



FoNS Improvement Insights

Developing a Recovery Based Quality of Life Service for People with Severe and Enduring Eating Disorders

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Project background

People diagnosed with an eating disorder are recognised as having a complex mental disorder that can compromise a person's physical, psychological and social wellbeing (NICE, 2004). In December 2011, an audit within Aneurin Bevan Health Board of patient care plans identified a number of patients with a severe and enduring eating disorder and highlighted that the majority of their care plans were maintenance based as opposed to having a focus on recovery. Some of these patients had had numerous admissions to both psychiatric and specialist eating disorder units for weight restoration and had longstanding physical and mental health problems.

Aim and objectives of the project

The aim of this project was to work in collaboration with patients to develop and implement a quality of life group for people with severe and enduring eating disorders within Aneurin Bevan Health Board. The objectives of the project were to:

- Work collaboratively with patients to understand their needs
- Develop and implement the quality of life group in partnership with patients
- Engage with key stakeholders in the patient journey
- Evaluate the impact of the group

Key activities and outcomes of the project

A number of activities were used to actively engage with patients to develop the clinic.

- Identification of patients

For the purpose of this project, the following criteria were agreed by the project team to identify those that may be invited to be part of the project: those living with an eating disorder for 10 years or more; those who have received care from mental health services for 10 years or more; and those whose mental health, physical health and social wellbeing is impeded by their eating disorder. A total of 21 patients were identified by the members of the Specialised Community Eating Disorders Service team. These patients were then invited to individual interviews with members of the project team.

- Patient interviews

Initial 1-1 patient interviews (n=11) took place in locations that were convenient to the patients and were designed to enable the project team to understand more about how eating disorders impact on the patients' quality of life. All the patients said they were very keen on the idea of a group specific to their needs and were able to share their past experiences of unhelpful treatment. None of the patients felt able to give up their eating

disorder but all wanted to improve their quality of life. Once all initial meetings had been held, the project team were able to invite patients to take part in a focus group to collaboratively plan the next stage of the project.

- Patient focus group

A total of five patients attended the semi-structured focus group. It was facilitated by the project team, both of whom have experience in facilitating groups. A variety of exercises were used including an icebreaker for introductions, hopes and fears for the project, cards with 'emotion' words on them were used to support patients to express themselves. Patients were then asked for their ideas for the group content and structure.

- Quality of life group development

The group started on 30th May 2013 with 25 sessions held to date. Based on patients' identified needs, a modular programme was developed. Using a non-clinical setting for the group proved invaluable, as patients reported feeling less stigmatised by this and felt more confident in a neutral environment. A total of eight patients initially started in the group, however, due to work and family commitments and current health problems a total of three patients have been able to fully commit to the group.

- Staff engagement

At the regular service away day, the project leader facilitated exercises designed to enable staff involved in the patient journey to engage with the project to encourage collaborative working and referrals to the quality of life group. Activities included a values clarification exercise and a claims, concerns and issues exercise to enable people to develop actions collectively.

- Evaluation of the quality of life group for people with a severe and enduring eating disorder

A number of qualitative and quantitative methods were used which strongly supported the effectiveness of the group. One person said *'As I say it's an escape place for me and I can say what I want to say about my eating and I won't be judged on it.'* While the team was disappointed that numbers were low, a new group has been commissioned following the learning from this project

Implications for practice:

- It is important to work in collaboration with patients from the outset of a project
- Creative activities can help patients express their experiences of a condition
- Focusing on quality of life rather than their eating disorder enabled the group members to feel heard and respected

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstdid=64664>

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