# EATING DISORDERS - A report for the Gloucestershire Director of Public Health's Annual Report 1997

## Introduction

Over the last few years, public awareness of eating disorders (especially Anorexia Nervosa and Bulimia Nervosa) has increased dramatically. Media features regularly occupy space in women's magazines, television chat shows and the occasional documentary. It is common for the media to talk in terms of an "epidemic" of eating disorders amongst young women.

However, despite the increase in awareness of eating disorders, relatively few people come forward requesting help and consequently professionals in primary care and secondary mental health care gain little experience of caring for people with eating disorders. Local health services have sometimes been ill equipped to cope with the complex needs of eating disorder sufferers. Changes in the NHS, combined with a rise in expectations regarding the quality of care available, have led many health authorities to purchase in-patient treatment for people with severe eating disorders from specialist tertiary centres. Although individuals have benefited, large sums of money have been spent without addressing the quality of care available within local services.

In 1995, Gloucestershire Health Authority decided to appoint a Clinical Co-ordinator to work with a project group to undertake a health needs assessment and to begin a programme of training to update staff in health and other relevant organisations. Future decisions regarding resources for eating disorders will be based on this thorough review.

Current expert consensus accepts that the causes of eating disorders are probably multi-factorial and can include emotional, psychological, physical, family, social and cultural factors. The eating disorder develops as a response to very low self-esteem and difficulties with relationships in vulnerable individuals. Their over concern with weight loss and body shape is an attempt to control one aspect of life and improve the way they feel about themselves. As the eating disorder progresses, physical, psychological and social consequences become more serious. The sufferer remains trapped in a self reinforcing cycle of behaviour that usually continues for years rather than months. The diagnostic criteria for Anorexia Nervosa and Bulimia Nervosa are: [1]

**Anorexia Nervosa:**

- Body weight is maintained at least 15% below that expected.
- Weight loss is self-induced by avoiding "fattening foods". One or more of the following may also be present: self-induced vomiting, self-induced purging, excessive exercise, use of appetite suppressants and/or diuretics.
- A dread of fatness persists as an intrusive, overvalued idea.
- A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis, resulting in amenorrhoea in women.
- If the onset is pre-pubertal, puberty is delayed or arrested.

**Bulimia Nervosa:**

- Irresistible cravings for food resulting in episodes of over-eating in which large amounts of food are consumed in short periods of time.
- The "fattening" effects of food are counteracted by self-induced vomiting or purgative abuse or alternating periods of starvation.
- A morbid dread of fatness.

Sufferer's symptoms can change over time from one diagnostic category to the other (normally Anorexia to Bulimia) and they may also present with atypical variations of the diagnostic criteria.

Eating disorders mainly affect young women in western industrialised countries. Men make up only 5-10% of cases of Anorexia Nervosa and far fewer cases of Bulimia Nervosa. Sufferers come from all sections of society, including minority ethnic groups. Medium term outcome studies suggest that although complete recovery is possible, 40-50% of patients remain ill despite appropriate treatment. Many of these people have severe and enduring mental illness, with persistent social disability, chronic physical morbidity and increased risk of early mortality.

## Epidemiology

### Prevalence

A review of the literature on the epidemiology of Anorexia Nervosa and Bulimia Nervosa [2] suggested the average prevalence for Anorexia Nervosa as 280 per 100,000 young women (0.28%) and for Bulimia Nervosa 1,000 per 100,000 young women (1%). The prevalence of Eating Disorders amongst children, men and older women is unknown. Estimates for the prevalence of atypical eating disorders vary up to 5% of young women.

Statistics from community based studies and a large primary health care based study undertaken in the Netherlands, [3,4] would suggest the following distribution of eating disorders at different levels of care within Gloucestershire at any one time.

| | |
|---|---|
| Living in the community | 1800-2200 |
| Conspicuous in primary care | 300-350 |
| Receiving mental health care | 180-220 |
| Receiving in-patient care | 5-15 |
| Detained under the Mental Health Act | 0-2 |

Community studies suggest that up to 90% of women with Bulimia have not received any help for their problem [5]. A detailed study in Sweden found that only 50% of young people with Anorexia Nervosa had been in contact with mental health services, despite encouragement to pursue help [6].

### Incidence

Hoek has estimated the incidence of Anorexia Nervosa and Bulimia Nervosa in primary health care and mental health care settings [3,4]. The figures for Anorexia

Nervosa are, in primary health care: 8.1 per 100,000 population (both sexes) per year, and in mental health care: 5 per 100,000. The figures for Bulimia Nervosa are, in primary health care: 11.4 per 100,000 and in mental health care: 6 per 100,000. These estimates would suggest the following incidence of new cases in Gloucestershire each year.

| ***Primary health care*** | ***Secondary mental health care*** |
|---|---|
| Anorexia Nervosa = 44 | Anorexia Nervosa = 27 |
| Bulimia Nervosa = 63 | Bulimia Nervosa = 33 |

Up to one third of referrals to eating disorder clinics tend to be atypical which would suggest an incidence in secondary mental health care of around 30. A local audit of referrals to secondary mental health services suggests a total incidence of 100 - 110 eating disorder referrals, 47% Bulimia Nervosa 30% Atypical Eating Disorders and 23% Anorexia Nervosa. It appears that most community mental health teams are currently unlikely to receive more than 10 referrals per year, with only two teams, in Cheltenham, receiving around 20.

## Evidence of Effectiveness of Intervention

### Aims of Treatment

The overall aim of treatment is to help the sufferer to be able to replace their eating disorder with healthier ways of coping and relating, taking personal responsibility for improving their own nutritional, mental and physical health. Specific goals will apply in each individual's case, but will probably include; establishing a healthy eating pattern, gradual restoration of weight to a normal range, cessation of purging behaviour, improving self-esteem, using healthier coping strategies and developing relationship and communication skills.

### Research

There are very few controlled studies of psychotherapy for Anorexia Nervosa, but many more for Bulimia. Outcome studies have been fraught with methodological difficulties and have virtually all taken place in specialist settings.

*Anorexia Nervosa*

In-patient re-feeding within a specialist unit has been shown to be effective in terms of weight restoration to a normal range, but medium term follow-up suggests that at least 40% of patients relapse [7,8]. More recent studies have questioned the necessity for routine admission to hospital by comparing in-patient care with day-patient care [9] or in-patient care with group therapy, individual and family therapy or "no treatment" [10,11]. Broadly, there were no advantages found for in-patient treatment over the alternative treatments and advantages cited for out patient or day care included cost effectiveness and compliance with treatment.

Several studies have compared out-patient treatments for Anorexia Nervosa, but have found all approaches to be roughly equal in terms of improving the patient's overall condition, except for patients with an early onset and a short duration of illness who benefited more from family therapy rather than individual therapy [12].

There have been few controlled medication trials, and no drug has yet been shown to have clinically significant use in the treatment of the core features of Anorexia Nervosa[13].

*Bulimia Nervosa*

Out-patient treatments for Bulimia were developed rapidly after its classification as a diagnostic category. Most studies have compared Cognitive Behaviour Therapy (CBT) with one other therapy (behaviour therapy, exposure with response prevention, supportive psychotherapy, supportive expressive psychotherapy and treatment with anti-depressant drugs). Short-term follow-up has shown that cognitive behaviour therapy is more effective than other treatments and results on average in at least a 70% reduction in the frequency of binge eating and purging. Between one third and one half of patients cease bingeing altogether. Treatment also results in a lessening of concerns about shape and weight and a marked improvement in psycho-social functioning [14].

A longer term follow-up study has compared CBT with Behaviour Therapy (BT) and focal inter-personal psychotherapy (FIT). The results showed that BT has a short lived effect, with a high relapse rate. Remission rates post-treatment were highest for CBT then BT then FIT. However, at 12 months follow-up, FIT had overtaken BT and at 6 years follow-up FIT had overtaken CBT, with over 70% of patients in remission compared to 60% for CBT and 20% for BT [15]. The addition of anti-depressant medication to CBT has not proved to be superior to CBT alone [16].

Recent approaches to the treatment of Bulimia Nervosa have included the use of self-help treatment manuals. In one study, a treatment manual was compared with 16 sessions of CBT and a waiting list control group. CBT produced a significant reduction on all the main outcome measures. The manual significantly reduced frequency of binge eating and weight control behaviours other than vomiting, but there was no change in the group on the waiting list [17]. At 18 months follow-up, 40% of the manual group and 41% of the CBT group were symptom free [18].

**Good Practice**

Statements of expert clinical consensus have established the principles of clinical management for patients with eating disorders [19, 20, 21]. Ideally, a multi-dimensional treatment approach should be offered on an out-patient basis. More intensive interventions (day hospital or in-patient) are reserved for patients who are severely ill. Clinical management is likely to include at least five components:

*Comprehensive assessment* of the sufferer's mental, nutritional and physical health, including where possible an interview with close relatives.

*Education* regarding the effects of eating disorders and dietary advice.

*Monitoring* of the sufferer's dietary intake, physical health, psychological problems and behaviour.

*Psychotherapy*, including the use of cognitive behaviour therapy techniques and especially for younger sufferers, family counselling/therapy.

*Support*, including encouragement to attend a support group (EDA) and long-term follow-up to help prevent relapse.

When *intensive intervention* is required, there should be sufficient skilled help available to ensure adequate nutritional intake and emotional support.

## Current Service Provision

At present most sufferers requesting help in Gloucestershire are seen within secondary mental health services (child and adolescent or adult) following referral from primary care. Sufferers might be seen by any one of a number of different mental health disciplines, but new referrals are mainly being seen by a key worker who is a nurse in East Gloucestershire NHS Trust or physiotherapist in Severn NHS Trust. A dietitian is often involved, but dieticians are not organisationally part of either of the two Gloucestershire mental health services.

At least 12 local mental health professionals have a special interest in eating disorders *and* see regular referrals. Several others have extensive experience, but no longer see many patients. The therapy available is predominately individually based, but there are 2 short-term groups available for Bulimia Nervosa and compulsive eating in East Gloucestershire. Patients with eating disorders use other general groups when appropriate. An EDA support group for sufferers and carers, meets fortnightly in Gloucester. Some family work takes place mainly in child and adolescent services.

Very few patients are admitted to hospital. Admissions to psychiatric hospital are often for general psychiatric reasons rather than re-feeding. Re-feeding on psychiatric wards is often problematic. Severely ill patients are sometimes admitted to a medical ward and a small number of patients are referred out of county to specialist in-patient units (adolescent or eating disorder). Gloucestershire County counselling services, voluntary counselling services and student counselling services all have contact with people with eating disorders, some of who also see mental health services.

Services for people with eating disorders are not co-ordinated across the county, but are provided within general mental health services. Consequently referral practise varies considerably, as does the level of knowledge, experience and expertise available. Patients with severe eating disorders often require intensive co-ordinated services, but the demand for these services occurs only occasionally within each mental health team.

Current referral patterns suggest that only around 28% of G.P.'s in Gloucestershire will refer a patient with an eating disorder to mental health services in one year and only 11% of those G.P.'s will refer more than one patient each year.

## Areas for change

Recent national reports [20, 22] have suggested the need for comprehensive local strategies for the care of people with eating disorders. At present, confidence, expertise and resources vary widely around the country, a situation that is reflected in Gloucestershire. Health care professionals rarely receive sufficient training and only occasionally meet patients with eating disorders. These factors, combined with the anxiety provoked by seriously ill patients, can lead to services being ad hoc and sometimes inappropriate.

There is no consensus regarding models of service for people with eating disorders. Services are delivered in a variety of different ways across the country. Models vary between separate specialist teams that deal exclusively with eating disorders, services designed to improve the quality of care within general mental health services and no extra specialist provision. Despite these variations, some conclusions can be drawn from the relevant literature, which should then guide the development of future services.

- Early identification and intervention are more likely to be successful.
- Sufferers need multi-dimensional assessment and management.
- Family members and carers should be involved in treatment.
- Sufferers find community, counselling based approaches to treatment the most helpful and research suggests these approaches are efficacious and cost effective.
- Sufferers find treatment from staff who understand eating disorders much more helpful, and can find uninformed help makes their problems worse.
- Eating disorders are often chronic, relapsing illnesses, so long term support and follow up may be required.
- Although the vast majority of sufferers can be helped in the community, a small number will continue to require intensive intervention, often in hospital, to manage physical and psychiatric crises.

Decisions regarding the funding of services for eating disorders need to balance the needs of the majority of sufferers who can be helped by community interventions, with the needs of the small number of people with severe disorders who require intensive hospital care. Whilst the number of sufferers requiring out of county treatment is unlikely to reduce in the near future, steps can be taken to improve the quality of community care available locally and the co-ordination of out of county referrals, potentially reducing the length of stay required and therefore the cost.

Gloucestershire Health Authority has invested £30,000 as revenue, to begin the development of local eating disorder services. A comprehensive strategy is being written in consultation with all relevant local organisations. Without wishing to prejudice the final conclusions of the project group, some initial recommendations are emerging from the work completed so far.

## Recommendations

- Early identification and intervention in the community and primary care should be facilitated by raising awareness of the signs of eating disorders and improving the accessibility of help. This could be achieved by;

1. Establishing a well publicised telephone help line for public and professional use.
2. Producing information leaflets on eating disorders, self help and how to access services.
3. Distributing the leaflets to all relevant organisations.
4. Supporting the co-ordination and development of the Eating Disorders Association support group.

5. Organising regular training for relevant staff in primary care, education, youth services and voluntary counselling agencies.
6. Providing guidance for the management of eating disorders in primary care.

- Specialist clinical management within local mental health services should be improved by;

1. Establishing a network of mental health workers (at least one from each Community Mental Health Team [CMHT]), who could continue to develop their special interest and skills by meeting regularly for shared supervision and training.
2. Providing specialist clinical supervision and consultation as required for other CMHT staff.
3. Ensuring that new assessments for people with eating disorders are undertaken with the participation of a member of staff experienced in the management of eating disorders.
4. Establishing annual research updates for CMHT staff and a variety of training courses.
5. Evaluating the care provided by using standardised measures of medium term outcome and service user satisfaction surveys.
6. Developing and auditing standards of care.

- The use of local hospitals and tertiary specialist treatment centres should be monitored, reviewed and co-ordinated across the county. Quality of care and cost effectiveness could be improved by;

1. Ensuring closer relationships with tertiary treatment centres.
2. Developing protocols for admission, discharge and liaison, including clear statements regarding the purpose of hospital admission.
3. Re-negotiating contracts, incorporating the protocols, to meet local need.
4. Monitoring the outcome of admissions, including the views of sufferers, carers and staff.
5. Reviewing the need for differing forms of intensive intervention and where they should be provided, in the light of the changes implemented and developments in research and practise.

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