\textsuperscript{16} conducted a prevalence study among college students in three periods, and found a lower point prevalence of BN in 1992 and 2002 compared to 1982. They suggested that, by normalizing being overweight, a secular trend of an increasing body mass index (BMI) of the general population\textsuperscript{35} might reduce the risk for developing BN. In the United States, the prevalence of obesity in both children and adults has stabilized in the first decade of the new millennium to around 17% and 35%, respectively.\textsuperscript{36,37} Obesity is less common in the Netherlands than in the United States; the prevalence in adults, however, has risen steadily from 5% in 1985-1989, via 8% in 1995-1999, to 12% in 2005-2009 (http://statline.cbs.nl/statweb/). More specifically, the mean BMI of 20- to 29-year-old Dutch women increased significantly by 1.7 kg/m\textsuperscript{2} during 1981-2004; a larger increase than for the total adult population (1.0 kg/m\textsuperscript{2}; men and women aged 20-69 years).\textsuperscript{38} In exactly that group - women aged 20-29 years - incidence rates of BN plummeted between the study periods 1985-1989 and 2005-2009 (IRR\textsubscript{P3-P1}=0.1, 95% CI: 0.0-0.5).

In a changing weight landscape, where a fuller-figured body is the norm, there might be less pressure to aggressively counteract the effects of binge eating by means of purging. Indeed, the declining rates of BN over time run parallel with the recognition of binge-eating disorder (BED) as a ‘new’ eating disorder diagnosis. BED was introduced in the DSM-IV in 1994 as a criteria set provided for further study, classified in the residual category ‘eating disorder not otherwise specified’ (EDNOS). In the latest edition of the DSM, DSM-5, BED is formally recognized as one of the specified eating disorders. BED and EDNOS were not covered in our study, and data on time trends in the occurrence of isolated binge eating in the Netherlands are not available. Circumstantial evidence comes from a recent community study of Dutch 20-year-olds, in which a relatively low lifetime prevalence of 0.8% for DSM-5 BN was found among young women, while the prevalence of BED was relatively high (2.3%).\textsuperscript{39} A related but different perspective on the relationship between increased BMI of the population and binge eating is provided by a South-Australian community study\textsuperscript{40} in which the point prevalence of disordered eating behaviors, including binge eating, doubled between 1995 and 2005, in parallel with a higher mean BMI of the sample. The authors argue that increased public
concern over obesity rates may lead to an increase in (unhealthy) weight control behaviors, with binge eating as a consequence of dietary restriction.\textsuperscript{40}

Eating disorders in general received a fair amount of attention from both the scientific field\textsuperscript{41} and the media from the nineties onwards.\textsuperscript{42} Press coverage paid more attention to the (detrimental) medical consequences of eating disorders,\textsuperscript{42} and prevention interventions were developed and tested, with variable success.\textsuperscript{43} In the Netherlands, no national program on the prevention of eating disorders exists, and though some preventive activities were performed in the 2000s, those efforts reached only a minority of people.\textsuperscript{44} However, eating disorders gained increased attention of Dutch policy makers: in 1998 the Steering committee Eating disorders Netherlands (SEN), a commission appointed by the Ministry of Health, Welfare and Sport, published a report with recommendations on specialized care for eating disorder patients. The first and only Dutch guidelines for the diagnosis and treatment of eating disorders were published in 2006.\textsuperscript{45} These developments have not only lifted some of the taboo of - especially - BN, an eating disorder particularly surrounded by shame and secrecy, but also made clinicians, parents and teachers increasingly aware of the signs and symptoms of eating disorders. This may have resulted in early ‘coming out’ and recognition of BN patients and thus in earlier interventions, which could be reflected in a decreased peak age of incidence between the 1980s and the 1990s-2000s.

Although for both AN and BN mean age at detection did not differ between the three study periods, the proportion of patients aged <19 years increased over time. Whether this only reflects earlier detection or also earlier age at onset in younger generations is unclear.\textsuperscript{46} In 2005-2009, virtually no new cases of BN were found in women aged 35-64 years. Beside the aforementioned hypotheses applying to the decreased incidence of BN in general, two additional explanations may hold for the decline in this age group in particular: first, the influx of more longstanding cases - previously undetected, but recognized after increased public and clinical awareness - coming to a halt.\textsuperscript{14} Second, though recent evidence indicates that the menopausal transition poses increased risk for the development of eating disorders in middle-aged women, EDNOS seems more preponderant than either AN or BN in this age group.\textsuperscript{47}

The majority of BN patients do not enter the (mental) health care system.\textsuperscript{6,31} An additional reason for the decreasing BN trend in primary care may be the surge of alternative sources of help, such as self-help books and the internet during the 1990s.\textsuperscript{11,42} The availability of self-help treatment may have helped many individuals to overcome their eating problems by themselves, and thus have prevented a
chronic course or the transition of subclinical symptoms into a clinical eating disorder.

The rapid expansion of internet availability in the Western world was a major sociocultural development in the 2000s. The Netherlands are in the lead when it comes to internet use: about 45% of Dutch citizens used the internet in 2000, to over 90% in 2010 (http://ec.europa.eu/eurostat/, http://statline.cbs.nl/statweb/). The influence of internet on eating disorders is a double-edged sword: on the one hand, pro-eating disorder websites exert a negative influence on eating disorders by promoting and reinforcing disordered eating behaviors; on the other hand, barriers to treatment such as shame and fear of stigmatization are lowered by the anonymity of the medium, which makes internet a promising vehicle of delivering treatment for eating disorders.

**Strengths and limitations**

Our study is the first that was specifically designed to examine secular trends by its focus on new rather than on prevalent cases of AN and BN. Another strength is that a large study population representative of the total (Dutch) population was investigated.

A potential challenge for studies covering three decades is that both case identification and case definition may have changed over time. Regarding case identification, in all three study periods the same criteria for case identification (see Appendix 3.1) were used. Moreover, a substantial proportion of GPs participated during the entire 25-year course of the study: of the GPs participating in 1985-1989 (n=67), 64.2% participated again in the second study period, and 34.3% in all three study periods. Taking into account that the participating GPs were annually instructed and that eating disorders have gradually become a standard component of the education program of medical schools, one would expect GPs to have become more familiar with eating disorders over time. This would have resulted in an increase in detection rates of eating disorders rather than a decrease, which was indeed our expectation at the start of the second and third study periods.

With respect to case definition, consistency of classification was ensured by applying DSM-IV criteria to all GP records of possible cases; including, in retrospect, to the records of the first study period, which had originally been evaluated using DSM-III-R criteria. Another potential bias is a change over time in the case definition process by the research clinicians. However, while some members of the research team have changed, the final diagnosis was made by the same psychiatrist (senior author H.W.H.) over the three study periods.
Unfortunately we could include only AN and BN, and not the DSM-IV residual category EDNOS. EDNOS is probably the largest group of eating disorders in the community.\textsuperscript{39,50} It is a heterogeneous category, which makes it difficult to assess consistently. Also, when this longitudinal study was set up in 1984, only AN and BN were defined in then current DSM-III and the case identification criteria were developed accordingly. To ensure methodological consistency over the years, these case identification criteria were neither changed nor adapted to developments in the definition and classification of eating disorders. Thus, the case identification criteria precluded the complete and systematic registration of residual category eating disorders such as for example binge eating without purging (BED) and purging without binge eating (purging disorder\textsuperscript{51}). It is only with the recent introduction of DSM-5, that the broad EDNOS category was redefined, including the official recognition of BED as a new, specified eating disorder.\textsuperscript{52} It seems unlikely that subjects who would currently be classified as BED were included in the BN cases. The same case identification criteria were used over the three study periods, and these criteria explicitly stated that compensatory behavior should be present in the case of BN. Furthermore, the frequency of purging behavior - necessary to fulfill DSM-IV criteria - was checked by the researchers based on the information provided by the GPs. Another limitation is that this study was conducted at the primary care level, so the reported incidence rates should be regarded as minimum estimates of the true rates in the community. Some underreporting cannot be excluded in this surveillance, which is integrated in routine medical care.

\textbf{CONCLUSION}

In conclusion, the incidence rate of BN decreased significantly over the past three decades, while the incidence rate of AN remained stable. Possible explanations for the decreased incidence of BN over time may be found in a sensitivity of BN to sociocultural influences and developments in the last 25 years, such as the effects of increasing obesity rates, and a rise of prevention efforts and alternative sources of help, augmented by the rapid expansion of internet availability.
ACKNOWLEDGMENTS

The authors thank the general practitioners and Gabriëlle van Son, Ph.D. for participating in the study. NIVEL Primary Care Database, Sentinel Practices was funded by the Ministry of Health, Welfare and Sport of the Netherlands.
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Three decades of eating disorders in Dutch primary care

Appendix 3.1

Criteria for case identification* of anorexia nervosa and bulimia nervosa

**Anorexia nervosa**

1. Intense fear of becoming obese, even when underweight
2. Disturbance in the way in which one’s body weight, size, or shape is experienced, e.g., claiming to “feel fat”, even when emaciated, believing that one area of the body is “too fat” even when obviously underweight
3. Refusal to maintain body weight over a minimal normal weight for age and height, e.g., weight loss leading to maintenance of body weight 15% below expected weight; failure to make expected weight gain during the period of growth, leading to body weight 15% below expected weight

**Bulimia nervosa**

1. Recurrent episodes of binge eating (rapid consumption of a large amount of food in a discrete period of time, usually less than 2 hours)
2. During the eating binges, a feeling of lack of control over the eating behavior
3. Regular self-induced vomiting, use of laxatives, or rigorous dieting or fasting in order to counteract the effects of binge eating

*Case definition (by the research team) was based on more strict DSM-IV criteria*