The cost of the illness that defies

A total of 408 days in a regional eating disorders unit, 478 days on an acute psychiatric ward, and 275 days on a general medical ward. That amounts to three years and two months as an in-patient in just over four years. These figures relate to a case of severe anorexia nervosa in a woman first diagnosed in 1989. Anorexia nervosa is neither primarily a psychotic illness nor an organic disease but perhaps its echoes of both are responsible for some of the enigma it presents. Perhaps its recent detailed elaboration in ICD-10 as a specific diagnostic category reflects the growing acknowledgement of it as a mental illness requiring independent recognition. References to it can be found as early as the 17th century and psychological factors, aetiological and perpetuating, have often been formally described and acknowledged. In more recent years with the increased forces of fashion and media concerns about slimness and related dieting, anorexia nervosa has been brought into the public eye with apparent disbelief that sufferers can be allowed to 'starve to death' whilst families and the medical profession sometimes appear to stand by. But how far does the profession truly realise the severity, chronicity and treatment-resistant nature of many such cases and, in this time of cost-counting programmes, the resource demand these may present? A recent study¹ of 20 anorectics in a specialist unit, revealed that some of them had successfully avoided correct diagnosis and previous interventions for years, despite serious illness; others, such as this case, had spent months or years in non-specialist units, costing the National Health Service tens of thousands of pounds.

This direct cost is not the only one. The crippled anorectic is significantly a non-contributor and, as despairing and guilt-ridden parents feel increasingly deskilled, the mother in particular may surrender her own employment to devote more time to care for her child. In countries without a safety net health service families may be bankrupted in their constant pursuit of treatment for their anorectic child. For the older anorectic there is the equivalent demand on social service funds, especially if children are involved. Moreover, we are now seeing private health care insurances increasingly restrict their funding for sufferers because of the perceived and real enormity of the burden.

With an incidence of the fully established syndrome of between three and eight per 100 000 population or 25-70 per 100 000 for woman aged 15-29 years,^{2,4} a female prevalence of around 0.2%,^{3,4} and a teenage schoolgirl prevalence of around 1%,⁵⁻⁸ and with a usual anorexia nervosa related mortality of between 13-20% at 20-year follow-up,⁹⁻¹¹ these figures may still seem relatively small when compared with the number of patients with schizophrenia in the population.¹² Nevertheless, every general practitioner, knowingly or not, is likely to have several fully fledged cases of anorexia nervosa on the practice list. Meanwhile, those of us involved in the assessment and treatment of identified anorexia nervosa recognise more acutely the enormity of demand across several specialties with often minimal visible therapeutic benefits.

The case illustrated in the figure is not atypical. Diagnosed at age 21 but with symptoms probably preceding this by one to two years, the weight biography shows the

dramatic weight loss punctuated by periods of weight gain during the in-patient care and two significant life-threatening incidents, an alarming cardiac event when she was semi-comatose and close to death and a significant suicide attempt. The 275 days on a medical ward involved refeeding from extremes of low weight, intensive nursing care and a large number of investigations. The 475 days on an acute psychiatric ward involved refeeding and multi-disciplinary input of psychological therapies. On the eating disorders unit she was involved in an intensive treatment programme combining a requirement for steady weight gain through normal eating with the provision of weekly individual psychodynamic psychotherapy (over 60 sessions in total), family therapy (over 20 sessions), twice weekly group psychotherapy together with expert dietary counselling, art therapy, communication skills training, and psychodrama. It is only after these latter admissions that we see any notable increase in weight, even then only approaching what is deemed statistically average for a women of her height. And even after such treatment we see steady weight losses. We may be tempted to explain this by questioning treatment methods but perhaps we are faced with the resistance to treatment by individuals with this illness or the need for even more prolonged and intensive treatment provision, but for how long? Such treatment methods, of comparably severe cases and involving psychological approaches to underlying emotional maturational problems have, after all, been shown to improve outcome significantly at both one-year and two-year follow-up.^{13,14}

In this particular case should a third admission to a specialist unit be supported by purchasers of her health care? Without it early death is likely. With it, at the least, death may be substantially delayed and recovery is still a real possibility; we would still put the chances of recovery in this case at about 10%, given the circumstances and our recent 20-year follow-up of 105 patients treated in this way

Figure Weight biography of a young woman with anorexia nervosa, height 165 cm, related to mean matched population weight. Dashed line on x axis = admissions to non-specialist medical and psychiatric units; unbroken line = admissions to specialist eating disorders service; LMP = last menstrual period

Anorexia nervosa

- a severe and serious disorder with 20% mortality at 20-year follow-up
- it is relatively common, eg, about 1 in 200 teenage females
- people with it avoid detection
- the costs of recurrent investigation and care can be very high
- specialist treatment is effective significantly often

which reveals a 4% mortality and 70% recovered.¹⁵ The patient may well come down in favour of her own survival if such help is not withheld.

Like the general public, many of us, general physicians, general adult psychiatrists, general practitioners, view the anorectic with both impatience and fear. This may provoke a desire to force-feed or withdraw, enacting out an often

overpowering transferred dynamic from the family. Those afflicted elicit an enormous anxiety with a refusal to accept any nourishment despite what would seem rational, sensible resolutions in a non-psychotic patient with no organic pathology. Despite this such patients evoke a great need to help in those in contact. Fundamentally, they wish for more than to be ignored and should not be.

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