

REVIEW ARTICLE

## The health service use and cost of eating disorders

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Eating Disorders Guideline Development Group†

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### ABSTRACT

**Background.** The economic burden and health service use of eating disorders have received little attention, although such data are necessary to estimate the implications of any changes in clinical practice for patient care and health care resource requirements. This systematic review reports the current international evidence on the resource use and cost of eating disorders.

**Method.** Relevant literature (1980–2002) was identified from searches of electronic databases and expert contacts.

**Results.** Two cost-of-illness studies from the UK and Germany, one burden-of-disease study from Australia and 14 other publications with relevant data from the UK, USA, Austria, Denmark and The Netherlands could be identified. In the UK, the health care cost of anorexia nervosa was estimated to be £4.2 million in 1990. In Germany, the health care cost was €65 million for anorexia nervosa and €10 million for bulimia nervosa during 1998. The Australian study reported the health care costs of eating disorders to be Aus\$22 million for year 1993/1994. Other costing studies focused mostly on in-patient care reporting highly variable estimates. There is a dearth of research on non-health care costs.

**Conclusions.** The limited available evidence reflects a general under-detection and under-treatment of eating disorders. Although both cost-of-illness studies may significantly underestimate the costs of eating disorders because of important omitted cost items, other evidence suggests that the economic burden is likely to be substantial. Comprehensive data on the resource use of patients with eating disorders are urgently needed for better estimations, and to be able to determine cost-effective treatment options.

### BACKGROUND

Eating disorders – anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED) and eating disorders not otherwise specified (EDNOS) – are common in young women in developed countries. A review of the literature

on the epidemiology of eating disorders, based mainly on studies from Europe and the USA, found the average prevalence rate being 0.3% for AN among young women. The prevalence rate of BN was 1% for young women and 0.1% for young men. The overall prevalence of BED was estimated to be at least 1% (Hoek & van Hoeken, 2003). Typically, these disorders are not self-limiting and many have a chronic course with notable psychiatric and medical co-morbidities and sequelae (Fairburn & Brownell, 2001).

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Common co-morbid psychiatric problems in eating disorders include depression and parasuicidal behaviour, anxiety disorders, obsessive-compulsive disorder and alcohol and substance misuse disorders. Physical complications include cardiovascular problems, renal problems, gastrointestinal disturbance, fluid and electrolyte abnormalities, menstrual and fertility problems, osteoporosis and osteopenia, and dental and dermatological abnormalities (Zipfel *et al.* 2003).

AN is widely regarded as having the highest mortality rate of any functional psychiatric disorder (Crow *et al.* 1999; Herzog *et al.* 2000; Lee *et al.* 2003), with the risk of death three times higher than in depression, schizophrenia or alcoholism (Harris & Barraclough, 1998). A meta-analysis of 42 outcome studies showed that the annual mortality rate was 12 times higher than in the general population, i.e. 0.56% (Sullivan, 1995). Another review of 10 outcome studies reported a standardized mortality rate of 9 (95% CI 7.5–11.5) for AN after 6–12 years follow-up (Nielsen *et al.* 1998). Deaths in AN mainly result from complications such as infections or cardiac arrhythmia, or from suicide (Sullivan, 1995; Nielsen *et al.* 1998). In contrast, no evidence of an increased risk of death has been found for BN (Nielsen *et al.* 1998). To date, very little is known about the mortality associated with BED and EDNOS, although the obesity common in BED is expected to increase the mortality risk (Crow & Peterson, 2003).

The disease burden of eating disorders is high. A recent Australian study showed that eating disorders were in 22nd place for women of all age, 10th place for girls aged 0–14 years and 4th place for women aged 15–24 years among the leading causes of burden of disease in terms of years of life lost through death or disability (Mathers *et al.* 1999). These estimates were based on follow-up studies reporting 24% persistence of AN after 10–15 years and 20% persistence of BN after 5–10 years (Keel & Mitchell, 1997; Strober *et al.* 1997). It is likely that similar rates apply in other developed countries as well.

Whilst the excess mortality and physical complications in these disorders are well recognized, other social, occupational and economic costs and the negative impact on quality of life

(Keilen *et al.* 1994) have received far less attention. The chronic nature of eating disorders and the numerous co-morbidities and complications suggest that people with eating disorders could be surmised to be high consumers of medical and social care. However, no comprehensive study (i.e. large observational study or patient survey) covering all aspects of current health or social care use by people with eating disorders has as yet been done (Garvin & Striegel-Moore, 2001). Nor has any attempt been made to systematically review the international evidence on these matters. The present study aims to fill this gap by summarizing the available evidence on the resource use and cost of different eating disorders, taking into account cost to different health care sectors and also broader social costs. Although such information cannot be used directly for resource allocation decisions, data on current levels of health service provision are necessary to estimate the implications of any changes in clinical practice for patient care and health care resource requirements. Such data also provide a helpful baseline for future economic evaluations. The review was conducted as part of a clinical guideline development process for eating disorders (National Institute for Clinical Excellence, 2004).

## METHOD

### Cost-of-illness methods

Cost-of-illness studies measure the economic burden of a disease. They usually report estimates for both the health care and the non-health care costs including non-health care-related direct costs (social services, patient and caregiver out-of-pocket costs, social benefit payments); indirect costs (productivity of the patient and caregiver lost due to morbidity or premature mortality); and intangible costs (negative impact on social functioning, carer burden). Intangible costs, however, are difficult to measure in monetary terms and are usually not included in cost-of-illness studies.

Cost-of-illness studies can be categorized based on the epidemiological data they use. Prevalence-based studies usually estimate the cost of a disease for the society for a given year and apply the annual prevalence of the disease for the calculation. Incidence-based studies measure the lifetime societal burden of a disease

caused by all new cases emerging within a base year.

The estimates of the cost-of-illness studies can also differ according to the method used to measure lost productivity costs. Indirect costs can be estimated either using the overall number of days lost from work due to the disease (human capital method) or the number of days necessary to fill the vacant position (friction cost method) (Sculpher, 2001).

### Literature review methods

Relevant health economics literature was identified from searching bibliographic electronic databases (Medline, EMBASE, CINAHL, PsycINFO, Cochrane Database of Systematic Reviews, Cochrane Controlled Trials Register, Database of Abstracts of Reviews of Effectiveness) and health economic databases (Health Technology Assessment, National Health Service Economic Evaluation Database, Office of Health Economics Health Economic Evaluations Database) using a specially developed search strategy of free text phrases and subject headings (details of these can be obtained from the authors). The searches were not limited for language or publication status of the papers. Studies from OECD countries between 1980 and 2002 were included in order to obtain data relevant to current health care settings and costs. To identify additional relevant published and unpublished studies, we checked the reference lists of eligible studies and relevant reviews and contacted experts.

The searches resulted in a total of 770 hits and a further eight studies were identified by hand searching and recommendations from experts. Titles and abstracts of all references were checked for relevance. Full texts of the 65 potentially relevant papers were then obtained and tested against a set of inclusion criteria (details of inclusion criteria and of excluded studies can be obtained from the authors). Altogether, 17 studies were deemed eligible for the review.

## RESULTS

Of the 17 included studies, two papers – one publication from the UK (Office of Health Economics, 1994) and one from Germany (Krauth, 2002) – could be classified as formal

cost-of-illness studies, and one further publication reported estimates of the health care costs of eating disorders in Australia (Mathers *et al.* 1999). Another 14 publications (Bryant-Waugh *et al.* 1992; Howlett *et al.* 1995; Nielsen *et al.* 1996; Turnbull *et al.* 1996; Brown, 1997; Ogg *et al.* 1997; Rathner & Rainer, 1997; Royal College of Psychiatrists, 2000; Striegel-Moore *et al.* 2000; Johnson *et al.* 2001; Lemouchoux *et al.* 2001; O'Herlihy *et al.* 2001; Crow & Peterson, 2003; Hoek, 2003) were found to have useful information for the cost or health care resource use of eating disorders. Relevant information was abstracted and summarized in a narrative way.

Table 1 lists all cost estimates for eating disorders in the countries' original currencies and, for ease of comparison, in 2002 Euros. National consumer price indices were used for inflation adjustment and 2002 exchange rates for currency conversion. Below, the methods and findings of the different studies are described in detail.

### Health care costs and resource use

In the UK (population 58 million), the National Health Service (NHS) cost of AN was estimated at £4.2 million per annum in a prevalence-based cost-of-illness study for year 1990 (Office of Health Economics, 1994). Using information from national surveys, the study attempted to calculate the primary and in-patient care costs and some medication costs for AN. The costing methodology was, however, blurred and the study did not attempt to account for the potentially substantial costs of out-patient care (including psychological therapies) and private eating disorder services. There are no more recent UK estimates for AN; nor are data available for BN, BED or EDNOS.

Based on disease prevalence, the health care costs were calculated at €65 million for AN and €10 million for BN in Germany (population 82 million) for year 1998 (Krauth, 2002). These estimates were based on health and pension insurance data for in-patient care and rehabilitation. They did not include the cost of primary care, out-patient care or medication. No calculations were made for BED or EDNOS.

The most comprehensive cost estimate including both the public and private sectors and all levels of health care originates from Australia (population 18 million). A burden-of-disease

Table 1. Cost of eating disorders in original currency and base year for costing (and in € for year 2002)

Study	Costing	Disorder	Health care costs*							Non-health care costs*	
			Total	Primary care	Secondary/tertiary care			Other†	Other direct	Indirect	
					In-patient	Out-patient	Rehabilitation				
OHE (1994), UK	1990, £	AN	4 (8.7)	0.5 (1)	3.5 (7.4)	—	—	—	—	—	
Krauth (2002), Germany	1998, €	AN	64.9 (68.8)	—	59.1 (62.9)	—	5.8 (6.2)	—	—	130.5 (138.9)	
		BN	9.8 (10.4)	—	6.9 (7.3)	—	2.9 (3.1)	—	—	113.9 (121.3)	
Mathers <i>et al.</i> (1999), Australia	1993/1994, Aus\$	All eating disorders	22 (15.5)	3 (2.1)	14 (9.9)	1 (0.7)	—	4 (2.8)	—	—	
Striegel-Moore <i>et al.</i> (2000), USA	1995, \$	AN	—	—	—	0.0060 (0.0076)‡	—	—	—	—	
		BN	—	—	—	0.0030 (0.0037)‡	—	—	—	—	
		EDNOS	—	—	—	0.0032 (0.0041)‡	—	—	—	—	
Rathner & Rainer (1997), Austria	1994, Schilling	AN and BN	—	—	140 (11.7)	—	—	—	—	—	
Nielsen <i>et al.</i> (1996), Denmark	1993, €	AN	—	—	4.6 (5.6)	—	—	—	—	—	
		All eating disorders	—	—	6.4 (7.8)	—	—	—	—	—	

AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorders not otherwise specified.

\* All costs are quoted as millions.

† Other: prevention, research, administration.

‡ Cost per person.

study reported the annual health care expenditure on eating disorders being Aus\$22 million for year 1993/1994. This estimate also included expenditure on prevention, research and administration (Aus\$4 million). Unfortunately details of the costing methodology were not available (Mathers *et al.* 1999).

#### Primary care

In the UK cost-of-illness study (Office of Health Economics, 1994), the estimate of the primary care cost of AN was based on the 3rd National Survey of Morbidity in General Practice (OPCS, 1986), which found that 1/1000 females and 0.6/1000 males consulted their general practitioner for AN during one year. Applying these rates to the UK population, the authors calculated that each year 46 806 individuals should consult their general practitioners with AN. Using a unit cost of £9.85 per consultation, this yielded a primary care cost of £0.58 million during 1990. It is not clear, however, how the population estimate of the authors was broken down by gender, what per person rate of consultation they used, and whether they considered

the likely variation in consultation rate with age. No similar primary care cost analyses are available for BN, EDNOS or BED in the UK. Other data on the primary care cost of eating disorders derive from Australia, where Aus\$3 million was spent on these services in year 1993/1994 (Mathers *et al.* 1999).

Several studies from the USA and Europe suggest that only a fraction of people with eating disorders are recognized and receive treatment for their eating disorders at primary-care level. For example, many general practitioners fail to consider eating disorders as a possible diagnosis in children presenting with typical eating disorder features (Bryant-Waugh *et al.* 1992). In a large US sample of female primary care and obstetric-gynaecology attendees fewer than one in 10 cases with BN or BED were recognized by the physician (Johnson *et al.* 2001). In The Netherlands, on average, only 40% of the AN cases are detected by general practitioners and 79% of these patients are referred on for mental health care (Hoek, 2003). In the case of BN, only 11% of the patients are detected in primary care and 51% of these cases

are referred to secondary care. In the UK, an epidemiological study (Turnbull *et al.* 1996) using the general practice research database found similar figures for eating disorder referrals: 80% of the AN cases and 60% of the BN cases were referred on to secondary care, the majority to psychiatrists. The study also revealed that prior to the patients' eating disorder diagnosis, general practitioners prescribed laxatives or diuretics for 27% and psychotropic medication for 45% of people suffering from BN.

Importantly, the poor detection rates of eating disorders do not suggest that these patients avoid contact with their general practitioner. Indeed, over the 5 years prior to the diagnosis of the eating disorder, these individuals consult their general practitioners significantly more frequently than do people without an eating disorder (Ogg *et al.* 1997). In these earlier consultations, patients typically present with psychological, gastrointestinal or gynaecological complaints which may be prompted by symptoms of the eating disorder or its complications. Nothing is known about the consulting behaviour in primary care of these patients once their eating disorder has been diagnosed. Taken together, these findings suggest that there are high levels of hidden eating disorder morbidity at primary-care level. Thus, existing estimates of the primary care cost of these disorders are likely to constitute a considerable underestimate.

#### *Secondary/tertiary care*

In the UK cost-of-illness study (Office of Health Economics, 1994), a total of 25 748 bed days was used to estimate the in-patient treatment cost of women and girls with AN. This was based on 1985 data showing that the average length of an in-patient episode was 21.5 days for AN. The most recent estimate of the UK Hospital Episode Statistics (Department of Health, 2004), however, reports the mean length of hospital stay being more than double this, 51 days, for eating disorders and obsessive-compulsive disorder. Although out-patient treatment is the norm with low hospitalization rates for eating disorders in the UK, no robust out-patient resource use or cost data could be found.

In Germany, Krauth *et al.* (2002) found the mean hospitalization cost to be much higher

for a patient with AN (€12800) or with BN (€11700) than the average hospitalization cost (€3600). The mean lengths of stay were 49.8 and 45.5 days resulting in an annual 229 976 and 26 845 bed days spent on AN and BN care respectively.

In Austria (population 8 million), the cost of in-patient treatment for AN and BN was estimated as 140 million Austrian Schillings in 1994 (Rathner & Rainer, 1997). This figure was based on prevalence data and the result of a national survey showing that the average length of in-patient stay due to eating disorders lies between 10 and 12 weeks. Although only 22.6% of all in-patient and ambulatory treatment centres for eating disorders responded to the survey, the authors point out that all large treatment centres did in fact reply.

In Denmark (population 5 million), Nielsen and colleagues calculated the cost of hospital bed days as €4.6 million for AN and €6.4 million for all eating disorders during 1993 (1996; quoted from Nielsen & Bara-Carril, 2003). The cost of managing dental and other physical complications (such as infertility, osteoporosis) of eating disorders has as yet not been reported in any country, but it is likely to be considerable.

In Australia, the reported spending on both private and public in-patient services was Aus\$14 million; the estimate for the annual cost of out-patient care and specialist community mental health services being only Aus\$1 million (Mathers *et al.* 1999).

Striegel-Moore *et al.* (2000) examined the in-patient and out-patient treatment costs for eating disorders using a national insurance database in the USA. They found that 21.5% of women with AN were hospitalized per year, and the average length of in-patient stay was 26 days among the hospitalized patients. Very much lower hospitalization rates were found for BN and EDNOS. The average numbers of out-patient episodes were 17, 15.6 and 13.7 respectively. Overall, the annual treatment costs of female patients were estimated at \$6045 for AN, \$2962 for BN and \$3207 for EDNOS. These costs of treating eating disorders were compared with the per person treatment costs of schizophrenia and obsessive-compulsive disorder. The analysis revealed that the mean treatment cost for AN was significantly higher than the mean

cost for schizophrenia, but mean treatment cost for BN was significantly lower than for schizophrenia. Treatment costs for any of the three eating disorders were much greater than that of obsessive-compulsive disorder (Striegel-Moore *et al.* 2000). Even so, it is likely that the true expenditure of eating disorders was underestimated in the analysis since cases were identified based on diagnostic codes. It is known that in the USA, diagnostic codes for eating disorders are often misrepresented due to their disadvantageous reimbursement status (Crow & Peterson, 2003).

#### *Specialist versus non-specialist services*

Treatment of more severe eating disorders, especially AN, by non-specialists can be problematic as there is evidence that short-term weight gain (Royal College of Psychiatrists, 1992) and longer-term outcomes (Dare *et al.* 2001) are poorer and mortality is higher (Crisp *et al.* 1992).

The study by Striegel-Moore *et al.* (2000) found that the level of specialist eating-disorder treatment provision is low, and eating disorders usually remain undetected or under-treated especially in the case of men in the USA. Similarly, a UK survey published by the Royal College of Psychiatrists (2000) on service provision for eating disorders found that only 48% of the health authorities participating in the survey had a specialist eating-disorder service in their area in 1998. One consequence of the low level specialist service provision in the UK was that many cases, particularly more severe cases, were referred outside their local area, often to private units. The total spending on out-of-area referrals reported by the survey was £8.4 million. However, as only about two thirds of existing health authorities did respond, the figure is likely to be an underestimate (Royal College of Psychiatrists, 2000). The results of a separate study from Scotland also showed that many services did not meet published recommendations for the provision of eating-disorder services, e.g. a population of 1.5 million was not covered by any specialist service (Lemouchoux *et al.* 2001).

A further result of under-provision of specialist services in the UK is that many AN patients, who require admission, may spend lengthy periods of time in non-specialist units

posing enormous extra costs for the NHS (Howlett *et al.* 1995). For example, the NICAPS study (O'Herlihy *et al.* 2001) has shown that more hospital beds were occupied by young people with eating disorders than any other diagnostic group (22% of the total). Approximately half of these were treated in specialist eating-disorder services and half in general Child and Adolescent Units.

#### **Non-health care costs**

##### *Non-health care-related (other) direct costs*

Currently no estimate exists for the non-health care-related out-of-pocket expenses of patients and their families due to eating disorders. Neither were any estimates available on the cost of social services or the magnitude of the social benefit payments due to eating disorders in the international literature at the time of the review.

##### *Indirect costs*

Eating disorders often result in lost productivity due to inability to work or premature death. The only attempt to calculate these indirect costs was by Krauth (2002). Using the human capital approach, he estimated the lost productivity cost of AN at €130.5 million (inability to work €8 million, death €122.5 million) for German society in 1998. The same estimate for the lost productivity cost of BN was €113.9 million (inability to work €1.7 million, death €112.2 million).

##### *Intangible costs*

Eating disorders have a substantial impact on social functioning, including occupational and educational impairment. The peak age of onset occurs when people are in secondary school, in higher education or at the beginning of their working careers, i.e. at a crucial stage in their educational and psychosocial development. Family members are usually the main carers for most of the duration of the eating disorder which is on average 6 years in the case of AN (Herzog *et al.* 1997). Two recent UK pilot studies found that carers of patients with AN and of BN reported similar experiences, in terms of the difficulties experienced, to carers of adults with psychosis, but had significantly higher level of psychological distress (Treasure *et al.* 2001; Winn *et al.* unpublished observations). The

burden of caregiving has never been examined in economic terms.

## DISCUSSION

The cost of eating disorders is a greatly under-researched area compared to that of many other mental disorders. To date, only two studies, one from the UK and one from Germany, exist that tried to estimate the cost-of-illness of eating disorders formally (Office of Health Economics, 1994; Krauth, 2002). Both studies are far from comprehensive. They are likely to grossly underestimate the health care costs, since none of the studies attempted to calculate the out-patient treatment costs or health care costs related to the complications of eating disorders. Although private provision of eating-disorder services is common in the UK – for example, in a survey, sent to all health authorities in England and Wales, 48 out of the 54 responding authorities reported referrals of patients with eating disorders to private providers (Brown, 1997) – these costs were not accounted for in the UK study. Neither did any of the studies include estimates of the private health care costs incurred by the patients and their families, costs which are also likely to be considerable. Furthermore, they both carried out diagnosed case-based costing.

Interestingly, the two cost-of-illness studies give strikingly different estimates of the total cost of in-patient treatment for AN (€7.4 million in the UK and €62.9 million in Germany) – the only area where a cross-national comparison is possible. The UK estimate is also much lower than the Danish estimate of €5.6 million (Nielsen *et al.* 1996 quoted from Nielsen & Bara-Carril, 2003). The differences remain after taking into account the different population sizes and the difference in service provision, namely that in Germany and possibly in Denmark the threshold for in-patient admission for AN is considerably lower than in the UK. Since other limiting factors common to cross-country comparisons (i.e. different prevalence, detection rate or diagnostic criteria of the disorder, or difference in the cost of health care provision) are unlikely to occur between these countries, the data suggest substantial underprovision of in-patient services for eating disorders in the NHS. The conflicting evidence from these studies

highlights the importance of assessing cost-of-illness results in the context of the study quality. In this way, the determinants of the differences in the estimates may be more easily uncovered.

Overall, given the lack of robust epidemiological and health-care resource use data, it is difficult to reach accurate and comprehensive estimates of the total health care costs of eating disorders. This highlights the need for research similar to a recently published cohort study, which attempted to address the issue of health service use of women with BED in the USA. The study analysed hospitalization rates and visits to emergency care and the use of specialist and non-specialist out-patient services for patients with BED in comparison with healthy controls and women suffering from other Axis I psychiatric disorders (Striegel-Moore *et al.* 2004).

The very limited international evidence on the broader social costs of eating disorders suggests that these costs may be even more significant than the health care costs. Krauth (2002) calculated the lost productivity costs of eating disorders as being substantially higher than their health care costs. This is likely to be the case even after taking into account an expected overestimation of the real costs as a result of the applied methodology. After the present review was conducted, Su & Birmingham (2003) published a study on the amount of disability benefits paid due to AN in British Columbia, Canada. In their survey, the authors found that 35% of patients with AN received disability payments. Their best case/worst case scenario analysis estimated the possible lowest spending on AN disability benefits equalling 70% and the possible highest spending equalling 300% of the overall annual government expenditure on tertiary care for all eating disorders.

This review has confirmed that eating disorders represent a considerable cost burden to the society. The results also suggest that early diagnosis, the use of appropriate and cost-effective treatments and the consequent prevention of chronicity would not just improve the outcomes of eating disorders, but could greatly reduce their economic burden. Therefore, it is essential to evaluate the gradual shift towards more effective recognition and treatment of eating disorders in primary care and the wider provision of specialist care from a broader

perspective. To be able to estimate the net cost arising from these trends, more comprehensive data on the current health-care resource use pattern of patients with eating disorders and more trials with good health economic components are urgently required.

## APPENDIX

Members of the Eating Disorders Guideline Development Group were: Lorraine Bell, Nicky Bryant, Rachel, Bryant-Waugh, Christopher Fairburn, Peter Honig, Pippa Hugo, Simon Gowers, Robert Mayer, Ciaran Newell, Jane Nodder, Bob Palmer, Stephen Pilling, Susan Ringwood, Ulrike Schmidt, Janet Treasure and Deborah Waller.

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## DECLARATION OF INTEREST

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