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

**Key words:** Severe and enduring eating disorders, quality of life, group work

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**Project Lead:** Emma-Jayne Hagerty, Tier 2 Clinical Lead for Eating Disorder

**Project team:** Beverly Williams, Specialist Occupational Therapist; Victoria Richards, Volunteer (Occupational Therapy Student)

**Contact details:** [Emma.Hagerty@wales.nhs.uk](mailto:Emma.Hagerty@wales.nhs.uk)

*In association with the Foundation of Nursing Studies and the Burdett Trust for Nursing*
Summary
People diagnosed with an eating disorder are recognised as having complex mental disorders that compromise a person’s physical, psychological and social wellbeing (NICE, 2004). For a small number of people they can be severe and enduring or even life threatening (Welsh Assembly Government, 2009). The aim of this project was to work in collaboration with patients to develop and implement a group for people with severe and enduring eating disorders within Aneurin Bevan Health Board with a focus on improving the quality of life of those involved.

A number of methods were used in the project including patient interviews, patient focus group, staff engagement activities and the development and implementation of the quality of life group. The quality of life group was run on a weekly basis for two hours. The first hour was led by clinicians and focused on teaching coping behaviours and the second half was focused on social or creative activities. In total 25 sessions were run and the three ladies that took part in the group were able to show an increased motivation to change behaviours towards their eating disorder.

A major objective for the tier 3 eating disorder service is to continue developing as a service, including developing new and effective treatment packages. This project enabled the service to work collaboratively with patients to challenge the idea that treatment had to focus on weight gain and provided an opportunity to explore how an eating disorder impacts on quality of life and explore ways of improving this while not focusing on changing eating disorder behaviours.

The project team were enthusiastic and motivated to find a more effective way of working with a patient group who historically are difficult to engage in treatment options. They were also motivated to challenge their own practice and consider new ways of working. This project provided the team with an opportunity to do this.

Introduction
People diagnosed with eating disorders (ED) are recognised as having complex mental disorders that compromise a person’s physical, psychological and social wellbeing (NICE, 2004). For a small number of people they can be severe and enduring or even life threatening (Welsh Assembly Government, 2009). In 2009, the Welsh Assembly Government introduced the Eating Disorders Framework for Wales outlining the roles and responsibilities of clinicians and services from primary care through to tier 4 specialist inpatient services. Prior to this there were no formal arrangements for the treatment of people with eating disorders. The project team had discussed this and noted that in Wales there seemed to be a high proportion of women, and to a lesser number men, living with an eating disorder of a severe and enduring nature. The framework sets out the following services (see Appendix 1):

Tier 1: Primary care
Tier 2: Generic mental health services e.g. community mental health teams (CMHT)
Tier 3: Specialist community based teams working with complex and high risk patients
Tier 4: Specialist inpatient services
The Gwent and South Powys Tier 3 specialist eating disorder service provides consultation, support and direct joint working to tier 2 and allied clinicians. Funded since 2010 by the Welsh Government, it provides individual, group and family interventions and has an explicit 'gate keeping' role for any patients requiring referral to the specialist inpatient services. The philosophy and working ethos of the tier 3 Specialist Eating Disorder Service is to respect and value the experience and views of sufferers and their carers in the planning and review of all aspects of their care and to engage with sufferers and carers as a valuable source of knowledge and expertise for service evaluation and planning. There is a designated contact with two ring fenced sessions for people with eating disorders within each CMHT in Gwent and South Powys. There is also a specialist tier 2 eating disorder Lead Clinician post to support the CMHT and the implementation of the 5 Standards identified within the Eating Disorders Framework. Together, these clinicians form the Specialised Community Eating Disorders Service (SCEDS). The SCEDS service meets on a fortnightly basis to discuss service development and clinical cases.

The nature of eating disorders means recovery is a very frightening prospect for those who are suffering from this condition (Vitousek et al., 1998). The eating disorder becomes such an integral part of the person’s life and identity that life without it often seems an unrealistic, daunting prospect. Eating disorders often affect every aspect of a person’s life; it is also very difficult for those who have not experienced the disorder to understand it. This can leave people feeling very isolated and alone in their problems. Consequently, some people with a severe and enduring eating disorder may be ambivalent regarding recovery or express a complete lack of interest in change. Often, recovery is focused on weight gain which can lead to poor engagement on the patient’s part and frustration with a lack of treatment options for clinicians (Geller et al., 2001).

Best clinical practice for caring for people with eating disorders is based on NICE guidance (2004) and recommends psychological interventions with a focus on risk reduction and weight restoration. However, there is no provision for the specific needs of patients with a severe and enduring eating disorder within these guidelines. As recognised by Robinson (2009), the needs of someone with a severe and enduring eating disorder will be very different to the newly diagnosed. This is a relatively new topic of focus for international research; therefore, there is currently limited evidence into best practice for this specific client group. Expert opinion suggests a recovery based approach with a focus on quality of life, similar to the models used for other severe and enduring mental health conditions including psycho-social interventions (Robinson, 2009; Tierney and Fox, 2009; Bramford and Mountford, 2010).

In December of 2011 an audit within Aneurin Bevan Health Board of patient care plans identified a number of patients with a severe and enduring eating disorder (SEED) and highlighted that the majority of their care plans were maintenance based as opposed to a focus on recovery. Some of these people had had numerous admissions to both psychiatric and specialist eating disorder units for weight restoration and had longstanding physical and mental health problems. This led the project lead to apply to the Patients First Programme at the Foundation of Nursing Studies to develop and implement a quality of life group for people with severe and enduring eating disorders.
Aims 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 with a focus on improving the quality of life of those involved.

The objectives of the project were to:
• Collaboratively work with patients to understand their needs
• Engage with key stakeholders
• Develop and implement the quality of life group
• Evaluate the impact of the group
• Help patients develop self management packs

Methods and approaches
A number of methods and approaches were used within the project. These included:

Table 1: Methods and Approaches

<table>
<thead>
<tr>
<th>Method</th>
<th>Date</th>
<th>Approach</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search current patient data base</td>
<td>May 2012-Dec 2013</td>
<td>Criteria agreed Presented at SCEDS Letters to CMHT</td>
<td>21 patients identified</td>
</tr>
<tr>
<td>Patient interviews</td>
<td>Jan 2013-March 2013</td>
<td>Invitations sent to patients Telephone follow up if no response Brief assessment tool developed</td>
<td>11 patients attended Follow up meetings arranged Invited to focus group</td>
</tr>
<tr>
<td>Focus group</td>
<td>1 April 2013</td>
<td>Neutral venue booked Invites sent Ice breakers Hopes and Fears Evoke Cards used to talk about emotions</td>
<td>5 patients attended Posters for group created Re-named HOPE project Start date agreed</td>
</tr>
<tr>
<td>Commencement of quality of life group</td>
<td>30 May 2013</td>
<td>Modules developed Evoke cards implemented</td>
<td>3 patients consistently engaged for majority of project. Positive outcomes- Improved QOL Increased motivation for change / changes to ED behaviours</td>
</tr>
<tr>
<td>Staff engagement activities</td>
<td>25 June 2013</td>
<td>SCEDS away day Values and Beliefs exercise Claims concerns issues exercise</td>
<td>Positive feedback</td>
</tr>
</tbody>
</table>
Identification of patients via patient data base search

A literature search identified a number of differing definitions for people with severe and enduring eating disorders. These results were compared with those patients identified in local audit and for the purpose of this project, the following definition was agreed by the project team:

1. Living with an eating disorder for 10 years or more.
2. Has received care from mental health services for 10 years or more.
3. Mental health, physical health and social wellbeing impeded by disorder.

The proposed project was presented at the regular SCEDS meeting with a request for referrals for patients who met the agreed criteria. Participants at the meeting comprised designated contacts from Tier 1, 2 and 3 services and provided access for the project team to a multidisciplinary group of nurses, occupational therapists, psychologists, dieticians, doctors and counsellors with a wealth of information and experience. Following this initial presentation, the project was then added onto the regular agenda for the SCEDS meetings and a letter was also sent to all Community Mental Health Teams (CMHTs) inviting further referrals (see Appendix 2).

A total of 21 patients were identified by the members of the SCEDS meeting. These patients were then invited to individual meetings with the project team (see Appendix 3 for copy of letter.) However, after initial disappointment by poor attendance at first appointments, the project team quickly learnt that an appointment letter was insufficient and they recognised the need to do more in order to engage patients fully. Telephone calls were made to all the identified patients, providing the opportunity for questions and clarification. A total of 11 people attended initial meetings following this approach.

Patient interviews

Initial 1-1 patient interviews were an essential part of developing the project. These interviews took place in locations that were convenient to the patients; NHS buildings, their home or neutral locations such as voluntary sector buildings. The interviews were designed to enable the project team to understand more about how eating disorders impact on their quality of life and how they would want this to improve. The interviews consisted of a brief informal assessment to gather information about their quality of life (see Appendix 4 for assessment template), this information was then used to inform the development of the quality of life group programme. All the patients gave feedback that they were very keen on the idea of a group specific to their needs and were able to share their past experiences of treatment that had been unhelpful. None of the patients felt able to give up their eating disorder but all wanted to improve their quality of life. The project team wanted to take a collaborative approach to the group development. Once all initial meetings were 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

Focus groups are an efficient way of obtaining opinions (McDonagh-Philp and Bruseberg, 2000) and allow for in-depth discussion and exploration of experiences (Gerrish and Lacey,
In order to ensure a fully collaborative approach to the development of the project, a patient focus group was held on 11th April 2013.

It was noted during the 1-1 interviews that those patients whose appointments were at neutral locations appeared more relaxed than those in NHS settings. Patients were also asked for their opinion on a suitable location for the focus group and the general consensus was that a neutral location would be preferable. The health board covers a large geographical area; the team researched the most central and cost effective location and a community centre was identified. The project team also felt that moving away from medical settings was more in keeping with the theme of the project. A map and instructions were included with an invitation to direct patients to the community centre.

A total of five patients attended, with apologies received from four others. The focus group was held over two hours, with a semi structured approach (see Appendix 5 for plan). The focus group was facilitated by the members of the project team, both of whom have experience in facilitating groups. An icebreaker was used for introductions and taking inspiration from the FoNS Patients First workshop, patients were asked to complete their hopes and fears for the project. These were sealed in a time capsule to use as an outcome measure at the end of the project. Emotional words were also used to assist patients in expressing themselves. Words related to emotions had been written on cards and patients were invited to pick the cards that related to how they felt about participating in the project. This allowed further exploration of their thoughts and feelings surrounding their needs. Patients were then asked for their ideas for the group content and structure. The project team then presented their ideas for group discussion to ascertain patients’ thoughts.

The phrase severe and enduring eating disorder is a very clinical term and can also suggest a lack of hope (Bramford and Mountford, 2010), therefore, as part of the focus group, participants were asked to design a poster/s of what the group means to them and to come up with a name for the group.

Three of the patients engaged well in the poster and naming activities whilst two opted to sit out. Patients opted to call the group ‘The Hope Project’, as they felt this reflected what the group meant to them, and is shown in the poster below.
Due to the nature of eating disorders, lunch or snacks were not felt appropriate so the project team opted to provide patients with a small gift bag and some items to demonstrate their contributions were valued. Tea and coffee refreshments were also provided. All costs for patient participation were met by the FoNS bursary.

Initially the project team were a little concerned by the small number of patients who were able to attend, however, on reflection it appeared that a smaller group of people was more conducive to discussion. The project team also felt they may have underestimated how challenging the event would be to people and therefore expected more contribution than was initially forthcoming. Patients initially struggled to share ideas, so the project team took the lead by making suggestions. In time, the patients became more involved in discussions.

**Quality of life group development**

Following on from the focus group, a mutually agreeable start date was set and the group commenced on 30th May 2013 with 25 sessions held to date. Based on patients’ identified needs, a modular programme was developed (see Appendix 6). Patients had appreciated the neutral environment for the focus group so, using the FoNS bursary, it was agreed to hire this for the duration of the project. Identifying a non-clinical setting for the group proved invaluable. Patients reported feeling less stigmatised by this and felt more confident in a neutral environment. A total of 8 patients initially engaged in the project, however, due to work and family commitments and current health problems a total of 3 patients have been able to fully commit to the group.

The group was held on a weekly basis for a 2 hour period and split into 2 sections. The first half of the session was more clinician led and focused on the module theme e.g. anxiety, with the second half focused on social or creative activities. The ability to participate in community based activities was also provided. Evoke cards were introduced to assist
patients in expressing their emotions at the beginning and end of the first group. Evoke cards use images and words to express emotions and can be used in a variety of settings by groups or individuals (Stokes, 2014). As this was a successful exercise; a group decision was made to utilize them at each session. The aim of this was; firstly, to assist patients in identifying and communicating their feelings and secondly, to provide feedback to facilitators on the impact of each group session.

Over time, there have been three main changes in the group. Firstly, initially the project team felt compelled to plan and structure the sessions. However, it was found that a more relaxed, semi-structured plan fitted the ethos of the project better as this allowed patients to be more involved in the design of the project on a weekly basis. This led to the original methods and content being adjusted based on need. Patients are now taking more of a lead in the sessions, making suggestions for future content and activities. Secondly, using the alternative approach, by focusing on strengths and new ways to manage difficulties, an improvement in confidence, communication and self esteem has already been recorded. Finally, patients were less keen on social and community based activities as a group with attendance at a pottery centre the only activity participated in.

Unfortunately, only one person was able to complete the group in its entirety due to the other members experiencing additional health problems. Final outcome measures for the patient who completed the group indicate an improvement in both ED symptoms and QOL.

**Staff engagement**

As the SCEDS have regular clinical and service development meetings, these were utilised to engage staff in the project. Due to the clinical and managerial workload of the various staff stakeholders it was felt this would ensure more engagement rather than hold additional meetings specific to the project. The SCEDS service also holds an annual away day that is facilitated by the project lead and more formal staff engagement activities were planned for this to ensure maximum attendance and participation. Eighteen people attended the away day namely, the community care co-ordinators, service managers, specialist clinicians and primary care clinicians from all tiers of both CAMHS and adult services. The day began with introductions using the Evoke cards as prompts. Attendees were asked to select a card that appealed to them and introduce themselves and provide an explanation for their choice of card; a project member went first to demonstrate the process. An update on the project was provided using patient quotes and posters and then stakeholders were invited to participate in some practice development exercises.

**A. Values and beliefs clarification exercise**

Values and beliefs influence a person’s behaviour and consequently professional practice, therefore, to ensure effective team working, shared values and beliefs are necessary (Clark, 2008). A values and beliefs clarification exercise facilitates the development of a shared vision which underpins practice development and can influence change (RCN, 2007).

A values and beliefs clarification exercise was facilitated by the project team to enable the development of a mission statement, or shared vision, for the SCEDS. A total of 1 hour and 10 minutes was set aside for completion of this task. Attendees were asked to complete the following statements individually:
I believe the ultimate purpose of SCEDS is:
I believe this purpose can be achieved by:
I believe the factors that help us achieve this purpose are:
I believe the factors that hinder us from achieving this purpose are:
Other values and beliefs I consider important in relation to SCEDS are:

Attendees were then asked to form small groups to discuss their answers. To support collaborative working and enrich the discussions, the small groups consisted of members from different services. Everyone was then asked to join a larger group discussion to enable a shared mission statement for SCEDS to be developed. The Specialist Eating Disorder Service is a relatively new and therefore still a developing service, so there were other developments and areas that also needed considerable time and attention from the SCEDS. Commencing with this exercise enabled discussion regarding these areas prior to focusing on the project in the next exercise. The following shared mission statement for SCEDS was derived from the values and beliefs clarification exercise:

“The purpose of SCEDS is to provide clinically effective evidence based interventions to ensure the best possible outcome for patients. This will be achieved through providing a supportive clinical network that provides a safe environment for professional and personal development, reflective practice and collaborative working.”

B. Claims, concerns and issues
Collaborative working is essential to practice development and needs participation from all stakeholders and person centred principles can support this process (RCN, 2007). A claims, concerns and issues exercise invites stakeholders to share their views on a topic; claims addresses positive assertions, concerns focus on the less favourable, while issues are questions which reflect on the topic (Guba and Lincoln, 1989).

Again, this activity was facilitated by both members of the project team with 1 hour and 10 minutes set aside. The process was explained and attendees were invited to consider the following questions individually:

- CLAIMS: What positive statements would I make about the HOPE project?
- CONCERNS: What are my concerns about the HOPE project?
- ISSUES: What questions do I have about the HOPE project?

The facilitators then invited attendees to write their answers onto ‘post it’ notes and attach them to the relevant sheet of A3 paper placed around the room under the titles: Claims, Concerns and Issues. The information was then collated by the facilitators and a large group discussion was held. This activity proved invaluable as it allowed the project team and stakeholders to reflect on and discuss their thoughts and concerns regarding the project. It was evident during the activity that everyone had very positive views regarding the aim behind the project and were supportive of a new way of working with this particular client group. Stakeholders were particularly taken with the patients’ poster and stated this instilled hope in them. From these concerns, the following questions were formed:
• What happens at the end of the project?
• Can people join at a later date?
• Are we colluding with the eating disorder?
• What will you do if people start sharing eating disorder tips?
• How will you manage risks?
• How is the bursary being spent?
• Will criteria be reviewed?

These questions were used by the project team to inform the action plans for the project.

Feedback from all those that attended the away day was positive, however, the project team were regretful that only verbal feedback was gathered. The project team plan to use creative methods for all future staff engagement activities.

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

A number of qualitative and quantitative methods have been used to evaluate the effectiveness of the group.

*Creative scrap book*

Creative evaluation methods were essential within this group as during our initial meetings with group members, many of them reported that they enjoyed creativity and found it meaningful. This was also evident in the initial focus group through the creation of the poster. Schmidt (2005) (cited in Peruzza and Kinsella, 2010) suggests that creative activities can increase self-esteem and develop a sense of purpose and belonging, as well as empower individuals and foster autonomy along with competence. The creative scrapbook was used in the group at a time when the focus shifted specifically to the impact of their eating disorder on their quality of life with the hope of increasing their motivation for change. The scrapbook provided group members a non-threatening means to explore their eating disorder in more detail and identify for themselves the negative effect it was having on their lives, this in turn had a positive effect on their motivation for change and this is clear within the scrapbooks. The scrapbooks also provided the project team with an opportunity to evaluate motivation, and provided the group members with a ‘tool box’, a way of coping when things became difficult either by reading back through the scrapbook or adding bits to it. During the creative scrapbooking the group members were given a different topic each week, such as life maps, how they would describe themselves, their values away from the eating disorder, future goals, dreams, safe places and recovery focused topics. Creative resources, such as a scrapbook, craft materials and magazines were purchased with the bursary and used to develop and expand on these topics in a creative and individual way for the patients to develop their own ‘tool box’.

*Hopes and fears time capsule*

The hopes and fears time capsule was opened on the last day of the group; members were asked to read out their hopes and whether the group had met these expectations. Fears were discussed and members reported that these had been alleviated by attendance at group.
Example of hopes and fears:
- To feel less alone in my battle against my eating disorder
- To have made some steps towards letting go of my eating disorder
- To be able to say I have made changes to my current relationship with food
- My anxieties surrounding food and weight to have reduced
- For recovery to feel possible
- To reduce guilty feelings around food

**Patient focus group**
A focus group was held approximately halfway through the group programme to ascertain views up to that point and help with planning the following six months. The project team felt that it was important that the group was led by someone who was independent of the group to enable feedback to be as honest as possible. A third year student occupational therapist on placement with the project team acted on a voluntary basis to receive feedback from the group. Two members of the group were present. The group began by using Evoke cards to express how they were feeling and then a semi structured interview was facilitated by the occupational therapy student. The main themes drawn from the focus group feedback were; the group providing a safe environment, reduction in isolation and loneliness, benefits of exploring different ways of working such as creative work and the group providing opportunities to build positive relationships.

Some examples of questions and answers from the focus group:

**What has been your overall experience of the group?**
A For me it’s a place I can come and say things that I need to say that I can’t say at home so …. and by saying them it helps me to improve my life at the moment.
B For me it’s been …. it’s alleviated a lot of the loneliness for me before I was just very alone in all of it, and I think having the group has just made me not feel quite as alone with it.

**What have you found most useful in the group?**
B I think the Evoke cards at the start and at the end are really helpful and also the structure and techniques whether it be a game or crafts, arts those kinds of things have been really useful.
A Same here, I think working on the things we have been doing in the last couple of weeks, the writing, we’ve been making posters for the eating awareness thing, that’s made me open my eyes a lot, I was really interested in them.

**Is there anything in the group that you don’t particularly like?**
A I’m not big on drawing and I tend to seclude myself from that because I draw and I write terrible, so I just sort of sit here. I don’t mind sitting and watching, it’s not that I’m sitting here thinking that I don’t want to be here, I’m quite happy to sit and watch someone else.
B I think for me as well it helped a bit when we do all these craft things I can lose myself a bit just sit there and draw or whatever it is and just a distraction.
B I think the thing that I found a little bit unhelpful would be I feel there have been no boundaries in place from the start so I suppose all of us at different points have either displayed things or said things which invariably at times have probably triggered something off in another, with no intention of causing any problems, that’s what I found hard, there’s no boundaries and I’m not really sure, it would probably be more helpful if there were boundaries in place, but that’s from my experience it might be different for other people. Yeah, kind of rules, it’s difficult to explain, but also what I find really nice about Professional A and Professional B and yourself is that I’m so used to having professional people and obviously they know so much about your life but they never tell you anything about theirs which is fine because there’s a whole issue of boundaries, I’m thinking of when I was in hospital which is fine, but with Professional A and Professional B it’s almost as if you are let into their life, because obviously we knew with Bev she’s getting married and I thought that was a really nice thing, I never felt able to say anything about it but I thought that the fact that they share a little bit with us is really nice. Because they know a lot about us and that’s the first time in all these years really I’ve encountered professionals who have let you into their life a little bit and I thought that was really, really nice, really genuine.

How has the group impacted on your life?
A 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.
B For me like I said earlier, it was reducing the loneliness, up until I had this group it was very much a secret, I felt very much on my own with it and having this group was just, has been really helpful because I’m not so alone and I’m able to talk about it, in the past it felt like I’ve never been able to talk about it. I feel my team, my professionals just ignored it as if it’s not a problem and I’ve just got on with it and on with it and struggled so much so to have this group, yeah was a huge relief really, a really, really big relief for me.
A I think with the consultants too, normally they talk and you just say ‘yes’ or ‘no’ when they get together and they’re talking about you but not to you in a way because you just say what you think you should be saying back to them all the time, you’re not actually included in the conversation. Do you find that?
B Yeah, and I find with Professional A and Professional B they’re so friendly you forget about their roles, being a CPN or OT, sometimes it’s quite intimidating with professional people, but I think with Professional A and Professional B it’s been nice.

Do you think you will feel better after this group?
A I feel stronger and in a better place, I try to stand up for myself a bit more which I wouldn’t before. Even the thing with Professional A last week I could never have done it before not in a million years, I planned what I was going to say before I came I planned it through whereas not in my wildest dreams would I have ever done it before, so it’s taught me that I can speak up, I will be heard, but I can’t do it to my own doctors though, it stops there!
B I think for me, this morning I’ll wake up and think I’ve got the group, I’ll lie in bed for a while and think how I feel and I think of the cards and the words so I’ll think of something ready to say, so it’s made me think about how I’m feeling, usually I just
plod on in my own little way and I don’t, not aware, so it’s made me more aware of how I’m feeling and what’s actually going on.

B With the arty crafty things I don’t read magazines or anything but once Emma and Bev they fetched some little crossword magazines and word searches and I bought one of the word search books as well, I find that’s quite a good distraction, you don’t realise how long you’ve been doing it for, so that’s been good because I don’t usually try anything like that because I never seem to be in the right frame of mind but since this group I thought about it and oh yeah that’ll be good I’ll try that. So yeah it’s definitely made me think about the things I can be doing to help myself.

Quality of life assessments
Prior to starting the quality of life group, the patients were asked to complete quality of life assessments. These were repeated at the end by the one patient who was able to attend all of the group sessions.

Quantitative
- Eating Disorders Examination Questionnaire (EDE-Q) (Fairburn and Beglin, 2008)
  The EDE-Q is a self report measure of eating disorder symptoms. It asks 28 questions regarding eating disorder thoughts and behaviours experienced over the previous 28 days. Patients are asked to score from 0 (no days) to 6 (every day). It has 4 subscales; restraint, eating concern, shape concern and weight concern; with the overall global scale being the average of these. A reduction in global score indicates an improvement.
- Clinical Impairment Assessment (CIA) (Bohn and Fairburn, 2008)
  The CIA is a 16 item self report measure of the psychosocial impairment due to eating disorder features. It focuses on the previous 28 days and covers the domains normally effected by eating disorder psychopathology; mood, self perception, cognitive functioning, interpersonal functioning and work. The scores range from 0-48 with a higher score indicating more severe impairment.
- Clinical Outcomes in Routine Evaluation (CORE-OM, 2015)
  The CORE-OM is a 34 item measure of psychological distress. Another self report measure, it focuses on important aspects of psychological wellbeing over the previous week. Higher scores indicate higher levels of distress.
- World Health Organisation Quality of Life questionnaire (WHOQOL Brief) (WHO, 2015)
  The WHOQOL is a 26 item self report measure examining how an individual feels about their quality of life. It asks people to rate their satisfaction with areas of their life and each answer is scored from 1 (not at all) to 5 (completely). Improvements are indicated by higher scores.

Total scores for the patient who completed the whole programme are as below and highlight an improvement in all areas.

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDE-Q</td>
<td>4.77</td>
<td>1.19</td>
</tr>
<tr>
<td>CIA</td>
<td>35</td>
<td>11</td>
</tr>
<tr>
<td>CORE</td>
<td>97</td>
<td>69</td>
</tr>
<tr>
<td>WHO-QOL</td>
<td>50</td>
<td>79</td>
</tr>
</tbody>
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• The number of psychiatric, medical or eating disorder inpatient admissions
  It was also felt important to explore the number of admissions the patients had during
  the time of the group, as historically this patient group spends large amounts of time in
  hospital. For 2 of the patients in the group their hospital admissions to both A+E and
  psychiatric wards reduced, and they were able to positively reflect on this and identify
  the use of more positive coping strategies.
  o 1 patient did not receive any admissions during time of group.
  o 1 patient had a number of admissions to both medical and psychiatric settings;
    unrelated to ED.
  o 1 patient had admission to general medical bed.

Discussion
The initial objectives of the project were to engage patients and stakeholders in the project.
Initially, the project group were concerned that stakeholders might feel that the small
number of patients recruited (8) and the fact that only one patient completed the group, did
not justify the time and resources. However, this was not raised during any of the staff
engagement activities and it was agreed that making a difference for just this small number
would be beneficial for the patients, staff and Health Board. The project has also provided
evidence to support the development of another QOL group for patients with other
presenting problems.

In terms of the group; the project has met the aims, albeit for a smaller number than
originally intended. Especially with regards to client engagement and ownership; the project
team quickly learned to be flexible and be guided by patients regarding their needs and
what factors would influence this. Whilst the overall aim and methods remained, there was
a recognised need to be less structured and allow the group members to decide the theme
and content of some sessions.

What went well - and why?
Taking the focus away from the patients’ eating disorder proved the most successful
method of the group. By focusing on their quality of life and moving away from a focus on
the eating disorder, enabled the group members to feel heard and respected. Working in a
smaller group enabled people to talk in more depth and really relate to their own
experiences. Patients frequently spoke positively of this experience and compared it
favourably to previous treatment experiences. Whilst they reported an improvement in
their understanding and management in areas covered by the modules, they recognised
their ED was preventing them from improving their quality of life further. Consequently, a
group decision was made to complete a module focused on contemplating change in ED
behaviours.

For the group member who completed the group in its entirety; there was a noticeable
improvement on Quality Of Life and ED symptomatology. She stated that her hopes for the
group as recorded in time capsule were met. Below are examples of the hopes she
identified in the time capsule:
  • To feel less alone in my battle against my eating disorder
  • To have made some steps towards letting go of my eating disorder
  • To be able to say that I have made changes to my current relationship with food
- My anxieties surrounding food and weight reduced
- Recovery to feel possible
- Guilty feelings about food diminished

The use of a neutral environment was very successful in engaging the patients in the project from the offset. Patients reported this provided a relaxing atmosphere and gave them a sense of equality. Patients were reassured by the financial support provided by the bursary in order to assist them in travelling to the location.

The Evoke cards proved an invaluable tool. A shift in the way patients utilized the cards was noted over time. Initially, patients would opt for images they liked but in later groups, they chose ones that were more expressive emotionally, as can be seen in the examples below;

**Early groups:**

I picked this picture of a beach as it looks nice and I would like to be there right now.

I picked this picture of a bird because I like birds.

I picked this picture of a teddy because I had one like it when I was younger

I’ve got a dog that’s tied to a post with a lead and that’s the way I feel at the moment a bit, but I’ve got a teddy and that’s how I’d like to be, you know content and happy.

**Later groups:**

I chose one picture which is some palm trees on a nice beach somewhere and I chose a picture with snow on top of a gate because I thought they were quite polar opposites and feel a bit like that’s a bit like my mind and body.

I’ve picked one with a puppy on because I’m spending lots of time with my mum and her dog at the moment and going for walks and stuff which is nice and I also picked one it looks like a forest, loads of trees and I feel a bit lost and loads of stuff to do and I can’t see the woods for the trees.

I picked this really old tired looking tree because I feel a bit like that today, I don’t think the weather helps, very worn out, but I’ve also got some nice things I’m looking forward to so I’m hoping I’m going to be, that’s why I’ve picked this pretty flower as well.

I’ve chosen a picture of the sunset over the calm sea, because firstly it’s nice to be reminded what the sun looks like, but I just feel quite calm today, quite bright and I think this picture represents it.

The group facilitators also participated in this exercise and patients expressed an appreciation of this as it felt a truly collaborative exercise. Patients found them such a useful tool they enquired into purchasing them for use in their everyday lives. Due to the success
of Evoke cards within the group; they were also utilized in the staff engagement activities as an ice breaker. Interestingly, professionals were more apprehensive about this approach than patients. However, on completion of the exercise, positive feedback was received. This highlighted that it’s possible to use these cards in various settings, both clinical and professional, for personal and service development; e.g. individual sessions and clinical supervision. The successful implementation of Evoke cards within this project highlights the importance of identifying new and creative ways of patient engagement and personal, staff and service development.

The use of additional creative activities also assisted in improving quality of life in a number of ways. They provided patients with distraction techniques, as often patients would repeat activities at home. Patients reported an increased confidence on completing these and also helped with family interactions as they would repeat them at home with their families. Allowing patients to decide what activities to participate in provided them with a sense of autonomy and staff also engaging in these activities meant patients felt more valued and included and provided a sense of normality for them.

A major positive outcome of this project is the support provided from the Health Board in both the development of the project and ongoing support to continue working with people with an enduring eating disorder, in this innovative way. The board has recognised the importance of working collaboratively with patients and appreciates the need to develop new ways of working. There is a plan to run a second group in 2015. The varied staff involved are also keen to use the approaches from this project in future service developments.

**What didn’t go well - and why?**

The small number of patients who engaged fully in the project was disappointing. A contributing factor to this may have been the length of time between initial assessment and the start of the group, however, essential planning needed to take place. In future projects the team will ensure there is a specified start date prior to engaging patients in the assessment process. The project team also had to remind themselves that this patient group has historically been difficult to engage in treatment programmes.

The small size of the project team resulted in the group having to be cancelled on rare occasions; patients were always provided with a minimum of a week’s notice prior to this, but this had an impact on the morale of the group the following week. This was addressed as a group and patients opted to meet independently on these occasions in the future. This highlighted the risk of dependency on the group and whilst patients were aware of the length of the group from the outset, a need to prepare for this early on was identified.

The initial objective of developing media resources such as purchasing MP3 players and making podcasts was not as well received as the project team had anticipated. This was not something group members were particularly interested in. The project team identified a need to collaborate with patients to find an alternative way of achieving the objective of developing self-help materials. The creative scrapbook provided an alternative resource for this.
The fact that only one person was able to complete the group was disappointing but was mainly down to influences outside of the group’s control such as poor physical health. This also led to some content and plans being altered at the request of remaining member; therefore, not all initial plans were able to be implemented. Whilst this initially felt like a failure on the team’s part; this also meant we were able to be flexible and therefore better at meeting an individual’s specific needs.

*What would you do differently – and why?*

If this project were to be repeated, the following changes would be made:

- **Initial recruitment to project; more would be done to advertise the group; posters, meet and greet sessions etc.** This will be easier to achieve with the knowledge and experience of this project. Clearer referral guidance and communication will be developed to encourage appropriate referrals for future groups.

  - **A larger project team; whilst there are a number of benefits of having only 2 fulltime facilitators and 1 part time volunteer, there are also some implications that would need to be considered.** Relying on a small number of facilitators makes it difficult to accommodate staff holidays, sickness or other commitments. This resulted in only 1 facilitator being present on some occasions and whilst this did not present too much of a problem for this group; an increased group size would require more facilitators.

  - **The clinicians involved would take more of a leading role in the initial stages of the group as it was recognised patients need to build their confidence and trust before being able to convey their opinions and ideas in a group setting.**

*What we learnt*

An important part of our team’s philosophy is to ensure that we work collaboratively with our patients. Throughout this project we have been able to explore many techniques to improve this collaboration and use these techniques to change our practice around group development. Historically groups have been developed in a very structured way and patients have been made to fit the group rather than, as was the aim of this project, developing a group to fit the patients. We were able to use the methods acquired during this process to change our approach to group development and to feel comfortable with this being led by patients. Some of these techniques are identified below:

- 1-1 interview and focus group to identify needs, hopes and dreams
- Emotional words around the aims of the group and the modules to be covered
- Poster designed by patients to establish a new name for the group

Throughout this project, the project team’s confidence has grown in utilising these new techniques to engage patients and staff. This confidence has had a significant and positive impact on our work, ensuring that our practice is truly collaborative. The practice development activities have taught us new ways to facilitate change and transform care and allowed us to share these new ways of working with colleagues. We have learnt that whist change is always going to be challenging; by developing shared values and beliefs and addressing others’ concerns; change is not only achievable but can also be a positive experience.
Conclusion

It is well known that there is a high proportion of people in Wales with a SEED. This project has shown that patients and those working with them in ABHB have a shared belief that services specific to this client group are needed and that a creative, alternative approach is required. It is obvious that those living with an eating disorder are in the best position to know what will help improve their quality of life, while having support from professionals to implement necessary changes. The HOPE group provided a safe environment for these issues to be explored and developed further in collaboration with patients. Both qualitative and quantitative outcome measures indicate an improvement in QOL and reduction in ED symptomatology and through focus group feedback, patients have expressed and demonstrated an improvement in confidence, communication and hope. Providing a link to others with a shared condition has proved invaluable in reducing isolation and feelings of being misunderstood.

In addition to patient engagement, practice and service development cannot occur without stakeholders’ engagement and their views and opinions are essential to successful change. The project team identified a need to use creative approaches to engage both patients and staff. The FoNS practice development workshops provided the project team with not only the ideas but also the confidence to introduce new approaches to practice and service development. The importance of collaborative working with all involved in patient care has been highlighted throughout this process.

References


Appendix 1- Framework of current services

The stepped model for ED services (Tier 1-4)

Specialist MDT Team
Offer assessment/treatment packages to support CMHT.
Gate Keepers to Tier 4

CMHTs
Assess for co-morbidity/care manage/offer interventions

Primary Care
GPs/Practice Nurses - early identification/physical risk/signpost
PCMHLNs offering guided self help /CBTE sessions
Appendix 2- Letter to all CMHT regarding the project

Dear Team

As you may be aware, we are currently in the process of reviewing all those patients with a severe and enduring eating disorder within the Health Board. The aim of the review is to develop a recovery based quality of life programme of care for this specific client group. The main focus of the project is to meet the needs identified by the patients as opposed to fitting them into a specific programme; therefore we are meeting with those identified to us for them to ascertain their needs. So far, those we have met with have suggested the following aspects that affect their quality of life.

- Structure to day, meaningful activities / employment
- Addressing high levels of anxiety, low mood, OCD
- Assertiveness skills
- Improving low self worth, confidence and body image
- Techniques in tolerating distress, healthy coping strategies
- Poor physical health, excessive exercising
- Socialisation and social eating.
- Relaxation skills

We aim to develop group and individual packages of care, whilst working closely with the CMHTs. I am also pleased to say, that the project is being supported by the Foundation of Nursing Patient First Programme who will provide us with a bursary of up to £5000 to fund the project, allowing us to purchase outside professionals, equipment to support self management and assist with travelling expenses for patients.

We have already identified a number of patients who are keen to engage in this programme but would like to ask you to consider if there are any other patients who may be appropriate for this. I have attached a copy of the patient letter we have sent out to those already identified for you to discuss with anybody you feel would be appropriate for this.

I would be grateful if you could contact myself, Bev Davies OT or Alison George on the following details if you have anybody suitable for the project:
Appendix 3-Invitations for patients

Dear .................

Your community mental health care co-ordinator has provided us with your name as they believe you may be interested in working with our service.

The Specialist Eating Disorder Service was fully established in 2011. We are a team of specialist clinicians working across Aneurin Bevan Health Board. As part of our role, we are planning to develop packages of care for people who have been living with an eating disorder for 10 years or more.

The aim of the review is to explore with you what we can do to make living with a long term eating disorder safer and to identify ways that may improve your quality of life. We recognise the impact living with an eating disorder can have on many aspects of a person’s life including; education, work, relationships, and social, emotional and physical areas. Our aim is to develop a number of group and individual interventions that can help you make changes in these areas whilst living with your eating disorder. The initial stage of this process will involve completing a number of questionnaires, meeting a member of our team for an initial assessment and some physical health checks. Your involvement in this will be very much dependant on your individual wants and needs and the programme content will be finalised after completion of an assessment process.

We would like to offer you an appointment on ......................... at......................... If you do not wish to take part in this project; please could you contact Alison George.

Please could you complete the enclosed questionnaires and bring them to the appointment with you.

If you would like to take part in this project; but are not able to make this appointment, please can you contact Alison on the number above to re-arrange.

If you have any further questions regarding the project or questionnaires please contact:

Yours sincerely

Tier 3 Specialist Eating Disorders Service
Appendix 4

Severe and Enduring Eating Disorder (SEED) Group
Assessment

Name:
Date:
Assessed by:
Care Coordinator:

Past History

Support and Relationships

Social Circumstance (work, social support, voluntary sectors)

Leisure Activities (hobbies, interests)

How eating disorder affects areas above?

What would you like to improve about your quality of life?

If you are interested in the group how far are you able to travel?

Highlighted to ...........that following this assessment:

Completed by:
Designation: Date:
Appendix 5

Focus Group 14.3.13 plan

- Introductions
- Magic Wand – If you had a magic wand, what would you change?

- Why are we here?

- Proposed Modules
  Coping strategies-
  Communication-
  Education-
  Other-

Break

- Posters - Create a poster to advertise the group as you imagine it to be

- Time capsule – Hopes and fears for group

- Next steps
  Start date
  Location
  Order of modules
  Bursary
  Travel
  Social activities
## HOPE PROJECT
### Group Programme

<table>
<thead>
<tr>
<th>Module</th>
<th>Length</th>
<th>Location</th>
<th>Facilitators</th>
<th>Equipment</th>
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<td>Ty-Du</td>
<td>Emma, Bev and Vicky</td>
<td>Flipcharts, Pens, Art and crafts, Evoke cards</td>
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<td>Ty-Du</td>
<td>Bev, Emma and Vicky</td>
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<td>Pottery – Newport</td>
<td>Emma, Vicky</td>
<td>Provided</td>
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<td>Ty-Du</td>
<td>Emma, Bev</td>
<td>Flipcharts, pens, arts and crafts, Evoke cards</td>
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<tr>
<td>Social activity</td>
<td>1 week</td>
<td>Cardiff winter wonderland</td>
<td>Emma, Bev</td>
<td>Transport</td>
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<tr>
<td>Contemplation Work and</td>
<td>10 weeks</td>
<td>Ty-Du</td>
<td>Emma, Bev and Vicky</td>
<td>Flipcharts, Evoke cards, Magazines, Card for posters, Stones, Scrapbooks</td>
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