

In-Sight: an evaluation of user-led, recovery-based, holistic group training for bipolar disorder

This paper reports outcomes from a holistic, recovery-based, user-led group training for people with DSM-IV bipolar disorder. Drawn from professional therapies and personal experience of the illness by the user-researcher, the training was delivered over 12 weekly sessions. Using a case-study approach, an experimental design incorporated pilot (eight participants), main study (five) and control groups (six). Self-report scales measured mood, coping, empowerment and quality of life pre-, post- and six months post-training. Semi-structured interviews noted individual change within the same time frame. Interviews with mental health professionals, medical note analysis and user-researcher observations also informed the study. Findings from self-report questionnaires indicated that participants experienced improved mood stability, symptom severity, coping and quality of life and greater empowerment. Out of the six controls, two indicated slight but slow recovery, four continued to use poor coping skills, and two of these four experienced major relapses.

This paper explores the effectiveness of In-Sight, a holistic, recovery-based group training for people with bipolar disorder, devised and delivered by the first author, who has experienced the illness. It is now commonly accepted that 'bipolar disorder is a complex disorder' (Lam & Wong, 2005) that is influenced by and impacts on all areas of an individual's life. Hence 'it needs an intervention to be multi-faceted' (Lam & Wong, 2005) in order to aid individuals in their recovery.

Research, however, has mainly focused on the comparative benefits of various therapies. Such therapies include group psycho-education (eg. Bauer *et al.*, 1998; Colom & Lam, 2005), cognitive behavioural therapy (eg. Lam *et al.*, 2003), group CBT (eg. Palmer *et al.*, 1995; Patelis-Siotis *et al.*, 2001), group psychoanalytic psychotherapy (eg. Retzer *et al.*, 1991; Cerbonne *et al.*, 1992), family-focused therapy (eg. Miklowitz *et al.*, 2000; Rea *et al.*,

2003), interpersonal and social rhythm therapy (IPSRT) (eg. Frank *et al.*, 1994; Frank & Swartz, 2004), and integrated family and individual interpersonal and social rhythm therapy (Miklowitz *et al.*, 2000). These, although sharing similar therapeutic components, appear to compete for effectiveness rather than combine their benefits.

If poly-pharmacotherapy is accepted in the treatment of bipolar disorder, then might not poly-therapy equally be considered as a new type of psychotherapeutic intervention (Priem & Potter, 1990)? The success of combinations of medication and combined psychotherapies for bipolar disorder suggests that a 'multi-modal', combined treatment model is indicated (George, 1998). George (1998) advocated an integrated treatment approach based on the concept of recovery and designed to address the multi-faceted needs of the individual. Jindal and Thase (2003) propose that in 'our quest to provide the best possible symptom relief to our patients in

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the quickest possible time, it makes intuitive sense to combine both [psychotherapy and pharmacotherapy] treatment modalities'. To take this argument further, might we not also usefully draw both on the expertise of those who 'know about' bipolar disorder and on the first-hand knowledge of those 'experts by experience' who 'know the illness itself'?

Recovery vs illness management

Recovery is often misinterpreted as 'cure' – a successful endpoint, not the journey (Repper & Perkins, 2003); outcomes are often associated with the benefits of illness management alone. This results in professionals regarding the maintaining of a stable condition as synonymous with recovery (Coleman, 1999). If mental illness often means the loss of a sense of self, power, meaning and hope, recovery is about regaining control over one's life and renewed self-belief (Repper & Perkins, 2003). In therapeutic approaches, it is also important to include non-specific treatment effects. Hope is the bedrock of recovery approaches (Copeland, 1992; 1997), underlining the importance of 'creating provider-patient partnerships that maximize non-specific treatment mechanisms' (Morris *et al*, 2005).

Davidson (1999) noted that recovery involves making sense of the illness experience in ways that allow individuals to preserve or reconstruct a sense of efficacy and control and to re-establish meaningful connections with others. Long-term recovery involves progressing from 'passive victim' of the illness to more active agent, in order to master its secondary negative effects, including ongoing vulnerability to relapse. The search for personal meaning, development of self-confidence and of the self beyond the illness, enjoyment and a sense of well-being, hope and optimism are all part of the process (Mueser *et al*, 2002). While mental health professionals may view complete recovery as a return to a pre-morbid state of functioning, service users view recovery more as positive social engagement despite still possibly experiencing symptoms (Warner, 1994). The Recovery Advisory Group's model of recovery (Ralph, 1999) postulates six stages towards regaining wholeness or well-being: anguish, awakening, insight, action plan, determination to become well and well-being/empowerment.

However, in terms of the concept of taking back control over one's life and in learning to manage the illness and personal growth, there is an overlap with illness management techniques, as defined by Mueser *et al* (2002). Illness management is seen as 'the practice of medicine of professionals teaching

persons with medical diseases and their families about the disease in order to improve adherence to recommended treatments and to manage or relieve persistent symptoms and treatment side effects'. Some of these psychotherapies focus on improving self-efficacy and enabling people to pursue their goals, and thus overlap with recovery ideals (Mueser *et al*, 2002).

The distinction between illness management and recovery often resides in the power differential between professional and peer teaching, in terms of where responsibility for the health of the individual lies, and the imparting of personal experience of 'self' management lessons (Mueser *et al*, 2002). Recovery is more the demand for a new approach to service delivery, wherein empowering service users is seen not as disempowering professionals but as allowing a more effective use of their power. Thus recovery can be seen as a paradigm shift, not towards how a limited amount of power is distributed, but how it may be more effectively deployed (Allott *et al*, 2002).

The National Institute for Mental Health in England's Guiding Statement on Recovery (NIMHE, 2005, taken from Woodbridge & Fulford (2004)), indicates that promoting recovery is one of the Ten Essential Shared Capabilities for mental health practitioners. Tackling mental health problems with 'hope and optimism, to work towards a valued lifestyle within and beyond the limits of any mental health problem' is advocated, as is 'enabling self-empowerment and self-determination'. A second shared essential capability is that of user-centred care, in that 'meaningful goals... primarily from the perspective of service users and their families' are achieved. These capabilities are situated within a multi-disciplinary approach to providing the best possible, user-centred care. Thus it is the service user, the person diagnosed with mental ill health, who takes charge of the direction of travel that he/she needs to take in order to optimise his/her meaningful life, over and above the limits of any mental health problem whose symptoms might abate through illness management alone.

Service users' experience

It is now accepted that service users' experience of services can be used to improve mental health knowledge (Whittingham & Parsons, 1999), and that the involvement of service users, through their understanding of their experiences and needs, is central to offering better NHS services (Sang, 1999). However, research into users' experiences of bipolar disorder remains limited (Scott, 1995; Hill

& Sheppard, 1996; Hill *et al*, 1996; Birchwood, 1998; George, 1998).

In the UK, the first user-led research into self-management in bipolar disorder, and the first into self-management of mental health conditions, was undertaken as a randomised controlled trial by the Manic Depression Fellowship with the Bipolar Organisation during 1998–2000 (personal communication). It aimed to teach participants to improve their management of the illness. The programme content excluded many CBT and IPSRT techniques; social and lifestyle components were not developed, and information on expressed emotion was lacking. Geographically remote training venues and the intensive course length of two/three days were not conducive to integration of the training into participants' lives, optimisation of the knowledge base or continued group cohesion and support after the training had finished.

Baker (2002) provides an insight into coping techniques commonly used by members of the Mood Swings Network. Interestingly, only 25% of the coping strategies used by people with a diagnosis of bipolar disorder in the Network involved medication and services, with the remaining 75% being essentially non-medical (family/friends, support groups, positive thinking, exercise, sleep, education, mood monitoring, routine, work, hobbies, understanding the illness, talking, space, self-management, good food, socialising and faith, in order of importance).

The Wellness Recovery Action Plan (WRAP) developed by Copeland (1992; 1997) – who was also diagnosed with the disorder – presented a generic (ie. not bipolar-specific) group programme over 40 hours, based on five key concepts of hope, personal responsibility, self-advocacy, education and support. This, while addressing planning for well-being and in case of illness, did not include detailed healthy lifestyle elements, or IPSRT and CBT techniques. Only 44% of participants completed pre- and post-course self-report questionnaires, with no longer-term follow-up or follow-up on drop-outs. There was no external evaluation to confirm that client perception of improvements had translated into actual positive change, and there was no control group. Mental health user participants reported improved knowledge about the illness, and increased use of coping and wellness skills and advanced planning.

Helping oneself to health

Putting to good use 'experiential knowledge' in a socially supportive environment (Borkman, 1990)

can enable group members to feel more understood and less isolated, and to have greater empowerment and more coping strategies (Helgeson & Gottlieb, 2000). Sharing similar experiences to enhance wellness and problem-centred coping (Ah-Mane, 1999) in supportive self-help groups enables service users mutually to aid their recovery. It also provides an effective and cost-effective service not otherwise offered by professionals.

There are concerns that self-help may interfere with treatment or provide inappropriate advice (Chinman *et al*, 2002; Salzer *et al*, 2001). However, self-help groups bring social support where an individual is without family or peer support (Bauer *et al*, 1998). They 'may be helpful to confront denial often seen in early phases of bipolar disorder' (Dion & Pollack, 1992). The group format for therapy enables more patients to be treated at one time and allows them to benefit from the non-specific effects of sharing in a group context (Yalom, 1975). The 'group provides the means by which self-management strategies can be reinforced and new ones developed' and represents 'an available network of contacts to members who can, if they wish, use [them] in times of crisis' (George, 1998).

The Expert Patient Programme, launched in England by the Department of Health in 2001 (Department of Health, 2001), targets chronic disease management in general. While viewed as furthering the recovery approach and enabling shared learning across diagnoses, it does not provide illness-specific therapy or offer the benefits of commonality of experience (Davidson, 2005).

Para-professional experience

Hossack & Robinson (2005) argue that para-professionals (service users delivering therapeutic interventions) in mental health services, like service users in general, remain an 'untapped, undervalued and underused' resource (Webb *et al*, 2000; Rose, 2001). Through 'already having lived the experience' (Gartner, 1979), para-professionals are able to help others; through modelling successful change, they provide motivation and hope to other service users (Atkins & Christensen, 2001). Para-professionals' shared understanding and ability to communicate with their clients in a common language enables trusting relationships to build and provides a model of success for others to follow (Abdul-Quader, 1992). Para-professionals are able to enhance their own prestige and further their own recovery by being positively rewarded and confirmed in this role, from which further positive effects on their status, self-esteem and quality of life can result

(Wilson & O'Leary, 1980). In modelling 'good lives' for others, they effectively live better lives themselves (Ward & Brown, 2003).

Interestingly, although many para-professionals lack formal training, studies have concluded that para-professionals and professionals 'are equally effective in therapeutic terms' (Hossack & Robinson, 2005). This presents the possibility that in some contexts the para-professional might be preferable to the professional (Christensen & Jacobson, 1994). Further, the proposition that high-cost training brings added value to the therapeutic relationship might also be questioned (Atkins & Christensen, 2001).

Bright and colleagues' (1999) randomised controlled trial illustrated both the effectiveness of para-professionals and the effectiveness of self-help. They compared the efficacy of group CBT and mutual support groups, both professionally and para-professionally led, for depression. The study showed that, from both a subjective (participant) and objective (clinical) point of view, outcomes improved. Support groups were seen to be just as effective as CBT groups, and para-professional leaders were just as effective as professional therapists.

The weight of evidence from the literature thus suggests that the literature, user need and government policy converge in advocating a more comprehensive approach to recovery from bipolar disorder. It can be argued that integrating para-professional experiential knowledge with a self-help group format, drawing on current professionally-derived integrated techniques specific to bipolar disorder, and placing these in a didactic and robust manualised training rooted in the ideals of recovery and whole life, might optimise treatment outcomes.

Methodology

This paper presents an evaluation of In-Sight, a mental health service user-led lifestyle development group training for people with bipolar disorder, devised to help fill this current gap in knowledge and practice.

The contents of the training were compiled from the user-researcher's own experiences of bipolar disorder and from professionally-delivered therapies that have found some success with the illness. A focus group of five people with a diagnosis of bipolar disorder commented on the draft training manual, and their suggestions for improvement were incorporated. The final training programme ran over 10 (pilot group) and 12 (main study group) weekly sessions of three hours duration, and

comprised two main components: lifestyle and skills training, supported by a range of tools. Lifestyle components included recovery, linking behaviour-thoughts-mood, sleep, diet and weight, exercise, meaningful activities, good basic living skills, medication and adherence, family and social relationships, financial management, suicidality and perfectionism. Skills training included relaxation, counteracting negative thoughts, positive thinking and maintaining optimism, coping strategies, problem-solving, and goal setting. The tools included life events chart, personal mood signature, self-monitoring behaviour-thoughts-mood diary, self-monitoring activity schedule, well-being activity diary and advance directives (the full programme is available from the author).

A case study approach was adopted. Quantitative (participant self-report questionnaires) and qualitative methods (interviews with participants and mental health professionals, researcher participant observations and analysis of medical notes) were used to achieve a comprehensive research strategy. This multiple data source and method triangulation aimed to increase the validity of the findings. Researcher triangulation was enabled through joint working with a research assistant in interview preparation and subsequent collaborative analysis of emergent themes. Raw quantitative data and analyses were verified by the University of Hertfordshire's independent research unit.

Participants

Outpatient participants with a diagnosis of bipolar disorder (DSM-IV: bipolar I, bipolar II, cyclothymia and not otherwise specified) were sought. Participants had to be 18 years or over, and were excluded at the outset if they had any major physical illness that would prevent regular attendance, had any special precautionary measures against suicidality in their current treatment plan, or had a dual diagnosis or learning difficulties. Comorbidity was not an exclusion criterion, provided this was not the current principal focus of clinical attention.

Pilot programme

For the pilot, a quasi-experimental design was established. The researcher recruited participants from a total sample frame of 180 clients regularly attending a day centre in a town. Eighteen were approached as being diagnosed with bipolar disorder or, on the basis of their current medication, as having experienced severe mood swings and therefore 'likely' to have the illness. Eight chose to

Table 1: Study participants

	Male	Female
Pilot total (8)	5	3
– of which with bipolar diagnosis (5)	(3)	(2)
Main (5)	1	4
Controls (6)	2	4
Total	8	11

take part in the study. All eight completed the study, and data were collected on all participants. There was no control group for the pilot. Three of these pilot participants later had their diagnoses confirmed as schizophrenia (one) and schizoaffective disorder (two), but were not excluded from the study (see below).

Main study

For the main study, an experimental design was established. The researcher recruited directly from a total sample frame of 150 clients attending a day centre in a second town. Of these, 14 were considered likely candidates and three were recruited. Recruitment for the main study was also undertaken by mental health professionals who had previously contributed to the pilot. They contacted 20 people, of whom 11 agreed to take part. Random allocation to either training or control group for the main study was undertaken by a third party, using number tables. Of these, 14 participants were recruited in total, all of whom had a diagnosis of bipolar disorder. Eight were allocated to the training group and six to the control group. Data were collected on all the controls and five of the training group participants. Two main study participants withdrew because of extreme mood swings (in one case owing to acute depression, in the other to hypomania) and one was excluded by the researcher during the training because of disruptive behaviour.

Thus the total sample of pilot and main study participants came to 19 (see table 1). Ages ranged from 24 years to 76 years. In the main study there were equal numbers of 'younger' and 'older' participants in the intervention and control groups. Average age was in the 40s range. Length of time with the illness varied, although many had experienced bipolar disorder for over 20 years. One main study participant had previously followed cognitive analytic therapy; two controls had followed cognitive behavioural therapy. All had a

variety of secondary mental health difficulties, including general anxiety, panic, agoraphobia, claustrophobia, obsessive-compulsive disorder, substance abuse, sexual difficulties and developmental issues.

Interested participants were given a client information leaflet and consent form and encouraged to discuss taking part in the study with their mental health professionals, family and friends before deciding to do so. All 19 participants allowed the researcher access to their medical notes and to consult with their mental health professionals. All 19 completed self-report questionnaires and gave interviews pre-, post- and six-months post training.

Mental health professionals who contributed to the study included six consultant psychiatrists, five day centre workers, three social workers, two community psychiatric nurses, one clinical psychologist, one befriending group organiser and one home support worker. Family members were not recruited; any comments from family members were reported by the participants or by their mental health professionals.

Data collection

The self-report questionnaires measured mood (Bauer *et al*, 1991), empowerment (Rogers *et al*, 1997), coping (Carver, 1997) and quality of life (WHOQOL Group, 1996). Pre-course interview schedules were semi-directive and standardised and covered a variety of lifestyle topics. Post-course and six months post-course interview schedules focused more closely on specific aspects of change that individual participants might have experienced during the training, and areas ascertained by the researcher as key to their improved coping. The majority of participant and mental health professional interviews were audio taped. All tapes were transcribed. Participant observations during the training delivery were recorded as contemporaneous notes immediately following the

Table 2: Mood (Bauer, 1991)

Domains	Pre-course	Post-course	Post- six months
<i>Symptom severity</i>			
Pilot (n=8)	200	150	130
Pilot (n=5)	120	50**	10
Main study (n=5)	480	120*	80
Controls (n=6)	730	830	810
<i>Activation</i>			
Pilot (n=8)	55.56	75	50
Pilot (n=5)	55.56	10*	10
Main study (n=5)	120	50	40
Controls (n=6)	125	80	145
<i>Well-being</i>			
Pilot (n=8)	130	180*	125
Pilot (n=5)	100	170*	110
Main study (n=5)	100	230*	180
Controls (n=6)	110	115	185*
<i>Conflict</i>			
Pilot (n=8)	90	20*	50
Pilot (n=5)	50	10**	0
Main study (n=5)	130	40**	40
Controls (n=6)	125	130	135
<i>Depression</i>			
Pilot (n=8)	60	10	30
Pilot (n=5)	60	10**	0
Main study (n=5)	50	0*	20
Controls (n=6)	170	150	120

Median values to 2 decimals

* = $p < 0.1$; ** = $p < 0.05$

(not all ps were available for comparison)

weekly sessions. Medical notes on all participants were synthesised in note form. Some 160 qualitative 'texts' were collected and used in this study.

The pilot study commenced with pre-course measures in August 2003. Training was delivered over ten weekly sessions from September to December 2003, and post-course measures taken in December 2003. One group session follow-up took place in January 2004 and six months post-course measures were taken in May/June 2004. Following feedback from the pilot group, the training for the main study was delivered over an extended 12 weeks from September to December 2004, with one follow-up session in January 2005. Pre-, post- and six months post-course measures were taken at similar seasonal times to the pilot data capture. The training, in manual form, was delivered in weekly sessions of three hours. Homework assignments were allocated, and regular attendance and commitment to the training emphasised. Participants were

encouraged to attend a meal together at a local restaurant after each session, free of charge.

One pilot participant later trained as a main study group co-facilitator. This pilot participant/co-facilitator was followed up over a period of 18 months.

The self-report questionnaires were analysed using SPSS software. Data were separated into four groups for analysis: pilot group (eight participants, of whom three had other diagnoses of severe mental illness); pilot group (five people with bipolar disorder only); main study group (five participants with bipolar disorder), and controls (six participants with bipolar disorder). Presented as descriptive statistics (medians), with references to 25%/75% quartiles (available from the author) for pre-, post- and six months post training, the Wilcoxon within-group test was also undertaken to identify any pattern in findings pre-/post- and pre-/six months post-training. The qualitative data analysis relied on

the theoretical proposition that the training would result in improved coping, compared with no change in the controls. The researcher predicted an increase in variety and effectiveness of coping strategies as a result of the holistic training.

The texts were coded using Nud*ist software, initially in an open manner according to different topics in the data that emerged as salient. These topics were then grouped together to construct main categories or themes in a more structured way. Training participants' texts were analysed first, in order, until all these data were thematically analysed. Data for controls were then analysed and incorporated into the themes. These emerging outcomes informed the construction of a model (available from author) that made explicit the associations between the outcomes, and in turn helped build the explanation of how the training appeared to benefit participants and how these outcomes were intrinsically linked.

Ethical considerations

Several participants commenced the training while recovering from a mood swing, or experienced a mood swing during the training. When a mood swing was evident, the researcher informed participants that it was necessary to break the group confidentiality rule and for their care coordinator to be informed, but that they would not be withdrawn from the study. Exclusion was considered likely to do more harm by depriving them of the information and support the training offered. Use of the training materials to aid them in their management of the illness and closer liaison with their mental health professionals ensured that the more acute phase of their mood swing and any suicidal or psychotic behaviours were successfully managed. The three pilot participants who were later confirmed as having a diagnosis of schizo-affective disorder (two) and schizophrenia (one) were also maintained in the study, as they were benefiting from attending the training and they and the other group members requested this.

Control group participants were given a copy of the training manual at the end of the study.

The hypothesis was that the In-Sight user-led group training for people with bipolar disorder would benefit participants in comparison with controls. It was hypothesised that the benefits would be illustrated not only by improvements in mood, coping, empowerment and quality of life but also by a positive impact more broadly on participants' lives.

Results

All the reported results referring to the training group participants include the pilot and main study groups, unless otherwise specified.

Self-report questionnaires

Mood

Bipolar training group participants reported lower levels of mood activation subsequent to the course; these were maintained or decreased further six months later (table 2). Controls also decreased their activation levels at post-course measurement, but reported higher levels of activation at the equivalent six-month follow-up point. There was a marked rise in well-being among training group participants following the course. At six months post-course well-being had dropped to pre-course levels among the pilot participants; among the main study group participants well-being was maintained at a higher level than pre-course scores. Controls showed no difference post-course but, interestingly, reported a marked rise in well-being at six months post-course in comparison with pre-course scores.

Well-being and activation subscales taken together at different cut-off points determine mood. Training group participants – with higher well-being and lower activation scores – tended to progress towards a more 'euthymic' (stable) mood. However, controls – with higher levels of activation and increased well-being scores – tended towards a 'hypomanic' or 'manic' mood. Pre-course scores were recorded in August/September, post-course scores in December, and six months post-course scores in May/June. Seasonal (winter/summer) mood fluctuations may account for higher levels of activation and well-being in controls; training group participants did not show similar seasonal disturbances.

Training group participants reported a marked decrease in conflict following the training; these levels either increased slightly or were sustained at six months post-course, but did not reach pre-course levels. Controls continued at pre-course levels immediately after the training and at six months post-training. Training group participants reported a marked decrease in depression after the training. These lower levels of depression were maintained at six months post-training. Controls reported a gradual and slight decrease in depression from pre- to six months post-course.

Symptom severity

Scales for conflict, depression and activation were used to establish the overall symptom severity of a

participant. Training group participants reported a marked decline in their overall symptom severity following the course, which decreased further at six months post-course. Controls reported a general deterioration in overall symptom severity during the study.

Coping

Good coping strategies were designated by the researcher within the COPE (Carver, 1997) scale, and included subscales for self-distraction, active coping, emotional support, instrumental support, venting, positive reframing, planning, humour, acceptance and religion. All participants who took the training course showed a marked increase in the use of good coping strategies immediately after the course; controls showed a decline in their use of good coping strategies (table 3). At six months post-course median values for training group participants indicated use of fewer good coping strategies in comparison with pre-course levels, although the spread in scores showed that some training group participants slightly increased or maintained their good coping strategies, while others used fewer of them. Controls showed a similar reduction in median values at six months post-course, indicating fewer good coping strategies were used in comparison with pre-course scores. However, there was also a decline in the spread of scores, indicating that the control group as a whole was generally using fewer good coping strategies six months post-course than they were pre-course.

Poor coping strategies were designated as denial, substance abuse, behavioural disengagement and self-blame. Immediately after the course, the median values for the training group and controls indicated that they were using fewer poor coping strategies. At six months post-course, median values indicated that the training group and controls tended to increase use of poor coping strategies; however these did not revert to pre-course usage levels. The spread of scores for the training group indicated that, six months post-course, participants were using fewer poor coping strategies as a group, in comparison with pre-course usage. However, spread of scores for controls indicated that some participants were using fewer poor coping strategies and some were using more poor coping strategies in comparison with pre-course usage.

Empowerment

Training group participants increased their empowerment immediately after the course (table 4).

Main study group participants markedly increased their empowerment. Controls decreased their empowerment in the same time frame. This difference between increased and decreased empowerment in participants and controls immediately after the training was quite marked. At six months post-course, those who followed the training maintained increased empowerment with regards to pre-course scores, with some indication that the scores of the group as a whole continued to increase. In the same time frame, at six months post-course controls increased their empowerment scores quite markedly in comparison with pre-course scores, with an indication that the scores of the whole group increased. It is plausible that the increasingly hypomanic or manic mood of controls might have been associated with, or might even explain, their increased reported empowerment, and that seasonal fluctuations in controls explained both changes in mood and in empowerment.

Quality of life

Overall quality of life included four separate domains: physical, psychological, social and environmental. All study participants with a diagnosis of bipolar disorder improved their overall quality of life immediately post-course, and maintained or continued to improve their quality of life in comparison with pre-course scores at six months follow-up (table 5). The main study group showed quite marked improvements during this time. The pilot group showed improvements immediately post-course and some improvements at six months post-course; however some participants (possibly those with other diagnoses) appeared to have a poorer quality of life in comparison with pre-course scores. Controls showed a very small improvement during this time frame; however this was due to some participants improving while others did not.

Themes from textual data

The analysis of emergent themes pointed to the training having benefited the participants through the user-delivery of the training, the self-help group format, illness management techniques, improved life skills, healthier lifestyle and structure, goal-planning and an intellectual change in perspective. A model has emerged of the overall findings (available from author).

The clinical perspective

Better coping skills

Mental health professionals reported that their patients who had followed the training course were

Table 3: Coping (Carver, 1997)

Domains	Pre-course	Post-course	Post-six months
<i>Good coping</i>			
Pilot (n=8)	51	53.50 (a)	45.50* (b)
Pilot (n=5)	49	56* (c)	39 (d)
Main study (n=5)	46	49.50* (e) (-)	41 (f)
Controls (n=6)	38	34** (g) (-)	35 (h)
<i>Poor coping</i>			
Pilot (n=8)	11	8** (i)	9.5 (j)
Pilot (n=5)	10	8* (k)	8
Main study (n=5)	13.5	8** (l)	11.5 (m)
Controls (n=6)	15	8**	13

Median values to 2 decimals

* = $p < 0.1$; ** = $p < 0.05$

(a) = * more planning, acceptance

(b) = * less instrumental support

(c) = * more active coping, planning; ** acceptance

(d) = * less instrumental/emotional support

(e) = * more positive reframing, religion, planning, acceptance

(f) = * less emotional/instrumental support, *less venting

(g) = * less humour

(h) = * less emotional support, venting, humour, positive reframing

(i) = * more acceptance

(-) = ** between good coping (main and controls) (Mann-Whitney)

(i) = ** less substance abuse; *denial, behavioural disengagement, self blame

(j) = * less substance abuse

(k) = * less behavioural disengagement

(l) = * less behavioural disengagement, less denial

(m) = * less substance abuse

Poor coping = denial, substance abuse, behavioural disengagement, self-blame

Good coping = self-distraction, active coping, emotional/instrumental support, venting, positive reframing, planning, humour, acceptance, religion

Table 4: Empowerment (Rogers et al, 1997)

Domains	Pre-course	Post-course	Post-six months
<i>General empowerment</i>			
Pilot (n=8)	73.5	80	76.5
Pilot (n=5)	73	80	78
Main study (n=5)	79	83** (a)	81.5
Controls (n=6)	76.5	73.5 (a)	82**

Median values to 2 decimals

* = $P < 0.1$; ** = $P < 0.05$; a) = * between main group and controls (Mann-Whitney)

Table 5: Quality of life (WHOQOL Group, 1996)

Domains	Pre-course	Post-course	Post-six months
<i>Overall quality of life</i>			
Pilot (n=8)	54.77	55.45	56.18
Pilot (n=5)	54.24	56.40	61.18
Main study (n=5)	42.92	52.56**	54.28**
Controls (n=6)	45.56	49.52	54.32
<i>Physical</i>			
Pilot (n=8)	13.14	12.86	13.71
Pilot (n=5)	12.57	12.57	14.29
Main study (n=5)	12.56	16.56*	9.32
Controls (n=6)	13.72	14.84	16
<i>Psychological</i>			
Pilot (n=8)	12.50	13.17**	13
Pilot (n=5)	12	13.33**	13.33
Main study (n=5)	9.32	12.32**	13.32**
Controls (n=6)	12	12.68	14.68
<i>Social</i>			
Pilot (n=8)	14	14.67	12.67
Pilot (n=5)	13.33	14.67	16
Main study (n=5)	10.68	13.32	12*
Controls (n=6)	12	12	13.32
<i>Environmental</i>			
Pilot (n=8)	15	15.5	14.5
Pilot (n=5)	15.50	16	16*
Main study (n=5)	15	15**	14.52
Controls (n=6)	13.72	14	14

Median values to 2 decimals

* = $p < 0.1$; ** = $p < 0.05$

more insightful, accepting and understanding about the illness, and more able to face up to the illness. They were more able to distinguish between what was the illness and what were their 'normal' feelings; better able to externalise the illness and less stigmatised by it; had a more sensible attitude to medication and had more leeway to self-medicate if necessary; were more mood stable, displaying less anger, fewer major depressions and better management of high moods; were better at recognising their moods and quicker at taking action to manage them by taking medication and seeking appointments with professionals; were more self-reliant and responsible, and more able to take stock of what had happened during episodes. They were more able to manage their moods in a positive way without devaluing themselves, and had more distance from or a greater comfort zone within the illness. Some mental health professionals reported

that a few participants were initially overly sensitised to identifying symptoms of an approaching high mood (symptom centric), and had anxieties about their ability to cope. This was particularly apparent in participants who had secondary anxiety or panic disorders. However, by six months post-course all participants were more confident in judging any change in mood and in managing the illness, were more assertive, and tended towards a greater sense of empowerment. They were also more relaxed and confident and their lifestyle balance improved.

Group as support system

Mental health professionals reported that their patients had referred to the self-help group as being helpful, practical, supportive when offloading and when managing the illness, de-stigmatising because they were with a group of similarly diagnosed people, socially supportive, and an aid to

developing social skills, resulting in increased socialisation after the training. Participants were able to express their feelings in the group – feelings that had previously been invalidated by the illness and by others – rather than intellectualising the illness. Some participants reported to their mental health professionals that the weekly group sessions had been a much-needed time for themselves; others said it had been the highlight of their week. Participants reported to their mental health professionals that the group members served as a useful comparison between themselves and others with the illness.

Positive effect for family members

Mental health professionals also reported that the training had given credence to the illness for the families of those taking part. The training had enabled the family to take the illness seriously, and some family members had reported their own positive feedback to mental health professionals: for example, that coping strategies of their family member participating in the training had improved since taking the course.

Relationships with professionals

Mental health professionals reported that they experienced a more positive and easier relationship with their patients, and they related this to participants' increased knowledge of the illness, better articulation of their feelings, greater constructive dialogue with a higher level of communication, improved coping and greater mood stability, and achievements in other areas of the patients' lives that were related to having followed the training. They reported that their job had become more straightforward. They also reported that their patients had changed in their attitude towards them: there was an increased trust and a perception that the patients now considered their professionals to be on the same side and the relationship as being of benefit. Some participants who had moved on substantially following the training were reported as now having to renegotiate the 'system', because it was no longer in synchronicity with their needs.

The participant perspective

Training group participants reported that they had benefited in many ways after following the training: the user-led nature of the training was helpful, as was the self-help group aspect. These two aspects combined with and strengthened participants' knowledge base of the illness. Overall,

these fed into improvements in mood recognition and improved mood management, with much improved capacity to deal successfully with their mood swings.

Training group participants reported that they had improved their communication skills and were more assertive in a variety of situations, with improved anger management for those who most needed this. These three life skills fed into improvements in a wide variety of personal and professional relationships, including improvements in their relationship with their mental health professionals, in which they felt that they were being treated differently following the training. This improvement in interpersonal skills fed into and enhanced their coping skills.

Training group participants reported greater structure in their lives (more balance and routine, more planning and more setting and achievement of personal goals) and a healthier lifestyle (more attention to diet, loss of weight, more exercise, improved physical health including sleep and relaxation, improved living situation and resolution of money problems). These aspects fed into and enhanced better coping strategies.

Reviewing past trauma in a positive light was observed as enabling participants to challenge their current beliefs about the illness and about themselves. This enabled them to change their actions stemming from these dysfunctional beliefs, which had hitherto led to negative interactions with others and had impinged on their mood state. Participants to a lesser or greater extent adopted a more considered approach to work, their activities and their relationships. In allowing this new perspective to enter into their common sense, participants took more responsibility for themselves.

This intellectual process and resultant greater responsibility and attitudinal shift fed into and enhanced participants' coping strategies. This enhanced coping led in turn to a more enduring mood stability as they progressed to a phase of maintaining wellness, rather than simply coping with the illness. Maintaining wellness for long periods led participants to personally develop in more far-reaching areas of their lives. These personal developments required that participants renegotiate the 'system', as they needed more latitude for further development.

The more participants integrated the various components that together contributed to greater coping (which led on to mood stability, maintaining wellness and personally developing),

the more empowered they felt, the more positive they felt about themselves and their future, and the more their quality of life improved over time.

While the training group participants with a diagnosis of bipolar disorder achieved the greatest benefits from the course, the three participants diagnosed with schizo-affective disorder and schizophrenia also benefited in a similar way, albeit to a lesser degree and with less sustainability. The pilot participant who later trained as a co-trainer showed the greatest benefits. Controls showed variability throughout the period of study. Two controls continued in their usual coping style, with some slow but gradual recovery. Deterioration was noted for four controls as they continued in their use of poor coping skills; two experienced a major relapse (depression with psychosis).

Discussion

The results indicate support for the hypothesis that the training would benefit participants in the form of a more stable mood, greater empowerment and improved coping and quality of life. Further-reaching benefits to participants' lives generally also emerged.

The findings confirm evidence that combined therapies are welcomed by service users (Seligman, 1995) and tend to improve outcomes for those diagnosed with bipolar disorder (Jindal & Thase, 2003). There were concerns expressed by professionals about how the user-led training might interfere with treatment (Salzer *et al.*, 2001; Chinman *et al.*, 2002). However these dissipated as the study progressed and participants were seen to benefit. Support for the study also increased as mental health professionals noted that they also benefited in their consultations with participating clients and that the training included recognised therapies, including medication adherence and promotion of the therapeutic alliance.

Participants successfully managed both high and low moods throughout the group training and during the six months follow-up period. Mood swings gave participants the opportunity to practise the new skills taught within the user-led group, with its understanding and support. Frank and Swartz (2004), in their instability model of relapse adapted from Ehlers *et al.* (1988), showed that, besides biological vulnerability, several factors might indirectly provoke an episode: medication non-adherence, disrupted social rhythms, and life events with personal meaning, mediated by factors such as coping strategies and social support. Participants in this study changed their attitude and behaviour towards medication, were more capable managing

their illness, showed a willingness to structure and plan their lives in a realistic way, were able to examine past traumas that had directed how they had hitherto inter-related with others and were able to use the group as a social support system.

The recovery approach of the training covered many aspects of importance to a person with bipolar disorder; however, some mental health professionals considered that some components of the training, while helpful, did not directly come under the domain of psychiatry. These more 'indirect' influences of the training content were nonetheless important in contributing towards successfully coping with the illness rather than simple illness management at times of crisis (for example, improved life structure, healthy lifestyle, change of intellectual perspective and interpersonal skills). These indirect components contributed to the building up of a wider variety of choice of behaviours and approaches to situations, thus helping participants avoid or attenuate mood swings.

The findings in this study are congruent with work undertaken on group psycho-education (Colom *et al.*, 2003a; 2003b; Colom & Lam, 2005), cognitive-behavioural therapy and the Sense of Hyper Positive Self (Lam *et al.*, 2005a; 2005b; Lam & Wong, 2005), the Life Goals Programme (Bauer *et al.*, 1998; Bauer, 2001) and Social Rhythm Therapy (Frank *et al.*, 1997; 1999; 2000), which points towards all of these elements contributing to successful coping with bipolar disorder. Specifically, participants reported benefits from an enhanced structure to their schedules, better sleeping patterns, improved routine and life balance, goal-planning and breaks to modulate stress. Life skills were developed and helped modulate this stress. The findings from this study are also in line with the group as a source of social support (Johnson *et al.*, 2003) and the satisfaction from group interaction (De Andre *et al.*, 2006). As Colom and Lam (2005) have indicated with psycho-education, which might be likened to recovery-based programmes, while it may not be established which element is indispensable for successful outcomes, it is the combination that has shown prophylactic success.

The findings as to the benefits for participants' lives more generally supports previous research on how the self-help group format can promote wellness (Ah-Mane, 1999) and coping strategies (Helgeson & Gottlieb, 2000). The user-led element of the training enhanced the therapeutic alliance between the participants and the para-professional facilitators, and aided a more constructive alliance between participants and their mental health professional team. This understanding reinforced

the impact of the self-help group format on the techniques of illness management. Learning was enhanced by the lived experience of the facilitators. Trust was not an issue to be worked at; it was an underlying foundation from the start of the group training. The resource-pooling of a self-help group format and enhanced socialisation during and after the group training served to reinforce the training content and create a social support system. The findings indicate that this user-led training might support previous work, indicating effectiveness on a par with professionally-delivered interventions (Bright *et al*, 1999). The pilot participant who later co-facilitated the main study training effectively modelled a 'good life' and lived a better life himself in the process as the study progressed, thereby supporting evidence from the literature (Ward & Brown, 2003). The self-help group format continued after the study through the establishment of a local self-help group for people with bipolar disorder, at the request of those who took part in the study.

The didactic nature of the training supports the necessity and effectiveness of structured, illness-specific therapy for bipolar disorder as more beneficial than any self-help group support on its own (Colom *et al*, 2003a; 2003b). Participants coped with mood swings by practising the illness management components of the training that would not have been offered in more generic recovery approaches such as the Expert Patients Programme and Wellness Recovery Action Plan. The findings support evidence of the importance of attention to a variety of non-medical aspects (Baker, 2002). These, although not accorded importance by psychiatrists contributing to this study, were viewed as vital by other mental health professional interviewees. Specifically, findings in this study indicated that, in line with work by Ah-Mane (1998) for support groups, Currey (1995) and Mason (1999) for healthy lifestyle, and Mondimore (1999) for lifestyle balance, many non-medical and non-service related factors emerged as being important contributors to participants' coping strategies.

While the training format provided the group with the opportunity to share experiences, very few participants had been offered the opportunity to take part in the catharsis of self-help to deal with loss engendered by the illness (Soloman *et al*, 1995), or to revisit their lifestyles leading up to an episode. The safe environment of the group offered participants much-needed time to offload and grieve while working towards resolving a variety of life issues in a positive way. Some had deep-rooted family or

interpersonal issues that had remained unresolved; some remained traumatised about past episodes. The weekly sessions provided a safe, holding environment to review expectations and life goals and work towards taking back responsibility and control over the illness. Participants widened their horizons within a more realistic framework, rather than lowering their sights or limiting future plans. This contrasts with the findings on downward adjustment of expectations by Mason (1998) and Wahl (1999).

The intellectual change of perspective resulting from participating in the training included challenging participants' unrealistic – sometimes perfectionist – standards, their need to achieve, and their often misplaced sense of personal responsibility for events out of their control. Participants demonstrated an almost extreme self-sufficiency and independence associated with their not wanting to show vulnerability, expose their deeply-felt emotions or their need of others in problem-solving, similar to findings by Lam *et al* (2005a). In the study, participants practised communication and assertiveness skills, and became more comfortable with asking for help from others. Participants were able to frame realistic expectations of themselves and renegotiate the expectations set by others that had become their own. Participants learned to put themselves, not others, first, although not without some initial guilt in changing these set patterns of behaving. They also reframed their desire to achieve high standards in a more structured and balanced way.

The user-led and group format aided participants to explore their experiences of stigma and discrimination. They became more honest about their illness, especially with new employers, and hence increased their feelings of self-esteem and hopefulness (in contrast with the difficulties found in the work by Jameson (1998) and Wahl (1999), although confirming the conclusions drawn by Morris *et al* (2005) that providing care that maximises client hope is important).

Limitations to the study

The number of participants was limited and follow-up data, apart from those on the co-facilitator, ceased at six months post-course. Given the effectiveness of this intervention, a randomised controlled trial would allow the training outcomes to be explored with a larger sample over a longer period of time.

Minor discrepancies in accounts arose when there were differences between the accounts of participants and those of their mental health professionals. These were few and arose from the

limited knowledge certain mental health professionals had about a participant's particular situation as related to the researcher in detail or observed by the researcher during the weekly sessions. Mental health professionals who were in more frequent contact with their client participants gave a more cohesive account, and this was confirmed through participant testimonies.

There were no major changes in medication for participants or controls prior to taking part in this study. This suggests the benefits reported here did not derive from their medication regime alone.

Conclusions

Findings from this study indicate that this service user-led, recovery-based holistic group training is acceptable and of benefit both to participants and mental health professionals. They also indicate that the training benefited those with non-bipolar illnesses experiencing mood swings, although to a lesser degree. Whether in its current form for clients with bipolar disorder or in an adapted form for non-bipolar diagnosed individuals, further study of the application of this training is warranted. The convergence of multi-dimensional, integrated therapies, multi-level theoretical approaches, government policy requiring a whole life and recovery-oriented approach and the needs of people experiencing bipolar disorder appears to indicate that a holistic, group-based and user-led training might provide a step towards valuing the experiences of service users in order to provide better NHS services in future (Sang, 1999). It might also shift the paradigm a little so that user need and user outcomes, as identified through user-led research, direct service design and delivery. It is hoped that the training that is the subject of this study may be viewed not as an adjunct to current service provision or at odds with it, but as an advancement of mainstream services. Greater therapeutic integration would incorporate both the 'baby' of current therapies for bipolar disorder and the 'bath water' of user-focused recovery and whole life approaches to achieve better outcomes for individuals. 🌀

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