Through the looking glass
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Chapter 7

General discussion
In this thesis several aspects of the epidemiology of eating disorders in primary care and the community were investigated. This chapter provides a discussion of the main findings, methodological considerations regarding the empirical studies conducted, and implications for clinical practice and further research.

**MAIN FINDINGS**

A comprehensive review of the literature on the incidence, prevalence and mortality rates of eating disorders (Chapter 2) found that, while the overall incidence rate of anorexia nervosa (AN) remained stable over the past decades, there was an increase in the high-risk group of 15-19-year-old girls. It is unclear whether this reflects earlier detection of AN cases or an earlier age at onset. The occurrence of bulimia nervosa (BN) may have decreased since the early 1990s. All eating disorders have an elevated mortality risk; AN the most striking. Compared with the other eating disorders, binge-eating disorder (BED) is more common among males and older individuals.

The primary care study examining the incidence of AN and BN in the 1980s, 1990s and 2000s (Chapter 3) showed that the incidence of BN decreased significantly indeed over 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, while the incidence of AN remained fairly stable (7.4 per 100,000 person-years in 1985-1989, 7.8 in 1995-1999 and 6.0 in 2005-2009). Explanations were sought in sociocultural developments in the last 25 years to which BN is probably more sensitive than AN, such as a secular trend of increasing body mass index (BMI) of the general population, which may normalize overweight and thus decrease the pressure to counteract the effects of binge eating by compensatory behaviors; increased attention of the media and policy makers to eating disorders, lifting the taboo of – especially – BN, which is particularly surrounded by shame and secrecy; and a rise of prevention efforts and alternative sources of help, augmented by the rapid expansion of internet availability in the first decade of the new millennium.

In Chapter 4 the literature on the epidemiology, course and outcome of eating disorders in accordance with the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was discussed. The lifetime prevalence of DSM-5 AN among women is estimated to be up to 4%, and of BN 2%. In a cross-national survey, the average lifetime prevalence of BED was 2%. Several studies confirmed that the DSM-5 criteria for eating disorders effectively reduce
the proportion of the residual diagnosis ‘eating disorder not otherwise specified’ (EDNOS), although the magnitude of the reduction varies across the studies. Data on long-term outcome, including mortality, are limited for BED. Follow-up studies of BED are scarce; remission rates in randomized controlled trials ranged from 19 to 65% across studies. On a community level, 5-year estimated recovery rates for DSM-5 AN and BN are 69% and 55%, respectively. Little is known about course and outcome of BED in the community.

In the study examining the prevalence and severity of DSM-5 eating disorders in a community cohort of adolescents (Chapter 5), the most common diagnoses among the girls were AN and BED, with a lifetime prevalence of 1.7% and 2.3%, respectively; and among the boys, BED (0.7%). In contrast, BN was relatively rare (lifetime prevalence among girls 0.8%). These results provide circumstantial evidence for the aforementioned hypothesis of declining BN rates due to a rise of isolated binge eating without compensatory behaviors. According to DSM-5 criteria, a minority of all diagnosed cases (15.5% of all eating disorder diagnoses; boys and girls combined) fell into one of the residual categories ‘otherwise specified feeding and eating disorder’ (OSFED) or ‘unspecified feeding and eating disorder’, compared with 64.4% for the DSM-IV residual category diagnosis EDNOS. Male and female adolescents combined, the lifetime prevalence of any eating disorder increased with 28.9% under DSM-5 criteria. This increase was mainly attributable to the inclusion of cases of BED that were subthreshold according to DSM-IV.

Next, the validity of the severity ratings for feeding and eating disorders was evaluated by examining their distribution in the community and their correlation with detection and treatment rates. As was to be expected for a community cohort, the severity of most cases was mild to moderate. A statistically significant association between severity and detection rate, and between severity and treatment rate was found. These results provide evidence for the validity of the DSM-5 severity ratings for feeding and eating disorders.

In the same community cohort of adolescents the role of self-perceived and peer-perceived social status in early adolescence as a potential risk factor for eating pathology in young adulthood was investigated (Chapter 6). Classroom social status in the domains of social acceptance, physical attractiveness, academic performance and popularity was assessed by means of peer nominations at age 13. Self-perception in corresponding domains was assessed at age 11. Both self-perceived and peer-perceived physical attractiveness were inversely correlated with eating pathology at age 22. Low peer popularity predicted eating pathology as well, but this effect was fully accounted for by the positive correlation between popularity
and peer status regarding physical attractiveness, and thus disappeared when the other peer-status domains were controlled for. On the contrary, high social acceptance by peers emerged as a predictor of eating pathology only after adjustment for the other status domains, showing that this effect was initially masked by social acceptance’s positive correlation with peer status regarding physical attractiveness and popularity, which have an inverse relationship with eating pathology.

**GENERAL DISCUSSION**

The DSM-5 has two major ambitions: 1. to use a more dimensional approach in the diagnostic classification of mental disorders than DSM-IV, and 2. to organize the chapters of the DSM-5 according to developmental processes and life course, in order to increase clinical utility and to facilitate etiological scientific research by providing better and more flexible diagnostic concepts, which transcend the individual categorical diagnoses. While a dimensional approach in diagnostic classification at first glance may look like a *contradictio in terminis* – how could one quantify something that is categorical? - , there are indeed several ways to describe a continuum of mental illness. To begin with, there is the fundamental continuum ranging from mental health to mental illness. Within the domain of mental illness, degrees of severity can be defined, as reflected in DSM-5 by the introduction of a severity rating for disorders, including feeding and eating disorders, ranging from mild to extreme. In Chapter 5, we have shown that the severity ratings for feeding and eating disorders are valid in terms of their distribution in the community, and their correlation with detection and treatment rates. Age at onset did not differ between severity categories, reflecting that age at onset is probably more disorder-than severity-dependent. Neither did we find a correlation between severity and clinical recovery rate, which could be explained by the relatively young age of the sample, combined with a high threshold for clinical recovery.

A related example of dimensional thinking is the lowered diagnostic threshold for AN and BN in DSM-5, thus recognizing that subthreshold AN and BN according to DSM-IV – categorized as EDNOS - are not qualitatively different disorders from full-blown AN and BN, but just milder forms. In the community cohort of adolescents (Chapter 5), applying the lowered diagnostic thresholds increased the female lifetime prevalence of AN and BN by 50% and 40%, respectively, compared with DSM-IV. In combination with the recognition of BED as a specific eating disorder in DSM-5, our results show that these alterations contribute to a substantial
reduction of eating disorder diagnoses in the residual category, which was an important goal for the Eating Disorders Workgroup for DSM-5.4

To regard mental disorders from a developmental perspective, where the same psychopathology can have multiple expressions during different phases of an individual’s life, is yet another example of a dimensional approach.2 This is best illustrated by a rather radical proposal by Fairburn & Cooper;5 they suggest to eliminate the categorical diagnoses of (subthreshold) AN and BN altogether, and simply acknowledge that someone has a single eating disorder characterized by the transdiagnostic psychopathology of an overvaluation of weight and shape, which can have different behavioral expressions over time.5 This proposal raises a fundamental question about diagnostic classification in psychiatry, namely, what is the purpose of such a system? Psychiatric diagnoses are phenomenological descriptions of symptoms, grouped into syndromes. Contrary to many somatic diseases, for mental disorders no additional ‘objective’ laboratory test (e.g., blood tests or neuroimaging) is available to confirm or rule out the diagnosis. While thus the underlying pathophysiology of most mental disorders eludes us still, the recognition of symptom patterns followed by diagnostic classification has proven to be effective in predicting course and prognosis of the disorder, and in deciding which interventions may be helpful.1,6 Bearing in mind this fundamental purpose of informing treatment decisions, the question raised by Fairburn & Cooper5 is: if the same psychological treatment works for patients from different diagnostic categories of eating disorders, what is the clinical utility of making the distinction anyway? That question lies beyond the scope of this discussion, but it illustrates how predictive validity is the central axis around which a diagnostic classification useful to clinicians should revolve.6 Validity refers to the ‘truth’ of a diagnosis; in other words, if the diagnosis corresponds to a real, underlying clinical phenomenon, about which antecedent, concurrent and predictive characteristics can be described.1 Reliability refers to the accuracy of a diagnosis; e.g., to what extent two clinicians examining the same patient arrive at the same diagnosis. General, unambiguous diagnostic criteria increase reliability but compromise the validity of a diagnosis, by summarizing and simplifying the complex and individual story of a patient’s symptoms.6,7

What could be the consequences – either positive or negative - of a broadening of diagnostic concepts by lowering a diagnostic threshold? In other words, what are the costs and benefits of declaring more people ill? Clearly, the goal of lowering a diagnostic threshold is to identify more people who would benefit from any form of clinical intervention in order to prevent longstanding suffering or impaired role
functioning, somatic or psychiatric complications, or progression to a more severe course. An important question is where to put a diagnostic threshold in order to include – ideally – all people who would benefit from such interventions (high sensitivity), but avoid accidentally including people who would not (high specificity). In general, lowering a diagnostic threshold will increase sensitivity, but decrease specificity. An example of a diagnostic threshold is the frequency and duration criterion of binge eating in BED: in DSM-5 binge eating needs to occur at least once a week for three months to warrant a diagnosis of BED; in DSM-IV a higher threshold was set: binge eating had to occur at least twice a week for six months. Furthermore, in DSM-5 a diagnosis of OSFED-subthreshold BED can be assigned to individuals with binge eating episodes who do not meet the diagnostic threshold of once a week for three months. Our results show that this lowered threshold for clinically significant binge eating is mainly responsible for the increase of almost 30% in the total number of eating disorder diagnoses.

The major downside of a mental disorder diagnosis is stigma and, especially when a diagnosis is assigned to mild deviations of normal behavior or to self-limiting responses to life’s challenges, the risk of receiving unnecessary pharmacological treatment thwarting an individual’s natural resources and resilience. On a public health level, a broadening of diagnostic concepts probably leads to an increase in expenses, since having an ‘official’ DSM diagnosis is often mandatory to get access to all sorts of insurance and government funds. In summary, by lowering a diagnostic threshold, certain unhealthy behaviors or transient responses to stressors run the risk of being unnecessarily medicalized, which may result in all sorts of unwanted costs for individuals, their environment and society.  

Since the consequences of a mental disorder diagnosis are far-reaching, a crucial question is where to place the cut-off between, for example, unhealthy behavior and a mental disorder. Many psychiatric symptoms are aberrations of common behaviors and phenomena, either in intensity, duration, or both. This is most clear at the extreme ends of the continuum. Many people diet, but nobody will doubt that a 21-year-old woman with a BMI of 14 kg/m² who still feels fat and restricts her food intake, has AN and deserves treatment. Likewise is it not so difficult to dismiss a diagnosis of BED in a 30-year-old man who is usually so absorbed by his work that he forgets to have lunch and at the end of the day rapidly devours two meals and some candy bars, without displaying any of the psychological criteria of

* Something could be said as well about the consequences and potential risks of raising a diagnostic threshold, but since the criteria for all specific eating disorders in DSM-5 have been broadened, this discussion is limited to the consequences of lowering diagnostic thresholds.
BED, such as, for example, feeling disgusted with himself, depressed or very guilty after overeating.\(^1\) The difficulties start in the grey area in the middle: where does ‘normality’ end and ‘abnormality’ begin? From a purely dimensional point of view, this question is irrelevant – if not impossible, because it assumes categories where none exist. From a clinical point of view, however, this question should be asked, in order to define groups of individuals who might benefit from clinical interventions, and exclude those who might not. On the continuum ranging from mental health to mental illness, cases of mild severity are closest to the ambiguous grey area in the middle. In the community cohort of adolescents (Chapter 5), mild cases constituted 53.2% of all feeding and eating disorder cases. Only a quarter of those were detected by the health care system, and a minority of 12.1% were treated. Would all mild cases benefit from treatment or any clinical intervention? Are mild cases on the slope to more severe pathology, or do they represent relatively common and self-limiting forms of eating pathology that do not require intervention? Our study could not answer this question, as clinical recovery rates did not differ between severity categories, probably accounted for by the relatively young age of the sample at diagnostic assessment. The DSM acknowledges the difficulty of making clinical decisions about the grey area where ‘normal’ and abnormal’ meet, and tries to solve this by setting another threshold for a mental disorder: the presence of significant distress or disabilities in social or occupational roles.\(^1\)

Normality in mental and physical functioning can be defined along population and individual norms.\(^6\) Population norms are visualized in a bell-shaped curve showing that for any characteristic most people cluster around the mean.\(^6,7\) Hence, normal is what most people are and - quite simplified - a deviation from the population norm and the individual norm can be regarded as a symptom.\(^6\) Regarding the population norm only, the domains of symptoms are the extreme ends of the bell-shaped curve, which would theoretically result in an equal prevalence for all symptoms. The fact that prevalences of symptoms and mental disorders do differ despite the uniformity of the bell-shaped curve for population norms, could be explained by, for example, large variations in societal and individual tolerance for deviations from the norm, and by the syndromal constellation of symptoms, in combination with the additional criterion of significant distress and disabilities in role functioning, which constitutes the general definition of a mental disorder.\(^1\) In the community cohort of adolescents (Chapter 5), confidence intervals of lifetime prevalence estimates of eating disorders to some extent overlapped, for example, of AN and BED among the girls, and of AN and BN among the boys, which renders the differences between those lifetime prevalences insignificant in this study. It is
likely, though, that a study with more power, that is: with a larger sample, would find significant differences between lifetime prevalences of eating disorders indeed.

For eating pathology and its concomitant features population norms have been shifting in the past decades, thus reshaping normality and abnormality. Take for example the rise of mean BMI of the global population over the past 40 years.\(^8\) Does the fact that the majority of the US population is overweight or obese at present\(^6\) mean that nowadays US citizens of normal weight have to be regarded as abnormal? Theoretically speaking, yes, but this example mostly serves to illustrate that normality does not equate with health, and that sometimes, the norm is a relative absence of health, or even illness. On the other hand, the normative increase in mean BMI, which to a lesser extent has affected the Netherlands as well, may actually be good news when it comes to risk of eating pathology: the norm of a fuller figure may be partly responsible for the decreased incidence of BN (Chapter 3); a hypothesis receiving support in Chapter 6, showing that adherence to group norms of physical attractiveness protects against the later development of eating pathology. This finding remained significant after adjusting for extremes of BMI (underweight and obesity). Whether group norms of physical attractiveness parallel a population norm (a fuller figure) or reflect an ideal norm (the thin-body ideal) is a question for further research.

The medicalization of normal variations and fluctuations in mental functioning is called diagnostic inflation, a process whose pitfalls are described by Allen Frances, chair of the DSM-IV taskforce and a prominent criticaster of the DSM-5, in his book ‘Saving normal’.\(^7\) Diagnostic inflation occurs when diagnostic labels are used – or misused – to serve interests that lie beyond the fundamental clinical purpose of a diagnosis, that is, of predicting course and outcome, and of informing treatment decisions. The main causes of diagnostic inflation are decreased societal tolerance for individual differences and eccentricity, and financial interests attached to mental disorder diagnoses, both for the individual (e.g., to get access to welfare and insurance funds) and for other parties (e.g., the pharmaceutical industry).\(^7\) Furthermore, diagnostic inflation can occur when the Aesculapian authority of the skilled and experienced psychiatrist,\(^6\) carefully evaluating a patient and assigning a diagnosis, is outsourced to less expensive - and less experienced – work forces. Examples include the use of lay interviewers in large-scale epidemiological studies, and general practitioners who are the first in line to evaluate and treat mental disorders before referral, if any, to a psychiatrist takes place. Another cause of diagnostic inflation is the creation of diagnostic hypes by experts with tunnel vi-
sion, the media producing sensational stories about mental disorders and, in the United States, direct consumer advertising by pharmaceutical companies. According to Frances, BED has the potential to become a future diagnostic hype. He questions the validity of BED by equating it with obesity and subsequently applies a social model of (mental) illness on BED/obesity: these conditions are the result of the food industry producing unhealthy yet abundantly and cheaply available foods, backed by governmental policy and subsidies. Results from our review on the course and outcome of eating disorders (Chapter 4) and the study on the community cohort of adolescents (Chapter 5) contradict these statements about BED. First of all, BED and obesity are not identical: while 60.0% of adolescents with a lifetime diagnosis of BED were obese at age 19, only 16.5% of all obese adolescents (at age 19) had a lifetime diagnosis of BED. Furthermore, BED is distinct from obesity regarding concurrent validators (e.g., levels of psychopathology, weight and shape concerns and quality of life). Also, the standard treatment for obesity - behavioral weight loss – does not work as well for binge eating as treatment with psychotherapy does, providing evidence for the predictive validity of BED. Furthermore, BED may confer a risk of components of the metabolic syndrome, over and above the risk attributable to obesity alone (Chapter 4). Based on these results, Frances’ approach of BED could be regarded as an example of diagnostic deflation, which could result in undertreatment, or offering an ineffective treatment, to a clinically significant problem. Finally, it could be disputed whether the application of a social model on BED/obesity is justified, or that it would be more appropriate to state that risk factors for overeating, and as such for obesity and BED, have increased.

Frances’ criticism that BED is an example of a diagnostic hype in the making seems slightly unfair since BED was introduced in DSM-IV under his leadership. It nevertheless provides a good opportunity to examine whether the forces allegedly setting the stage for a diagnostic hype – experts, media and Big Pharma – will also play this role in the predicted dissemination of BED. Although it is impossible to forecast the future, the epidemiological history of the other specific eating disorders - AN and BN –, as examined in Chapter 3, may offer clues to BED’s fate.

Up to now, the powerful searchlight of the pharmaceutical industry has not managed yet to illuminate an effective drug for the treatment of eating disorders.
Hence, diagnostic hyps – if any – have not come from that direction”. The fact that eating disorders lack the ‘patronage’ of the pharmaceutical industry does not mean they dwell in some obscure corner of psychiatry though. On the contrary: perhaps more than any mental disorder eating disorders have been in the lime light – directed from many corners of society. In Chapter 3 we have discussed that from the 1990s onward, both AN and BN received a great – and increasing – amount of attention from the scientific field and the media. For example, the struggle of celebrities with eating disorders was discussed in the popular press, thus increasing awareness of these mental disorders among the public and potentially setting the stage for a diagnostic hype. This was augmented by reports of an ‘epidemic’ of eating disorders; a sensational terminology not limited to the popular press. The primary care study examining the incidence of AN and BN in the 1980s, 1990s, and 2000s showed, however, that the incidence of AN remained remarkably stable in the past three decades, while the incidence of BN even sharply decreased (Chapter 3).

The ability to nuance sensational reports of an ‘epidemic’ constitutes one of the core values of well-conducted epidemiological studies with sound and rigorous methods. Such studies have proven to be invaluable in nuancing reports of epidemics of AN and BN, and they will hopefully serve this purpose for BED as well. There is, however, some aspect unique to BED which potentially makes this diagnosis not only more prone to diagnostic inflation, but to diagnostic deflation as well. BED may be a less accurate diagnosis than either AN and BN, as reflected in the key parameters of severity in DSM-5. BMI constitutes the key severity parameter for AN, which is highly objective in the sense that it can be measured by the clinician. For BN, frequency of purging episodes determines severity, which cannot be measured directly, but is an unambiguous pathological symptom that can be regarded as a categorical phenomenon: either you vomit, or you don’t. Accuracy of diagnosis here depends on the willingness of the patient to disclose such – often shameful – behaviors to the clinician. For BED, severity is defined by the frequency of binge eating episodes. The core feature of binge eating is loss of control, a variable and subjective experience that cannot be assessed directly, but

** Eating disorder treatment centers offering residential treatment programs may fill the marketing gap left by the pharmaceutical industry. A recent article in the New York Times discussed the rapid expansion of profit-based treatment centers for eating disorders in the United States since the introduction of the Affordable Care Act, enabling more patients with an eating disorder to afford treatment. Thus, this law increases the reservoir of potential ‘consumers’ of eating disorder treatments. The treatment centers directly advertise to consumers and clinicians with alluring descriptions and pictures of often spa-like facilities.
can only be addressed by circumstantial questions, partly reflected in the B-criteria of BED in DSM-5.\textsuperscript{18} This inherent subjectivity of the core feature of BED increases the risk of an inaccurate diagnosis, and therefore of both diagnostic inflation and deflation.

Frances’ criticism on BED also opens an interesting discussion about the role of societal forces and population norms in defining mental illness in general and eating disorders in particular. Regardless of whether his theory of a social model of BED/obesity is right, wrong or incomplete, it does give an example of which powerful societal and cultural forces may exert their influence in both creating the conditions and reshaping the norms of what is normal and what is abnormal; and consequently of what is (mental) illness. What cultural and societal forces may influence the occurrence of eating disorders? If we return to the notion that psychiatric symptoms are often aberrations of common behaviors, what pathological extensions of normality could eating disorders represent? These so to speak macro-level questions were studied on a micro level in Chapter 6, in which the role of self-perceived and peer-perceived social status in the risk of developing eating pathology was investigated. Like all social groups, adolescent peer groups have a hierarchical structure in which a member’s status determines the amounts of respect, influence and attention assigned to that member.\textsuperscript{19,20} Peer groups translate norms from a macro level (society) and apply them on a micro level. The other way round, peer group norms may offer insight into societal norms.

Physical attractiveness was the most salient domain of both self-perceived and peer-perceived social status in early adolescence regarding risk of eating pathology in young adulthood (Chapter 6). What does that say about the importance of physical attractiveness in the society at large? Present-day Western society is full of paradoxes: mean BMI has gone up, yet the beauty ideal of a thin body is a collective desire, its achievement demanding a restraint and self-control that is countered by the liberalism of doing whatever you like and your ‘right’ to indulge and enjoy yourself. We are pressed to distinguish ourselves and to be individualistic, yet the pressure to conform and to adhere to the prevailing norms is just as strong. Women have demanded and received equal opportunities to men regarding education and occupation, yet the societal demands on appearance and attractiveness are still most stringent for women, thus contradicting – if not refuting - that it is the inside that counts. These conflicting values and desires are capitalized on by all sorts of industries: the food industry coaxing us to eat more, the diet industry to eat less, the fashion and beauty industry promising us an improved look, and social media spreading a global and uniform sort of individualism.
Many of these paradoxes are played out in the field of physical appearance, not only because we are what we eat, and what we eat – or don’t eat - affects our weight and consequently how we look, but also because these paradoxes are about how others perceive, judge and rank the part of us most readily visible to them - or how we think they do. It is therefore not surprising that physical attractiveness was the most salient domain of both self-perceived and peer-perceived social status regarding risk of eating pathology (Chapter 6). It is important to note that self-perceived and peer-perceived physical attractiveness are not necessarily two sides of the same coin. Looking good in one’s own eyes may not mean a self-judged adherence to the prevailing cultural norms of physical attractiveness, but just as well being immune to them. Hence, it is truly the inside that counts, and peering through the looking glass is to see beyond reflections indeed.

METHODOLOGICAL CONSIDERATIONS

In this thesis, the occurrence of eating disorders was established at two levels of morbidity: primary care (Chapter 3) and the community (Chapter 5). Epidemiological studies at these levels of morbidity are important because the majority of eating disorder cases in the community do not seek help and are thus not detected by the mental health care system (Chapter 2). This underdetection may result in an underestimation and a distorted view (the so-called clinician’s illusion) of the true scope and spectrum of eating disorders. Both the primary care and the community study employed a two-stage approach, which is considered the gold standard for relatively low-prevalent disorders such as eating disorders. In the first stage, a wide net of case identification was cast to avoid missing possible eating disorder cases (high sensitivity), followed by stringent case definition by eating disorder experts to establish or dismiss a final eating disorder diagnosis (high specificity). In the primary care study, the first stage - screening for new eating disorder cases - was performed by a nationwide network of general practitioners (GPs), serving a representative sample of the Dutch population. As such, we made use of the best qualities of GPs as central players in the health care and insurance system: they are the first to be consulted for any physical or mental problem, and they serve as gatekeepers to specialized care, thus being notified of all specialist consultations. Consequently, each GP has an overview of the diverse health problems of a large group of individuals in the community. The inherent generalist nature of their profession in combination with time constraints, however, make GPs less
equipped to establish accurate eating disorder diagnoses, so this part of the procedure was performed by the research team. In the community study, a cohort of 2,230 adolescents was screened for eating problems by means of data collected at a previous assessment wave. Again a wide net was cast to avoid missing possible cases: of the 312 adolescents considered to be at high risk for an eating disorder, a high proportion (95%) could be interviewed by experts, resulting in 58 adolescents with a definite lifetime eating disorder diagnosis.

Some fundamental methodological differences exist between the two studies, which are related to their respective purposes. In order to examine secular trends in the incidence of eating disorders, it is quintessential that the definition of disorder does not change over time, because a changed definition may confound any finding of a changed incidence over time. Therefore, the case identification criteria employed by the GPs in the primary care study were neither changed nor adapted since the start of the study in 1985, when only AN and BN were defined according to the then current DSM-III. A limitation of this methodological consistency is that new developments in eating disorder classification could not be incorporated in the study method. This mainly pertains to the DSM-IV residual category diagnosis EDNOS, which is the most common eating disorder in the community, a finding that was discussed in Chapter 2, and replicated in Chapter 5. The community study examining the prevalence of DSM-5 eating disorders, on the other hand, had the explicit purpose to investigate the epidemiological results of new developments in diagnostic classification, and hence used the most recent definition of eating disorders.

In the study examining the impact of self-perceived and peer-perceived social status in early adolescence on the development of eating pathology in young adulthood (Chapter 6), a continuous symptom score was used as the outcome measure (the overall symptom composite score of the Eating Disorder Diagnostic Scale).\textsuperscript{21,22} This has the advantage of increased power over categorical outcomes (e.g., DSM-diagnoses), provided a linear relationship exists between the predictor variable and the outcome, which we assumed. A potential disadvantage is that we could not differentiate between eating disorder diagnoses, which may have different risk profiles. If we return to the notion of Fairburn & Cooper\textsuperscript{5} of a transdiagnostic psychopathology of eating disorders – an overvaluation of weight and shape –, the use of a general eating pathology outcome measure seems valid. It must be noted, though, that Fairburn & Cooper\textsuperscript{5} described predictive validity of the transdiagnostic approach, while antecedent validity was assumed in our study.
IMPLICATIONS

To prevent diagnostic inflation, Frances suggests a stepped-diagnosis approach, in which a definitive diagnosis is only assigned after the healing properties of time, social support and the placebo effect have not resulted in remission of the complaints.7 The stepped-diagnosis approach may be a good choice when assessing mild forms of eating disorders, especially subthreshold forms of BED, which are classified in the DSM-5 residual category OSFED.

An important question arising from the general discussion, for which no clear answer yet exists, is how to handle mild cases of eating disorders in the community. Which of the mild cases will remit spontaneously, and which will progress to a more severe form? It would be worthwhile to investigate the predictive validity of severity ratings in terms of course and outcome, and to identify predictors of spontaneous remission. This especially pertains to BED, as not much is known about long-term course and outcome of BED at a community level. This knowledge will help to define individuals who may benefit from clinical interventions and prevent unnecessary treatment in those who will not. Severity ratings are designed for clinicians to track a patient’s progress, but they serve as well in deciding how intense or invasive treatment should be. As such, severity ratings should go hand in hand with a stepped-care approach. Finally, the validity of the severity ratings for feeding and eating disorders could be further investigated by examining their correlation with other parameters, such as quality of life.

The finding that both self-perceived and peer-perceived physical attractiveness protect against later development of eating pathology provides evidence for the rationale of prevention efforts aiming to increase body satisfaction23 and the use of peers in eating disorder prevention.24 It would be of interest to investigate whether a discrepancy between self-perceived and peer-perceived judgement of physical attractiveness is associated with risk of eating pathology. Furthermore, whether peer group norms of physical attractiveness parallel a population norm (a fuller figure) or reflect an ideal norm (the thin-body ideal) would be another question for further research.

CONCLUSIONS

This thesis aimed to explore several aspects of the epidemiology of eating disorders in primary care and the community, with an emphasis on the effects of
changed diagnostic criteria, a changing sociocultural environment over time, and the impact of self-perceived and peer-perceived social status on the occurrence of eating disorders. It was found that the lifetime prevalence of any eating disorder increased with almost 30% under the DSM-5 criteria, and that this increase was mainly attributable to cases of BED that were subthreshold under DSM-IV criteria (Chapter 5). Since little is known about course and outcome of BED in the community (Chapter 4), it is as yet unclear what would be a cost-effective intervention strategy for mild or subthreshold cases of BED in the community. Furthermore, the DSM-5 criteria effectively reduced the proportion of the DSM-IV residual category diagnosis EDNOS, by making BED a specific eating disorder and by lowering the diagnostic thresholds for AN and BN (Chapter 5). The incidence of AN remained relatively stable over the past three decades, while the incidence of BN decreased substantially (Chapter 3). This finding illustrates the importance of sociocultural factors in the occurrence of eating disorders, especially for BN and perhaps for BED as well. Sociocultural factors and influences, such as the media, may also increase the risk of inaccurate diagnoses, diagnostic inflation and diagnostic hype, to which BED may be more prone than the other specific eating disorders. On a micro level, that is: among peers, self-perceived and peer-perceived physical attractiveness protected against later development of eating pathology (Chapter 6). This finding was extrapolated to prevailing and often contradicting cultural values and norms in the society at large.
REFERENCES


Summary
Eating disorders are severe mental health problems with harmful consequences for physical and psychosocial health, which usually develop in adolescence. Their causes are relatively poorly understood. A classification of eating disorders can be found in the Diagnostic and Statistical Manual of Mental Disorders (DSM). The DSM is a reliable guideline to diagnose mental disorders. It offers a universal and transparent language to clinicians to inform treatment decisions in an individual patient; besides, it is well suited for examining the epidemiology and etiology of disorders. The fourth edition of the DSM, DSM-IV, specifies two eating disorders, anorexia nervosa and bulimia nervosa, and a residual category ‘eating disorder not otherwise specified’, which lists some examples such as binge-eating disorder. The majority of eating disorder cases in both clinical and community samples fall into the DSM-IV residual category, which is considered problematic. A major goal of the revision of the eating disorder section for DSM-5 has been to reduce the proportion of residual category diagnoses. For this purpose, the diagnostic thresholds for anorexia nervosa and bulimia nervosa were lowered, and binge-eating disorder was added as a specific eating disorder. Furthermore, DSM-5 includes a severity rating for disorders, ranging from mild to extreme, in order to help clinicians track a patient’s progress.

Epidemiological studies provide information about the occurrence of disorders and may shed light on risk factors. Studies examining long-term trends in the occurrence of disorders may uncover risk factors that affect the society at large. In the case of eating disorders, this knowledge is salient since sociocultural factors are thought to play a major role. While examining long-term trends may provide knowledge about risk factors on a macro level (in the the society at large), studying a cohort of adolescents may offer insight into sociocultural risk factors on a micro level (e.g., at school or at home).

This thesis aims to explore several aspects of the epidemiology of eating disorders in primary care and the community, with an emphasis on the effects of changed diagnostic criteria, a changing sociocultural environment over time, and the impact of self-perceived and peer-perceived social status on the occurrence of eating disorders. A general introduction to eating disorders and epidemiology is offered in Chapter 1.

Chapter 2 provides a comprehensive review of the literature on the epidemiology of eating disorders, focusing on the basic epidemiological parameters incidence, prevalence and mortality rate. The incidence rate is the number of new cases of a disorder in the population over a specified period. The lifetime prevalence is the proportion of the population that has suffered from a disorder at any point in life.
From the 1930s until the 1970s, there was an increase of the registered incidence of anorexia nervosa in Europe. Since 1970, the incidence in Europe seems to have been rather stable. Less is known about long-term trends in the incidence of bulimia nervosa.

Chapter 3 examines changes in the incidence of anorexia nervosa and bulimia nervosa in the Netherlands during the 1980s, 1990s and 2000s, using data from a nationwide network of general practitioners, serving a representative sample of the total Dutch population. The incidence of bulimia nervosa decreased significantly over the past three decades, while the incidence of anorexia nervosa remained fairly stable. Explanations are sought in sociocultural developments in the last 25 years to which bulimia nervosa is probably more sensitive than anorexia nervosa.

Chapter 4 discusses the literature on the epidemiology, course, and outcome of eating disorders in accordance with the DSM-5. The first part describes the consequences of the revised diagnostic criteria for the incidence and prevalence of anorexia nervosa, bulimia nervosa, binge-eating disorder, and the residual diagnosis of not otherwise specified eating disorders. The second part reviews course and outcome studies regarding the three specific eating disorders in DSM-5 – anorexia nervosa, bulimia nervosa and binge-eating disorder. Several studies confirm that the DSM-5 criteria for eating disorders effectively reduce the proportion of the residual category ‘eating disorder not otherwise specified’. In a number of studies, course and outcome of both anorexia nervosa and bulimia nervosa according to DSM-5 criteria did not differ significantly from course and outcome of these disorders as defined in DSM-IV. Data on long-term outcome, including mortality, are limited for binge-eating disorder. Moreover, the available data are solely based on clinical samples; therefore, little is known about course and outcome of binge-eating disorder in the community.

Chapter 5 reports on the prevalence and severity of DSM-5 eating disorders in a community cohort of Dutch adolescents. The most common diagnoses among the girls were anorexia nervosa and binge-eating disorder, and among the boys, binge-eating disorder. In contrast, bulimia nervosa was relatively rare. According to DSM-5 criteria, a minority of all diagnosed cases fell into one of the residual categories ‘otherwise specified feeding and eating disorder’ or ‘unspecified feeding and eating disorder’, compared with a majority of cases for the DSM-IV residual category ‘eating disorder not otherwise specified’. Male and female adolescents combined, the lifetime prevalence of any eating disorder increased substantially under the DSM-5 criteria. This increase is mainly attributable to the inclusion of cases of binge-eating disorder that are subthreshold according to DSM-IV.
The validity of the severity ratings for feeding and eating disorders was evaluated by examining their distribution in the community and their correlation with detection and treatment rates. As was to be expected for a community cohort, the severity of most cases was mild to moderate. A statistically significant association was found between severity and the proportion of cases detected and treated by (mental) health care services. While only a minority of mild cases had been detected and treated, the opposite was true for cases of extreme severity. These results provide evidence for the validity of the DSM-5 severity ratings for feeding and eating disorders.

Chapter 6 investigates whether self-perceived and peer-perceived social status in early adolescence are associated with eating pathology in young adulthood. Data from the same community cohort of Dutch adolescents as described in Chapter 5 were used. Both self-perceived and peer-perceived physical attractiveness in early adolescence were inversely correlated with eating pathology in young adulthood. On the contrary, social acceptance by peers, that is: being liked, surprisingly emerged as a predictor of eating pathology.

The final chapter provides a discussion of the main findings, methodological considerations regarding the empirical studies conducted, and implications for clinical practice and further research. I conclude that the revised DSM-5 criteria effectively reduce the proportion of residual category diagnoses, whereas the total lifetime prevalence of eating disorders increases under the DSM-5 criteria. The severity ratings for feeding and eating disorders are valid in terms of both the distribution in the community and the correlation with detection and treatment rates by health care services. Furthermore, sociocultural values and norms, both in the society at large and in the proximate environment, influence the occurrence of eating disorders. This is illustrated by the finding that the incidence of bulimia nervosa decreased substantially over the past three decades, while the incidence of anorexia nervosa remained relatively stable, and by the finding that peer-judgements of physical attractiveness protect against future eating pathology.
Samenvatting
Eetstoornissen zijn ernstige psychiatrische aandoeningen met schadelijke gevolgen voor de lichamelijke en psychosociale gezondheid, die meestal ontstaan in de adolescentie. Over de oorzaken is nog relatief weinig bekend. Een classificatie van eetstoornissen is te vinden in de *Diagnostic and Statistical Manual of Mental Disorders* (DSM). De DSM is een betrouwbare handleiding om psychische stoornissen te diagnosticeren, die clinici een universele en transparante taal verschaf, waarna vervolgens beslissingen genomen kunnen worden over de meest geschikte behandeling van een individuele patiënt. Verder is de DSM zeer geschikt om de epidemiologie en etiologie van eetstoornissen te onderzoeken. De vierde editie van de DSM, de DSM-IV, specificerdtwee eetstoornissen, anorexia nervosa en boulimia nervosa – en daarnaast een restcategorie ‘eetstoornis niet anderszins omschreven’, waaronder enkele voorbeelden worden opgesomd zoals de eetbuistoornis. De meerderheid van de patiënten met een eetstoornis, zowel in klinische als in bevolkingsstudies, valt in de DSM-IV-restcategorie, wat als een probleem wordt beschouwd. Een belangrijk doel van de revisie van de eetstoornissectie ten behoeve van de DSM-5 is geweest om het aantal restcategorie-diagnoses te reduceren. Hiertoe werden de diagnostische drempels voor anorexia nervosa en boulimia nervosa verlaagd en werd de eetbuistoornis toegevoegd als een specifieke diagnose. In de DSM-5 kan daarnaast de ernst van een stoornis worden gespecificeerd, waardoor clinici het beloop bij patiënten kunnen vastleggen. De ernstscores lopen uiteen van mild tot extreem.

Epidemiologische studies verschaffen informatie over de frequentie van stoornissen en kunnen inzicht geven in risicofactoren. Studies die langetermijn-trends in de frequentie van stoornissen onderzoeken, kunnen risicofactoren blootleggen die de gehele maatschappij aangaan. Voor eetstoornissen is dit soort kennis zeer relevant, aangezien socioculturele factoren waarschijnlijk een belangrijke rol spelen. Terwijl het onderzoeken van langetermijn-trends kennis kan verschaffen over risicofactoren op een macroniveau (in de maatschappij als geheel), kan het bestuderen van een cohort van adolescenten juist inzicht geven in socioculturele risicofactoren op een microniveau (bijvoorbeeld op school of thuis).

Dit proefschrift heeft als doel om verschillende aspecten van de epidemiologie van eetstoornissen in de bevolking en de eerste lijn te onderzoeken. Daarbij ligt de nadruk op de gevolgen van de veranderde diagnostische criteria, een veranderende socioculturele omgeving door de tijd en de invloed van sociale status op de frequentie van eetstoornissen. Een algemene inleiding in de eetstoornissen en de epidemiologie wordt verschaf in hoofdstuk 1.
Samenvatting

Hoofdstuk 2 biedt een uitgebreid overzicht van de literatuur op het gebied van de epidemiologie van eetstoornissen. Het spitst zich toe op de fundamentele epidemiologische parameters incidentie, prevalentie en sterftecijfer. De incidentie is het aantal nieuwe ziektegevallen in de populatie over een bepaalde periode. De lifetime prevalentie geeft het percentage van de bevolking weer dat een bepaalde stoornis of ziekte nu heeft of ooit heeft gehad. Van de jaren ’30 tot de jaren ’70 van de 20e eeuw nam de geregistreerde incidentie van anorexia nervosa in Europa toe. Vanaf 1970 lijkt de incidentie in Europa redelijk stabiel te zijn gebleven. Er is weinig bekend over langetermijn-trends in de incidentie van boulimia nervosa.

Hoofdstuk 3 onderzoekt veranderingen in de incidentie van anorexia nervosa en boulimia nervosa in Nederland tijdens de jaren ’80 en ’90 van de vorige eeuw en in het eerste decennium van het nieuwe millennium. Hierbij werd gebruik gemaakt van data van een nationaal netwerk van huisartsen die met hun praktijk een representatieve steekproef vormen van de gehele Nederlandse bevolking. De incidentie van boulimia nervosa nam significant af in de laatste drie decennia, terwijl de incidentie van anorexia nervosa relatief stabiel is gebleven. Verklaringen worden gezocht in socioculturele ontwikkelingen in de afgelopen 25 jaar, waarop boulimia nervosa waarschijnlijk gevoeliger reageert dan anorexia nervosa.

Hoofdstuk 4 bespreekt de literatuur met betrekking tot de epidemiologie, het beloop en de uitkomst van eetstoornissen zoals geoperationaliseerd in de DSM-5. Het eerste deel beschrijft de consequenties van de gereviseerde diagnostische criteria voor de incidentie en prevalentie van anorexia nervosa, boulimia nervosa, de eetbuistoornis en de restcategorie van niet anderszins omschreven eetstoornissen. In het tweede deel worden studies besproken die het beloop en de uitkomst onderzochten van de drie specifieke eetstoornissen in de DSM-5, te weten anorexia nervosa, boulimia nervosa en de eetbuistoornis. Verschillende studies bevestigen dat de DSM-5-criteria voor eetstoornissen het aantal restcategorie-diagnoses ‘eetstoornis niet anderszins omschreven’ met succes hebben verkleind. In diverse studies waren het beloop en de uitkomst van zowel anorexia nervosa als boulimia nervosa volgens de DSM-5-criteria niet significant verschillend van het beloop en de uitkomst van deze stoornissen zoals gedefinieerd in de DSM-IV. Gegevens met betrekking tot uitkomsten op de lange termijn, inclusief sterftecijfers, zijn beperkt voor de eetbuistoornis. Bovendien zijn zij uitsluitend gebaseerd op klinische onderzoekspopulaties, waardoor weinig bekend is over het beloop en de uitkomst in de algemene bevolking.

In hoofdstuk 5 worden de prevalentie en de ernst van DSM-5-eetstoornissen in een bevolkingscohort van Nederlandse adolescenten gerapporteerd. De meest
voorkomende diagnoses bij meisjes waren anorexia nervosa en de eetbuistoornis en bij jongens alleen de eetbuistoornis. Boulimia nervosa was relatief zeldzaam. Volgens de DSM-5-criteria viel een minderheid van alle gestelde diagnoses in een van de restcategorieën ‘andere gespecificeerde voedings- of eetstoornis’ of ‘ongespecificeerde voedings- of eetstoornis’, vergeleken met een meerderheid van de diagnoses in de DSM-IV-restcategorie ‘eetstoornis niet anderszins omschreven’. De totale lifetime prevalentie van eetstoornissen nam substantieel toe bij hantering van de DSM-5-criteria. Deze toename is vooral toe te schrijven aan enkele milde gevallen van de eetbuistoornis, die de diagnostische drempel van de DSM-IV niet halen.

De validiteit van de ernstscores voor voedings- en eetstoornissen werd geëvalueerd door hun verdeling in de algemene bevolking te onderzoeken en daarnaast ook hun correlatie met detectie- en behandelpercentages. Zoals te verwachten in een bevolkingscohort, was de ernst van de meeste ziektegevallen mild tot matig. Daarnaast werd een statistisch significant verband gevonden tussen de ernst en het percentage ziektegevallen dat was gedetecteerd en behandeld in de (geestelijke) gezondheidszorg. Terwijl slechts een minderheid van de milde ziektegevallen was gedetecteerd en behandeld, gold het omgekeerde voor ziektegevallen van extreme ernst.

In hoofdstuk 6 wordt onderzocht of sociale status in de vroege adolescentie, zowel zelf-ervaren als ervaren door klasgenoten, is geassocieerd met eetproblemen in de jongvolwassenheid. Hiervoor werd gebruik gemaakt van data van hetzelfde bevolkingscohort van Nederlandse adolescenten dat in hoofdstuk 5 werd beschreven. Er goed uitzien - zowel in de eigen ogen als in de ogen van klasgenoten – bleek te zijn geassocieerd met minder eetproblemen op jongvolwassen leeftijd. Opvallend is dat aardig gevonden worden door veel klasgenoten juist naar voren kwam als een voorspeller van eetproblemen.

Het laatste hoofdstuk biedt een bespreking van de belangrijkste bevindingen, de methodologische overwegingen bij de empirische studies en de implicaties voor de klinische praktijk en verder onderzoek. Daarin concludeer ik dat de gereviseerde DSM-5-criteria met succes de proportie eetstoornissen in de restcategorie reduceren, terwijl de totale lifetime prevalentie van eetstoornissen juist toeneemt bij het toepassen van de DSM-5-criteria. De ernstscores van voedings- en eetstoornissen zijn valide, gezien de verdeling in de algemene bevolking en de correlatie met detectie- en behandelpercentages in de gezondheidszorg. Verder beïnvloeden socioculturele normen en waarden, zowel in de maatschappij als in de directe omgeving, de frequentie van eetstoornissen. Dit wordt geïllustreerd door de bevinding
Samenvatting

dat de incidentie van boulimia nervosa substantieel is gedaald in de afgelopen drie decennia, terwijl de incidentie van anorexia nervosa in diezelfde periode relatief stabiel is gebleven - en door de bevinding dat mooi gevonden worden door klasge-noten bescherming biedt tegen latere eetproblemen.
Dankwoord
Dankwoord

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"Kom! Lopende op blote voeten…"
(M. Vasalis)
Curriculum vitae


Vanaf januari 2016 heeft zij zich geheel gericht op het afronden van dit proefschrift; na haar promotie zal zij het vak van psychiater hervatten.
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