Avoiding deaths in hospital from anorexia nervosa: the MARSIPAN project

Paul Robinson[1]

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[1]Barnet, Enfield and Haringey Mental Health NHS Trust, London, UK

Correspondence to Paul Robinson (paul.robinson@beh-mht.nhs.uk)

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Summary The MARSIPAN (MAnagement of Really SIck Patients with Anorexia Nervosa) project was established in response to reports of patients admitted to medical wards and proving refractory to treatment, sometimes dying on the ward. Psychiatrists, physicians and other clinicians in nutrition and eating disorders were brought together to discuss key issues in the assessment and management of such patients. The resulting guidance report, which applies to adult patients over 18, addresses: assessment of risk, where to treat the patient, specialist support for medical teams, key elements of treatment, namely (a) safe refeeding to avoid refeeding syndrome and underfeeding syndrome, (b) management of problematic behaviours, (c) support for the family, and (d) transfer to a specialist eating disorder unit when appropriate and possible.

Declaration of interest None.

Eating disorders are among the most lethal of all psychiatric disorders[1] and anorexia nervosa is recognised to have a high mortality at an estimated 5.9%.[2] Causes of death vary but complications of malnutrition and suicide appear to be the most common.[3] However, there is little published evidence on fatal outcome in patients with anorexia nervosa, other than death certificate statements, and only rarely is it clear whether the patient died in or out of hospital, and if in hospital, whether in a medical or a psychiatric facility. Moreover, death certificate studies suggest that anorexia nervosa is frequently not mentioned when it should be, and sometimes given as a cause of death when it has no bearing on the death.[4]

Patients admitted to medical units with severe anorexia nervosa combine several worrying characteristics. They are usually very unwell indeed. They are sometimes poorly motivated to recover, because that would mean increasing weight. And staff may have limited experience in dealing with this potentially lethal combination. From time to time, concern has been raised about the difficulties encountered by medical units attempting to treat patients with severe anorexia nervosa. A fatal case in point was discussed at length at a national conference in the UK and following that the MARSIPAN project was launched. The present paper is a description of the process that led to the publication of the group's report,[5] and a summary of the main recommendations therein.

The MARSIPAN project

In the MARSIPAN (MAnagement of Really SIck Patients with Anorexia Nervosa) project, the problems staff faced in the management of patients with anorexia nervosa at highest risk were reviewed, discussions on how to address such problems were held and a guidance document on the management of these severely ill patients was produced.

Development of the group

In 2008, a case was presented at the annual meeting of the British Association for Parenteral and Enteral Nutrition (BAPEN): a young woman with anorexia nervosa died after admission to a medical unit in which every effort was made to save her. It was concluded that more interdisciplinary work was required to meet the considerable clinical challenges presented by the rather rare group of patients she represented. After the meeting, it was resolved that a group would be set up to generate guidelines to help manage this situation.

Following the BAPEN conference the physician in charge of the case and myself consulted with professional colleagues within the Royal College of Physicians, the Royal College of Pathologists, BAPEN, the Intercollegiate Group on Nutrition, and the Royal College of Psychiatrists. The members of BAPEN and of the Royal College of Psychiatrists Eating Disorders Section were requested to provide details about their management of patients with severe medical problems. Almost all the consultations between group members were made via email, with one meeting in London in June 2009. We recruited 13 doctors, including 6 adult eating disorders psychiatrists, 1 child and adolescent eating disorders psychiatrist, and 6 nutrition physicians (including one professor of paediatric nutrition), 1 dietician in intestinal failure, 1 dietician in eating disorders, 1 medical pharmacist and 1 intensive care physician, a professor of general practice, a nurse, 2 of the authors of the National Institute for Health and Clinical Excellence (NICE) guideline on nutritional support for adults, the chief executive of Beat (the main eating disorders user and carer organisation

in the UK), and 2 carers. The names of the contributors and consultants are given in the MARSIPAN report.[5]

Collection of case histories

After establishing the group, members were asked to submit brief accounts of patients with severe anorexia nervosa in whom a fatal or near-fatal outcome had occurred in spite of medical treatment, and others in whom management in medical settings had been successful. The accounts came from their own experience and from experience of colleagues. This survey of physicians and psychiatrists revealed 16 fatal cases (some detailed below) of mostly young people with anorexia nervosa in medical settings over the previous few years. This seemed to be an underestimate of those cases known to colleagues, and it is likely that some doctors did not feel free to share these events with us, perhaps for fear of criticism. It appeared that the problem was sufficiently common to give rise to serious concern.

Scenarios described by MARSIPAN group members and their colleagues

Failure to implement compulsory treatment
We heard of two cases, one rapidly fatal, in which the psychiatrist consulting stated that it was not possible to force a patient with anorexia nervosa to have treatment.

Lack of liaison psychiatry support
A complaint from one physician was that 'psychiatry seems to disappear from the scene once the patient is in such a poor physical shape'.

Inadequacy of eating disorder services
In some cases, there was no local eating disorder service available to give advice to the physician.

Inappropriate palliative care
A patient in her 50s with long-term anorexia nervosa who had never had specialist treatment was being given palliative treatment by a general practitioner and physician.

Problems in medical management
A young patient with a body mass index (BMI) about 12 (normal range 18.5–25; below 13 is considered high risk for collapse) with abnormal electrocardiogram and biochemistry died after receiving no specific treatment for her physical condition.

Failure to recognise refeeding syndrome
An 18-year-old female died after admission with refeeding syndrome undetected by the medical team.

Failure to manage eating disorder behaviours
A 24-year-old female on a general medical ward, BMI 11, prior to a planned move to an eating disorders unit exercised by standing and wiggling her toes and fingers for the whole weekend, day and night, in front of two nurses employed exclusively to observe and treat her, before collapsing and dying from hypoglycaemia on the Monday morning.

Inadequate nutrition leading to fatal underfeeding syndrome
A female patient of 20 years with BMI of 13 was transferred from the eating disorders ward to a local accident and emergency unit because of chest pain. In accident and emergency, cardiac causes were excluded but she was admitted to a medical ward where she was given a very low calorie intake, around 200 calories per day. She remained in the ward while mild liver abnormalities were investigated and died after 5 days in hospital.

Comments

Disturbing as some of these accounts are, a request to eating disorder and general physicians produced very few further cases, suggesting a reluctance to share information about these tragedies. We heard from individual psychiatrists and physicians that when these deaths occur, the experience (including formal investigations and questions from the family and the media) is so traumatic that they prefer not to talk about the whole occurrence. This may explain why the case histories are rather hard to obtain. Some cases of people with anorexia nervosa dying because of inadequate care are, however, reported in the media[6,7] The father of the model Isabelle Caro, admitted to a French hospital with a BMI of 11.8, recounted that the doctors said, shortly before her death, 'We want to do some tests but, so as not to bother you, we are going to let you have some sleep'.[8] A published inquiry into the death of a 20-year-old woman with anorexia nervosa[9] concludes that 'Medical hospitals are ill equipped and ignorant of the disease [anorexia nervosa]' (p. 46). There is evidence that cases such as those described by the MARSIPAN group occur, but also that there may be a reluctance to speak about them, and for this reason it is very difficult to know how widespread a problem this is.

Development of the guideline

Having studied these accounts and reviewed in detail the case that was presented at the BAPEN conference, the MARSIPAN group was in little doubt that there was a problem in both medical and psychiatric management of seriously ill patients with anorexia nervosa. We set to work to outline the areas that seemed problematic and provide guidance as far as the present state of knowledge allows.

The method used was for the chair (P.R.) to send a draft document to all group members and to alter the draft according to comments received. It was then sent round again for approval. Only one issue led to very different views being expressed, namely the practice of treating patients with very low starting calories. In general, physicians were more cautious about refeeding than psychiatrists. The latter would start refeeding at 1000–1500 calories per day or higher, reporting that they had never run into problems with refeeding. Physicians held that they had indeed seen cases of refeeding syndrome in anorexia nervosa and that following the NICE guidelines for nutritional support in adults[10] was appropriate. This guideline recommends starting refeeding at 5–10 kcal/kg/day in patients at risk of refeeding syndrome. However, published advice on the management of anorexia nervosa[11] states: 'Intake levels usually begin at approximately 600–1000 kcal/day and are increased by 300–400 kcal every three to four days' (p. 3).

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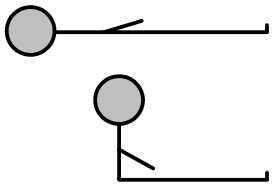
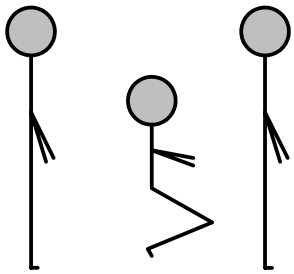


1. Sit-up: patient lies down flat on the floor and sits up without, if possible, using their hands.

Scoring (for Sit-up and Squat–Stand tests separately)
0: Unable
1: Able only using hands to help
2: Able with noticeable difficulty
3: Able with no difficulty



2. Squat–Stand: patient squats down and rises without, if possible, using their hands.

Fig. 1 Sit up–Squat Stand test to detect muscle weakness. Modified from: Royal College of Psychiatrists, 2010.[5]

The matter is not helped by an unfortunate caveat in the NICE nutrition support in adults guideline,[10] which states: 'What the guideline does not cover: . . . Patients with eating disorders. This is covered in the NICE guideline on eating disorders' (p. 38). The eating disorders NICE guideline[12] does mention refeeding syndrome, but devotes only one paragraph to refeeding, advising a weight maintenance diet in the first few days of refeeding in those most at risk. Such a diet would certainly contain more than 5 kcal/kg/day. Advice therefore was contradictory and in practice medical units varied, some applying the NICE nutrition support guidance,[10] some not. In addition, some patients seem to have been grossly underfed, as in the last of the cases described earlier ('underfeeding syndrome'), perhaps because clinicians feared inducing the refeeding syndrome.

The variation in views on initial refeeding rate observed in the MARSIPAN group was resolved by compromise. The guidance aims to avoid overfeeding on the one hand and prolonged underfeeding on the other. The advice was that if a patient is at risk for refeeding syndrome (such as patients with infection and other comorbidities who are more likely to be admitted to a medical unit), starting at very low calories (5–10 kcal/kg/day) is justified, provided that blood is checked 12-hourly and calories increased as long as there is no sign of refeeding syndrome. We hoped that the confusion surrounding this matter was at least partly resolved by the MARSIPAN guidance.

The present paper and associated guideline apply to adults over the age of 18. A similar guideline, concentrating on the child and adolescent population, has been prepared by the junior MARSIPAN group.[13]

Summary of guidance

Readers are encouraged to consult the MARSIPAN document for a full account of the guidance.[5] Here, some key points will be indicated.

Risk assessment

Patients with anorexia nervosa should have a risk assessment whenever they present to healthcare services. The physical assessment should include physical examination, especially weight and height (BMI) and muscle power (the Sit up–Squat Stand (SUSS) test, Fig. 1), blood tests, including electrolytes and liver function tests, and electrocardiograph, with special attention to bradycardia and prolonged QTc interval (>450 ms). A risk-scoring system was avoided, because any of the measures could be serious enough to warrant an assessment of high risk, even if all other factors were normal. Thus, the patient is at high risk if any measure is life threatening and potentially at high risk if any measure is close to life threatening, especially if it is deteriorating.

There should also be a psychiatric risk assessment, given that in patients with anorexia nervosa who die the rate of suicide as a cause of death is substantial.[3]

Where to treat?

The consensus was that the safest place for most severely ill patients with anorexia nervosa who require admission is probably a specialist eating disorders unit (SEDU). Admission to other facilities may be desirable or unavoidable in certain circumstances.

a When a SEDU does not have services that the patient requires: for most SEDUs these would include intravenous infusion, 24-hour cardiac monitoring and treatment of serious medical complications.
b When there is no bed on a SEDU: in this situation, the best available alternative should be arranged, and a SEDU bed awaited. This might be a medical ward or a psychiatric ward. In either case, special nursing and specialist management would need to be set up temporarily for as long as the patient was in the unit.
c When a non-SEDU bed is the best alternative: in some (rare) services, a physician with a special interest had set up a comprehensive service with sufficient medical and psychiatric (eating disorders) skills within the unit. Such arrangements effectively reproduce the services of a medical unit and a SEDU in one place.

Support for medical teams

Wherever patients with severe anorexia nervosa are treated, there must be regular, frequent, senior consultation between medical and psychiatric (if possible, specialist eating disorder) services, including medical, nursing and dietetic staff from both services.

Key elements of management

Treatment of the patient should be such that:

a refeeding of the patient is accomplished safely

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- refeeding syndrome is avoided or recognised and treated
- underfeeding syndrome is avoided

b behavioural problems of anorexia nervosa are effectively managed
c compulsory treatment is provided when appropriate
d family concerns are effectively addressed
e the patient is moved to a SEDU as soon as that is appropriate and a bed is available.

Key points

Patients with anorexia nervosa admitted to medical wards may appear to be relatively well, but in fact be gravely physically ill. Their treatment may be compromised by their behaviour, which may sabotage attempts at refeeding. Training of all staff involved in such cases and close liaison with specialist eating disorder clinicians is advised.

Key questions for further research

1 The number of patients with anorexia nervosa admitted to medical wards who die or develop serious complications is unknown and should be surveyed.
2 The management of severely physically ill patients with anorexia nervosa who resist nutritional treatment is uncertain and requires study.
3 A model of cooperative care between medical and specialist psychiatric services should be developed and implemented.

Discussion

There is no doubt that some patients with severe anorexia nervosa admitted to medical units have died as a result of their illness, and it is likely that with appropriate medical and psychiatric management at least some of these patients could have survived. There is doubt about the numbers involved and the proportion of all admitted patients with anorexia nervosa affected. Emborg[14] reported that of 231 deaths of patients with eating disorders, 56 patients (24.2%) had been admitted only to a 'somatic' unit, although the death may have occurred out of hospital. Button *et al*[15] reported that two out of eight deaths in their service occurred in a medical unit. It is also uncertain whether the problem is stable, declining or growing.

The reasons for the difficulties also require attention. Two linked areas are, first, how staff deal with feelings evoked by patients with eating disorders and, second, the degree of education in nutrition that has been provided in their training. Patients with eating disorders may engage in behaviours in 'defence' of their illness that may sabotage their treatment and frustrate the clinical staff charged with their care.[16] Among medical and nursing staff in a general hospital, Fleming & Szmukler[17] found that patients with eating disorders were less liked than patients with schizophrenia and were seen as responsible for their illness almost to the same degree as those who recurrently overdosed on drugs. Nurses have reported that they find the deception in which patients with eating disorders sometimes engage wears out their sympathy: 'My heart just doesn't warm to them any more. Disgusting, sad you know, that's not a nurse' (p. 142).[18] Similar accounts are not confined to general medical settings, and can be found in general psychiatric units and in specialist eating disorder units. At the very least, such emotions make caring for patients with anorexia nervosa hard to do. At worst, they might make care less effective. George[19] concludes that for a nurse caring for the patient with anorexia nervosa the challenge is substantial: 'These [deceptive] behaviours are those such as secretive disposal of food, drinking of large volumes of water before weighing and vigorous exercise whilst on bed-rest… it is vital that nurses understand this behaviour as resulting from this extreme fear [of weight gain] and are able to convey this understanding to the anorexic patient, whilst also not condoning such behaviour (p. 903).'

It is also recognised that the teaching of nutrition in medical and other relevant courses is inadequate and steps are being taken to improve the situation.[20] Education in the management of patients with severe malnutrition who nevertheless may not cooperate with treatment should be part of the training of every doctor, nurse and dietician.

There are substantial gaps in knowledge in this area. The cases described in the MARSIPAN report necessarily come from the UK, and it was apparent that clinicians were often reluctant to disclose details of cases that had gone wrong, perhaps for fear of criticism, lawsuits or disciplinary action. It is likely, however, that similar cases, with circumstances modified by different arrangements for provision and funding of healthcare, are to be found in other countries.

I would like to request clinicians aware of patients in whom issues similar to those described here were apparent to send a description of the case, with both patients and clinicians anonymised, containing enough clinical detail to allow an assessment of the key problems experienced (and the patient's initials to avoid double counting) to: paul.robinson@beh-mht.nhs.uk. Collection of such information is the next step in identifying the problems that can occur. Following that, definitive prospective studies of patients with anorexia nervosa severe enough to warrant in-patient care to save life should be mounted and evidence-based guidance produced.

About the author

Paul Robinson Research Consultant Psychiatrist, Barnet Enfield and Haringey Mental Health NHS Trust, Research and Development Department, Block H, St Ann's Hospital, St Ann's Road, London N15 3TH, UK.

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Assessing fitness to drive in dementia and other psychiatric conditions: a higher training learning opportunity at a driving assessment centre

Matthew P. Sheridan[1]

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[1]Elderly Mental Health Services, North West Kilmarnock Area Centre, NHS Ayrshire & Arran, UK

Correspondence to Matthew Sheridan (m.sheridan@doctors.org.uk)

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Summary With an ageing population and expected rise in cases of dementia, driving safety will become increasingly important. Doctors have a professional obligation to identify patients who are unsafe to drive and in cases of dementia this decision is often complex. As a result, many centres in the UK offer driving assessments for people with medical conditions that may affect their on-road performance. I aim to identify a valuable learning opportunity for psychiatrists in training, particularly those working with older adults, to improve their knowledge of driving assessment. I also provide an overview of the Scottish Driving Assessment Service and reflect on my visit there.

Declaration of interest None.

Much emphasis has been placed within medical practice on professionals' obligation to have a good working knowledge of driving guidance. In psychiatry this is reflected in the higher training curriculum[1] and within old age psychiatry clinicians are frequently challenged with the assessment of driving safety in individuals with dementia. In the face of an increasingly older population, driving safety will become even more important. By 2021, the number of people with dementia in the UK is expected to rise from 750 000 to over 1 million, rising to 1.7 million by 2051.[2] The number of older people holding driving licences is also increasing. The percentage of people aged over 70 who have a driving licence has increased from 27% in 1985 to 54% (76% in males, 37% in females) in 2009.[3]

Dementia and driving safety assessments: research evidence

Iverson and colleagues performed a systematic review of the evidence for predicting driving safety in dementia.[4] They