Mind the gap: service transition and interface problems for patients with eating disorders

JANET TREASURE, ULRIKE SCHMIDT and PIPPA HUGO

Summary  Recent reports and guidelines that have an impact on the management of people with eating disorders are summarised. The core competencies of every psychiatrist should include: the ability to assess acute risk (including a medical evaluation) and long-term prognosis, and to know what treatments effectively address these needs.

Declaration of interest  All authors were members of the NICE guideline development group for the clinical guideline on eating disorders.

Two guidelines using an evidence-based medicine approach were published in 2004 for the management of people with eating disorders: the National Institute for Clinical Excellence (NICE) guidelines in the UK (National Collaborating Centre for Mental Health, 2004) and the Australian and New Zealand guidelines (Beumont et al., 2004). It remains for the recommendations enshrined in these to be integrated into current medical and psychiatric practice.

The eating disorders have notable psychiatric and medical comorbidities and sequelae. Anorexia nervosa has the highest mortality of all psychiatric conditions; this is a result of both physical ill health and suicide. In recognition of these risks the NICE guideline states:

‘The level of risk to the patient’s mental and physical health should be monitored as treatment progresses because it may increase – for example following weight change or at times of transition between services in cases of anorexia nervosa’ (National Collaborating Centre for Mental Health, 2004).

We explore the implications of these risks for psychiatrists.

THE PROBLEMS

The peak age at onset of anorexia nervosa is the mid-teens and that of bulimia nervosa is 2 or 3 years later. The average duration of anorexia nervosa is 6 years. Thus these disorders span the transition between child and adolescent and adult services. Bulimia nervosa is the more common disorder but anorexia nervosa requires more complex service resources as the associated medical risk is greater. However, there is little high-quality research concerning treatment for anorexia nervosa.

On the basis of Grade A evidence (at least one randomised controlled trial as part of a body of literature of overall good quality and consistency), the NICE guideline recommends that out-patient cognitive–behavioural therapy should be provided for bulimia nervosa, usually over a 6-month period. In contrast, there are no Grade A recommendations for anorexia nervosa and only one Grade B (well-conducted clinical studies but no randomised clinical trials on the topic of recommendation):

‘Family interventions that directly address the eating disorder should be offered to children and adolescents with anorexia nervosa’ (National Collaborating Centre for Mental Health, 2004).

Eating disorders are now commonly managed within mental health services, with the addition of medical/paediatric services for those with high medical risk. Treatment may need to be divided between services near the family and those at the place of higher education. Simultaneously patients may move from adolescent to adult services and away from parental involvement in treatment. The current organisation of the health service does not take the needs of older adolescents into account.

Thus the admixture of risks, problems and age at presentation of these patients raises questions about transitions between services involved in the care of people with eating disorders. Tiers of intensity/skills within different organisational structures and links between them have to be negotiated:

(a) general practice, four tiers of child and adolescent mental health services (CAMHS) and paediatricians;

(b) general practice, secondary and tertiary general adult psychiatric services and physicians;

(c) student services.

We will discuss the difficulties that this entails and suggest some tentative solutions.

WHERE ARE EATING DISORDERS MANAGED WITHIN HEALTH SERVICES?

In the UK 20% of those with anorexia nervosa and 40% of those with bulimia nervosa are treated exclusively in primary care (Turnbull et al., 1996). People with anorexia nervosa can present for treatment to CAMHS, paediatric, adult psychiatric or student services. The approach to and resources for eating disorders differ considerably between these organisations. Eating disorders are considered ‘bread and butter’ in CAMHS and student services. A recent survey of child and adolescent in-patient provision (for those aged 12–18 years) in England and Wales reported that 20.1% of all beds were occupied by patients with eating disorders; approximately half of these were general adolescent beds and half were within specialist eating disorders units (O’Herlihy et al., 2003). Student services manage many cases of bulimia nervosa and a few cases of anorexia nervosa. In Oxford, 10% of female students had an eating disorder at the time of study (Sell & Robson, 1998). In adult psychiatry, community mental health services increasingly function as ‘psychosis only’ services. Consequently, most of those with eating disorders are managed within tertiary services. Where there are limited eating disorders services paediatricians and physicians manage these individuals.

The setting of services for people with eating disorders also varies between cultures; in Germany, for example, they are frequently managed within the specialty of psychosomatic medicine.
TRANSITIONS: BRIDGING THE GAPS

Primary and secondary care

The National Service Framework for Mental Health recommends that locally agreed care protocols be developed between primary and secondary care for common mental disorders, including eating disorders (see http://www.rcpsych.ac.uk/college/sig/eatdis.asp for an example). The NICE guidelines recommend:

’Where management is shared between primary and secondary care, there should be clear agreement among individual healthcare professionals on the responsibility for monitoring patients with eating disorders. This agreement should be written and should be shared with the patient and, where appropriate, their families and carers’ (National Collaborating Centre for Mental Health, 2004).

Secondary and tertiary care

Transition between tiers of services can be problematic, particularly for adult services. Community mental health teams sometimes argue that they lack the skills to manage such cases or that eating disorders fall outside their remit of managing severe mental illness. This raises questions about the definition of severe mental illness and the core competencies required by these teams. Goldberg & Gournay (1997) suggested that anorexia nervosa fulfils several defining criteria of severe mental illness:

‘...unlikely to remit spontaneously; associated with major disability; ...whose care will usually involve both the primary and the community mental health team; ...have grossly elevated standardised mortality rate ...will need at least a brief admission’.

Some individuals with bulimia nervosa have serious comorbidity such as major depression and/or personality disorders. It is beyond the resources of specialist eating disorders units to manage these complex cases single-handedly.

Family home and student abode

Services are linked to primary care at the place of the family’s residence. The idea of a patient having lengthy but flexible care from two teams while they are students is an anathema to many service providers who prefer to remove patients from ‘their books’ if they are out of the area for a period. Treatment for eating disorders cannot be easily compartmentalised to fit within eating academic terms or holidays.

The recent report The Mental Health of Students in Higher Education (Royal College of Psychiatrists, 2003) provides a useful framework for resolving the difficulties posed. Its list of recommendations includes:

’Local mental health teams and counselling and medical services in HEIs [Higher Education Institutions] to work more closely together when jointly supporting those with severe mental health difficulties; to develop frameworks and clear protocols for cross-referral which take account of local mental health and counselling provision and expertise. Student counselling services to participate in the care programme approach (CPA) for students when necessary, although it must be recognised that student counsellors are not mental health workers and cannot fulfil the role of CPA care coordinator.’

and

An enabling policy to allow students to move smoothly between home and university, to ensure continuity of NHS treatment (including CPA) and without arguments about which Trust should pay’ (Royal College of Psychiatrists, 2003: p. 55).

Child and adolescent mental health and adult psychiatry

The move between CAMHS and adult services is not well defined. The timing of the transition is variable and sometimes depends upon the complexity of the case. The links are unclear – should CAMHS link to community mental health teams or to tertiary eating disorder services? There is often no procedure for managing this transfer, or local protocols dictate a pathway that is not always in the best interest of the patient. A sudden change in treatment ethos, towards increased individual responsibility, can be bewildering and dangerous for patients and their families. Parents can subsequently find that they are excluded from decisions about care.

A recent intercollegiate report highlighted this issue. One recommendation was that

’For young people with mental health problems specific services should be available for those in the 16–19 gap’... (Intercollegiate Working Party on Adolescent Health, 2003: p. 40).

The need for young people’s services to bridge this important developmental interface has been recognised for people with psychosis. It is lamentable that this has not yet been addressed in many eating disorder services.

CORE COMPETENCIES FOR PSYCHIATRISTS IN EATING DISORDERS

Three basic aspects of the management of anorexia nervosa should be core competencies for every general adult and child and adolescent psychiatrist. These are the ability:

(a) to estimate the acute risk posed by the disorder to the patient (in addition to the standard psychiatric risk assessment, a brief medical assessment is required);
(b) to determine the longer-term risk and prognosis from the clinical features;
(c) to assess the elements of care necessary to address these needs.

Knowledge of the care required for acute medical risk, if necessary using compulsory treatment, is crucial.

Acute risk

A simple guide to the assessment of medical risk in anorexia nervosa is available in appendix 7 of the NICE guideline (National Collaborating Centre for Mental Health, 2004). The criteria for in-patient admission are given in the Australian and New Zealand guidelines (Beumont et al, 2004). The management of high-risk cases is difficult and usually requires specialist expertise.

Long-term prognosis

Skilled early intervention has a profound beneficial effect on the course of anorexia nervosa. A randomised controlled trial showed that 90% of patients given an effective treatment (family therapy) within 3 years of illness onset had a good outcome at 5 years (Eisler et al, 1997). Only 20% of cases have a good outcome when treatment is given after 3 years of illness. The Australian and New Zealand guidelines summarise the predictors of outcome at first referral (Beumont et al, 2004). Good outcome is associated with minimal weight loss (body mass index > 17 kg/m²), absence of medical complications, strong motivation to change behaviour, and supportive family and friends who do not condone the abnormal behaviour. Poor outcome is indicated by vomiting in emaciated patients, onset in adulthood, coexisting psychiatric or personality disorder, disturbed family relationships and a long duration of illness.

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Matching risk with intensity of care

The NICE guideline (appendix 7) includes an evaluation of both the acute and long-term risk and a summary of services required to match patient needs. For example, people with severe unremitting anorexia nervosa (in common with other severe psychiatric conditions) may require social help, long-term psychotherapy, and crisis support for self-harm and rehabilitation. Emergency admissions are needed when there is acute medical risk. The NICE guidelines recommend that:

‘People with anorexia nervosa requiring inpatient treatment should be admitted to a setting that can provide the skilled implementation of refeeding with careful physical monitoring (particularly in the first few days of refeeding) and in combination with psychosocial interventions’ (National Collaborating Centre for Mental Health, 2004).

CONCLUSION

The NICE guideline provides evidence-based guidance for the management of bulimia nervosa, usually within specialised services or primary care. The best management of those with severe comorbidities is unresolved. The complexities, transition and service interface issues raised by anorexia nervosa have implications for policy and training. A number of documents, frameworks and guidelines relevant to eating disorders have recently been published. It is hoped that these will clarify the needs of this group and will facilitate a greater emphasis on teaching the core skills and competencies that all adult, adolescent and child psychiatrists require, thus reducing some of the confusion, fear and avoidance that surround these disorders.

Services need to clarify treatment policies for anorexia nervosa and to liaise with medical colleagues about protocols for the management of those at high risk. A clear understanding of the problems is necessary and good collaboration and communication between services are paramount. Finally, there needs to be an acceptance that anorexia nervosa is a severe and enduring mental illness with a high morbidity and mortality warranting consideration throughout psychiatric services.

REFERENCES


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