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CURRENT OPINION

Review of the burden of eating disorders: mortality, disability, costs, quality of life, and family burden

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Purpose of review
To review the recent literature on the burden of eating disorders in terms of mortality, disability, quality of life, economic cost, and family burden, compared with people without an eating disorder.

Recent findings
Estimates are that yearly over 3.3 million healthy life years worldwide are lost because of eating disorders. In contrast to other mental disorders, in anorexia nervosa and bulimia nervosa years lived with disability (YLDs) have increased. Despite treatment advances, mortality rates of anorexia nervosa and bulimia nervosa remain very high: those who have received inpatient treatment for anorexia nervosa still have a more than five times increased mortality risk. Mortality risks for bulimia nervosa, and for anorexia nervosa treated outside the hospital, are lower but still about twice those of controls. In people with an eating disorder, quality of life is reduced, yearly healthcare costs are 48% higher than in the general population, the presence of mental health comorbidity is associated with 48% lower yearly earnings, the number of offspring is reduced, and risks for adverse pregnancy and neonatal outcomes are increased.

Summary
People with a current or former eating disorder are at risk of increased mortality, high YLD rates, a reduced quality of life, increased costs, and problems with childbearing.

Keywords
eating disorders, economic cost, mortality, quality of life, years lived with disability

INTRODUCTION

'Eating disorders are disabling, deadly, and costly mental disorders that considerably impair physical health and disrupt psychosocial functioning', as Treasure *et al*. [1] state. This makes effective treatments the more important. For bulimia nervosa [2,3] and binge eating disorder (BED) [4], there are effective psychological treatments, especially cognitive behaviour therapy (CBT). However, for anorexia nervosa, a recent meta-analysis could not establish its efficacy over an active control condition [5]. For the most severe and enduring cases of anorexia nervosa, there is a paucity of evidence-based treatments [6].

The efficacy of treatment (or lack thereof) is reflected in illness duration and remission rates. A series of publications on very long-term (10–20 years) follow-up studies of inpatients with an eating disorder showed that, respectively 64% of persons previously diagnosed with anorexia nervosa, 53% of those previously diagnosed with bulimia nervosa, and 30% of those previously diagnosed with BED, still met diagnostic criteria for an eating disorder at follow-up; a further 6% for anorexia nervosa, 9% for bulimia nervosa and 31% for BED had remaining eating disorder symptoms [7,8▪▪,9]. Higher recovery rates of anorexia nervosa were reported in two smaller long-term (≥20 years) follow-up studies of adolescent-onset anorexia nervosa; one on an outpatient sample [10], the other on a community sample [11▪▪]. In both studies, around 65% of the cases were in complete remission at follow-up. Thus, across eating disorders, a considerable 62–70% of people who had received inpatient treatment and

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KEY POINTS

- The mortality risk for people followed up after inpatient treatment for anorexia nervosa is over five times higher than for age-matched and gender-matched people in the general population
- In people followed up after treatment for bulimia nervosa, or after outpatient treatment for anorexia nervosa, the mortality risk is around two times that in the general population.
- Anorexia nervosa, bulimia nervosa, and BED have substantial negative consequences for the number of years lived in good health (delayed recovery, and persistence of partial/full eating disorder pathology) and for quality of life.
- Yearly costs for healthcare use are almost 50% higher for patients with an eating disorder compared with noneating disorder controls.
- Eating disorders carry risks for fertility and health risks in pregnancy and newborns.

35% who had received outpatient treatment, still met full diagnostic criteria or had remaining eating disorder symptoms at long-term follow-up.

Protracted eating disorder pathology means that eating disorders have a great impact on the present and future health and quality of life of affected persons, their caregivers and society. In this journal in 2016, Erskine *et al.* [12] described the inclusion of eating disorders in the Global Burden of Disease (GBD) study in 2010 as a watershed in the recognition of these disorders in the wider global health community, and presented findings on the burden of eating disorders from the GBD 2013 database. Here we review current GBD data on eating disorders. Furthermore, we widen the scope of burden to address some of the limitations of the GBD concept of burden as 'within-the-skin' health loss: as Erskine *et al.* [12] noted, the impact of eating disorders on families and other support systems is neither reflected in the GBD burden estimates nor do they represent the future adverse impact of an eating disorder on an individual's psychological and economic well being. And as only anorexia nervosa and bulimia nervosa have so far been included for burden quantification, the GBD data only pertain to a subset of eating disorders. This review addresses eating disorder-related mortality, disability, economic cost, and other individual, caregiver and family burden.

METHODS

This review is based on a literature search using Medline and Pre-Medline, Medline Epub ahead of print and in-process and other nonindexed citations, and Embase psychiatry resources (via OvidSP), using several key terms relating to eating disorders and burden (terms on request available from the first author). We supplemented the results with Google Scholar searches for specific combinations of terms. The search was conducted up to 8 May 2020. We limited the search to publications in English from 2018 onwards and to studies reporting on formal eating disorder diagnoses [anorexia nervosa, bulimia nervosa, BED, Avoidant/Restrictive Food Intake Disorder (ARFID)]. The titles and abstracts of 1234 unique listings were screened by the first author for relevance. Studies in which eating disorders were comorbid with other health conditions (e.g. diabetes) were excluded, as well as studies on fewer than 25 subjects. In order to put information in perspective, we focussed on studies that used population-based metrics or that compared people with an eating disorder to noneating disorder controls.

GLOBAL BURDEN OF DISEASE STUDY

A major global effort to gather, combine, and compare information on the burden associated with a large range of disorders, both somatic and mental, is the ongoing Global Burden of Disease (GBD) study, which started in 1990. Information is regularly updated and available online through the Global Health Data Exchange (GHDx) site of the Institute of Health Metrics and Evaluation (Seattle, Washington, USA): http://ghdx.healthdata.org/. Anorexia nervosa and bulimia nervosa have been included since the GBD 2010 study.

The burden of disease is defined as the gap between current health status and an ideal situation in which everyone lives into old age free of disease and disability. Causes of the gap are premature mortality, disability, and exposure to certain risk factors that contribute to illness. An important metric to express this gap is the disability-adjusted life year (DALY). One DALY expresses one lost year of 'healthy' life. The burden of a disease is the sum of DALYs for this specific disease across a population. DALYs are calculated as the sum of the years of life lost (YLL) because of premature mortality and the years lost due to disability (YLD), thus incorporating both mortality and morbidity information. Using DALYs, the burdens of various diseases can be compared, from those that cause premature death but little disability to those that cause disability but not death.

For mental health disorders, YLD are the main contributors towards DALYs. Table 1 shows the GBD 2017 data on YLD for eating disorders, all mental disorders (substance use disorders not included), all

Table 1. Global Burden of Disease 2017: counts, age-standardized rates per 100 000 population, and percentage change from 2007 to 2017 for years lived with disability (YLD)

	YLD		
	Counts (thousands)[c]	**Age-standardized rate per 100 000 population[d]**	**Change 2007–2017 (%)[a]**
All causes	853 043	10 870.5	−0.9
Noncommunicable diseases[a]	678 294	8579.1	0.1
Mental disorders[b]	122 746	1560.1	−1.1
Eating disorders	3 352	43.1	9.4
Anorexia nervosa	716	9.4	6.2
Bulimia nervosa	2 636	33.8	10.3

[a]Including mental disorders.
[b]Substance use disorders not included; these form a separate category.
[c]Data from [13▪].
[d]Data from [14].
YLD, years lived with disability.

noncommunicable diseases (of which mental disorders are part), and all causes [13▪,14].

It was estimated that in 2017, worldwide over 3.3 million healthy life years were lost to eating disorder-related disability, amounting to an age-standardized YLD rate of 9.4 for anorexia nervosa, and 33.8 for bulimia nervosa, per 100 000 population. YLD rates for eating disorders contributed 2.8% to the overall YLD load of mental disorders. Whereas from 2007 to 2017, YLD rates remained constant or decreased slightly for all causes, noncommunicable diseases, and mental disorders overall, for anorexia nervosa and bulimia nervosa these rates increased by 6 and 10%, respectively.

Challenges to the estimation of eating disorder burden were noted by Erskine *et al.* [12] in 2016, for instance that 'the representativeness of the available eating disorder prevalence data, measured as 'coverage', is poor' where 'no or limited data results in large uncertainty intervals around prevalence estimates and subsequently burden estimates', and these still hold. Thus, GBD data on eating disorders and other mental health disorders must be interpreted with caution.

In the following two sections we look into the basic parameters for burden of disease, mortality and disability, in persons with an eating disorder as compared with persons without an eating disorder.

Mortality

Studies are reviewed that have been published since the review by Smink *et al.* [15] in 2013 in this journal, and which report mortality rates for eating disorder relative to a reference population: either an age-matched and sex-matched control group (death hazard ratio), or relative to expected death rates in the age-matched and sex-matched general population as a whole (standardized mortality ratio: SMR) or in the subset of the general population that has no eating disorder (mortality rate ratio: MRR). Another commonly used measure of mortality, the crude mortality rate (CMR), represents the rate of mortality within the study population (e.g. eating disorder) over a specified period. As it does not allow for comparison across study populations like the age-matched and sex-matched controlled studies do, it is not reviewed here.

In users of secondary mental healthcare services an SMR of 5.2 (95% confidence interval (CI): 3.8–7.0) was reported for anorexia nervosa and atypical anorexia nervosa according to ICD-10 criteria [16]. Also using ICD-10 criteria, Suokas *et al.* found a hazard ratio of 6.5 (95% CI: 3.5–12.3) for people with anorexia nerv-osa and atypical anorexia nervosa treated in tertiary care [17]. These rates were comparable to the SMR for anorexia nervosa of 5.9 (95% CI 4.2–8.3) calculated in a landmark meta-analysis of worldwide eating disorder mortality rates published in 2011 [18], but higher than the relative risk of 2.2 (95% CI: 2.1–2.3) for mortality of mental disorders versus controls, pooled over 148 studies [19].

One recent study, linking data from primary and secondary care, reported mortality rates for anorexia nervosa comparable to the mortality risk pooled for various mental disorders [20▪▪]: the HR for anorexia nervosa and atypical anorexia nervosa (diagnosed according to ICD-10 or Read Version 2 primary care diagnostic criteria) was 2.3 (95% CI 1.9–2.8); both genders combined. Female patients had the highest hazard ratio 2.5 (95% CI 2.1–3.1). The majority of the patients had not been referred to a hospital, and thus the eating disorders may on average have been

less severe than those in previous studies, which included cases identified mainly through hospital records or eating disorder treatment facilities. In the same study, a hazard ratio of 1.4 (95% CI 1.1–1.8) was reported for bulimia nervosa and atypical bulimia nervosa, diagnosed according to ICD-10 criteria [20▪▪]. This rate is similar to the SMR of 1.5 (95% CI 1.1–2.0) of DSM-IV defined bulimia nervosa reported by Fichter and Quadflieg [21] and the SMR of 1.9 (95% CI 1.4–2.6) in the meta-analysis by Arcelus *et al.* [18].

In their review, Smink *et al.* identified one study that reported an SMR for BED of 2.3 (95% CI 0.0–5.5) [9]. Since then, two follow-up studies have reported relative mortality rates for BED: in Finnish inpatients the hazard ratio was 1.8 (95% CI 0.6–5.3) [17], and in German inpatients, the SMR was 1.5 (0.9–2.4) [21]. None of the mortality rates for BED were significantly higher than in controls.

For the combined category of anorexia nervosa, bulimia nervosa, and other eating disorders (ICD-10 code F50), in a study linking data from the Danish Psychiatric Central Research Register (containing information on inpatient treatment and outpatient and emergency room visits) with the Danish Register of Causes of Death, an overall MRR of 2.9 (95% CI 2.6–3.1) was reported [22▪].

Finally, in one male-only, 30-year follow-up study of inpatients, SMRs were 5.9 (95% CI 3.6–9.2) for anorexia nervosa, 1.9 (95% CI 0.9–3.6) for bulimia nervosa, and 3.4 (95% CI 1.4–7.0) for EDNOS; all diagnoses according to DSM-IV [23]. These results are largely in line with previous studies reporting mortality in male patients with an eating disorder.

Disability and functioning

Erskine *et al.* [12] extended the GBD context for disability from time lived with loss of health to a broader concept capturing deficits in other areas and the impact on caregivers and the community. This was reflected in disability weights derived from population surveys where respondents make pairwise comparisons of health conditions as to which of the two they consider the most 'unhealthy'. On a scale of 0 (perfect health) to 1 (death), disability weights for anorexia nervosa were calculated at 0.224 and for bulimia nervosa at 0.223. These are worse (higher weights) than, for example, for chronic state kidney disease (0.104) or severe heart failure (0.179), but better than for schizophrenia (0.778), which had the highest disability weight among 301 acute and chronic diseases and injuries [24].

Disability and functioning are two sides of the same coin. The WHO International Classification of Functioning, Disability and Health (ICF) provides a framework for measuring functioning and disability in relation to health conditions [25]. The WHO Disability Assessment Schedule (WHODAS 2.0) is the associated measuring instrument and looks into psychosocial activities and participation. In DSM-5, the WHODAS 2.0 has been put forward to replace the Global Assessment of Functioning (GAF) scale used in DSM-IV [26]. The original version is patient-based. However, for patients with severe mental illness who lack insight into their health problems, Koopmans *et al.* [27]. advocated the use of the proxy version by a caregiver or well informed health professional.

Despite the fact that DSM-5 has been introduced in 2013, the WHODAS 2.0 has not so far been widely adopted in mental health research and practice. Although Edlund *et al.* [28] indicated that eating disorders 'might be highly disabling', in their nationally representative population surveys using the WHODAS 2.0, the authors did not include eating disorders because of their relatively low prevalence. The two studies that did assess a patient-reported version of the WHODAS in patients with an eating disorder either did not have a noneating disorder control group [29] or did not report separately on patients with an eating disorder [30]. As yet, no study has used the proxy version of the WHODAS 2.0 in people with an eating disorder. For anorexia nervosa, in particular, the proxy information may be warranted, as patients with anorexia nervosa often deny that they are ill. Furthermore, parents are an important source of information on children and adolescents, as anorexia nervosa shows a peak incidence between 12 and 19 years old [31].

Quality of life

A report commissioned by a UK national charity indicated that, according to both patients with an eating disorder and their caregivers, eating disorders had a significant impact on patients' participation and productivity at education and work, overall well being, and quality of life, and on social and family life for both patients and their caregivers [32].

Several recent studies have reported problems in quality of life for current and former patients with an eating disorder. A general population cohort study in the USA revealed that those with a lifetime history of eating disorder (anorexia nervosa, bulimia nervosa, BED, and other eating disorder diagnoses combined) had a significantly lower quality of life (as measured with the EQ-5D-5L) than noneating disorder controls [33]. In a review of residual eating disorder symptoms and clinical features in patients who were in remission or had recovered, Tomba

et al. [34▪] reported that former eating disorder patients had a significantly lower quality of life and reduced capabilities in several areas of social functioning compared with noneating disorder controls, and that psychological well being did not improve up to the level of healthy controls. De Vos *et al.* [35] reported that patients with anorexia nervosa, bulimia nervosa, BED or Other Specified Feeding and Eating Disorders (OSFED) had significantly worse scores than the general population on overall, emotional and psychological well being; social well being was significantly lower only for patients with anorexia nervosa and bulimia nervosa. They also looked at 'the other side' of the spectrum of mental health states and found that some of those with an eating disorder reported they were flourishing; ranging from 9.3% (anorexia nervosa) to 24.6% (BED) compared with 36.8% in the general population.

Comorbidity is common in eating disorders and may increase the burden of disease. A 2019 review in this journal by Rijkers *et al.* [36] indicated that the prevalence of PTSS in eating disorders ranged from 9 to 24%. Patients with an eating disorder ($n = 6560$) were reported to experience higher levels of personality disorders (odds ratio (OR) = 10.8; 95% CI 6.6–18.6), alcohol dependence syndrome (OR = 6.0, 95% CI 3.9–9.4), and depressive disorders (OR = 5.9; 95% CI 4.8–7.4) than a group of age-matched and sex-matched controls [20▪▪]. The impact of eating disorders on well being may already be visible in health service use data prior to diagnosis as indicated by increased general practitioner prescriptions for central nervous system and dietetic drugs in the 2 years before the diagnosis of an eating disorder [20▪▪].

Economic cost

Another way to look at illness burden is to consider the costs to the individual and to society. In 2005, Simon *et al.* [37] reviewed the health service use and cost of patients with an eating disorder. They concluded that much less was known about this topic in eating disorders than in many other mental disorders. This was still found to be the case as recently as 2019 [38]. Mental illnesses, in general, reduce the chances of completing school, getting and keeping a full-time job, and earning high wages [38]. The long-term costs of an illness may be higher when the peak age at incidence is relatively low and chronicity is high, such as in eating disorders.

Disease costs of eating disorder involve treatment costs, and direct financial burden and loss of earnings for both patients and caregivers. The BEAT report calculated direct yearly costs of eating disorders in Wales at £1500 for patients and £2800 for caregivers, and the average costs for treatment per patient at £8850 per year [32]. Yearly costs of time off work and education were found to be £650 for patients with an eating disorder under 20 years old, £9500 for those over the age of 20, and £5950 for caregivers. The loss of earnings was reported to extend beyond the average treatment period of 6 years. How these costs related to healthcare costs for people without an eating disorder was not assessed. A review by Agh *et al.* [39] analysed 17 studies reporting healthcare costs of eating disorders; none of these compared costs with those of noneating disorder controls. Samnaliev *et al.* [40] reported that people with an eating disorder in the USA had yearly healthcare costs that were on average 48% higher than in the general population, and that within those with an eating disorder who were employed, the presence of mental health comorbidity was associated with an almost 50% reduction of yearly earnings. Another study found that healthcare use and associated costs in the year prior to a diagnosis of BED were already higher than for controls [41].

Family burden

Finally, eating disorders may not only impact the person with an eating disorder, but also affect relatives, in particular caregivers (parents) and offspring as well. There are very few studies that address caregiver's burden in eating disorders, let alone compare these to other health conditions or noneating disorder controls. A comparison by Martín *et al.* between caregivers of patients with an eating disorder, with depression or with schizophrenia, indicated that the caregiver's burden (worrying, tension, urging) was higher for carers of patients with an eating disorder [42]. In a study on anorexia nervosa, negative perceptions of the consequences of anorexia nervosa for young people also negatively impacted the caregiver's burden, regardless of anorexia nervosa symptom severity [43].

In a small-scale longitudinal study, Martini *et al.* [44] found that at 6 months postpartum, mothers with current and past eating disorder reported higher concerns about their child being or becoming overweight, and were less aware of hunger and satiety cues in their child, compared with healthy controls. A systematic literature review of studies comparing mothers with and without an eating disorder and their children revealed a range of differences that indicate an impact of maternal eating disorder on the child's psychological, cognitive, and eating development, such as more behavioural difficulties regarding feeding and eating, more

socioemotional difficulties, and possibly an increased risk for the development of eating disorder in the child [45]. Reports of children's difficulties by mothers with an eating disorder may be biased and need to be considered with caution.

In women from Utah, USA, with a previous eating disorder, age at first birth (anorexia nervosa: 26.4 years; bulimia nervosa: 25.7 years; EDNOS 25.6 years) was significantly higher than in matched controls from the general population (24.1 years) [46]. Taking marital status into consideration, fertility rates for anorexia nervosa were 18%, for bulimia nervosa 23.3%, and for EDNOS 18.6%, compared with 48.3% in age-matched general population controls. This indicates that women with an eating disorder history may experience delay or disruption of their reproduction because of their previous eating disorder. In Sweden, a large birth register study revealed increased risks for adverse pregnancy and neonatal outcomes, such as preterm birth and microcephaly, both for women with a current eating disorder as well as those with an eating disorder in remission [47▪].

CONCLUSION

Long-term studies showed considerable rates of persisting eating disorder pathology. This protracted eating disorder pathology means that worldwide, each year an estimated 3.3 million healthy person-years are lost to disability. Also, anorexia nervosa and bulimia nervosa are accompanied by significantly increased mortality rates. Patients with anorexia nervosa who have received inpatient treatment have higher rates than average for mental disorders. Eating disorders also negatively affect years lived with disability, the individual's quality of life, economic costs for patients and their caregivers, and childbearing and parenting. Only a few studies compare disease burden between people with and without an eating disorder, or use standardized rates for relevant data. Further eating disorder research is needed on patients' functioning as measured with the WHODAS 2.0 introduced by DSM-5.

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Conflicts of interest

There are no conflicts of interest.

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- ▪ of special interest
- ▪▪ of outstanding interest

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