ANOREXIA NERVOSA IS A SERIOUS DISEASE

Professor Pierre Beumont (MBBS; RANZCP) worked with eating disorder patients for more than 30 years, published widely in the area, ran specialist units in the UK, RSA and NSW (public and private). He was an international consultant to the APA Practice Guidelines for eating disorders, as well as for its DSM-III-R and DSM classification manual, and WHO's ICD-10, and had a keen interest in the education of health care professionals. Professor Beumont sadly passed away in 2003.

Today, in developed countries such as Australia and New Zealand, anorexia nervosa is the most common serious disease of adolescent girls and young women. This is a big claim to make, but it can be justified.

How does one rate the seriousness of different diseases? Surely one needs to bear in mind how common the disease is, its mortality rate, persistent morbidity, chronicity, effect on the sufferer's life and on the family. On each of these criteria, anorexia nervosa is very severe. Although often dismissed as a "rare illness", anorexia nervosa is actually highly prevalent when compared with other serious diseases in this population group. Point prevalence for girls in the age group15 - 19 is 0.5%, and about half that in women aged 20 - 24. After obesity and asthma, it is the most common disease in this population group, and it is a much more deadly condition than either of the others. It is 10 times more common that insulin dependent diabetes mellitus (IDDM) in these subjects. Its prevalence rate of 0/5% in one group should be compared with the lifetime risk of 1% of schizophrenia. In NSW at least 400 new cases are diagnosed each year, and about 5,000 patients are affected by anorexia nervosa at any one time.

The mortality rate on a number of follow-up studies is about 20% at 20 years. This is completely unacceptable for a disease whose sufferers have an average age of onset of 17 years. The overall mortality rate for anorexia nervosa is 5 times that of the same aged population in general, with deaths from natural causes being 4 times greater (eg cardiac arrhythmia, infection), and deaths from unnatural causes 11 times greater than expected. The risk of successful suicide is particularly high, being 32 times that expected. These figures may be compared with major depression, in which the overall mortality risk is 1.4 times that expected, with deaths from unnatural causes being 7 times and those from suicide 20 times greater than expected.

Anorexia nervosa has a chronic course even in those who "recover"; the average duration of illness is 5 years. Even those who "recover" are unlikely to return to fully normal health, and women who have had anorexia nervosa often have anorexic daughters. The risk of a first degree relative of a proband for developing the disease is 10 times that of the general population. Many patients become chronic, and the disease brings about a degree of social handicap comparable to schizophrenia.

Persistent psychiatric morbidity in common, especially dysthymia, major depression and obsessive-compulsive disorder. The disease leads to brain atrophy and a disorder of myelination, and there is controversy about whether it has persistent effects on cognition. Certainly, because it usually occurs at the crucial stage in the girl's physical, psychological and social development, it causes serious impairment of functioning and interferes with education, work training, adaptation to peer relationships, sexual relationships and separation from the family of origin.

Cardiac arrhythmias are a common cause of death in anorexia nervosa patients. Long-term physical morbidity is also common and serious. Growth retardation is present in some patients who have an early onset of disease. Anovular infertility is common in some women who have only partially recovered. Terming this "hypothalamic anovulation" is misleading and dangerous, as it leads to medical intervention to induce pregnancy. This is unwise, as the pregnancies of such women are known to have more complications, result in more premature births, and to be associated with poor Apgar scores and underweight neonates. Osteopaenia leading to osteoporosis is a serious complication of the active disease, but may also have long-term effects because bone mineralisation in women terminates with the menopause. Those who have not accumulated sufficient bone in younger life are prone to developing osteoporosis with ageing earlier than their peers. More women die as a result of a fractured femur than of breast cancer. Renal [kidney] and hepatic [liver] function are frequently permanently impaired by anorexia nervosa, and a neurogenic bowel with subsequent rectal prolapse is common, sometimes but not invariably associated with laxative abuse.

The effects of the disease on the family are horrendous. Unfortunately, parents have been blamed for causing the disease in their offspring. Anorexia nervosa is often claimed to be the result from sexual abuse, but this is less common than alleged. As a result, parents are made to feel guilty. The sick person imposes strain on all members and relationships within the family, leading to family dysfunction, marital discord and the relative neglect of siblings.

Anorexia nervosa is extraordinarily expensive to treat. Because of the long duration of hospital admission and the frequency of relapse, anorexia nervosa patients occupy one-tenth as many hospital beds as do those with schizophrenia in New Zealand, and the same appears true of New South Wales. MBF, a major health insurance provider in Australia, has published figures showing that anorexia nervosa patients are consistently among those making the highest claims.

Despite the devastating nature of the disease, services for anorexia nervosa patients are inadequate. Until recently, the only specialised units in England and Wales were in the metropolitan London area and Oxford, and the only specialised facility in Scotland was an outpatient service. In the USA, managed care is leading to the extreme restriction of treatment facilities for anorexia patients. In New Zealand, the whole of the South Island is serviced by a unit in Christchurch. In Toronto, funding cuts have led to the closure of an inpatient unit and its relocation as a day unit in a mental hospital. This has led to a raised mortality rate for anorexia nervosa in Ontario. In New South Wales, there are only about 20 public beds available for specialised care of anorexia nervosa, and this is in a State that has approximately 2,000 sufferers of the disease, with about 400 new cases every year. Patients who are privately insured have more facilities available, but these too have been severely restricted by providers of private mental health care in the State.

Because of step-downs in renumeration for long-stay patients, anorexia nervosa in not a financially rewarding condition to treat.

The only health authority that has reason to be proud of the facility if provides for anorexia nervosa is the province of British Columbia in Canada, where, under the leadership of Elliot Goldner and Laird Birmingham, a province-wide service has been established. However, it is under-funded.

Why is this devastating illness treated so poorly? Part blame must go to the bad press it usually receives from the popular media. Anorexia nervosa is either sensationalised or made

into a silly girl's experience. The general public is also at fault. Slenderness is promoted as an ideal for beauty, and beauty is given more prestige than any accomplishments that a woman may achieve. Anorexia nervosa is by no way a modern illness: it was first described in its present form in the mid-19th century, and earlier accounts can be found in the prior medical literature and in the accounts of the lives of some saints. It has fluctuated in epidemics that correspond to the level of social pressure applied to young to diet, whether to be fashionably slim, or to suppress sexuality. However, a feminist perspective of these pressure needs to be viewed with caution. Anorexia nervosa is most common in those societies in which women have come closest to achieving equal rights, and there is an almost perfect opposition between countries with high female illiteracy rate and those with a high prevalence of the disease.

The medical profession must assume some responsibility for this tragic circumstance, partly because of sins of omission, partly for sins of commission. Because it usually starts in adolescence, anorexia nervosa is considered an adolescent illness. For instance in the DSM-III classification of the APA, it was listed under disorders or adolescence. In fact, because of its chronic cause, patients most at risk are usually young or middle-aged women rather than adolescent girls. However, physicians by and large are poorly informed about the disease and not interested in treating its sufferers. Because of an erroneous assumption in Simmond's original description of panhypo-pituitarism (viz that it was associated with emaciation, which in fact was due to the presence in his population of some patients with tuberculosis or neoplasia), anorexia nervosa temporarily lost its importance for psychiatrists. They were replaced by endocrinologists, who undertook extensive but unnecessary laboratory investigations, but did little if anything about treatment.

Since its return to psychiatry, anorexia nervosa has been subjected to well-meaning but ultimately harmful reassessment. In 1979, a paper entitled "Bulimia nervosa, an ominous variant of anorexia nervosa" was published by Gerald Russell, who had taken several years to collect the small number of patients that he described. Bulimia nervosa appears to have exploded shortly thereafter. Within a few years thousands of patients were seeking treatment for it. Habermas has argued convincingly that bulimia nervosa is an iatrogenic condition. Whether or not this be so, it has diverted attention from anorexia nervosa.

The medical care of anorexia nervosa is split between various branches of the medical profession, none assuming overall responsibility and each working according to different paradigms. In the younger age patient, treatment of the severely ill patient is usually in the hands of paediatricians and adolescent physicians, who with perhaps unjustifiable enthusiasm use naso-gatric feeding to effect nutritional restoration. Psychological treatment is usually relegated to child psychiatrist or other mental health workers, who often avoid assuming any responsibility for the patient's physical condition. For older sufferers, physicians often refuse to treat these patients, or treat them only on condition that they do not mention their main psychopathology, viz the extreme concern and guilt they feel about their weight and eating.

Proponents of the view that psychiatry should concern itself more with caring for the seriously psychotically ill, and not be distracted by the "worried-well", usually neglect any consideration for anorexia nervosa.

As a result, anorexia nervosa has become demedicalised. While previously those most concerned with its treatment were medically qualified, nowadays it is more likely that a psychologist, social worker or dietitian will be in charge of its management. Although these health professionals are well equipped to deal with less serious conditions such as bulimia

nervosa and binge-eating disorder, they do not have the training to recognise the important physical manifestations of anorexia nervosa. Worse, the treatment of anorexia patients often passes to lay therapists, who are at best untrained, at worst charlatans.

Even the laws pertaining to the treatment of anorexia nervosa are uneven. They differ from country to country, and from state to state in the USA and Australia. Some authors claim that compulsory treatment is never indicated in anorexia nervosa, but offer no reasonable alternatives, and others have allowed anorexia nervosa patients to starve themselves to death without intervention. In the UK, about 11% of anorexia patients are treated following compulsory admission under the Mental Health Act. This is a less than satisfactory provision, as patients with anorexia nervosa pose completely different sorts of problems from those usually dealt with under these laws, i.e. those with psychotic illness. In NSW, anorexia nervosa was excluded from the Mental Health Act of 1990, and the issue of compulsory treatment is dealt with under the Guardianship Act of 1987. Unfortunately, the Guardianship Act was not amended to empower the guardian to take the sorts of decisions that are necessary for these patients. For instance, the public guardian in NSW decided that cognitive-behavioural therapy is a psychological matter rather than a medical treatment, and refused to endorse its use in anorexia nervosa. Because of difficulties of this kink, and the need to undertake urgent medical procedures, a precedent has been set to schedule anorexia nervosa patients under the Mental Health Act in appropriate circumstances.

Even those doctors who have interested themselves in research into anorexia nervosa have done their patients little service. Many academic careers have been based on a thorough exploration of endocrine dysfunction in anorexia patients, but it is now clear that the endocrine manifestations are epiphenomena, not relevant to the cause of the illness. A great deal of research effort has been wasted on the concept of a distortion of body image in anorexia nervosa, with little use resulting to the patient. More recent work on taste discrimination, genetics, cognitive functioning, body composition, energy utilisation, and the newly discovered hormone leptin, do not appear to be leading to significant treatment advances, and are of academic more than of practical interest. In contrast to bulimia nervosa, there is an alarming paucity of evidence-based medicine relating to anorexia nervosa.

What is to be done to correct the situation? First, the general public and the professions need to be educated about how serious and common an illness anorexia nervosa really is. Extreme weight-losing activities should be acknowledged as dangerous risk-taking behaviour, similar to the abuse of narcotic drugs, unprotected sex, and drink-driving. Second, doctors need to assume responsibility for this disease, which threatens the lives, future health and happiness of young and vulnerable people. Third, all doctors must know how to recognise and take appropriate action with patients presenting with anorexia nervosa. Secondary prevention may be successful, whereas primary prevention, on which much money has been spent, appears to be ineffective or even counter-productive.

Fourth, the treatment of anorexia nervosa patients should be shifted from so-called centres of excellence to a periphery of excellence that includes community health clinics, day-hospital units, and a collaborative, shared care programme with general practitioners. Fifth, the State medical services need to include an integrated service with ready access for all patients requiring treatment. Sixth, research should be directed at discovering treatments that really work, such as the present programme: the outcome of patients treated even by the experts of today is appalling. The outcome should be judged in more sophisticated terms than those measured by existing measures, and issues such as nutritional state and quality of life should be included. Seventh, until such evidenced-based studies are available,

clinical practice guidelines should be drawn up by authoritative clinicians with contributions from all legitimate stake-holders, including general practitioners, physicians, paediatricians, psychologists, nurses, dietitians and, importantly, consumers and carers. These have now been commissioned by the Royal Australian and New Zealand College of Psychiatrists.

Eighth, a consistent decision needs to be made about the laws relating to anorexia nervosa that steers a middle path between excessive compulsion and the medical neglect of failing to protect a psychologically distressed patient from the effects of her illness. Preferably, this legislation should be different from that providing for the needs of psychotic patients. Ninth, government authorities should take action against those who promote unhealthy messages about weight control, such as magazines that present picture of emaciated girls, or even computer-modified pictures to exaggerate their inanition, as a fashion idea.

Hopefully, at last we are beginning to take some of these actions in NSW.

by Professor Pierre Beumont