

**EATING DISORDERS IN THE UNITED KINGDOM:
REVIEW OF THE PROVISION OF HEALTH CARE SERVICES
FOR MEN WITH EATING DISORDERS**



**Prepared for Eating Disorders Association
First Floor Wensum House
103 Prince of Wales Road
Norwich NR1 1DW**

Media 01 603 624 310
Admin 01 603 619 090
Fax 01 603 664 915
e-mail info@edauk.com

**By Jeanette Copperman
14 February 2000**

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1. Summary

1. Overall Findings

- Overall findings suggest that not enough is being done at present to address the needs of men with eating disorders.
- Whilst there is considerable overlap between men and women in the causes of their eating disorders, the treatment and outcomes, much is based on small studies and there has been little exploration of the specific treatment needs of men.
- There are clear problems with access to services for men

2. Incidence and Prevalence

- Estimates of the numbers of men in the population with eating disorders varies with the criteria adopted and is between 1:6 and 1:20¹. The most commonly used proxy is 10% of all cases of eating disorders will be male.
- It is estimated that 60,000 - 90,000 people known to clinics have eating disorders at any one time in the UK.² This suggests that between 6,000 – 9,000 men at any one time should be known in eating disorders services in the UK. Community studies indicate a far higher prevalence of eating disorders, so this is likely to be an underestimate.
- This suggests that in a health district of 500,000, approximately 4 new cases of anorexia and 6 cases of bulimia will be male each year, with approximately 1 man each year requiring in patient admission.³
- Gender and sexuality are significant factors. Most at risk are heterosexual women, then gay men then gay women then heterosexual men. The overwhelming majority of those with eating disorders are heterosexual women.⁴
- Approximately 20% of men with eating disorders identify as gay,⁵ double the estimated proportion of gay men in the population.
- The reasons for these divergences in gender and sexuality are debatable.

3. Routes into the Disorders

- There is considerable overlap between the risk factors and the age of onset in men and women, typically in the late teens. There are however some significant differences.
- As there is less cultural endorsement for slimming amongst men, the onset of eating disorders usually has a specific trigger. These include:⁶

Avoiding childhood bullying/teasing for being overweight

Body building/Exercise

Specific occupations including involvement in athletics

- **Women are more concerned with body weight, men with body shape and muscles.**

4. Accessing Services

- **There are clear indications that the general lack of recognition of eating disorders in men makes it more difficult for men to access services.**
- **Cultural expectations make it harder for men to recognise in themselves that they have an eating disorder and to seek help. The mean time it took men in the study to get help was 6 years, two men had taken 14 years to have their problems recognised.**
- **Their disorders are less likely to be recognised and diagnosed by professionals, including GPs and psychiatrists.**
- **Weight loss is more likely to be attributed by themselves and health professionals, to physical causes rather than to psychological ones.**
- **Even when men seek help they can encounter disbelief from health professionals.**
- **The length of time taken to recognise the disorders is for some men leading to treatment in later life, when the eating disorder has already become established.**
- **Interviews suggest that the macho culture associated with being men make it more difficult to discuss eating disorders with peers.**

5. Appropriateness of Treatments

- **Findings suggest that access to a specialist service and the level of skill, empathy and understanding shown by the practitioner was more important than the gender of the practitioner.**
- **Service providers felt that some men were inhibited from joining groups (in both statutory and self-help groups) by the preponderance of women.**
- **The majority of men interviewed felt that many of their issues were the same as those for women and that there was inadequate and patchy service provision for both genders.**
- **A minority felt that their problems were substantially different.**
- **Most service providers had not considered offering services targeted specifically at men.**
- **Only one specialist service was identified - a group for men operated within an eating disorders unit in Newcastle.**
- **Evaluation of the Newcastle group indicated that it was well received and seen as helpful by the men taking part. It had not required a vast investment of resources to achieve.**
- **There is a lack of information about the potential benefits of a specific programme for men as eating disorders work with men is still in an exploratory stage. Further investigation is needed about the most appropriate way to offer provision specifically for men.**
- **The EDA offers male helpline workers and male contacts.**
- **Of all EDA helpline calls received in 3 randomly selected months, approximately 10% referred to male sufferers. This is in keeping with the incidence and prevalence figures and higher than the**

percentage of men using most specialist services. This might indicate that helplines are more accessible to men and their friends/relatives than specialist services with a referral system.

Service providers wanted:

- **An awareness campaign amongst men, particularly those involved in body building and exercise and work targeted specifically at recognition by GPs in primary care, parents and teachers and colleges including student unions and health centres.**

Men wanted:

- **More information about eating disorders.**
- **To be able to contact/ talk to other men with eating disorders.**
- **An awareness campaign in the gay male community.**

2. Introduction

Eating Disorders Association (EDA) is a national charity, which provides information, help and support to people whose lives are affected by eating disorders. The head office of the charity is in Norwich, though local services are co-ordinated through a network of volunteers in each area.

EDA as part of its strategic work, is interested in exploring the needs of minority groups with eating disorders whose needs are not always recognised. EDA commissioned this study to look at men as one of these groups. The review was carried out by several means. These included a limited literature review, interviews with a group of specialist providers suggested by EDA and telephone interviews with men with eating disorders, drawn from the membership of the EDA and from men who contacted the EDA following publicity about men with eating disorders.

1. Background - Literature Review

Defining Eating Disorders

There are three main types of eating disorder: anorexia nervosa, bulimia nervosa and binge eating disorder. The definitions that follow are based on definitions in a review conducted by the Health Advisory Service (HAS)⁷

Anorexia nervosa is characterised by a profound self induced starvation, marked weight loss, cessation of menstrual periods in women, a distorted body image and fear of fatness.

Bulimia nervosa is characterised by constant dieting with episodes of binge eating, followed by purging, with self induced vomiting, laxative abuse, or both.

Binge eating disorder describes episodes of binge eating similar to bulimia nervosa but without purging behaviour although there may be periods of starvation between the binges.

Variants of these three disorders exist, and people can move between the three conditions.

Determining the extent of the problem in men

Incidence.

There is considerable variation in the figures given in different studies for both the incidence and prevalence of eating disorders. This study has dealt primarily with anorexia nervosa and bulimia nervosa in adult males and not with binge eating disorder. These range from the percentages in Hoek's study of the community in Holland which would indicate that 500,000 people in the UK⁸ at any one time suffer from eating disorders to the figures from specialist services compiled by the Royal College of Psychiatrists. Another study estimated that 0.5% of males suffer from eating disorders. The figures given below are for adult males:

Prevalence

There is variation in the percentage of males estimated to be suffering from eating disorders.

The Royal College of Psychiatrists suggest that the point prevalence for anorexia nervosa and bulimia nervosa in the UK in total, is 60,000 people (which varies according to the diagnostic criteria adopted) and of whom an estimated 10% will be men.⁹ This is based on clinic studies and is likely to be an underestimate.

Whilst some specialist services estimate the percentage as high as 20% in specialist services, the more commonly cited figures are about 10% for community based epidemiological studies and between 5% and 15% for clinic based ratios.¹⁰ There was no consensus on the ratio in child/adolescent services and this could bear further investigation.

In some studies men had been specifically excluded because of their small numbers.

Age of Onset

Eating disorders generally are most commonly reported to develop between the ages of 15 and 25 years. The literature suggests that this is the same for males, however diagnoses and treatment take longer to access.

Some recent literature and anecdotal evidence suggests that eating disorders are on the increase amongst men and in particular young men, but this is hard to substantiate without good baseline data.

Diagnosis and features of eating disorders in men

Overall there was not a great deal of difference reported in the literature between men and women in the outcomes and their treatment. The different constructions of maleness and femaleness in the society did however, have a significant impact on some aspects of the disorders including vulnerability factors and their access to services.

The literature made the point that it is difficult to isolate the relative influence of the socio-cultural and biomedical factors in the aetiology and maintenance of the particular disorder.

Anderson has also noted that the number and scope of studies, which deal with men and eating disorders are small although increasing so there remain a number of areas of uncertainty.

Vulnerability factors and triggers to the disorder

There were some significant differences between men and women

- A predisposing factor was being fat or picked on at school for boys/men.
 - Whilst men who became anorexic after feeling they were fat actually were 15% over ideal bodyweight, women thought that they were fat at 90% of ideal bodyweight. So men actually were overweight when they thought they were.
 - One route in for men is through exercise and bodybuilding. This is consistent with the overall picture of the differences between men's and women's views of what is they think is significant. In the general health literature women have been shown to be more concerned with controlling their food intake and men with exercise (Lloyd 1996).
 - Particular professions were also more at risk such as jockeys, body builders, and athletes. A study quoted by Anderson of the Canadian army and navy showed a high rate of eating disorders amongst men where physical fitness was a priority. For example, amongst the 4,800 men surveyed there was a
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prevalence of 2.5% for anorexia, 6.6% for bulimia and 40.85% for Eating Disorders Not Otherwise Specified (EDNOS). Use of laxatives, diuretics, diet pills, vomiting, and fasting for standards increased during the body measurement and fitness periods.¹³

- Conflict over gender identity or over sexual orientation may precipitate the development of eating disorders in males.
- Young men may be more vulnerable, the typical age of onset for both genders is during adolescence.
- Men with eating disorders are more likely to have alcohol related co morbid conditions than women
- More men with eating disorders were more likely to be HIV+.

Gay men

- The average frequency of gay orientation in males with eating disorders is approximately 21%.
- Gay men were a significant subgroup of men accessing services with eating disorders.
- Whilst homosexuality in males was a vulnerability factor, in women it appeared to be a protective factor against developing an eating disorder.

Causes

There are a number of possible causes for the differences between the ratio of men and women.

There is no overall consensus in the literature on the reasons for the different ratios, but there has been exploration of the socio-cultural context for the development of eating disorders which suggests that the lower number might be associated with less socio-cultural reinforcement for slimming amongst men.

Recent research has shown that people with eating disorders, both male and female have similar personalities and symptoms except that men seem more achievement orientated and show more sexual anxiety.

Access to Services

- There is evidence that access to and take up of services may be different, both because of the lack of awareness of health professionals and the difficulty that men themselves experience in recognising that they might have an eating disorder.
- There is a difficulty with professionals diagnosing eating disorders in men. Cessation of menstruation is used as a diagnostic tool by clinicians for anorexia nervosa, there is little that is analogous with males.
- Binge eating may go unrecognised in men.
- Diagnosis can be confusing as the terms used to express conflicts about shape and size by men are often different from those used by women, and which professionals would recognise as a vulnerability factor.

Treatment¹⁵

Treatment is basically reported in the literature to be the same for either gender - restoring normal bodyweight, interrupting abnormal behaviour, treating co morbid conditions, persuading patients to think differently about the value of weight loss/shape change.

However, Anderson points out that males have developed with social learning pattern, societal role and genetic patterns that differ from women and suggests that while the major goal of clinicians is to acquire gender neutral practices for treatment of eating disorders, some aspects of treatment call for a gender specific approach. He also suggests that there are many areas where the impact of eating disorders in males is under researched.

Particular points made are:-

- It is helpful to have more than one man in a programme
- It is useful to explore individual aetiology rather than follow a norm
- In general the more ill the person, the less gender related their treatment
- Anderson reports that men appear to do well in a separate group for some of the time.
- The hormonal reproductive milieu of males is different to women, testosterone levels need to be monitored and noted.

Outcomes¹⁶

Outcomes are generally reported in the literature to be the same for men and women once treatment takes place. The literature is clear however that eating disorders are easier to treat in their early stages before a pattern becomes established. Once anorectic or bulimic thinking and behaviour patterns have become entrenched, the patient has a poorer prognosis. The problems with access to services experienced by men, may affect their outcomes and prolong their treatment.

4. Data from Interviews with Service Providers

Telephone Interviews and e mail questionnaire with Service Providers

Method

EDA supplied a list of professionals working in specialist eating disorder services across the UK and these were contacted (four responded). In addition, two self help group co-ordinators /facilitators were interviewed and two professionals, who were suggested by other interviewees and who run a specialist group for men with eating disorders in Newcastle. Also all the specialist service providers in London were e mailed with a set of questions, two of these responded. A list of professionals who responded and the schedule of questions is appended.

Many of the themes from the literature review overlapped with those of the professionals interviewed and the men with eating disorders.

Profile of Professionals

The statutory professionals interviewed and responding to the questionnaire worked in a range of specialist services providing various treatment approaches to a catchment population. These included community based treatment, hospital outpatient treatment, medical services and in some cases in patient services. Most of the statutory services were provided on a day/outpatient basis and offered therapies including weight management, family, individual and group therapy, medication, a day programme and some would also see people at home. One of the professionals also specialised in providing advice and support to mental health services and training and advice to mental health workers, There was a geographical spread of providers with a concentration in London and the surrounding area but including Newcastle, Bristol, Gloucestershire and Scotland.

There were however significant differences between the philosophy and practice in responding services. For example, some were significantly more geared towards treating the disorders with medication and weight control whilst others offered a larger component of psychotherapeutic and psychosocial interventions. Statutory services received the majority of their referrals through GPs and this was an area of considerable concern. The two EDA self help group co-ordinators /facilitators worked in local groups and were involved with running a helpline and self help groups.

Determining the numbers of men with eating disorders using services

All professionals were asked how many men had used their service in the last year and about their overall impressions of the extent of the problem. The following points were made: -

Male referrals were patchy and on the whole, lower than the figures given in the literature.

There was variation in the number of men reported by professionals to be using services but services reported a figure between 5% and 10%. Most services experienced a male referral rate closer to 5% or even lower.

This suggests that men are still experiencing significant problems in accessing services.

One of the factors identified by practitioners as affecting access to services, was the amount of publicity that the issues had received . For example, clinicians received more referrals when there was publicity about men and eating disorders. In Scotland three male referrals had taken place a short time after the clinician had been on TV. **This suggests that ongoing publicity is needed to raise awareness of eating disorders and their treatment amongst men.**

The following are examples of the numbers quoted for male service referrals (either self referral or through a GP).

In Gloucestershire, during the last year, no male adolescents had been admitted to the adolescent unit out of 3 admissions overall. Out of a total of 6 ECR admissions, there had been 1 male admission.

In Bristol, the estimated referral rate was 1:18 for men during the previous year.

At the Royal Free Hospital, out of 250 referrals a year, approximately 5% are male (normally 50 referrals would be needed to provide a specialist service).

Between January and June 1999, there had been 100 referrals to the service of whom 5 were men.

A number of practitioners commented on the unreliability of figures for eating disorders as a whole, and that community studies indicate that overall 90% of people with eating disorders were untreated and remain in the community. Clinicians repeatedly made the point that the studies, which deal with men are generally on a small scale.

Gay men and service use

Three of the practitioners noted a significant association with homosexuality amongst men with eating disorders in their services. One in Inner London estimated that between 30% and 40% of the male users were gay. Most services did not routinely collect data on this.

Accessing Self Help Groups

Men were reported to access helplines and one to one help but found groups more difficult to access or use.

Publicity and demand

All agreed that there was a lack of images of men with eating disorders and a lack of publicity about the issues. When there is publicity about the issue, more men come forward. For example, when one of the professionals interviewed carried out a television interview for Scottish TV about men and eating disorders, he received three male referrals shortly afterwards.

Self help groups

The Luton self help group said that they had a few men on their books but it was rare that they came to groups, they mainly accessed one to one counselling. Over the last year, they had seen four men overall in the context of 30-40 clients a week.

They thought that having a male counsellor available might increase the number of men coming forward. Similarly they tried to target their publicity to the whole community.

Routes into the Disorder - Specific Triggers and Vulnerability Factors

Most of the clinicians had found few differences in the vulnerability factors for men and women. The ones that were noted were:

Three of the clinicians reported that men were more interested in body shape and body tone than only in weight per se. They also noted that the route into an eating disorder had been through exercise and bodybuilding.

Shame

More shame was seen as being attached to having an eating disorder for men, as it was seen as being at odds with the cultural construction of being a man.

Access to Services

Lack of diagnosis and recognition in Primary Care

Accurate diagnosis and recognition and appropriate referral from primary care was an area of concern for all the specialist service providers interviewed.

One professional commented *'GPs are referring late, they have stereotypes of who develops eating disorders and that is middle class girls'*

Most of the professionals felt that more publicity was needed to raise awareness in particular amongst primary care. One of the problems seemed to be that the signs GP's looked for, for example, lack of menstruation, was not present in men. One commented that GPs were unlikely to ask about loss of early morning erections as an indication of an eating disorder, whilst they would ask about cessation of menstruation.

There was a concern that the lack of recognition at a primary care level meant that in some cases, men were being seen at a later stage in their illness than women and when they were often more ill and a pattern had become established.

For example, in Bristol of four men using services in a one year period, all had been admitted to in patient services.

All the services felt that there was a need to raise awareness of the issue in general practice.

Men more reluctant to seek help

Professionals reported that they experienced men leaving it later to seek help, often until a family member or friend got significantly worried or it significantly interfered with their life. As one clinician commented *'Work with men with eating disorders is where women with eating disorders were 20 years ago, and it has to catch up.'*

Gearing Services to Men

Gender specific provision

In the course of the study only one specialist service aimed at men was identified in Newcastle. The other services offered a mixed service with a minority of male patients. Two of the providers also reported offering a choice of gender of practitioner wherever possible. The reasons for not offering a specific service were reported as the small number of men who used services and also doubts as to the necessity and efficacy of this in terms of improving treatment outcomes.

Gender of practitioner

The majority of the staff working in eating disorders services were reported to be female. For example, at The Royal Free Hospital, there are 25 staff members, 4 of whom are men. The clinicians did not think however, that this had presented a barrier to appropriate treatment.

Overall the providers did not report the gender of the practitioner as that important whilst the skill and knowledge of the practitioner and relationship were seen as crucial.

Specialist services for men

The small numbers of men who come to services mean that extra effort is needed to provide a service specifically for men within the context of a large service. For example, if a service is to be provided then it would have to be prioritised and include men who had been referred over a period of time. A description of the specialist work in Newcastle is appended.

The two workers interviewed from this service raised the following general issues –

- there is insufficient research on the differences between men and women and eating disorders
- there is insufficient knowledge about the therapeutic process with men and how it might differ from women
- there is insufficient knowledge about the therapeutic goals for men.

Group work

The small numbers of men using services at any one time meant that several clinicians reported that they had had one man in a predominantly female group. There were mixed reports about the involvement of men in predominantly female groups. Some clinicians reported that this worked well whilst others thought that it was problematic.

Both the self help group co-ordinators had experienced one man in a group at various times and had mixed accounts of this. Men were reported to be using counselling lines and one to one counselling more than group work, possibly because of their relative isolation within a group.

5. Data from Interviews with men with eating disorders

Telephone Interviews with Men with Eating Disorders

Many of the themes raised by the men with eating disorders echoed the points raised by the literature review and the professionals working with men with eating disorders. All the men felt that a great more needed to be done to raise awareness of the issue amongst men and within the wider community. They had all experienced some degree of difficulty in recognising and coming to terms with having had an eating disorder as a male.

Method

All the male members of EDA (approximately 45) were contacted to ask if they were willing to give a telephone interview and asked to return a slip in a freepost envelope. Several other men came forward as a result of the publicity that EDA conducted about men with eating disorders, and who were not necessarily members of EDA.

10 men agreed to be interviewed and of these, nine were interviewed by telephone,

Profile of respondents

Respondents were from different geographical locations around the UK although none were living in Scotland or Northern Ireland. The men ranged from those in employment to those dependent on benefits and from those leading an active social life to those who were socially isolated. Whilst three of the men (including the two young men in the sample) saw themselves as relatively recovered, others felt that their eating disorders were always present, if held under control.

Ages of respondents

Two respondents were under 20 (17 and 19 years old)

Five respondents were between 30-40 years

Two respondents were between 40-45 years

Sexuality

Four of the men self identified as gay.

Types of Disorder

Most of the men had experienced both anorexia and bulimia nervosa at different times, but three of them reported anorexia alone. The older men in the sample had all experienced several episodes of eating disorders over a period of years, which came and went in severity. One of the younger men in the sample reported that his eating disorder had cleared up after two and a half years.

Age at first eating disorder

All but one of the men said that they first developed an eating disorder when they were in their teens, in two cases, as young as 10 years. In some cases it took 6 years or more for this to be recognised.

Routes into the disorders - Specific triggers and vulnerability factors

Childhood obesity and teasing/bullying

The majority of the men reported that their eating disorders had started in their school years when they were fat and called names. Several reported being severely overweight in their younger years for a variety of reasons to do with low self esteem, crises at home, difficulties with coming to terms with themselves. For example, one man was 10 stone at 10 years and was put on a 'diet' by the school. This led to him eating on his own and being teased.

Being overweight led to them being bullied and teased and isolated at school and they began to lose weight to become more popular. It is interesting that the gay men in the sample experienced this cycle as well and that their eating disorders preceded their conscious involvement with the gay community.

As the number of obese boys grows in the population, the possibility of this leading to eating disorders needs to be raised with teachers and schools and parents.

Exercise/body building

Another route into eating disorders was through exercise. One of the men reported becoming obsessed with exercise as well as limiting his food intake. He became obsessed by going to the gym and cycling. For several of the men this went alongside a pattern of eating disorders that had already become established.

This suggests that it might be useful for services to target men who are involved in these activities.

Being gay

The particular pressures in the gay male community to have the 'body beautiful' and be slim in order to get a partner was mentioned by all four gay men.

'The scene can be a real meat market.'

One of the men talked explicitly about the difficulties he had in coming to terms with his sexuality as a believing Christian and felt this had been a trigger for his eating disorders. Some of the other gay men talked about the conflicts they had experienced when younger. It was felt to be a bigger problem in the gay male community than has been acknowledged and amongst some men, 'throwing up' as weight control measure had become a normal way of life.

Eating Disorders as a way of coping with life stresses

One man commented that most men turn to alcohol and drugs as a method for coping but that for some men an eating disorder is a way of coping with life stresses. Four of the older men had experienced episodes of eating disorders throughout their lives, in relation to loss of a partner, illness of a parent, relationship breakdown, change of job, stresses of a PhD etc.

One man said that whilst he was in a relationship, he felt able to maintain a healthy lifestyle. When his relationships had broken down, he reacted with eating disorders. This combined with the social isolation of being gay and the lack of recognition of relationship breakdown amongst his family had precipitated the development of an eating disorder. For another, the loss was the serious illness of his mother.

Social isolation/change

Social isolation was reported as a factor by most of the men at some point in their lives, which the secrecy surrounding the disorder had compounded. Most of the men in the sample had been to college and reported this to be a particularly stressful time when their eating disorders got worse.

This raises the issue of what assists men to seek help?

It appears that help intervention from an external person, a family member, friend or professional is one route to seeking help or that the situation becomes so bad that the men ended up in hospital.

This raises the question of what can be done to ensure that men come to services earlier and under their own volition?

Access to Services

Time it took to recognise an eating disorder and get help

It took between 1 month and 14 years to get help from the services. One man had never sought formal help except for one visit to a doctor. Four of the men had taken between 9 and 14 years to get help. The mean length of time was 6 years.

There were two aspects to this, the length of time it had taken men themselves to recognise that they had a disorder and the length of time that it had taken services to recognise the problem. The stereotypes of eating disorders as being something that young girls develop, affected both the men's own perceptions and those of clinicians.

The experience of this man was not atypical of the men who had taken longer to get help.

'Looking back I can see that I had a problem even when I was 19 with laxatives and exercise. I had experienced times of depression since my late teens when friends were settling down.'

In his mid 20s, he lost 2 stone in 3 months and when he went into hospital, he was given a barrage of physical tests. He continued to lose weight.

'I became so weak I could not cycle up hills, but I thought it must be the bike'

He was finally diagnosed after 6 months of physical tests.

'I thought I'm a 25 year old bloke, blokes don't get this kind of disease.'

Disbelief from professionals

Two men, even when they sought help, experienced outright disbelief from professionals, including a psychiatrist!

Difficulty with peers

Men also experienced particular difficulty discussing their illness with their peers

One young man commented

'It is more difficult to come forward, you cannot admit to your feeling in a macho culture; people think you are weak and you fear that you are going to lose respect from your friends.'

Severity of disorder

For several of the men the length of time it had taken to access specialist services meant that they were more severely ill by the time they had reached services and were at a real crisis point.

Things that would help with access to services

Many of the men commented that help and intervention from an external person such as a family member, GP, teacher, or friend had helped them to finally access services.

One young man of 19 years old had first developed an eating disorder at 16. He first talked to his teacher who suggested he see the doctor so he went with his mum.

This suggests that it is important to target mothers and teachers with publicity as well as men and doctors in primary care.

How appropriate do men consider service provision to be?

The men in the sample had experienced the gamut of service provision. Three had experienced in patient treatment, all had seen a doctor at some point, eight of the men had seen a psychiatrist, eight specifically mentioned seeing a GP. Others had seen counsellors, two had attended EDA groups, one man had attended a men's group run by the hospital, another had used alternative therapies such as reflexology and imaging.

The men were asked about their good and bad experiences of care and identified the following issues:

Access to sympathetic professionals and specialist help

The importance of access to sympathetic professionals who did not moralise, who knew about eating disorders and could provide specialist help was mentioned time and time again by the men in the sample. This could prove difficult to realise either because of geographical location, for example one man in Nottingham had found it difficult to get specialist help, or because of the reluctance of professionals to recognise the problem.

One potential case of dangerous practice was identified. This was of a local psychiatrist who point blank refused to accept that one of the men could have bulimia.

Importance of a knowledgeable, prompt and sympathetic response by the GP

Whilst some of the men had received a very prompt response from the GP; for example, it was a GP who identified that there was a problem with one of the young men when he saw him in town and referred him to a child psychiatrist. The lack of recognition by the GP of the problem or the severity of it and the consequent time it took to get specialist help, was a difficulty experienced by five of the men on at least one occasion. For one man, it was only when he did not see his normal GP that he finally got referred to a specialist service after 14 years of suffering from severe anorexia and bulimia. By the time he reached the specialist service, he was severely ill and it was the first time that anyone given him appropriate medical checks.

GPs were seen as crucial, both because they often dealt with men on an ongoing basis and because they had the power to make appropriate referrals and also to issue medical certificates.

A clear need was identified to make GPs more aware of the issue.

Dealing with life issues as well as weight

Whilst specialist expertise was considered important, four of the men reported that it was also important to them that the practitioner did not just deal with weight issues and doled out medication. It was beneficial if they took a broader view of life issues and allowed more general exploration of these. They also wished for the weight issues to be viewed in the context of their lives and problems.

In Patient Treatment

The in patient regime in hospital was described as 'harsh' and 'like a prison' by two of the men, who were eager to leave as soon as possible, although they had been ill. One described it as 'like prison' where you had to eat everything put in front of you, if you did not it was piled up meal after meal.

Two of the men had found themselves being in patients in their 30s; one spoke about being a middle aged man in a ward with mainly 16 and 17 year old girls but felt, that there was a considerable overlap between their issues and his.

'I thought that men did not get eating disorders. It came to me when I was in a psychiatric unit, it took time to come to terms with that (he spent 7 months in a unit). He said he experienced the same thoughts and feelings as the girls, fear of weight gain, control, secrecy.'

This does suggest however, that the length of time it can take to get problems recognised can mean that men end up dealing with their eating disorders later on in life after a pattern has been established, rather than having that opportunity when they are younger.

Gender of practitioner

The men were asked whether they considered the gender of the practitioner to be important. None of the men considered this to be the most important issue; several said that they found it easier to speak to a woman. Others had experienced good and bad professionals of both genders and thought that the skill and attitude of the professional were far more important than their gender. For example, one man had seen a male counsellor who he thought was 'useless' and had gone on to see a female child psychiatrist who he found was 'brilliant'.

Knowledge of men's issues

Whilst knowledge of men's issues was not considered the most important issue, being in a group with men had given one man in the sample an opportunity to explore a wider range of issues to do with masculinity and self image. It is logical to assume that access to a sympathetic trained man might be of benefit on some occasions and that knowledge about the specifics of eating disorders in men, should be acknowledged as important by practitioners. For example, some of the men identified issues to do with the different times and ways in which men and women experience adolescence, and bodily changes, the pressure to be seen as strong as a man etc.

Overall the men identified considerable overlap between the thoughts and feelings that women experienced and their own.

Access to Groups/ other men who had experienced eating disorders

Two of the men had been involved with EDA groups. Others had either not considered it because they wanted to put the disorder behind them or did not know about groups in their area or were wary about them for a variety of reasons, including the likelihood of being the only man in the group.

Having contact/access to other men who had experienced eating disorders was seen as desirable by almost all of the respondents. One suggestion was an e mail list for men, another a clearly publicised way in which EDA could put men in touch with each other.

Three of the men had volunteered to be a contact for EDA and one of the men is already involved with EDA as a male contact.

The gay men highlighted the importance of having a visible gay male contact.

Only one had experienced any service particularly aimed at men (the men's group in Newcastle). He reported this as having been very useful for social support and lessening the isolation of the disorder. He keeps in touch with another member of the group in between the sessions.

What helped in addition to services?

One man reported that his partner had helped him a lot.

Another that he decided to take control over his life after seeing a programme about people starving in Somalia, where they had no alternative.

Another had found a group dealing with being gay and a Christian invaluable.

6. Conclusions and Recommendations

There was a great deal of interest from both professionals and men with eating disorders in taking this work further, a variety of ideas were suggested (see below).

There was a good deal of overlap between the literature review, the input from clinicians and the men themselves in what constitutes good practice for men and women,. There were however, some differences in the routes into the disorders, the vulnerability factors, accessing services and the appropriateness of treatments.

Masculinity plays a part in the way in which eating disorders develop and are experienced by men whilst overall there is still a great deal that is not known about the development, treatment and outcomes in males.

There are ongoing problems with men accessing services at an early stage of their disorders.

Recommendations

EDA need greater publicity about men with eating disorders and to highlight this issue.

Consideration also needs to be given to the most appropriate ways to effect this with different subgroups of men.

Bodybuilders for example, are a significant subgroup who develop eating disorders

Eating disorders are a significant issue in the gay male community and ways to raise the profile and understanding of these illnesses needs to be found.

Earlier recognition both by professionals and by men and their friends/family is an important issue, which needs to be addressed in schools, universities, the press and in primary care.

Suggestions that were made by professionals and men with eating disorders that the EDA might wish to consider were:

Including more men's stories in the newsletter and publicity

Explicitly targeting men in a publicity campaign

Recruiting a man with eating disorders to the Board of the EDA (if there is not one already there).

Carrying out a survey in primary care to raise awareness amongst primary care practitioners.

Targeting the gay press, running a workshop/training aimed at the gay male community

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Appendix 1

Aims of the study.

The EDA as part of its development strategy has commissioned this preliminary study to explore the perspectives of men with eating disorders. EDA has previously commissioned and supported research into the take up and acceptability of provision of treatment for all people with eating disorders in the United Kingdom. As part of its development strategy EDA decided to look at the needs of groups whose views have been underrepresented in this field. This study will explore the issues for men with eating disorders.

The aims of the study were identified as;

To identify the incidence and prevalence of eating disorders among men in the UK based on reviews of existing evidence

To gather information from male service users about the accessibility of services and the acceptability of service provision and factors which might hinder or assist their take up of services

To explore with key professionals and those involved with self help groups the current take up of service provision amongst men with eating disorders and whether they have identified particular issues in working with men

To produce a report which will inform discussion about the acceptability of current provision for men with eating disorders and highlight particular issues

After initial discussions a focus emerged for the brief on the views of men with eating disorders themselves. Although the sample cited in the study is very small the data does indicate some directions for further work. A number of other issues emerged in discussion, these were

How much overlap is there between what constitutes good practice for women and for men? Can their needs be clearly differentiated? What information exists about men and how reliable is it?

Appendix 2

Interview Schedule with service providers

Looking at needs of men with eating disorders

Contact with men in the last year? Is that typical?

Do they refer themselves/are they referred?

Do men and women seem to have different causes for their eating disorders?

Do men and women present differently?

Do men and women access the service differently?

Are men more reluctant to come forward?

Are there particular issues in treating / working with men with eating disorders?
For example?

Particular ages of men? Sexuality?
Circumstances?

Use particular gender of therapist?

Men able to talk about their difficulties?

Do you take gender into account within service, if so how?

Sense of what the optimum service might look like for men?

Do they know of any services specifically for men?

Do men and women use the service differently?

If so in what ways?

Who do you think you provide the better service to , men or women?
(Outcomes)

Appendix 3

E-mail questionnaire with service providers

I am carrying out this study on behalf of EDA about the needs of men with eating disorders. The National Eating Disorders Association has commissioned an initial review of the needs of men with eating disorders in the UK. They are interested in finding out how the needs of this group are addressed at present and in identifying ways in which services to men could be improved. I am interviewing/ contacting both men with eating disorders who are in contact with the EDA and a number of specialist service providers to gather information.

I am e-mailing the specialist service providers in London to see whether you would be willing to provide some more information relevant to the study about your service. I attach some questions as a guide which I would be grateful if you could e-mail back to me, by the (date). Please feel free to add information you think is important or skip parts if they are not relevant to your service. I would of course be interested in any other information or views you have which you think might be relevant to the study. If you would prefer to speak to me or have any queries I can be reached on xxxxxxx (home and messages), or xxxxx extension xx (Wednesdays, Thursdays and Fridays.) Thank you for your help and I look forward to hearing from you.

I. What kind of services do you provide?

Outpatient?

In patient?

Psychotherapy/counselling

Community based support

Group work

Helpline

2. How big is your service

How many people does it serve (approximately)

How many male staff/women staff work directly with service users in it?

How many people were referred to the service in the last year? (approx)

How many men were in contact with the service in the last year? Is that typical?

Do men come themselves/are they referred?

Have you noticed any differences on referrals for example

are the men older/younger roughly the same age as the women?

Are their circumstances similar/different? If so how?

To your knowledge what proportion of the men you are seeing are gay? Do you provide any specialist support for them?

Are there any particular issues with referral that you would like to raise?

(For example Do you think that men more reluctant to come forward?)

Vulnerability Factors

Do they present differently? If so how?

Do men and women in your experience seem to have different vulnerability factors for their eating disorders?

Treatment

Do you take gender into account within your service? If so , how?

Are there any particular issues in treating/working with men with eating disorders?

For example?

Were there particular parts of the service which were used more heavily by men

Do men take part in group work(if you offer it?) how well does that work?

In your experience are there any significant differences in the outcomes for men and women?

Any differences?

Specialist services for men

Do you know of any services specifically for men with eating disorders? (Apart from the work in Newcastle?)

Have you considered offering any particular service?

Do you have a sense of what the optimum service might look like for men?

Are there any steps you would like to see taken by the EDA/others to improve service provision for men?

Any other comments?

Appendix 4**Interview Checklist** (Interviews with men with eating disorders)**About self**

How long had an eating disorder? (What kind? If relevant)

When did it first come on? (Anything that brought it on?)

Where looked for help?

How long took to find help?

What needed at the time?

Contact with services over the years? (GP, specialist services, self help groups, inpatient treatment)

How well services met needs at those times?

What kind of treatments had for eating disorders?

Was this influenced by gender?

Their views

Anything that would have been useful in the treatment of their eating disorders?

Are the issues different for men and women?

A good experience or a particularly bad experience?

How would they rate the response of services overall?

Have they ever been offered a choice of gender of practitioner?

Is this important?

Anything that they think the EDA could do to help?

Anything else would like to say

What kind of treatments had?

Appendix 5

Example of work with men

(NB Sadly this group closed down in mid 2000)

Since 1997, a group has run in Newcastle, three times for an 8 week period each time.

The men were recruited from different parts of the service, internally.

14 letters were sent out and 6 responses received initially.

It ran as a support not a treatment group, run by 2 male nurses and a trainee psychologist. The professionals came primarily as men not as professionals so they came prepared to discuss issues about masculinity.

Rationale for the group

The social pressures on the male group were seen as being different from women. Most of the work on eating disorders has treatment worked out from the female point of view in the psychology literature. They saw the need to think about practice for men with eating disorders. There was no blueprint for a male group. It was felt that although there was considerable overlap, the issues about sexual confusion and sexual identity was not the same for men as for women. Issues about where men can get support from were also discussed.

Each group ran for an hour and a half. The men themselves came up with the topics, a sample of these were their own problems, coping strategies, unemployment, relationships, depression, benefits, relaxation, and body image. The nurses structured part of the group to cover these topics.

The response to the groups was positive although the attendance was small. About 3-6 in the first group, 4-6 for most of them.

Men said that their trust of the facilitators and the group increased and their relationships within the group developed over time. They also kept in touch outside of the group and although initially, the discussions were superficial, this changed over time and the men were able to trust each other more.

