Preventing hospital admissions and improving quality of life are key priorities for those working with people with severe and enduring eating disorders.

Managing anorexia nervosa in the community

In this article...

- Identifying the need for a community service
- How the service was set up
- Evaluation and feedback

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This article describes the development and evaluation of a new specialist intensive community-based service for adults (those aged 18 years and above) with severe and enduring eating disorders (SEEDs). The service was developed by the Yorkshire Centre for Eating Disorders based in Leeds. We developed and evaluated a nurse-delivered community-based service that aimed to manage the complex needs of people with SEEDs without hospital admission. The service was shown to improve quality of life, reduce the number of hospital admissions and improve communication with other health professionals involved in service users’ care.

Anorexia nervosa is a severe psychiatric disorder with a mortality rate of 6% (Arcelus et al, 2011). For service users, the outcome is variable and recovery is often slow, particularly as treatment dropout rates range from 20% to 50% in inpatient settings (Wallier et al, 2009). The average service user with anorexia nervosa may have the disorder for a few years, but many will continue to be anorexic for many years, and some for life.

Service users with chronic anorexia nervosa have ongoing physical health problems, such as electrolyte and mineral imbalance, and psychological difficulties such as low mood and low self-esteem. The disorder can lead to social isolation, an inability to work and learn, and a loss of social activity (Birmingham et al, 2004).

Literature review

Despite the huge impact of severe and enduring eating disorders (SEEDs) on individuals’ lives, there is little evidence to guide care and treatment. An extensive literature review by Kaplan (2002) identified fewer than 20 controlled clinical trials into the effectiveness of using psychotherapy to treat anorexia nervosa. Evidence for the effectiveness of this intervention, with the exception of family therapy for younger service users with short illness duration, remains questionable. Kaplan concluded there is little empirical evidence behind the use of psychological treatments for anorexia nervosa.

Bulik et al (2007) conducted a systematic review of randomised controlled trials looking at psychological therapies for anorexia nervosa and found 11 studies, three of which included trials with cognitive behavioural therapy that had mixed results. One of the studies (Pike et al, 2003) found CBT had: a lower dropout rate than nutritional counselling; good outcome at the end of treatment; and service users did not relapse as quickly. Channon et al (1989) compared CBT with behavioural therapy and the usual care service users receive as outpatients and found no advantages to the use of CBT. A New Zealand study conducted by McIntosh et al (2005) found that, during the acute phase of the illness, non-specific supportive clinical management was more effective than CBT and interpersonal therapy.

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5 key points

1 Chronic anorexia nervosa can lead to social isolation, an inability to work or learn, and a loss of social activity
2 There is little evidence to support the treatment of those with severe and enduring eating disorders
3 Long-term eating disorder care is often provided in a hospital or hostel, or through ongoing support by a non-specialist community service
4 Community workers often feel treatment does not adequately meet the complex needs of people with eating disorders
5 Providing individualised specialist care in the community can help improve service users’ quality of life

Keywords: Eating disorders/Anorexia/Community services

● This article has been double-blind peer reviewed
Different interventions aimed at chronic eating disorders and its treatment was not addressed in the 2004 clinical guidelines issued by the National Institute for Health and Clinical Excellence (now the National Institute for Health and Care Excellence). The most commonly available models of service delivery include:

- Long-term care in an NHS environment or in a hostel;
- Ongoing support by a non-specialist community service;
- Physical health monitoring by GP alone.

None of these appears to meet the complex needs of this group.

**Identifying a need for change**

At Yorkshire Centre for Eating Disorders, the SEED service users were previously offered ongoing support by a non-specialist community service, which took on the care coordinator responsibilities. They were offered regular outpatient appointments with a specialist to monitor progress and saw their GPs for physical health monitoring. Service users were regularly admitted to the YCED inpatient unit as a result of their eating disorders.

We assessed the success of these treatment methods by surveying both community staff and service users. Community workers expressed dissatisfaction about failing to meet the needs of a relatively small yet highly specialised group. Service users reported that the local mental health services did not meet all of their needs. With this in mind, we developed a model of specialist community care that aims to:

- Promote fully independent living;
- Improve confidence, self-efficacy and autonomy.

The model is similar to the community-based programmes established for people who have chronic mental ill health.

**Developing the service**

We developed and evaluated this nurse-led community-based service over two years. The aim of it was to provide a comprehensive and flexible clinical service that met the needs of service users and prevented unnecessary admissions to hospital. This was to be achieved through the following objectives:

- Coordinate care across multi-professional settings;
- Provide a quality service in the community;
- Prevent readmission to hospital;
- Manage risk, including physical risk, in partnership with primary care professionals;
- Act as an intermediary between service users and other professionals;
- Provide support for service users and their carers;
- Promote self-management skills;
- Identify early signs of relapse;
- Provide more intensive management during high-risk periods.

The team included a clinical team manager, health support workers and a part-time dietitian. A consultant psychiatrist met with the team weekly to review the progress of service users; this individual also offered service users informal contact such as email.

The main focus was on the individual needs of the service users and the interventions that would support them in achieving fully independent living by promoting confidence, self-efficacy and autonomy. The team supported service users in developing strategies to self-manage their symptoms.

In the absence of an evidence-based definition for severe and enduring anorexia nervosa, standard referral criteria were adopted for the pilot phase of the community service (Box 1). The service accepted referrals that met at least two of these criteria. Those people who had a body mass index of <12 were assessed for admission to the YCED inpatient unit or a general ward, depending on severity of their physical health.

Service users were initially assessed by the clinical team manager in their own home. The health support workers, under the supervision of the team manager, visited service users on a regular basis, but changed the frequency of the visits to meet individual needs. Service users’ physical

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**BOX 1. PILOT REFERRAL CRITERIA**

Participants had to meet at least two of the following:

- DSM-IV diagnostic criteria for anorexia nervosa for minimum of four years
- Body mass index of 12 and above
- Several admissions to specialist eating disorders services
- Lack of response to long-term individual or group therapy
- Aged 18 years and above

Note: DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, fourth edition.
Innovation

BOX 2. OUTCOME MEASURES
● World Health Organization Quality of Life – Bref
tinyurl.com/WHO-BREF-score
● Eating Disorders Quality of Life Scale
http://edqsl.com
● Hospital Anxiety and Depression Scale
tinyurl.com/score-HAD
● Rosenberg Self-Esteem Scale
tinyurl.com/Rosenberg-Self-Esteem-Scale

health continued to be closely monitored by their GPs.

Obtaining funding for new initiatives can take time. The funding for the pilot phase of our service was provided by NHS Leeds and the process took several months.

The service started in April 2010 and the pilot was completed at the end of March 2012. It took approximately six months from the funding being secured to the point when service users were able to access the service (Fig 1).

Evaluation
The service was evaluated throughout the two years of the pilot and included both quantitative and qualitative data.

The team had contact with service users either face to face, by telephone or text. The majority of contacts were provided by health support workers as predicted in the service specification. The length of contacts varied from two to 7.5 hours, and the frequency of visits varied from weekly up to five visits per week, depending on service users’ needs and level of risk.

The team had regular contact with other health professionals involved in service users’ care including GPs, practice nurses, social services, and staff from the local general hospital. Health support workers attended the dietetic sessions with clients to ensure both services were offering consistent advice about dietary intake.

Service user feedback
Six service users agreed to participate in a semi-structured interview and reported that the team provided care they felt was specific to their diagnosis and individual needs. The treatment reflected the priorities of the service users, and care was well coordinated among primary and secondary health professionals. All participants said their experience of the community service was positive. The main themes were improved quality of life and accessibility and approachability of staff, as well as a reduction in the number of hospital admissions. In addition, service users reported that the interventions helped them to become more confident, particularly as they were often involved in planning and reviewing their own care.

The following are comments from two service users:

“...I have made a big difference. My eating has become a bit better, I am more able to do things, to go out and eat with my friends, more flexible with what I eat.”

“My health support worker was fantastic and supportive; it was like having a friend that supports you at the same time, it fits around my normal life.”

Health professional feedback
Eight members of YCED clinical staff – the nursing, medical, dietetic, occupational therapy and health support workers and three administrative staff – participated in a semi-structured interview. The findings showed a high level of satisfaction with the service. Staff identified a number of positive ways that it has impacted their work and recommended the community service be expanded to include service users with a less-severe level of anorexia nervosa so early discharge from the inpatient unit can be facilitated.

General hospital staff reported the service had helped to:

» Improve access for people with SEEDs to general wards by facilitating admission at an earlier stage;
» Have a clear plan of action in place for service users before admission;
» Support staff to manage SEED service users while on the ward.

Other benefits
A number of outcome measures were used to assess whether the service had an impact on users’ quality of life (World Health Organization Quality of Life – Bref, and the Eating Disorders Quality of Life Scale), mood (Hospital Anxiety and Depression Scale), and self-esteem (Rosenberg Self-Esteem Scale) (Box 2). The mean scores on all outcome measures were slightly improved at the end of the evaluation compared with the baseline. The average score for quality of life increased from 2 to 2.3, with social interaction the most improved area.

The community service reduced costs by 30% over two years as a result of reductions in the use of psychiatric hospital beds. On the basis of cost effectiveness, these results support the provision of specialist community services for SEEDs. By investing in the community model, the service reduced the number of inpatient admissions by 38%.

Conclusion
The community service was successful in reducing hospital admissions and consequently saved money. More importantly, it improved service users’ quality of life by providing intensive specialised support in the community, allowing them to stay in familiar environments and with the family unit. The findings of the interviews, feedback questionnaires and outcome measures show service users and health professionals are satisfied with the service.

The evaluation showed that service-user engagement had greatly improved as had professional relationships between stakeholders. The service started as a pilot, but its positive outcome has encouraged the trust to make it permanent.

References

Nursing Practice