



scottishdevelopmentcentre
for mental health

Taking back control

An evaluation of self-management training for people with bipolar disorder

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The Scottish Development Centre for Mental Health

The Scottish Development Centre (SDC) is an independent, not-for-profit organisation that aims to achieve better mental health and wellbeing for people in Scotland. We believe that everyone's mental health is important and that good mental health is everyone's business.

We work all over Scotland for and with all kinds of organisations. We also have good networks outside Scotland. Our clients and partners include voluntary organisations, businesses, health boards, local authorities, national bodies and networks. This breadth and scope means that SDC is ideally placed to bring a vision of the 'bigger picture' of mental health to inform everything we do.

We have an excellent record in seeking people's views about mental health and what affects mental health. We have experience in working with the general public, including children and young people as well as with those who have experience of mental health problems, to help people's voices be heard clearly and promote their participation in decision-making.

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Foreword

Taking Back Control is the evaluation report of the first four Self-Management training courses run in Scotland over the past three years (2005-2008) for people who experience Bipolar Disorder. The courses have been delivered as a partnership between MDF The BiPolar Organisation who provided the training material and facilitators and Bipolar Fellowship Scotland, who organised the courses, identified and provided support to participants. It is the aim of Bipolar Fellowship Scotland to work towards providing a rolling programme of Self-Management training courses in Scotland.

The aim of the Self-Management training course is to teach people how to recognise personal triggers and signs of episodes and manage these effectively at an early stage, thereby preventing a more serious escalation. Course participants not only manage their own condition effectively, but some are trained as future facilitators. The benefits can have a life long impact.

The report has provided valuable material for adapting the content and delivery of future courses. We intend to look at incorporating recommendations into a revised training package.

Funding for these pilot courses relied on ad-hoc grants from Charitable Trusts, (*Allen Lane Foundation, Incorporation of Bakers, Pilgrim Trust and Tesco Charity Trust*). The Scottish Government have also provided funding for three further courses during 2008-2011.

We believe this programme has proved it offers real value and we would like to work towards funding being mainstreamed through Health Boards/Community Health Partnerships, giving people across Scotland equal opportunity of access.

The evaluation report demonstrates a sound evidence base to support future applications for mainstream funding. The course represents an investment both in terms of the long term benefit to those individuals participating and to Health Boards who are working towards demonstrating a *recovery* based approach in delivering mental health services.

**Bipolar Fellowship Scotland
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Executive Summary

The Self-Management Training for people with bipolar disorder has been running since 1998. Developed for and by people with experience of bipolar disorder the programme aims to teach people how to recognise the triggers for, and warning signs of, an impending episode and how to take action to prevent or reduce the severity of an episode.

The programme is based on a six module course involving between eight and 14 participants and two facilitators. The facilitators are themselves people with experience of bipolar disorder who have undertaken the self-management course and facilitator training.

The course has now been run four times in Scotland over the past three years as a result of an agreement entered into by Bipolar Fellowship Scotland and MDF The BiPolar Organisation. The main aim of the SMT evaluation was to identify what impact, if any, undertaking SMT has had for participants.

Of the 48 people who have attended SMT training across Scotland in the past three years, 17 took part in the evaluation. Also involved were six people nominated as being close to the participants, three training facilitators from MDF The BiPolar Organisation. Evaluation forms completed at the end of three training courses were also scrutinised.

The major issues described as problems for participants in the evaluation were lack of knowledge, feeling they had no control of the illness and for some a feeling of isolation and of not knowing much about their diagnosis and it was these issues that were so effectively targeted by the Self-Management Training course.

Participants on the whole came away with an increased knowledge and understanding of their illness and their own patterns of behaviour, triggers and warning signs. In addition, some very much enjoyed getting access to tools and methods to measure or anticipate these triggers and signs as a means of gaining more control. The majority of respondents rated various aspects of their lifestyle as improved since attending the SMT course and three quarters had not been readmitted to hospital since attending the course.

The course also helped people understand their condition and their treatment options, enabling them to develop new levels of confidence. This was reinforced by the opportunity to meet others in a similar situation.

If the course was to be repeated more regularly across Scotland, the evaluation findings suggest that consideration be given to the length and intensity of the course, which many respondents found tiring and to the addition of a more formalised three months 'follow-up', to reconvene participants and to prompt them to review what they have taken from the course.

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1. Introduction and background

1.1 Bipolar Fellowship Scotland

Manic Depression Fellowship (Scotland) was formed in 1992 and became a company limited by guarantee in 1996. In 2005, the name was changed to Bipolar Fellowship Scotland.

Bipolar Fellowship Scotland is a membership based voluntary sector organisation. It is administered by a Board of Directors. The majority of directors either have a diagnosis of bipolar disorder or care for someone with the diagnosis. The Fellowship currently employs four members of staff, who are responsible for carrying out its work.

The aims of Bipolar Fellowship Scotland are to provide information, support and advice for people affected by bipolar disorder, their carers and others with an interest in its work.

The Fellowship's work covers the following areas:

- Support for a network of self-help groups throughout Scotland
- Promoting and running Self-Management Training courses
- Providing information on bipolar disorder (books, information booklets, leaflets and a quarterly newsletter)
- Providing training and talks to various organisations/groups
- Representation and in-pu to national and local committees/forums

1.2 Self-Management Training

The Self-Management Training for people with bipolar disorder has been running since 1998. Developed for and by people with experience of bipolar disorder the programme aims to teach people how to recognise the triggers for, and warning signs of, an impending episode and how to take action to prevent or reduce the severity of an episode. The programme is based on a six module course involving between eight and 14 participants and two facilitators. The facilitators are themselves people with experience of bipolar disorder who have undertaken the self-management course and facilitator training.

Previously courses had been available only to members of MDF The BiPolar Organisation in England and Wales. As a first step to introducing Self-Management Training (SMT) into Scotland, the Bipolar Fellowship Scotland entered into an agreement with MDF The BiPolar Organisation in England for an initial three day training session in Glasgow in September 2005, followed by further sessions in Scotland held during 2005, 2007 and 2008. The aim is to build up a body of facilitators in Scotland with a view to rolling out SMT across the country. To date there have been four Self-Management Training (SMT) events held in Scotland over the last three years, these were in 2005 (2 courses),

2007 and most recently early 2008. In total, 48 participants have attended courses in Scotland.

When Bipolar Fellowship Scotland are preparing to run a Self-Management course, they write to all their members in the area that the course is being held and ask if they would be interested in taking part. As well as being given information on the dates/venue of the course, members are sent information on what the course is about, which makes it clear that you need to be well to undertake the course and advises you against undertaking the course if you have had an in-patient stay in the preceding three months. The member is also sent an application form to sign up for the course. Application forms are returned to the London office of MDF The BiPolar Organisation. Places are allocated on a first come/first served basis and a reserve list is also drawn up. Occasionally some of the people who first sign up may drop out and the reserve list will be utilised. MDF The BiPolar Organisation will phone everyone about a week before the commencement of the course to ensure that they are still available and happy to take part. This allows prospective participants to raise any queries or concerns.

1.3 The SMT course in context

The objective of enabling people to develop the skills and capacities to manage their own health experiences is highly consistent with the emphasis on improving self-management set out in *Delivering for Health* (Scottish Executive, 2005), and with the Scottish Government's *Better Health, Better Care* to both support and encourage people to take responsibility for their own health and wellbeing and improve opportunities for self-care for people with long term conditions (Scottish Executive, 2007).

In mental health there has also been increasing interest at national level in the development and application of self help based programmes as part of the mental health promotion and prevention improvement agenda. The principles of SMT fit well with the goals of the recovery movement in Scotland and the initiatives facilitated by the Scottish Recovery Network. It is also congruent with the growing development of a range of different approaches to foster self help and enable people to use information and education, plus support, to be able to take greater responsibility for their own health and mental health. Recent examples include the initiatives that emerged from the Doing Well by People with Depression programme such as Living Life to the Full that includes web based resources and college courses:

<http://www.livinglifetothefull.com/index.php>

The Glasgow STEPS programme is a community initiative that provides help and support, information, training and education as a means to reach a wide range of people who require differing levels of assistance.

<http://www.glasgowsteps.com/>

Health Scotland recently commissioned a review of evidence based mental health promotion messages and this work concluded:

“Overall, the strength of the evidence and the views of the general public and of professionals across all sectors suggests a good case for informing and empowering people to take action to look after their own mental health.”

(Friedli et al, 2007, p6)

The review of psychological therapies undertaken by NHS Education Scotland regards self help and supported self-management programmes as an essential element in a stepped care model of provision for psychological therapies.

1.4 The course structure

The course was divided into six sessions that were carried out over three days. The course content was as follows:

Session 1: Introduction

- Introduce facilitators and participants to one another
- Introduce the principles of self-management and aims and objectives of the course
- Discuss personal expectations of the course
- Draw up acceptable ground rules for the course
- Explore impact and nature of bipolar disorder
- Provide safe environment to enable participants to share feelings and experiences
- Introduce concept of life chart and enable participants to draw one

Session 2: Triggers and warning signs

- Review participants' Life Charts
- Share experiences and gain/offer support
- Introduce and explore triggers
- Enable participants to identify and record their own triggers
- Introduce and explore warning signs
- Enable participants to identify and record their own warning signs
- Introduce distinction between early and late warning signs

Session 3: Coping strategies and self-medication

- Review participants' work on triggers and warning signs
- Summarise the material covered in the 'Recognition' section
- Encourage participants to relate their own experiences
- Show how keeping a Mood Diary can help to monitor warning signs
- Outline some coping strategies
- Introduce concept of self-medication as part of self-management
- Increase knowledge of individual medication options
- Increase awareness of good practice in self-medication strategies
- Increase participants' confidence in negotiating with mental health professionals

Session 4: Support networks and action plans

- Review participants' work on coping strategies and self-medication
- Build confidence and encourage effective action in managing mood swings
- Considering the needs of others
- Explore the purpose of an action plan
- Review elements of an action plan
- Participants to write a personal action plan
- Revisit participants' expectations of the course and ensure these are being met

Session 5: Maintaining a healthy lifestyle

- Review completed action plans
- Look at lifestyle choices and changes
- Crisis management
- Concept of 'advanced agreements'
- Issues in the use of advance agreements and allow participants to draw one up
- Develop coping strategies
- Discuss development and maintenance of relationships

Session 6: Bringing it all together

- Review participants' work on advance agreements
- Build portfolio of complementary therapies
- Retaining autonomy
- Lifestyle options and use of problem solving skills
- Review the whole of the course
- Understand the theory of the 'contract letter'

2. The evaluation of the Self-Management Training programme

2.1 Evaluation aim

The main aim of the SMT evaluation was to identify what impact, if any, undertaking SMT has had for participants.

2.2 Evaluation design

The evaluation comprised various elements:

- Evaluation sheets that were distributed and completed by individuals at the end of each course
- Telephone interviews with participants including those who completed the first courses and those who completed courses in the past six months
- Focus group with participants completing the course held in March 2008
- Questionnaires to people significant to participants who completed the first three courses
- Telephone interviews with three course facilitators from MDF The BiPolar Organisation

This design reflects the fact that 'participants' fall into three groups:

- Group 1: people who signed up for the first set of courses in 2005 and who have had time to reflect on and perhaps implement the learning
- Group 2: people who took the course comparatively recently in 2007
- Group 3: people who took the course in March 2008

For Group 1, the information collected focused on the comparatively longer-term impacts (or otherwise) of the course (longer-term group). For Group 2, the focus was on the shorter-term impacts (medium term group). For Group 3, the focus was more on views on the delivery of the course and initial feelings (immediate impact group).

This design was intended to provide some exploration not only of the immediate impacts or outcomes, but also whether, and how, these impacts are sustained or develop over time.

2.2.1 Sample recruitment

Of the 24 individuals who completed the SMT in 2005 and 2007 and for whom contact details were available (contact information for all but one of the individuals who took part in the course held in Aberdeen was unavailable at the time of the evaluation), 12 individuals responded to the letter and consent form they were sent by Bipolar Fellowship Scotland and were contacted by telephone to arrange a suitable time to complete a telephone interview.

Table 1.1 Sources of information regarding SMT course

Source of information	No. provided	Total
Telephone interview Group 1: 2005	8	12
Telephone interview Group 2: 2007	4	
Written questionnaire by people 'close to' the participant	6	6
Focus Group 3: 2008	5	5
MDF The BiPolar Organisation SMT course facilitators	3	3
Evaluation forms 2005	10	31
Evaluation forms 2007	8	
Evaluation forms 2008	13	

2.2.2 Interviews with Group 1 and Group 2 participants

12 participants were interviewed, of whom eight had completed the early courses (Group 1) and four who undertook a course more recently (Group 2).

Interviews were carried out by telephone and notes of respondents' responses were taken. The aims of the interviews were four-fold: to obtain baseline socio-demographic information (including health information); to give participants an opportunity to describe expectations and anticipated/desired impacts; perceived medium or longer term impacts; views on the content and organisation of the course; to identify aspects of the course that were particularly helpful in achieving these personal outcomes and/or which were felt to be unhelpful or not covered; and to establish if they were interested in being trained as course facilitators.

The interviews were semi-structured and qualitative.

- Socio-demographic information e.g. age, gender, ethnicity
- Health information: date of first episode, date of diagnosis, medication/treatment received, feelings about treatment and treatment providers
- Reasons for undertaking SMT course
- Expectations of the course and whether these expectations were fulfilled
- Reasons for not completing the course (where appropriate)
- What participants had learned from the course
- What impacts, if any the course had, and in which areas of their lives, including:
 - Quality of life
 - Self-reliance and self-confidence
 - Stress tolerance
 - Frequency and severity of mood swings
 - Capacity to make constructive lifestyle choices

- Manage the 'damage' caused by episodes of mania/depression
 - Personal and family relationships
 - Reliance on health professionals, use of medication
 - Hospital admissions
 - Employment
 - Financial impact
 - Impact on people close to them
 - Other areas
- Aspects of the course which have been helpful in achieving these impacts
 - What, if any, follow-up support have they received since completing the training
 - Did they feel a need for follow up support, and why
 - Views on relevance of course content and whether anything needs to be added or taken away
 - Views on delivery of course, including use of text based materials
 - Whether they would want to be trained as future course facilitators
 - What would they say to others thinking about going on a SMT course

2.2.3 Postal questionnaires to significant others

Where consent was given from the course participant for the researcher to approach a non-professional that they felt was important to them, a postal questionnaire (with a stamped addressed envelope to be returned to the Scottish Development Centre) was sent to this person following the interview with the participant.

Issues covered in the postal questionnaire to significant others included:

- What they understand about SMT
- How they felt initially about the person they know going on the course
- What do they feel now about the person having been on the course
- What changes, if any, have they seen in the person since they have been on the course
- What they feel have been the benefits for the person
- What, if any, they feel may have been the disadvantages for the person
- What impact, if any, has the person's going on the course had on them as carers, friends, relatives
- What would they say about the course to others who knew someone who was thinking of doing the training

2.2.4 Focus groups with Group 3 participants

To obtain the perspectives of people immediately on completion of the course consenting participants from February-March 2008 course were invited to take part in a focus group in June 2008.

This enabled an exploration of:

- Reasons for undertaking SMT course
- Expectations of the course and whether these expectations were fulfilled
- Views on relevance of course content: for them personally and for Scottish participants
- Views on delivery of course, including use of text based materials
- Aspects they would like to change, see added or removed
- What would they want to say to others thinking about going on a SMT course

2.2.5 Telephone interviews with MDF The BiPolar Organisation course facilitators

Three course facilitators were interviewed by telephone. This served two purposes: to learn from their experience as facilitators; and to get a sense of any differences between delivering the course to people in Scotland compared to people in England and Wales. Interviews included:

- How facilitators came to be recruited and why they wanted to be a facilitator
- How they were trained and views on training
- On-going support received as facilitators
- As appropriate, views on any differences between delivering the programme in Scotland compared to England and Wales
- What they advise others who might be thinking about training as a course facilitator

2.2.6 Evaluation Form, Self-Management Training Programme

All participants in the SMT course were asked to complete an Evaluation form on the final day of the course. Where these forms were available they were analysed by the current evaluation team. As with contact details for the individuals who took part in the course carried out in Aberdeen in 2005, the completed Evaluation sheets from this course were also unable to be included in the evaluation.

The Evaluation forms asked respondents to rate aspects of the course and the usefulness of each session, there was also the opportunity for each respondent to make further comments about each session and practicalities of the course, including, venue and organisation of the course.

3. Evaluation findings

3.1 Characteristics of the sample

3.1.1 SMT Participants

Of those participants who attended a Self-Management Training course, 24 were contacted initially by Bipolar Fellowship Scotland (BFS) and asked to give their consent to be contacted by the researcher, 12 respondents gave their consent to be contacted and interviewed by telephone at a time suitable for them. Of these 12 participants, eight made up Group 1, seven of these had attended the first SMT course held in Glasgow in 2005 and one attended the course in Aberdeen later the same year. Three individuals were male and five female and were aged between 38 and 62 years old. Group 2 comprised the four respondents who had attended the course in Fife in 2007, two were male and two female and they were aged from 25 to 63 years old.

A further five participants, four female and one male, who had attended the most recent Self-Management Training course in March 2008 took part in an Evaluation Focus Group, three months later.

All of the participants in the Self-Management Training course were asked to complete a course Evaluation form on the last day of the course and the analysis is based on 31 completed Evaluation forms. There were 10 Evaluation forms completed by participants who attended the Glasgow course in 2005, eight were completed by those who attended the course carried out in Fife in 2007 and 13 completed by those who attended the 2008 Glasgow course. Evaluation forms completed by those who attended the course held in Aberdeen in 2005 were not able to be included in this evaluation.

3.1.2 People close to participants

Respondents were asked to nominate someone who could talk about their experience, 10 respondents did so and of these, six people close to participants completed a postal questionnaire. Three of these individuals were male and three female. The three female respondents were parents of a participant, two of the male respondents were either husband or partner of a participant and one male respondent described himself as a friend.

3.1.3 Facilitators

Telephone interviews were completed with three facilitators, each of whom had each facilitated at least one course in Scotland, two of these were male and one female.

3.2 Participants' experiences before the SMT training

3.2.1 Diagnosis of bipolar disorder

Seven of the 12 participants who took part in a telephone interview had experienced what they considered to be an episode of bipolar disorder before they were formally diagnosed. In the majority of cases the respondents could remember a first episode of bipolar disorder many years before they were diagnosed. One 62 year old female respondent who recalled her first episode at age 19, had not known she was diagnosed with bipolar disorder until several decades later. Most respondents could recall a stressful period or incident around either their first episode or the episode that led to their diagnosis. For three of the women, it coincided with having a baby. For one individual it was around the time of their marriage breaking-up, for another they had 'neighbours from hell' keeping them awake. Another person was bullied at school and the final respondent had dropped out of education, left his job, broken up with his girlfriend and was misusing drugs at the time of his first episode.

3.2.2 History of bipolar disorder

The majority of the 12 participants had been on various medications throughout the intervening years. In some cases, participants had changed medications between the time they attended the self-management course and taking part in the evaluation.

The most common treatment reported was medication with drugs. Each of the 12 respondents had been prescribed at least one of type of drug treatment and many had been prescribed several medications and various combinations of medication over the years.

Several respondents described themselves as having 'no insight' regarding drugs or drug options but equally several were grateful to have been diagnosed and to be getting treatment.

Two of the respondents had been treated with ECT and two had received some form of group work while hospitalised, for one this was a form of art therapy. The remaining respondents were not given any other types of treatment.

3.2.3 Participants' motivations for attending the Self-Management Training (SMT)

The majority of Group 3 participants recalled that they had initially heard about the course in the Bipolar Fellowship Scotland newsletter and had then applied successfully for a place. One person had been given a place on the reserve list and was telephoned the week before the course started and offered a place. One of the participants had applied unsuccessfully on two previous occasions.

Four participants from Group 1 found out about the course from the website or BFS newsletter, two found out through word of mouth, one recalled being invited

by the Bipolar Fellowship Scotland office and another heard through another "bipolar group".

In Group 2, two individuals recalled initially hearing through word of mouth, one saw it in the newsletter and the other had already tried to do the training course initially in England but had not completed it then and so applied to repeat it in Scotland.

Participants had different reasons for wanting to go on the course. In several instances this entailed developing more confidence and knowledge in relation to treatment options. One individual stated that they wanted the confidence and knowledge to challenge their psychiatrist. Another related that they were already living medication free against the advice of the psychiatrist. One participant talked of the many side effects and issues she had experienced with various drugs.

"I didn't really have any say" (Focus group participant)

"I was hoping to make life more manageable, I couldn't sustain it and I knew I would need other supports to maintain the drugs" (Focus group participant)

Some of those who had attended earlier courses were keen to improve a particular aspect of their life, for example to get back into working again, to gain some structure to their lives, to get better at managing relationships. Others wanted to learn more about their own triggers and to learn different techniques for self-management. One participant from the 2005 course recalled that for her problems arose after she had children, then became a single parent and the stress got worse. She wanted to, as she described it 'get a better grip on it'.

"I didn't want it to beat me" (2005 participant)

For some participants there was a definite tipping point that led them to the realisation that they needed to make changes. One person had been admitted to hospital every year for the previous four years and wanted to change that pattern. Another wanted to be on the minimum amount of medication. Another had only just begun to accept the diagnosis, after seeing a pattern in his own behaviour.

"I had reached the point" (2007 participant)

"Give me more insight into mental health and what's available, no-one ever tells you what there is you have to find it for yourself" (2005 participant)

A further attraction of the course for some participants was the desire to meet other people, get ideas from one another, share experiences of being ill:

"I wanted to see people in a better place, people who were working" (2005 participant)

3.2.4 Participants' expectations of the course

Although two individuals who attended the courses that took place in 2005 and 2007 stated they had no expectations, just an open mind when they applied to take part in the training course, the majority of respondents could articulate what they wanted or hoped for as a result of taking part. Several individuals talked of looking for a routine or a way of coping, to get some sort of stability, address difficulties with practical day-to-day living or a healthier lifestyle. One respondent was agoraphobic and wanted to regain time and for this person getting to the course on that first day was a personal achievement. Most wanted more understanding of their condition and how they could best manage it, as one individual described it ' I expected to learn tricks of the trade'.

"I remember thinking I hope they do this for more people" (2005 participant)

3.3 Perspectives from significant others, prior to the course

All six of the respondents knew in advance that the participant was going to attend the SMT course except one friend who was told afterwards. In three cases the participant discussed their attendance with this significant person prior to attending. One mother had actively encouraged her son to attend the course.

In each case the significant person reported that they had not known what to expect from the person's participation in the course. However, all of the respondents reported feeling hopeful and positive about the fact that person was to attend the course. One parent felt that the participant had lost his confidence and although was on the way to recovery was 'at a loss as to what to do'. Another felt that anything that allowed the participant to express his opinions was a good thing. One significant other felt it would be educational and an 'eye opener', two were happy to see their partner gain more insight and tools to manage their conditions and the final respondent was very positive in general about self-help groups and support groups with 'expert-patients'.

3.4 Reflections on the course itself

3.4.1 Organisation and delivery

Of the 12 participants who took part in the telephone interview after attending the SMT course, 10 completed the full course. One individual did not attend the second day because they had felt that the first day had triggered an episode of mania and although they were anxious about returning, they did so and successfully completed the rest of the course. Another individual did not return for the third day of the course due to tiredness.

All of the respondents who completed the Evaluation forms immediately following the course felt that training ground rules were followed either completely or to a large extent and several highlighted the facilitators' abilities in helping this to happen. Two respondents mentioned how relaxed things were and another said

how important these rules were because, as they described; '....some people can overpower the group dynamics'.

One respondent who had attended the course in 2005, described the facilitators as 'excellent, quite inspiring, just seeing that you can live quite a fulfilling life with manic depression'. Another participant of the 2005 course who was very enthusiastic about the discussions they had during the SMT training described it as 'it was us running the course, the facilitators just helped us travel the journey'.

The respondents rated the venue as between four and 10 out of 10 but with more than half rating the venue at 10 out of 10. In each of the three courses more than half of the respondents rated the venue as 10 out of 10. The organization of the course was rated as above eight out of 10 by all respondents.

All of the respondents felt that their expectations of the course were met either in full or to a large extent. Several stated that their expectations had been surpassed by the course and the facilitators were complimented by many.

3.4.2 Review of each course

The Evaluation forms asked participants to give their views on each session and a summary of these views follows.

Comments made about session 1

Although one respondent found it moved too slowly and another felt there was too much to take in, feedback from most respondents was positive. One person was comforted to find that the facilitators were also diagnosed with bipolar disorder. All respondents rated this session as mostly or very useful.

Comments made about session 2

Several individuals were pleased to find out about triggers in general and how these related to their own experiences. Two respondents found formalizing and recording their experiences of triggers as useful and another was helped by speaking to others. However one individual stated that they did not like the word 'trigger'. All respondents rated this session as mostly or very useful.

Comments made about session 3

A few individuals were very interested and as one described 'cautioned' in hearing about some people's attempt to self medicate. Others felt this was very important information, one participant who admitted to not complying with medication felt it was handled sensitively by the facilitators and another felt that they would want to talk to their doctor if they were to consider self medicating. One respondent rated this session of limited use but the remaining participants rated it as mostly or very useful.

Comments made about session 4.

Although one respondent felt that they already had a good network of friends and family several others found this session useful either because they live alone

or this is an area of their life that they feel needs to improve, one respondent who attended the course in 2005 felt it was useful to think that 'you have to think of others therefore the focus is taken from [your]self'. An individual who attended the course in 2007 pointed out that 'the network in (this area) is spasmodic (sic) and so it can be difficult'.

"Very practical and useful, important to leave with something to work on rather than just leave with reading material" (2008 participant)

Several respondents felt that this session would give them something to focus on and work on with some feeling they could work on their action plan.

One individual suggested that the section dealing with the 'needs of others' could perhaps have been longer because it was so important to discuss this, although they acknowledged that it was hard for some people. Two participants rated this session as being of limited use while the remaining 29 participants rated it as mostly or very useful.

Comments made about session 5.

One respondent from the 2008 course felt that this session had been too formal, while a participant from each of the 2005 and 2007 courses felt it was too brief. However, several of the respondents found the session inspiring with one individual declaring that they intended to stop smoking and reduce their drinking and another admitting that when it comes to food and eating sensibly they were 'chaotic', one individual had taken a list of books away to read on the subject, while another appreciated the fruit plate provided at coffee break time.

All except one of the respondents rated this session as mostly or very useful, the remaining participant rated it as of limited use.

Comments made about session 6.

Four respondents felt that the session had gone very well, one participant from the 2005 course felt a bit tired on this day, while a participant from 2007 felt there was too much to do and not enough time to do it. However, all of the respondents rated the session as mostly or very useful.

3.4.3 Positive features of the course

The Evaluation sheets contained a range of comments about the features of the course that people valued. There was an overwhelmingly amount of positivity for the facilitators of the course. Many respondents felt the facilitators had been very effective in keeping the course on track, enabling people to learn, sharing their experience and knowledge, encouraging questions, and creating a relaxed and friendly atmosphere.

"[the facilitators] are lovely and made the course both meaningful and fun and gave me hope" (2008 participant)

"it helped me relax knowing both facilitators had the diagnosis" (2005 participant)

Also complimented by several respondents were the materials used in the training and the information on how to spot trigger signs. A respondent who completed the course in 2005 felt that it was comforting to know that others have had similar experiences and that they were 'hopeful for the future'.

"Very useful, just as important as medication, everyone with a mental health problem should have the opportunity to experience SMT" (2007 participant)

"Very valuable insight to this condition has enabled me to accept this condition but also to be less frightened of it as I can now put steps in place to stop it becoming out of control, every person with BP should be able to access this course" (2008 participant)

3.4.4 Suggested improvements to the course

A number of suggestions were put forward:

- One of the participants at the most recent course suggested that an electronic copy of the course materials would be useful, perhaps highlighting how commonplace computers have become for many people
- One respondent did not think the 'two chairs' exercise worked as only a few people could speak throughout it and it had become a counseling session
- Another individual stated they would have liked to know more about the disorder, specifically 'what happens to my brain when I get ill?'
- Two participants felt that assertiveness training would have been of benefit for them
- A participant from 2005 felt that the visual quality of the PowerPoint presentation could have been improved with the addition of pictures and colours
- The same person also suggested that more information could be provided on emotional literacy, intelligence, recovery, confidence building, moving on, building health promotion and goal setting
- One respondent felt that two major omissions from the course were 'mixed episodes' as they had felt the course concentrated on highs and lows, they also felt there was not enough information provided on 'rapid cycling' where there is, by definition, less time to see warning signs and take steps
- One respondent stated that they would like a 'follow up' after the course

3.5 After the course

3.5.1 Participants' perceptions of gains

Respondents from the most recent course who attended the focus group were positive about the course and what they had gained from it. Several talked specifically about the resulting increase in knowledge of various drug treatments and an increased confidence to discuss this new knowledge with their psychiatrists.

"... then when the rollercoaster started I asked the psychiatrist, I wouldn't have known enough before to ask for certain drugs" (Focus group participant)

"I learned from other people" (Focus group participant)

Several of those taking part in the focus group described feelings of isolation, prior to the course and felt that meeting other people with the same diagnosis but who were living full lives was eye opening for them. Another participant was encouraged by one of the facilitators who made her see 'how much positivity you could get from bipolar disorder'

"Came away with knowledge of illness, felt less isolated, know there are people just like me, came away thinking people with bipolar aren't mad" (Focus group participant)

"... it was good finding out there are normal people with normal jobs and a normal home" (Focus group participant)

Individuals from Group 1 talked of what they had taken from their participation on the course. These were often practical outcomes, for example the advance statement was mentioned by several respondents as being helpful, unfortunately one individual who had attended the course in 2005 and who had completed an advance statement with the help and support of family and CPN found it had not been adhered to during her crisis. This resulted in the individual being admitted to a particular hospital and prescribed a particular drug that had been expressly forbidden by the individual in the advance statement.

Several individuals talked of using the Mood Diary: one person who had attended the course in 2005 had used this to identify that her menstrual cycle was making a difference to her moods; others had learned how to work within their moods. One person had found concentrating on something completely different, like a puzzle, was effective if they felt agitated, another mentioned using exercise in the same way as a method of de-stressing and becoming more calm. Adding structure to their life was something that proved useful for several people, as was identifying and recognising triggers and being aware of consequences of life style, such as sleep patterns, diet and exercise. Two individuals stated that they were now integrating exercise into their daily life. Five respondents specifically mentioned gaining confidence and how important this was for each of them.

"How to live with this thing, sometimes it feels like it might engulf you, I am me" (2005 participant)

"I gained tools, a new way of thinking, instead of problems and symptoms I had ways to overcome" (2007 participant)

3.5.2 Perceptions of 'significant people'

People close to participants felt there was no negative outcomes from the participant attending the course. The positive impacts described by these

individuals included both practical steps and also a greater self awareness and understanding of their condition. One respondent felt that the positives gained from the course included an increased understanding and also positive thoughts combined with greater self control. Another felt that the participant was more able to understand how bipolar disorder can affect someone, so again an increase in awareness. This view was echoed by another respondent who reported an increased awareness or insight and also talked of new techniques being acquired, for example the Mood Diaries. The mother of one participant described how her son was more aware of the things that can affect his mood, how he gained more knowledge of the medications and choices open to him and improved his attitude towards accessing services. The partner of one participant perceived steady improvement and considered that the SMT course might have been one factor in that improvement.

“It was a turning point, it gave him hope, it changed his life” (Participant’s mother)

With one exception, all respondents gave examples of positive changes they were aware of in the participant since they had attended the course. The single respondent who could not identify any changes in the participant stated that although they felt the person had been steadily improving, they were unable to attribute it to attending the course. The other five respondents, however, gave several examples of increased confidence in the participant in the following ways:

- More confident in settling disputes
- An increased sense of self
- A more positive attitude to medications, more disciplined in avoiding unwelcome triggers and quicker to seek psychiatric help if required
- Discovery of new abilities and talents
- Increased awareness of moods and triggers

3.5.3 Impact on ‘significant people’ of course attendance

Each respondent felt there had been a positive effect on them in having the participant attend the Self-Management Training course. The mother of one participant simply said that knowing that people care, helps her. The husband of another participant felt that it was positive for him seeing his wife more able to cope with her illness. One person highlighted the tools available for when things get difficult and a parent was ‘thrilled’ that her son was now living an independent life and was helping others. Another person felt it had been a tremendous help describing the course as ‘every bit as valuable as that given by psychiatric services’.

Four of the respondents felt that there had been a positive impact on the participant’s family since they attended the SMT course. A friend of one participant felt that they had an improved attitude since the course, the husband of one participant felt that they were now better educated about her condition which helped her have fewer relapses and the mother of one attendee felt that the future was now ‘bright’

*"We are all more able to discuss his problems with him and encourage him"
(Person important to participant)*

However, one respondent felt that the family still have to 'tread on eggshells' around the participant while another was not sure that the participant's attendance on the course had any effect on the family.

A similar pattern was seen in regards to the effect on the participants' friends: one respondent did not know if there was any effect, another felt that his wife had always had good relationships with friends, while the remaining respondents felt that the effect on friends was a positive one.

3.5.4 Comparing 'before' and 'after'

Eight of the 12 participants of the SMT course had not been hospitalised since they attended the course. Half of those from Group 1 had not been hospitalised since and none of those from Group 2.

Three respondents were not able to rate the severity of their mood swings (this asked people to rate their mood swings on a scale from one to 10, with 10 being the most severe) as part of the evaluation. However, for those that could use this rating scale, the majority rated the severity of their mood swings as lower after they had attended the course. One person rated his mood swings as of the same severity but explained that he now reacted differently and experienced fewer symptoms.

During the telephone interviews, participants were asked to rate on a scale from one to four their perceived quality of life, their self reliance, self-confidence, stress tolerance, ability to make constructive lifestyle choices, their relationships, ability to manage any damage as a result of an episode and their reliance on health professionals both before and after they had attended the course. 11 of the 12 participants completed this aspect of the interview.

Those respondents who had rated their quality of life as 'bad' or 'really bad' prior to attending the course changed their rating to 'good' and in one case someone increased their rating of perceived quality of life from good to very good. Those who did not change their rating already felt that prior to the course their quality of life was good.

When it came to the question of self-reliance, many of the respondents improved their own rating since attending the course: seven individuals who previously rated their self-reliance as 'bad' increased their rating to 'good' or in two cases 'really good'. The remaining four felt that their self reliance was already good prior to attending the course.

Six respondents rated their self-confidence as better since they attended the course than before, in one case it improved from a 'bad' rating to one of 'really

good'. Four felt it had stayed the same: for three of these, their self rating was 'bad' both before and after the course, while for one it remained 'good'.

Eight respondents felt that their ability to tolerate stress had improved since attending the course; the other three respondents had already rated their stress tolerance as good or very good and this did not change.

When asked to rate their ability to make constructive lifestyle choices, seven respondents rated their ability higher since they attended the course and for three of those their rating changed from 'really bad' to 'good'.

Again seven respondents described their personal and family relationships as better since the course than before it and seven had also improved how well they felt they dealt with any 'damage' that might be caused by an episode of mania or depression.

"The really dark phases are much less frequent ... I have accepted that the depressions will pass" (2005 participant)

3.5.5 Changes in lifestyle or behaviour since the course

One focus group participant stated that since attending the course they took more exercise and were also more sociable, as this exercise involved a group of people. A participant from the 2007 course talked of incorporating exercise into her daily routine now and also how she had begun yoga and found it relaxed her moods.

Three of the respondents, two who attended the 2005 (Group 1) and one who attended the 2007 (Group 2) SMT course mentioned that they had changed job or career since they had attended the course.

Five of the 12 respondents stated that they were managing better financially since they attended the course than prior to it.

Five of the 12 respondents mentioned in the telephone interview that as part of their current drug regime, since attending the course they had reached an agreement with their consultant psychiatrist or GP that allowed them to maintain a supply of some medications at home to use on an 'if and when required' basis, this could benefit their lives in two ways, first that any changes in mood can be dealt with more quickly than before and second that this allowed them a greater measure of control.

3.5.6 What worked well?

In the days before the focus group took place, several of the participants from the most recent course (Group 3) had received back a letter they had written to themselves as part of the training course and several people found this had a big emotional impact. As one individual said, if you are dealing with someone else you would be more supportive but when it's yourself you are sometimes not

supportive enough, another described it as ‘...like I was talking to myself in the future, really nice, quite moving’

Facilitators’ sharing their own experiences was something that appealed to participants, also the chance to network and find out what worked for others in the group. Recognising warning signs was considered helpful, for example, food was a particular issue for one participant who found it very useful to recognise that and see the behaviour for what it is, in her case, a warning sign of impending mood swing.

“A sense of being included not excluded” (Focus group participant)

Sharing experiences was found to be useful for many, although people are all different many have had similar experiences and discussing these experiences was felt to be useful, living with the threat of being sectioned, knowing that you might well have another episode were all issues they felt they could share.

“I was socially isolated when I went and then I was sitting there with 10 other people and talking” (2007 participant)

3.5.7 What worked less well?

Although one participant felt that the intensity of the course was beneficial for them, this was unusual, the majority of participants, in contrast, had found it tiring. One focus group member described feeling exhausted for two weeks following the course. Others felt that they were simply too tired at the end of each day to process what they had learned and experienced. An individual who attended the course in 2007 pointed out that two people had left after the first day of the course because they could not concentrate. Two people taking part in the evaluation had also missed several sessions due either to tiredness or feeling that a mania was being triggered by their attendance on the course.

The first day in particular was described by one individual as being too rushed and that they would have liked more time spent on the early signs and warning signs to allow them to write down their own personal warning signs to put it in context before the group moved on to the next stage of the course.

A suggestion from one member of the focus group was for a list of services in the local area tailored for each training course to be provided, it was felt by this participant that there are so many services out there that perhaps people don't know about them all and some of the participants had described feeling isolated and alone, with one stating they had never met another person with a diagnosis of bipolar disorder before attending the SMT course, perhaps a list of local services might be beneficial.

Some participants felt they wanted something to disseminate to other local groups or other people, it was suggested that perhaps the section on triggers or warning signs might be a useful aspect of the training course to pass on.

A couple of respondents felt it might have been appropriate to have carers or family members involved for some part of the course, highlighting the importance of relationships and the strain bipolar disorder can place on these relationships. One of the individuals from Group 2 had attended the SMT course with her husband who was able to attend when a space had become available at the last minute and who had found it really useful.

"I feel most guilty about it, about the effect of my bipolar disorder on my family"
(Focus group participant)

One participant noted that there was no mention of self-medicating through alcohol use and she would have found that particularly useful.

Formal feedback after the course was felt by several focus group participants as being something that would be desirable, one individual mentioned that it was a shame that not all training participants could attend the focus group that day because they had found revisiting the course in this way, helpful. Another felt that they would be more likely to revisit the SMT folder now. It was suggested that there should have been an organised link-up with the people on the course to meet up again, year on year.

A dedicated help line for participants after attending the course was suggested by one focus group participant because as she described: 'the course does stir up worms'.

3.5.8 Advice to others attending future courses

Each participant in the focus group said they would encourage others to attend the course but there were also words of caution. One person pointed out that the course is not the whole answer, while others cautioned that it could be a 'bumpy ride' and a challenge that led you to reconsider the things you like and to look differently on your relationships.

When people close to the participants were asked what advice they would give to somebody considering attending the SMT course, every respondent strongly urged others to go on the course if given the opportunity. One respondent pointed out you had 'nothing to lose and everything to gain, it can only help' and another arguing, 'you will learn a lot from the trainers and the other people attending'. The parent of one participant cautioned that it will be both 'daunting and scary' but that 'you will meet people like yourself who you can talk to about what it's like' she ended by saying 'it will help you on your way'.

3.5.9 Is there a need for follow up?

Although the majority of respondents from the earlier courses stated that they did not feel the need for a formal follow up, several stated that the act of taking part in the evaluation had either inspired them to revisit the folder and think again about what they had learned or had been reminded how far they had come by responding to questions about their past. This was mirrored in the focus group involving those individuals who had completed the most recent course, who felt that it was a shame that not all of the course participants were able to come back for the evaluation because they had enjoyed meeting up again and revisiting the course.

3.6 The Facilitators' story

The facilitators have all had a diagnosis of bipolar disorder, had completed the course themselves and been trained to facilitate the Self-Management Training. During each course two individuals work side by side to present the three days of sessions.

As part of the SMT evaluation, the three facilitators who had facilitated at least one course in Scotland took part in a telephone interview. One of them had facilitated three courses in Scotland the other two had facilitated one each.

One of the respondents was involved in the initial design of the training course, another had heard about the Self-Management Training in the Manic- Depression Fellowship magazine, in fact she had heard about the need for people to be trained as facilitators prior to signing up to complete the SMT course herself, the remaining facilitator had completed the SMT course and then afterwards had heard that there was a call for people to be trained as facilitators.

"It's a very personal thing, we have all had different personal experiences, we all have the condition and personal experience of the condition" (SMT course facilitator)

Each had different experiences of facilitating, but for those without any previous experience the facilitator training involved completing a recognised course in facilitating groups and then, most usefully perhaps, time spent shadowing other facilitators. One felt that perhaps more emphasis should have been given to people management skills as difficult situations can arise.

The facilitators were all very different and had different personal experiences of the disorder. However they all shared an enthusiasm for the course and what it can do for individuals.

"People have said it has been a life changing experience, liberating and empowering" (SMT course facilitator)

"The facilitating has been useful for me, it's like a reality check and it reminds myself of where I have been and I can learn from them and their techniques they use, it's about the sharing of knowledge, it's extremely rewarding. Seeing people emerge from their shells over the course of three days, gaining in confidence,

getting a positive attitude and starting to look to the future" (SMT course facilitator)

Issues in the course, recognised by the facilitators, included the intensity of the course and the amount of information that is presented over the three days. Individuals can be upset by certain sessions, for example the life cycles session. Also mentioned was that moods can change and individuals can experience highs or lows and this can affect the mood of the whole group. If an individual is ill while they attend the course this has the potential to disrupt the course, as one facilitator said we don't want to ask people to leave the group but that 'people need to be well to do the course but people do turn up not as they should be and it's because they are desperate I know what that feels like, you don't want to miss the chance'.

"I have said that deciding to go to the event makes you half way there" (SMT course facilitator)

Facilitators were of the view that there were no significant differences between facilitating courses in Scotland, England or Wales, other than the longer and more tiring journey to get there. However, one felt that participants in Scotland in her experience were more open from the beginning of the course, whereas it can take those attending courses in England a little longer 'to warm up'. Another facilitator would have liked a little more written information about the differences in the mental health system, although this had not been an issue on the day, the individual had felt a little anxious beforehand. None of the facilitators felt they needed any additional training in order to facilitate the training course in Scotland as one facilitator said: 'things like triggers and strategies are common'.

Facilitators appreciated that they could get informal help or support from one another at any time by phone and more formally once or twice a year with a meeting held at Head Office, each facilitator referred to the ability they had to suggest changes in the structure or content of the training at these meetings, in fact one facilitator described how the section on medications had ended up being changed after a course in 2007.

It was felt to be important that two facilitators should work together to facilitate each course and that once a relationship was forged it helped the course run well. Having two facilitators also helped them because of the additional support they gave each other in general.

4. Conclusions and discussion

4.1 Limitations of the evaluation

The limitations of the evaluation scale and design mean that the findings need to be interpreted carefully and with some caution. The study was small scale and qualitative in nature involving 17 of the 48 individuals who had ever attended a course in Scotland, i.e. 35%. In addition, the evaluation design had to rely on course participants opting in. Although individuals who took part in the evaluation had largely positive views of their experience of the course and many reported that their lives had improved in many ways, it is not possible to determine whether these effects were experienced by all those who took part.

4.2 Overall benefits of the course

It is worth noting that the majority of respondents described feeling confused by their initial diagnosis. In many cases bipolar disorder or manic depression was not their initial diagnosis, several had been diagnosed with different disorders at different times. This issue was highlighted in recent NICE guidelines on bipolar disorder which observe that the condition can often remain undiagnosed as it is confused with 'normal' depression and that a true diagnosis can take up to 10 years after first contact with services, at times resulting in lack of appropriate care for the individual and increased healthcare costs. The NICE guidelines emphasise the importance of collaborative working between the patient and healthcare professionals and the provision of information about the nature, course and treatment of the disorder.

The major issues described as problems for participants in the evaluation were lack of knowledge, feeling they had no control of the illness and for some a feeling of isolation and of not knowing much about their diagnosis. It is these issues that were so effectively targeted by the Self-Management Training course. Participants came away with an increased knowledge and understanding of their illness and their own patterns of behaviour, triggers and warning signs. In addition, some very much enjoyed getting access to tools and methods to measure or anticipate these triggers and signs as a means of gaining more control. The course also helped people understand their condition and their treatment options, enabling them to develop new levels of confidence. This was reinforced by the opportunity to meet others in a similar situation.

4.3 Key learning points for the future development of the SMT programme in Scotland

The section below highlights key findings of the evaluation that have implications for the future development and potential roll out of the SMT programme across Scotland.

4.3.1 Course design

Using facilitators with a diagnosis of bipolar disorder adds value to the course content, gives participants reassurance and provides them with inspirational, positive role models.

The volume and intensity of the course content requires careful consideration as participants can find it very demanding.

4.3.2 Course content

The course covers issues which can be sensitive and emotive and it is important to ensure that participants have access to appropriate support to enable them to reflect on what they have learned and its significance for them.

4.3.3 Recruitment and readiness

The current Self-Management Training course is limited to those who are stable enough to participate and who have a firm diagnosis of bipolar disorder. There may be a need to give further consideration to how the principles of self-management can be applied for a wider range of people affected by the disorder who may not be in a position to take on the commitment of a full course of this type.

4.3.4 Course follow up

Although the general view, particularly from the earlier course participants that follow up was not necessary, there were also indications that people found it helpful to be prompted to review what they had learned or derived from the course, to revisit the materials and to have the chance to reconvene with their fellow participants. This suggests that further consideration is warranted to determine how best to reinforce the value of the course and maintain any benefits achieved.

The course elicited considerable enthusiasm among those who had completed it. However due to tiredness at the end of the course respondents tended to feel they needed a break before following through on what they had learned. Therefore, the optimum time to instigate any follow up appears to be around three months after course completion, to offer further prompting and guidance. This could build on the 'letter to yourself' exercise, in which participants write to remind themselves of what they learned and of what they intended to undertake after the course.

4.3.5 Long term impact

The evaluation indicated the difficulties of tracking the impact of a course of this nature over time. However, although not many of the participants were still carrying out actions or tasks (e.g. completing a Mood Diary) as described in the training folder and as taught on the course, many did this for at least a period of time. And perhaps more importantly, every participant rated various aspects of their life as more positive since the course than before the course.

Participants' own accounts indicated that they had benefited as a result of gaining:

- Increased understanding of bipolar disorder
- Increased knowledge of drug therapies
- Increased confidence in making informed decisions, or asking informed questions of primary care services
- Greater awareness of the factors that preceded or precipitated a further episode of the disorder

Taken together these findings suggest the course has the potential to make an important contribution to supporting the capacity of people who have bipolar disorder to develop skills, confidence and techniques for self-management. The course contains key elements that are known to be effective in improving mental health: promoting control, reducing anxiety, increasing opportunity for social interaction and engagement and enabling people to participate more fully in decisions that affect their lives.

5. References

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