Publications

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(A)
Straughan HJ, Buckenham MA (2006) "In-Sight": an evaluation of user-led, recovery-based, holistic group training for bipolar disorder. Journal of Public Mental Health **5** (3) 28-41.

(B)
Straughan HJ (in press, due Oct 2007) Learning to Cope Together: Self-help, peer support and a multi-faceted approach are fundamental to learning to manage the complexity of bipolar disorder. Mental Health Today, Brighton.

(C)
Straughan HJ (2006) From the Edge: What a Difference the Channel Makes. French and European Conference on Self-Help Groups. Lille, France 1 & 2 February, 2006. EastForwards, Care Services Improvement Partnership, **24** 7.

(D)
Straughan HJ (in press, due 2008) Influencing Change: User or Researcher? Elitism in Research, Chapter 13 in This is Survivor Research. Beresford P, Faulkner A, Nettle M, Rose D & Sweeney A (eds). Supported by the Mental Health Foundation, for PCSS Books, London.

(E)
Straughan HJ (in press, due end 2006) as "Helen". NICE Bipolar Disorder Guidelines.Developed by the National Collaborating Centre for Mental Health, commissionedby the National Institute for Health and Clinical Excellence. Published by the British Psychological Society and The Royal College of Psychiatrists. Alden Press UK.

(F)
Straughan HJ (in press, due 2008) "In-Sight": recovery training for people with bipolar disorder and depression. Course manual. Pavilion Publishing, Brighton.

Learning to Cope Together
Mental Health Today

Heather Straughan

It is now commonly accepted that bipolar disorder is a complex mental illness[1] that is influenced by and impacts on all areas of an individual's life, often with devastating consequences. Hence, a multi-faceted intervention is needed[1] to help people in their recovery from it. Integrating various therapies for which evidence of effectiveness exists might surely create a more complete therapy[2] that might better 'encapsulate its complexity'[3] and address more fully the multi-faceted needs.[4]

The NICE bipolar guidelines[5] indicate some treatment effect for a variety of psychological therapies. Recommendations include a wide variety of strategies to enable people in their recovery: self-monitoring of triggers and warning signs; coping strategies; lifestyle advice, including regular sleep and stable and structured social and work patterns; diet and exercise; support after significant life events; increased social support, including improved family support, and participation in user groups and befriending.

Illness management skills may be the cornerstone of moving on from a diagnosis of bipolar disorder and dealing with the illness, but recovering one's whole life is not about illness management alone. Baker[6] found that, for members of the Mood Swings Network, only 25% of coping strategies used involved medication and services, whereas 75% involved essentially non-medical aspects. This points towards a holistic approach whereby family and 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 are used in order of importance, depending on individual need.

In-Sight training
The components of the Insight training reported here were compiled from my 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 programme ran over 12 weekly sessions of three hours duration, and comprised two main components: lifestyle and skills training, supported by a range of tools (see insert).

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 a life events chart, a personal mood signature, a self-monitoring behaviour-thoughts-mood diary, a self-monitoring activity schedule, a well-being activity diary and advance directives.

** NB: This paragraph could be removed and readers signposted to the adjacent box where the training contents from the slide (attached) are represented**

The training was first piloted with a group of eight participants (without a control group), who included one person with a diagnosis of schizophrenia and two people with a diagnosis of schizo-affective disorder. The training was then run again with five participants, and their outcomes after six months were compared with those of six people in a control group (who received normal care). All had primary bipolar disorder diagnoses. I delivered the pilot training on my own, but recruited a pilot group participant to co-facilitate the main group training.

The ages of the participants ranged from 24 years to 76 years. Length of time with the illness varied, although many had experienced bipolar disorder for over 20 years. 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.

Self-report questionnaires were used to measure mood, empowerment, coping and quality of life. Semi-structured interviews were also conducted with the participants pre-course, and immediately post-course, and six months post-course. Clinicians with knowledge of the participants were also interviewed throughout the study, including consultant psychiatrists, day centre workers, social workers, community psychiatric nurses, a clinical psychologist, a befriending group organiser and a home support worker.

The quantitative self-report questionnaires provided a rough 'group snapshot' of general tendency in outcomes.[7] Participants became more mood stable, improved their coping strategies, increased their sense of empowerment and improved their quality of life six months after the course had finished. The people in the control group generally fared less well over the same time period. They reported seasonal fluctuations in mood, worse coping, fluctuation in empowerment dependent on seasonal mood, and variable improvement in quality of life. A third of the people in the control group relapsed and a further third experienced deteriorating health with risk of relapse.[7]

Thematic analysis of the self-reports from the 13 participants produced rich qualitative data describing how the training had benefited participants.

User-led
That the training was user-led and situated within a self-help group format with socialisation and group sharing increased and deepened participants' knowledge of the illness and enabled them to establish a wider social network and friendships within the group. Self-expression and communication were also enhanced through this peer support. These benefits in turn were seen to enhance participants' general coping strategies.

'Before the course I wouldn't really have been… aware of my mood… I have become better at the kind of emotional exchange with people. I found it easier to do in a group, that I had come to know, that you trusted in that way.' (Participant, post course)

'I think the group helped get things into perspective… people learn from other people's experiences, 'cos we all have highs, we all have lows. It was a common core of experience there. How you deal with it, people have different strategies… people can learn what other people do, and that's good". (Participant, post-course)

These changes were also remarked on by mental health professionals:

'[He] felt very isolated before the group started… now he doesn't need to rely on me so much. He can discuss it with his friends and his new social network, instead of looking to me for answers.' (Day centre worker)

Therapeutic alliance
This improved self-expression and communication helped to improve relationships between participants and their mental health professional team and improved the therapeutic alliance. Coping with a mood swing with the help of the group support enhanced participants' general coping strategies. Participants became more responsible for themselves, more independent and less reliant on their mental health professionals. They had more distance on the illness. All of these changes enhanced their general coping strategies:

'The conversations I have with him are more constructive and it is more about how I can help him rather then listening to him get things off his chest and not come up with any solutions or answers for himself… I wouldn't say he needs less input but it is a different kind of input, and it is two-way now, rather than one-way.' (Day centre worker)

'I think the course gives me a better vocabulary to talk to [my psychiatrist]… to describe a high, or a low… I haven't had conversations like that with other people and so when I am in the situation, I go along to talk to psychiatrist, I am actually trying to figure out what on earth he is talking about in order to answer the questions. Well, I have kind of gone beyond that.' (Participant, post-course)

Lifestyles
Participants reported healthier lifestyle (healthier diet, weight loss, more exercise, better sleep patterns, healthier attitude towards food and alcohol, more knowledge about medication, more relaxation, healthier living situation and resolving money situations), improved structure to their life (better balance and routine, better schedules, more breaks and better planning around stressors) and personal goals that were often about a healthier lifestyle and structure to their life:

'And now I can probably deal with it more, by relaxing, or going out for a walk… not to go to bed, that was my failing. I just went to bed to shut everything out.'

'One of the goals I set myself was to improve my social circle and I have done this by starting up a social group... I now feel that if I want to go out and do something I have always got someone to call on to go with and need never be stuck in on my own bored.'

Relationships
The practice of assertiveness and anger management skills enabled participants to improve their relationships with others. Addressing past traumas in a positive light and challenging ingrained patterns of behaviour resulted in a greater sense of responsibility for self and greater independence from mental health professionals:

'I just thought, I don't want to do this anymore. If people are going to say stuff to me, they should know how I feel about it… the emotional confidence now is there. It just fed into a new sense of "I am worth it".'

'He used to have frequent angry outbursts when he would get very upset with people and he would make threats, or say he was feeling threatened. We haven't had any of that. Generally, his mood has improved a great deal. He is obviously managing his mood better than before. He is certainly picking up and recognising things.' (Day centre worker)

Better boundaries
Challenging deeply-seated beliefs and ingrained patterns of behaviour led participants to take a more considered approach to work and activities, and to feel less responsible for others, and less guilty about this:

'I used to be self-critical that you're down, so try to do something, but don't do it particularly effectively, and then criticise yourself for that. That kind of cycle, whereas by letting go, I don't worry too greatly about my level of accomplishment. I just get on with things and then actually find the enjoyment comes along with it… that keeps you in that stable area.'

'I think I learned that a lot from all the discussions I had in the group… 'Cos you can't make everything right all the time, can you? I think that's taken off a lot of pressure off me… I just felt that I've got to keep rescuing them [her parents], but I can't 'cos I need rescuing sometimes.'

One mental health professional summarised this change:

'Better boundaries… he has been empowered to get what he wants – a job or social group… He now takes a step back and thinks before saying. He copes by taking time out. He has self-restraint, especially with boundaries, and therefore he is quite well.' (Befriending organiser)

Mood management
Participants reported improved mood recognition and swifter mood management, helped by the self-help and user-led format of the training:

'I now know what the first steps of my mood are now… I feel that I can actually stop my moods swinging and I've controlled this upswing within in a week, so I don't lose contact with me friends. If I would have been in a job, I probably would have been able to get through it and still have the job at the end of it. So it's given me a lot more hope for the future.' (Participant post-course)

'He has been much more responsive in trying to change it [medication]… if he changes it, he tends to change it in sensible fashion… in a way that is helpful to him… And he has been much better at reading what is going on… he has got more of his own resilience.' (Consultant post-course)

Mind-set
Through success in challenging ingrained patterns of behaviour, a different 'mind set' was achieved:

'I didn't know there was even any coping strategies. I just thought, you just get down and depressed and have got to pull yourself out of it, and then it happens again. It was like the best thing that had happened to me, coming to something where I could see that just by taking responsibility for actions, you can actually change your behaviour to help yourself…

Because, no one is going to do it for me, they are not actually going to be inside my head, doing it for me.'

'A massive change from how I felt last time we spoke. Just having belief in yourself, and what you now know, and that you can cope. I think that dealing with things like suicide, suicidal thoughts, if that ever comes about again, I believe that I will have many more tools to handle it, and much more resilience. It certainly made me review the fact that, in the end, whatever is said about it, this is my shit, and I have to take responsibility for it.'

Hope for the future
Throughout the process, the improvement in general coping resulted in greater hope, and improved outlook for the future:

'If you look through my diary, the word "enjoyment" has actually cropped up quite a lot, whereas in the last 20 years, I didn't know what enjoyment was. I am just going out and enjoying myself.'

'… [to] know that despite feeling depressed a lot of the time in the past I have still managed to achieve quite a lot. So if I can do that feeling dreadful, then there is hope that feeling a bit better will be more positive and therefore I'll feel even better in myself.'

Negotiating the health system
Maintaining wellness meant that, in order to continue to move forward, participants had to use their new skills of communication and assertiveness to renegotiate their care plans with their mental health team:

'They tend to listen more to what I have got to say… Not just the day centre manager – my social worker, my consultant psychiatrist, they give me more leeway, they agree with what I am doing and they think I am actually doing the right thing most of the time.'

'I think he sees us [his mental health team] as being on the same side… it has been much easier going the last few months because he's been well. His social worker at the last Care Plan Approach meeting, she was sort of giving a gentle prodding, which is different than saying, previously where we have said: "Don't do it, that's it, just don't do it". (Consultant)

Conclusion
Participants used a range of techniques from the training to attenuate and avoid a mood swing, thereby improving situations in their lives or coping successfully with fluctuations in their mood. This skill-building enabled participants to draw on these various components at different points in their illness cycle, while the range of techniques had a knock-on effect, each enhancing the effect of other techniques. The overall effect was a more rounded, stable resilience in recovery, and better equipped, skilled and knowledgeable individuals more able to deal with situations in their lives. For further information, please contact Heather Straughan (h.straughan@btinternet.com).

1   Lam D, Wong G. Prodromes, coping strategies and psychological interventions in bipolar disorders. Clinical Psychology Review 2005; 25, 8: 1028–1042.
2   Miklowitz DJ, Richards JA, George EL et al. Integrated family and individual therapy for bipolar disorder: results of a treatment development study. Journal of Clinical Psychiatry 2003; 64, 2:182–191.

3   Jones SH, Sellwood W, McGovern J. Psychological therapies for bipolar disorder: the role of model-driven approaches to therapy integration: a review article. Journal of Bipolar Disorders 2005; 7: 22–32.

4   George S. Towards an integrated treatment approach for manic depression. Journal of Mental Health 1998; 7: 145–156.

5   NICE. The management of bipolar disorder in adults, children and adolescents, in primary and secondary care. London: NICE, 2006.

6   Baker JA. The service and illness experiences described by users of the Mood Swings Network. Journal of Mental Health 2002; 11, 4: 453–463.

7   Straughan HJ, Buckenham MA. In-Sight: an evaluation of user-led, recovery-based, holistic group training for bipolar disorder. Journal of Public Mental Health 2006; 5, 3: 28–41.

Chapter 13 – Influencing Change

User or Researcher? Elitism in Research
Heather Straughan

Society expects qualifications

Whether we like it or not, society demands and expects qualifications that attest to the level of education or training required to do a job well. It is usual in whatever field to expect a certain experience and competence in the skill acquired. When we speak of putting "our lives in their hands", I know of no one who would go happily into the operating room without the assurance that their surgeon is suitably qualified, having previously carried out the procedure with success for several years. Undertaking research has these same implicit expectations.

Whether it is research from a user perspective or not, research must stand by the quality of the work, not by the quality or meaning of the standpoint alone. That we make a distinction at all might lead non-user researchers into considering that our work, although worthwhile and perhaps slightly fashionable at the moment, lacks the traditionally accepted standards, levels of training and competence of traditional research, and hence the quality of the outcome might be doubted. It might wrongly mislead others into considering that "user-research" is a somewhat subordinate, second-class field whereas "researching from a user standpoint" is simply announcing our values plainly where all can see them

Whether we like it or not, when users and mental health professional teams meet together, although the user viewpoint might be given weight in the debate, the conclusions are often drawn by the professionals with their status of "Doctor", their extended knowledge of training in mental health and their experience in the field. Whilst user expertise is viewed as a useful although perhaps rare input on a client's case review meeting, it is the professional who takes the direction, leads the debate and makes the conclusions. How then, as users, can we meet professionals on equal terms and ensure that our standpoint is not put aside, albeit with reasoned politeness, in the final summing up?

Living the hypothesis

I had never considered re-training in the field of mental health until I was diagnosed with bipolar disorder. Doing a BSc (hons) in psychology seemed a cheaper and more convenient way to work through issues of mental health whilst gaining a qualification than 3 years of private counselling would have offered. I had never considered pursuing an MSc in social research methods nor undertaking a PhD until I realized that my ideas for living a more balanced and happier life with the illness might be put to the test and, if successful, might be made available to others to enable them to also live more fruitful lives.

It seemed that since I had got my life back on track after two manic episodes with psychotic features, lost 4 stone in weight and stopped drinking for a year whilst building a new life in England after 14 years spent abroad, that I was effectively living this healthier lifestyle. It also seemed plausible that I could formulate my ideas for a lifestyle development training into a course manual that could be taught to others. It seemed a plausible hypothesis that this might also result in tangible benefits for the group participants. It seemed reasonable that if I could change for the better, if successful, the training could help others to change and I might influence the adoption of the training by services so that it could be offered more widely to those who might benefit from it.

This then was my aim: to influence change from a standpoint of equality, from within the group not from without and equipped with tools to make that influence stronger. Effectively, to win them over or to beat them, I had to join them. I had to achieve the similarly highly held status of 'doctor'. In order to influence change, I had to take account of what perspective they had in evaluating the research they considered worthy. I also had to sell my perspective by being a walking advertisement for it. I had to ensure a presence amongst them.

Researching with an eye on others' perceptions

A number of issues naturally cropped up: design, methodology, outcome measures, analysis, my own standpoint, validity of findings, etc and how the training would be presented to both participants and mental health professionals I intended to engage in the study. All these issues were considered with an eye on what I considered to be of value but also what would be

considered of value by the 'professionals' both in the field of research and of mental health, so that the study would be taken not only as a piece of user-research but as a piece of research in its own right.

Indeed, why make the distinction of user-research as opposed to just plain research from a user standpoint? I do not see this as advancing our work from a user perspective, only damning us to a separate, perhaps subordinate sub-group of researchers.. All research is value-laden. Whether we admit it or not, we all start with a history, a perspective, a hypothesis. Research from a user perspective is still research but with the twist of penetrating that world where academia and mental health care professionals have until recently been allowed free rein. Research is research and I was determined that my work would stand or fall on the quality of the work, not from its standpoint alone. Indeed, whilst reading this, some might question whether I am a 'user-researcher' at all?

The Training: Not throwing the baby out with the bath water

In writing the training, I took the view that whilst considering what techniques users had found helpful in dealing with the illness, I must also look further afield at what techniques were being used by professionals in their work with clients with bipolar disorder. A variety of therapies were on offer from professionals – social rhythm, interpersonal, cognitive behavioural therapy, family, medication, etc –and only illness management or more 'soft' self-help were provided by user groups. I felt that it was a didactic or taught training encompassing a more holistic or 'whole life' approach to a person's life that was needed, as it touched all areas of life. I had decided on a more concrete taught approach as, with learning any other new skill for the first time, like driving a car for example, it is traditionally accepted, indeed required by law, that best results are acquired after a period of learning, assimilation and practice with feedback.

Additional 'common sense' techniques derived through my own personal experiences of getting the most out of life were incorporated so that the training now addressed a person's whole life. Whilst this seemed sensible to me, having had to rebuild my own from scratch, it also seemed wise to incorporate tried and tested professional methods. Rebuttals for acceptance of the training would be fewer as effectively many of the methods employed in

the training are currently available, although not widely on offer, from services and to date are not presented in this more holistic form.

Called "In-Sight", my training for people with bipolar disorder was named with a view to helping others achieve greater awareness of the illness and a practical "can do" approach to managing it. It was also so named because, from a professional standpoint, loss or maintaining insight is often taken as a vital gauge in the assessment of a person's mental health or ill health.

Insider's view outward - Outsider's view inward

A case study approach was chosen for the overall design as, working on my own, this allowed for a minimum number of participants for the study. It also allowed multiple sources of data - questionnaires and interviews from clients, professional interviews, medical notes, my own observations. Triangulation of these sources of data would allow an overall picture to be built up to establish any change in participants following the training. I was conscious that whilst my aim was to clarify participant change through their own accounts, I wanted this change to be confirmed (or not) by mental health professionals, especially consultant psychiatrists as team leaders, to act as a sort of 'external validity' to the findings. It was important to me that both a subjective perspective from the participants and an objective perspective from the mental health professionals triangulate to confirm validity, and for me to attempt to explain any discrepancies in reports.

Whilst both professionals' and participants' reports on any change might be considered subjective, this standpoint is taken to mean that objectivity is from the outsider's perspective looking in on the participant, and subjectivity the insider's perspective of the participant looking outward. In this way, external validity could be likened to an objective view on what is a subjective state of mind and reports would likely describe detailed behaviours, rather than changes in mood states or associated feelings or meanings connected to these. It was also possible that participants might report changes that were not observable by or reported to their team, and professionals report changes that had gone unnoticed by participants.

Again, as a researcher, and even more so as a researcher working from a user standpoint, I needed this confirmation of findings in order to give more weight to my work and increase

the likelihood of having the training adopted by services, should it prove successful. This aim of incorporating mental health professionals' views would be encompassed within what was a user-led piece of research, with my own participant observations making sense of the whole. This sense of directing and making sense of the whole project I believe is vital to the final understanding and emphasis that is placed on the findings. I hoped that this, coupled with the research being carried out towards achieving doctoral status, would rule out any objections about the work being a second class or weaker piece of research due to its user standpoint.

Incorporating others' standards for greater change

Within this case study approach, an experimental design was adopted for the research. This was both strategic and through choice. Society awards high status to randomised controlled trials. Randomly allocating participants to either the training group or a control group (care as usual) seemed the best way of appealing to those who would judge this work with an eye on that benchmark. So, whilst the pilot group had 8 participants with no controls due to poor recruitment, the main study group started with 8 participants and a control group of 6. It was also my personal choice to use an experimental design; I know of no one who would consider taking medications in any area of health without the assurance that these had been tested rigorously and been found more effective than sugar pills alone.

Data collection methods were similarly chosen on the basis of techniques that are nowadays given more weight, ie. quantitative data methods (questionnaires) were used together with more user-friendly qualitative data methods (interviews, my own observations and medical notes). Interestingly, I chose subjective participant views collected by quantitative methods and objective professionals' views collected by qualitative methods.

Outcome measures for questionnaires covered aspects of mood, coping, empowerment and quality of life. It seemed that whilst mood stability and coping were essential to managing the illness, quality of life was equally essential to gauge how the training might positively influence many different areas of life impacted upon by the illness. Empowerment, the only user-constructed measure, indicated for me enhanced belief in coping and personal development.

Whilst quantitative analysis with SPSS for the questionnaires gave a good overall 'group snapshot' on overall change following the training, the qualitative analysis with Nud*ist for the texts enabled a more detailed and personal picture to build up for each participant and for the group as a whole. Effectively, the numbers data gave me the broad brush strokes; whereas the texts, some 160 in all, enabled me to fill these brush strokes in. The whole of the data informed the case study and the emergence of an overarching model of how the training appeared to impact on positive change.

Whilst working on the study, it was interesting that my two supervisors came from two different backgrounds and different epistemologies. One, an academic, favoured a more phenomenological approach and qualitative textual data; the other, a psychiatrist, favoured a more positivist, quantitative, experimental approach. During the past few years, I have happily sat in the middle of them and made up my own mind that both approaches and epistemologies are useful and have much to add, hence a more eclectic approach to my work. My own initial eclecticism and also the need to explore the different 'tools of the trade' of a researcher were great motivators for putting this eclecticism into practice.

Validity of findings

I was conscious of the fact that this research was 'user-led' – in fact it was user inspired, user developed, user written, user delivered, user analysed and user reported – it could in fact be viewed as 'user invented'. I wanted to dispel any doubt as to the validity of my findings and as a student learning new research tools, have a second pair of eyes to check for any mistakes. I therefore decided to have my quantitative data audited for the pilot and checked thoroughly for the main study by unbiased University researchers (i.e. objective as outsiders' looking in on the work). With one or two data errors, without resultant change to the findings, my findings were confirmed.

In a similar manner, I had the opportunity to take on a research assistant during the study with whom I compared my analysis of the texts for one participant who was followed for 18 months. Similarities of categories and of emphasis given to changes were noticeable, as were changes that were on-going. Joint interview preparation and joint interviewing with this non-user research assistant and confirmation from a consultant psychiatrist on changes in this participant confirmed validity of findings of this textual analysis.

Some interesting results, from within and without

You may be wondering what the study results showed? I am pleased to say that those who participated in the training groups reported more stable mood, more good coping strategies (such as instrumental and emotional support, positive reframing) and fewer bad coping strategies (such as denial, substance abuse) They reported greater empowerment and improved quality of life post-training in comparison to pre-course scores. The control group showed no changes in these areas. Further, participants generally reported improvements in the 'skills' area of the course (better communication, greater assertiveness and anger management) which impacted on better relationships in general and interestingly on a change in attitude towards their mental health professional team. Improvements were also reported in the 'lifestyle' area of the course (more structure and balance, awareness of healthy eating and weight management, more exercise and an improvement in living conditions). Participants also reported a greater understanding and a more positive approach to viewing past traumas in their lives and how this had impacted on their current behaviour.

They took more responsibility for themselves and less responsibility for others leading to what one participant called 'stepping a different way' in her life. All participants who experienced a mood swing coped with it successfully during the period of the study and these improved coping strategies were fed into and reinforced by improved skills, lifestyle development and the positive reframing of past trauma. These improvements in coping serve to maintain mood stability, help a person stay well for longer and serve to move a person on in their own development where he or she then starts to renegotiate the system to move on further. The interaction between these improvements led to a sense of greater empowerment, improved sense of self, a brighter future outlook and improvements in quality of life which in turn fed back into the areas that would confirm the continued use of adaptive coping strategies, helping to maintain greater mood stability and personal development. (NB please refer to the diagram of the model at the end of this chapter).

Interestingly, mental health professionals also reported that participants showed a greater understanding and acceptance of the illness, were more able to articulate their feelings and differentiate between what was the illness and what were their 'normal' feelings. They reported that participants were more stable in mood, better able to recognize signs of illness

onset quicker and quicker at putting into practice adaptive coping techniques, thus attenuating a major mood swing. Professionals reported that participants acted more responsibly towards themselves and towards medication and some were noted as having developed their relationship with their professional team towards a more constructive partnership and away from needing a more directive approach. Participants reported through their mental health team that they had enjoyed the course, the vital 'time out' for themselves and found the group of similarly diagnosed people to be supportive, de-stigmatising and enabling greater socialisation.

Some mental health professionals reported that participants were more aware of symptoms, although this initial post-course reaction to learning about mood management and gaining more insight into the condition appeared to be quite natural and later faded as this new awareness was integrated into a person's own standards of what was 'normal' for them and what was not. Like learning to drive a car, when every gear shift is a conscious action, participants took time before assimilating this new knowledge into a more automatic and less thought-demanding process. Whilst some mental health professionals were delighted that their participants were more responsible for themselves after the course, others needed their participants' reassurance that they would not be sidelined in the event of a mood swing. As the coping strategies also included consulting mental health professionals in the event of becoming unwell, this had been incorporated into the training. Finally, it is worth mentioning that in progressing along their own individual path towards recovery, participants had to renegotiate their further progress with their mental health professionals and that these professionals had to step back in order to give this process of development and responsibility room to grow. Needless to say, the timing of this renegotiation of progress was not always synchronised.

When researching for change, these 'positive for the insider' and 'observable as positive by the outsider' perspectives triangulate to confirm benefits for both the participants in the progress they wanted to make in their lives and for the mental health professionals in the improved quality of their therapeutic alliance and the progress in the approach to the care they might now offer. These double benefits are more likely to lead to the training being offered to those with the illness. In research terms at least, it would appear that 'further study' is indeed warranted with a larger study sample. The fact that I have remained mood stable for the last nine years whilst living and writing this training might be considered by some

researchers as irrelevant. However, it might be considered by others to be the very crux of the hypothesis itself and illustrative of what research from a user standpoint is all about.

User-Researchers as pioneers in the 'grey zone'

Whilst I was conscious of working in an environment that might be difficult to penetrate as a lone user-researcher, I was also conscious that I was crossing into some sort of grey area, some pioneering zone that stretched between the users and the professionals, especially in the field of mental health and mental health research. It was for this reason that, whilst I had chosen for my base a day centre run by the voluntary sector, and had gained permission to use their address on my personally created letterhead, I also felt I needed the logos of both the University and the county NHS Trust. I felt that this piece of research would have a greater potential for change if it was perceived to be interdisciplinary and collaborative. In addition, as a prerequisite of doing the study, after an honorary contract signed with the Trust, the title of Clinical Research Fellow was duly added under my name. To influence change, I believe there has to be change. This initial change gave me status and my Trust identity badge gave me membership of a closed circle that initially did not take to my presence comfortably at their weekly case study meetings.

However, attend them I did, as these doctors would be those who would give me their feedback on changes in participants (their patients) and I was aware I had to work at this goodwill to win them over. Several were welcoming from the start, one or two took years of my presence to accept me; thankfully a hostile response was rare. I knew that since I had crossed over the professional boundary into the area called 'mental health service user', I would always be perceived as the user first, and the researcher second, as unfortunately some people's perceptions would implicitly seek to prevent a person ever to make the 'return journey'.

I felt I needed to achieve doctoral status to make the user perspective somehow more valid, for it to carry more weight in the debate and possibly to enable me to challenge this incongruence from a viewpoint of equality. Being called 'doctor' would just make things simpler and cut through the status of it all, making my point of view as important as anyone else's in the room, at the summing up of the case study meeting. I wanted the user standpoint to have equality but that meant refusing the 'user' label, brushing off others' perceptions as

inadequate and outdated, and trying to cross back over the boundary to re-enter the 'researcher' area.

I was grateful that my own consultant psychiatrist, who encouraged me in my work, was comfortable with a patient who was fast becoming more of a work colleague. In my discussions with him, I often referred to this as the 'pioneering grey zone' and we both acknowledged that some were not as comfortable as others with this new challenge. Fundamentally, though, I believe it is very much their problem, not mine. Even as I am writing this, I am aware that the us/them dichotomy is still being imposed upon me; other people are uncomfortable about allowing me to look any differently on an opportunity that might not only be helpful for me in my own personal development, but might open up the possibility of development in research in general.

User-Researcher: 2nd class researcher or ideal travel guide?

From the very beginning, I was conscious of this 'user/researcher' dichotomy – to professionals I was the user, to my participants I was the researcher. This No-man's Land between the two became what I perceived to be this perfect bridge and unique insight that could bring the two together to influence change. I believe that a more rounded and detailed work can be rendered by users who are researching - more complete for having this knowledge of the sensations, depths of feelings and meanings and the abject horrors of how illness can impact on ones life. Textbooks on research can be read; personal experience is lived real experience and no reading or memorising of texts or testimonials can ever hope to make this a living and breathing experience for non-user researchers.

Unlike Schutz's researcher who takes on the viewpoint of a 'stranger' who arrives for the first time in a town and builds up his understanding of people's actions through noting patterns of behaviour through close observation, I believe that the user-researcher is the perfect translator of understanding and meaning from a user perspective. The user-researcher is the person who would guide Schutz's stranger as he alights to take his tour of the town, showing him local colour that he would miss in the recommended guidebook, exploring with him the importance of the town and meanings for its people with the appropriate vocabulary that he would not otherwise experience or indeed ever hope to truly understand.

Some might liken being a user-researcher to the stance of a native ethnographer who bridges two cultures.. Native ethnography again picks up the theme of the identification between two differing cultures, serving as bridge between two worlds or what I like to call the ideal cross-cultural 'translator-travel guide'. If we are to be mindful that academia may be elitist, we must also allow for the possibility that as user-researchers working in this rare pioneering age of cross-culturalism, we could also find ourselves as a somewhat small sub-group or 'elite' and whether this actually serves our purpose well?

User-researchers: their own elite?

In calling ourselves 'user-researchers', we are not well served by distinguishing ourselves as a race of researchers apart from the rest, implying that we would tend to put our standpoint first, rather than the quality of the work that would seek to emphasise this very standpoint. We do not need to do this as our work is already doing that for us.

As perceived firstly as service users with the research quotient tacked on behind, we risk being viewed by some as dabbling in research, not primarily as competent, trained and experienced researchers who stand by the quality of their work. We risk being sidelined into a sub-group whilst mainstream research maintains its super-ordinate status, into which we are denying ourselves entry.

In announcing our standpoint first, we are perhaps unaware that the outcome of our work will be initially considered on the basis of that standpoint and viewed from that perspective alone. Resultant outcomes, like behaviours emitted from a person with a mental health diagnosis, are then perceived in the light of this overriding theme, and the actual competence and quality of the work, like clients' behaviours, are only explained within the confines of this limited view. We in turn might find this limiting. If we do not remove this primary emphasis, we are not likely to achieve much nor very quickly as we are in fact boxing ourselves in, just as any diagnosistic label might inhibit the person from achieving any more than the label will allow. By standing outside that which we wish to influence and not putting our research skills first, we are probably not making a good long-term choice. In as much as we try to refrain from using nouns to describe people's mental illnesses, i.e. we replace 'schizophrenic' with 'a person experiencing schizophrenia', likewise I feel we might be better served if the

abbreviated 'user-researcher' was reversed to 'researcher from a service user standpoint' or, as no work is value-free, simply 'researcher'. I feel we would get more mileage out of that.

Whilst we may fear being assimilated into the overriding 'traditional research' identity, or being sidelined by more traditional approaches not favouring our own, we are not allowing ourselves the possibility of belonging to the wider research community. This participation does not mean giving up our own user standpoint identity but being both within the wider research community and separate from it in our own standpoint group. I find it interesting that, at a time when the different sections of psychology are going through a period of change, researchers engaged in work from a user standpoint might also benefit from the more positive approaches to conflict and diversity management applied, so that we might position our work for maximum benefit within a more organic pluralist approach. This would seem to allow for the wider research community housing many different standpoints involving all in the change and developmental processes which I feel sure we would wish to influence.

When we speak about engendering change, it is also the change of the whole group of researchers from a user standpoint that must be aware that if our work is to have real effect on mainstream research, we must influence it by participating in it. We must allow ourselves to enter that wider 'research' group, not stand outside of it by announcing our differences, rather than our similarities, first. As in my own research study, it is not easy to be allowed by mental health professionals to cross back over the boundary and leave the 'service user' subordinate to the 'researcher' but it is a necessary journey for real change, for both service users and mental health professionals.

For change there must be change

I thought it a testimony to my consultant's forward thinking that he was aware that these were pioneering days in user involvement and research and that he was comfortable with this. For those who were not so at ease, my attendance at these case study meetings had apparently changed the tone of them. But I was aware that to engender change there must be change. Coming from two different perspectives, two different standpoints, one medical, one user, could mean that we would meet somewhere in the middle of this grey pioneering area, but still remain with our two different and opposing views. That was not what I hoped for nor how I see this story ending if we are indeed all to move forward together. I wanted not to start

from the 'user perspective' but to start from a different one, a fresh one that I hoped would be more constructive. However, how to start from this fresh perspective if others are more comfortable viewing you as the service user with its inherent standpoint? I realised that I would meet professionals coming from their standpoint, defending their values, their training and personal experience, their way of how things might be done, and up until then, how things had been done. Effectively, they would be defending their power as unable to choose from other more constructive behaviours.

It seems to me that we have a choice of how users, and researchers from a user standpoint, might proceed. Either we start from opposing sides and achieve equality through hard-bitten struggles, and we win out, as win out we undoubtedly will, or we start from a new perspective which I hope my research is testimony to: we incorporate both perspectives to move forward together. Therein lies the challenge: whilst some are willing to work in this new pioneering area that lacks clarity, that makes you question what you do and how you do it, some are unwilling or unable to leave their past behind, whether professional or user, to go a new way. As my own research participant reminded me, it is a case of 'stepping a different way' and for me that means change for all of us, as researchers from whatever standpoint, and for mental health professionals and service users in general, else we limit our own potential for real change.

Do we want change or transformation?

In these pioneering days of researching from a service user standpoint, a standpoint that is theoretically at the heart of mental health services, those who have the skills and tools and the lived experience, as well as the insight into the meaning and value attached to that lived experience, have the chance to engender real change. The question is whether researchers engaged in user viewpoint work would wish for permanent transformation and to lead on good practice in allowing us all to 'step a different way'?

In my work, in as much as I have incorporated both the outsider and insider perspective to note changes resulting from my training, I also think that choosing one perspective above the other is not much of a choice at all. It is neither the user viewpoint nor the more medical traditional research perspective that should be given more weight than the other. As services become increasingly 'client-centred' and indeed 'client-commissioned' it seems clear which

perspective will eventually win out. However, as in my own research, not throwing the baby out with the bath water would mean improving on the old, not simply disregarding it. Whatever route research from a user standpoint takes to develop and engender what I hope will be permanent transformation, it is all hard work!

Like anything worth doing - academia means work!

Academia is all hard work, and that means that anyone can do it if they are prepared to put the effort into it and want it enough. That means you. It is certainly not easy; working as a lone researcher can be isolating and your self-reliance and thinking processes are always developing, but it's never boring. It is never without value and it never loses its motivating forces for you, as you aim to drive through change in an environment that may seek to question every move you make or decision you take and whose behaviours you naturally question in turn. Your ultimate responsibility for the project resides with you. Whether the work gets done or not is up to you, but ultimately the greatest motivator is that your work, now validated as effective, may be offered (as in my case) to all the other service users with bipolar disorder. The final act for change must be the aim to make practical use of your study in making it available to all: hence my current challenge of establishing a new service where the training might be offered - not another object on my shelf to dust!

As my study is concluding, there is a great sense of personal satisfaction that I have worked hard at developing my skills and thinking processes to gain the status of a recognized trained professional researcher with doctoral status. I feel that, as the ideal 'translator tour guide', I am able to offer up a deeper understanding of the user perspective to those who will always be without this vital component. As you may imagine, this has also been a time of much personal development. The final impact of influencing change and increasing the swiftness with which we have become accustomed to see this change take place is hopefully also likely to increase. As I have consistently worked with this aim in mind, I would certainly hope that to be the case. I find that an interesting hypothesis that I hope many of you reading this would like to explore further. I wish you all the best in your future doctoral work!

A Personal Testimony on experience with Bipolar Disorder
For the NICE Guidelines on Bipolar Disorder, 2006

Square One – the Diagnosis
Heather Straughan

At 31 years old I had a "breakdown" in France where I had been living for some 10 years. I was told by a French psychiatrist that "I would always be vulnerable, like a vase which had cracked" but was offered no diagnosis or explanation of how this might have happened or how I might try to make some sense of this experience. Whilst trying to come to terms with the frightening experience that had shaken me to my very core beliefs and values and questioned everything I had hitherto come to take for granted, and challenge any rosy future that I had counted on until that point, this message of vulnerable and unrepairable self was reinforced by all contact I had with French services. At 34 I had my second "breakdown", still without any diagnosis offered, but a consistent message of ever-growing vulnerability, an increasing dependency on a system that offered no hope outside medication and a second unnecessarily protracted section in a French asylum, which resulted in my father having to come to get me out in person.

Returning to England, and no need for continued hospitalisation, after translations of medical notes and a plain commonsense approach from a locum psychiatrist, I was given a diagnosis and my hope of recovery and determination to understand the implications of this was allowed to begin. It was initially a handy "hook to hang things on" as I attempted to sort out my two manic episodes with psychotic features, three sections in a foreign country and my ensuing disrespectful treatment in a French asylum from a now British more forward-looking, supportive, client-centred recovery-based approach in the community that offered hope, empowerment and support in enabling me to move forward and out of a tangled mess, of my life and my psychosis.

It is hard to describe psychosis. It is like a waking dream and reality that merge, slowing leaving reality behind as you enter an increasingly frightening new 'reality' of seeing things and people that aren't there, hearing voices which don't exist telling you to do ever increasingly irrational, dangerous and injurious things. All this tinged with ever-growing paranoia. As the psychosis takes hold, and this is combined with a manic mood swing, it is possible not to feel hunger, not to need sleep, not even to feel pain, as the body is whipped up to maximum motor output, the mind is racing at top speed making impossible connections between evens and the heightened euphoric emotions all combine together to direct some deluded 'mission' that you are convinced that you are on. The ultimate heights are when such is the now ingrained belief of this mission, a personae is adopted at full mania. My adopted personae thankfully tended towards the good ones: Mother Earth and God's Daughter as the second coming of Christ. I say thankfully as my psyche did not go for the Angel of Death or other 'evil' characters.

Square One, I called it – the day I was given a diagnosis. Despite the horrors of psychosis, believe me it is actually less frightening than not to have been told what the illness was and to live in the fear of something you know nothing about happening again, and for it to actually happen again, and having been given no hope to understand and no skills to be able to cope with it. The fear of the unknown is always the worst. I've faced my worst fears.

My psychiatrist could offer little practical help other than to mention the Manic Depression Fellowship whom I contacted to join a local self-help group and follow their self-management training course some years later. During this 6 week course, I learned to call a breakdown an 'episode' and how to recognize and cope with them. I learned there were others like me with the same illness and accepted it as such. I learned that people with bipolar disorder were actually quite talented, intelligent, empathic individuals who had much to offer society and I was one of them. Drug maintenance with mood stabilisers was discussed at length with my psychiatrist although it was not until some three years after my second episode that I was given a 6 week psychological therapy dealing with becoming more assertive in relationships, a weakness I wanted to strengthen. I had decided early on that Square One would not be my Final Square and that the diagnosis, although much needed to move forward, would not make up my entire person. I was more than my diagnosis and always would be.

I am sorry to say that what I needed was not on offer at the time. Nor is it still. I needed a therapy that would teach me the skills and encourage me to rebuild my life, my 'self' which had been shattered by my experiences. Rather than dwell on this through possibly years of expensive private counselling, I followed and gained an honours degree in psychology, determined to improve my understanding. I worked for the Manic Depression Fellowship coordinating their research into their self-management training programme whilst realizing that, like me, people with bipolar disorder were much more than their illness and hence needed a more holistic, comprehensive approach to training than simple mood recognition and management, so I started to develop my own.

Following on from my masters in social research methods and now completing my PhD investigating "In-Sight", a lifestyle development training programme for people with bipolar disorder I wrote, and have found effective, I can look back and honestly say that I have turned this luck of the draw of having bipolar disorder into a benefit for others with the same diagnosis. The training offers insight into the condition and a hopeful recovery approach that is attainable. I wrote the training by living it to get better. But this training is still not available to those who might wish for it, only piecemeal therapies leaving a holistic positive approach, user-led in a group format for social support, untouched. Why is that? When research points to bipolar disorder affecting every part of your life, often leaving it in ruins, that a holistic therapy does not exist that would help people to rebuild it as a whole?
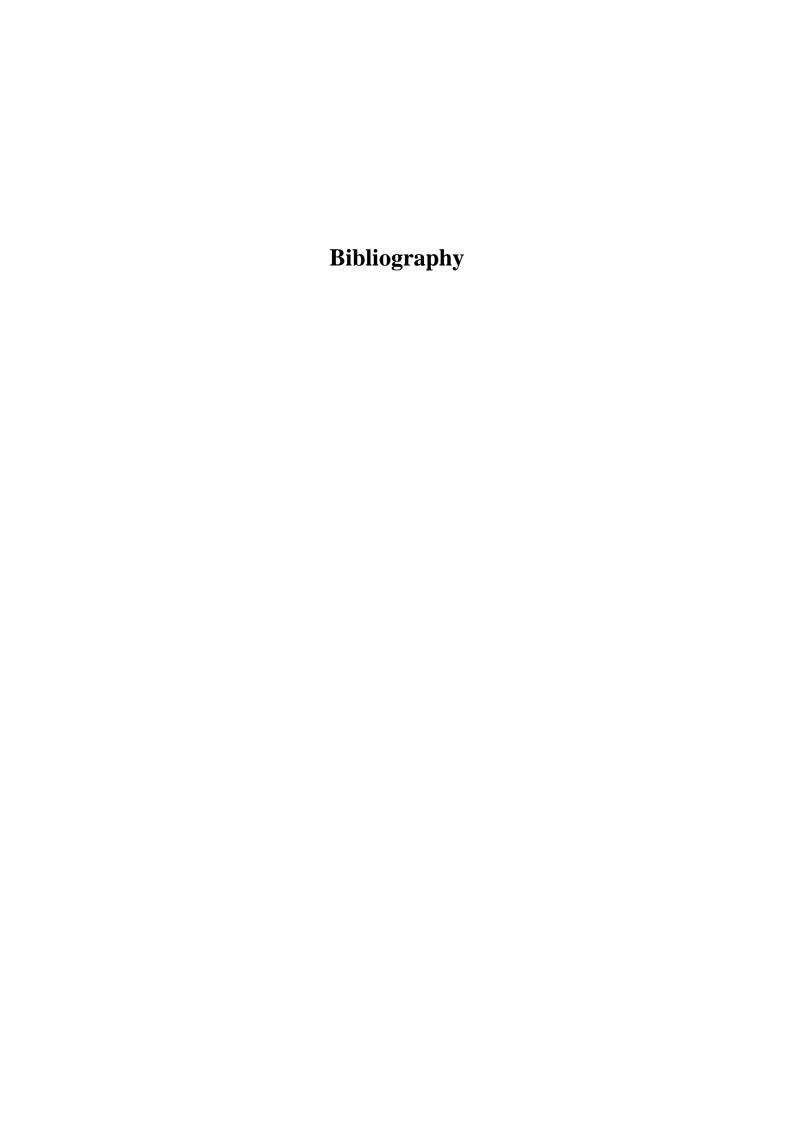
My relationship with my psychiatrist has been excellent. I could not have wished for a more supportive, person-centred, empathic individual who has encouraged me in my understanding and later research of this disorder. He often threw my questions back at me as he was aware that I was now working in mental health and was regarded more of a 'coach' or my 'sounding board'. It was I who asked if my diagnosis was indeed Bipolar I, which he confirmed. The initial rare visits from Community Psychiatric Nurse and Social Worker did nothing to support my desired ambitions only limit them to cautious, lowly objectives combined with opportunities for them to monitor. After a few visits of this nature, I felt I had to tell them that I would telephone them if they were ever needed. Now discharged from secondary services, I am reluctant to rely on primary care who are not yet equipped to deal with mental health issues and so prefer to keep the door open with psychiatry, so that I might receive support as and when I might require their valued perspective. My relationship with my GP is limited to e-mailing requests for repeat prescriptions for Carbamazepine, 200mg/day, which I have fine-tuned down to twice annually.

My PhD work has brought me into contact with many psychiatrists who in the majority are genuinely striving to empower the client whilst having to balance this with the ultimate power of being able to decide who is sane and who is not and to deprive of liberty in a section. Not an easy job. My recent work as Chair of ViewPoint, the Hertfordshire charity enabling mental health service users to put forward their views in order to shape services has allowed me to encourage others to hope for a greater recovery and to take a greater part in how they would wished to be treated. Empowered, I am empowering others.

Since Square One, I consider I have come a long way. I have had the painful but liberating opportunity to discuss my upbringing with my now deceased mother and how her expectations and protectiveness of her single daughter contributed to my hitherto perfectionism, criticalness, self-doubt and need for approval. I learned to call this 'expressed emotion' and know how much this plays a part in the illness and the recovery from it. I also learned in her lifetime not to attribute blame to what were her good intentions for me and to forgive.

As to the Final Square, I don't believe there is one. I believe that although mood swings will come and go – I have experienced only minor short-lasting bouts which have been successfully self-managed since my last episode over 8 years ago in France - I believe that after a period of mental illness, there is the real possibility of growth. Not simply a return to pre-morbid functioning, which was obviously not functioning that efficiently in the first place, but a real opportunity to turn mental illness inside out and derive personal development from it, towards self-actualisation. Now concluding my research to achieve the status of 'Doctor', I also believe that bipolars have a depth to their talents and their personalities, have enriched society with them in the past and have much to offer society in the future. Such are the life destabilising horrors of a full-blown manic episode with psychotic features, such can be the potential for turning this psychic depth to a positive flip side. Like Piers Allott, the NIMHE Fellow for Recovery, I too believe that recovery can mean moving on to achieve more, not just recuperating what is lost.

It all starts with Square One.

Bibliography

Bibliography

Abdul-Quader AS (1992) Injecting drug users and female sexual partners of drug users outreach on the Lower East Side of New York City. British Journal of Addiction **81** 681-688.

Ah-Mane S (1999) Service users are gaining strength by sharing their insights into the mental health service. Nursing Times **95** 42.

Atkins DC, Christensen A (2001) Is professional training worth the bother? A review of the impact of psychotherapy training on clients outcomes. Australian Psychologist **36** 122-130.

Allott P, Loganathan L, Fullford KWM (2002) Discovering Hope for Recovery from a British Perspective: A review of a selection of recovery literature, implications for practice and systems change. In: Lurie S, McCubbin M, Dallaire B (Eds) (2002) International innovations in community mental health (special issue). Canadian Journal of Community Mental Health**, 21** (3).

American Psychiatric Association (1993) Practice Guideline for major depressive disorder in adults. American Journal of Psychiatry **150** (4) 1-26.

Anthony WA (1993) Recovery from mental illness: the guiding vision of the mental health system in the 1990s. Innovations and Research **2,** 17-24.

Baker JA (2002) The Service and illness experiences described by users of the Mood Swings Network. Journal of Mental Health **11** (4) 453-463.

Bandura, A. (1982) Self-Efficacy mechanism in human agency, American Psychologist, Vol. **37**(2), pp. 122-147.

Bandura, A. (1986) The explanatory and predictive scope of self-efficacy theory, Journal of Social and Clinical Psychology, Vol. **4**(3), pp. 359-373.

Bandura, A. (1991) Social cognitive theory of self-regulation, Organisational Behaviour and Human Decision Processes, Vol. **50**(2), pp. 248-287.

Barlow, J.H., Williams, B., Wright, C. (1997) Improving arthritis self-management among older adults: "Just what the doctor didn't order", British Journal of Health Psychology, **2**(2), pp. 175-186.

Basco MR, Rush AJ (1996) Cognitive-behavioral Therapy for Bipolar Disorder. New York: Guilford Press.

Bauer MS (2001) The collaborative practice model for bipolar disorder: design and implementation in a multi-site randomised controlled trial. Journal of Bipolar Disorders **3** 233-244.

Bauer MS (2001) An evidence-based review of psychosocial treatments for bipolar disorder. Psychopharmacology Bulletin Summer **35** (3) 109-134.

Bauer MS (2002) Psychosocial interventions for Bipolar Disorder: A Review. In: Maj M, Akiskal HS, Lopez-Ibor JJ, Sartorius N (eds). Bipolar Disorder 3 in WPA Series; Evidence and Experience in Psychiatry. Chichester: John Wiley & Sons Ltd.

Bauer MS, McBride L, Chase C, Sachs G, Shea N (1998) Manual-Based Group Psychotherapy for Bipolar Disorder. A feasibility study. Journal of Clinical Psychiatry **59** (9) 449-455.

Bauer MS, McBride L (2003) Structured Group Psychotherapy for Bipolar Disorder: The Life Goals Programme (2nd ed) Springer, New York.

Bernhard B, Schaub, A, Kummler P, Dittmann S, Severus E, Seemuller F, Born C, Forsthoff A, Licht RW, Grunze H (2006) Impact of cognitive-psychoeducational interventions in bipolar patients and their relatives. Journal of European Psychiatry **21** (2) 81-86.

Birchwood M (1998) New directions in the psycho-social approach to the psychosis. Journal of Mental Health **7** 111-114.

Borkman TJ (1990) Understanding self-help/mutual aid: Experiential learning in the commons. New Brunswick NJ: Rutgers University Press.

Bright JI, Baker KD, Neimayer RA (1999) Professional and paraprofessional group treatments for depression: A comparison of cognitive-behavioural and mutual support interventions. Journal of Consulting and Clinical Psychology **67** 491-501.

Butzlaff RL, Hooley JM (1998) Expressed emotion and psychiatric relapse: a meta-analysis. Archives of General Psychiatry **55** 547-552.

Cerbonne MJ, Mayo JA, Cuthbertson BA, O'Connell RA (1992) Group therapy as an adjunct to medication in the management of bipolar affective disorder. Group 1992 **16** 174-187.

Chinman M, Kloos B, O'Connell M, Davidson L (2002) Service providers' view of psychiatric mutual support groups. Journal of Community Psychology **30** 349-366.

Christensen A, Jacobson NS (1994) Who (or what) can do psychotherapy? The status and challenge of non-professional therapies. Psychological Science **5** 8-14.

Copeland, M. E. (1992) and 2nd edition 2001. The Depression Workbook: A guide for living with depression and manic depression, New Harbinger Publications Inc., Oakland, CA, United States.

Copeland ME (1997) revised 2002. Wellness Recovery Action Plan. West Dummerston VT: Peach Press. Revised 2001.

Coleman R (1999) Recovery: An Alien Concept. Handsell Publishing, Gloucester.

Colom F, Vieta E, Martinez A, Jorquera A, Gasto C (1998) What is the role of psychotherapy in the treatment of bipolar disorder? Psychotherapy and Psychosomatics **67** 3-9.

Colom F, Vieta E, Martinez-Aran A, Reinares M, Benabarre A, Gasto C (2000) Clinical factors associated to treatment non-compliance in euthymic bipolar patients. Journal of Clinical Psychiatry **61** 549-554.

Colom F, Vieta E, Martinez-Aran A, Reinares M, Goikolea JM, Benabarre A, et al (2003a)A randomised trial on the efficacy of group psychoeducation in the prophylaxis of recurrence in bipolar patients whose disease is in remission. Archives of General Psychiatry **60** (4) 402-407.

Colom F, Vieta E, Reinares M, Martinez-Aran A, Torrent C, Goikolea JM, Gasto C (2003b) Psychoeducation efficacy in bipolar disorders: beyond compliance enhancement. Journal of Clinical Psychiatry **64** 1101-1105.

Colom F, Vieta E, Sanchez-Moreno J, Martinez-Aran A, Torrent C, Reinares M, Goikolea JM, Benabarre A, Comes M (2004) Psychoeducation in bipolar patients with comorbid personality disorders. Journal of Bipolar Disorders **6** (4) 294-298.

Colom F, Lam D (2005) Psychoeducation: improving outcomes in bipolar disorder. Journal of European Psychiatry **20** (5-6) 359-364.

Colom F, Vieta E, Sanchez-Moreno J, Martinez-Aran A, Reinares M, Goikolea J, Scott J (2005a) Stabilizing the stabilizer: group psychoeducation enhances the stability of serum lithium levels. Journal of Bipolar Disorders **7** (5) 32-36.

Colom F, Vieta E, Sanchez-Moreno J, Reinares M, Martinez-Aran A, Torrent C (2005b) Psychoeducation in bipolar patients with comorbid personality disorders. Journal of Bipolar Disorders **6** 294-298.

Cowen, E.L. (1994) The enhancement of psychological wellness: Challenges and opportunities, American Journal of Community Psychology, **22**(2), pp. 149-179.

Craighead WE, Miklowitz DJ, Vajk FC, Frank E (1998) Psychosocial treatments for bipolar disorder. In: Nathan PE, Gorman JM (eds) A Guide to Treatments that Work. New York, NY: Oxford University Press 240-248.

Craighead WE, Miklowitz DJ, Frank E, Vajk FC (2002) Psychosocial treatments for bipolar disorder. In: Nathan PE, Gorman JM (eds) A Guide to Treatments that Work. New York, NY: Oxford University Press 263-275.

Craighead WE, Miklowitz DJ (2000) Psychosocial interventions for bipolar disorder. Journal of Clinical Psychiatry **61** (13) 58-64.

Craighead WE, Craighead LW (2001) The role of psychotherapy in treating psychiatric disorders. Medical Clinics of North America **85** 617-629.

Currey C (1995) Managing manic depression. OpenMind **75** 14-15.

Daly I (1997) Mania. The Lancet **349** 1157-1160

Davidson, L. (1999) From 'non-specific factors' to disorder-specific treatments for schizophrenia: commentary on Williams and Collins, Journal of Psychiatry: Interpersonal and Biological Processes, **62**(1): pp. 79-82.

Davidson L (2005) Recovery, self management and the expert patient – Changing the culture of mental health from a UK perspective. Journal of Mental Health **14** (1) 25-35.

De Andre, RD, Aillon N, Bardiot MC, Bourgeois P, Mertel S, Nerfin F, Romailler G, Gex-Fabry M, Aubry JM (2006) Impact of the Life Goals Group therapy program for bipolar patients: An open study. Journal of Affective Disorders **93** (1-3) 253-257.

Deegan P (1990) How recovery begins. In: Proceedings of the Eighth Annual Education Conference Alliance for the Mentally Ill of New York State, Binghamptom, New York, USA. Published by the Center for Community Change Through Housing and Support, Trinity College, Burlington, Vermont.

Department of Health (2001) The Expert Patient: A new approach to chronic disease management for the 21st Century. London, Dept. of Health. Forward by Professor Liam Donaldson.

Department of Health (2001) The Journey to Recovery – The Government's vision for mental health care. London, Dept. of Health.

Dion GL, Pollack WS (1992) A Rehabilitation Model for Persons with Bipolar Disorder. Comprehensive Mental Health Care **2** (2) 87-102

Drayton, M., Birchwood, M. and Trower, P. (1998) Early attachment experience and recovery from psychosis, British Journal of Clinical Psychology, **37**(3): pp. 269-284.

Ehlers CL, Frank E, Kupfer DJ (1988) Social zeitgebers and biological rhythms: A unified approach to understanding the aetiology of depression. Archives of General Psychiatry **45** 948-952.

Faulkner A, Thomas P (2002) User-led research and evidence-based medicine. British Journal of Psychiatry **180** 1-3.

Fava GA, Bartolucci G, Rafanelli C, Mangelli, L (2001) Cognitive-behavioral management of patients with bipolar disorder who relapsed while on lithium prophylaxis. Journal of Clinical Psychiatry **62** 7 556-559.

Frank E, Kupfer DJ, Ehlers CL, Monk TH, Cornes C, Carter S, Frankel D (1994) Interpersonal and social rhythm therapy for bipolar disorder: integrating interpersonal and behavioural approaches. Behavioural Therapy **17** 143-149.

Frank E, Hlastala S, Ritenour A, Houck P, Tu XM, Monk TH, Mallinger AG, Kupfer DJ (1997) Inducing lifestyle regularity in recovering bipolar patients: results from the maintenance therapies in bipolar disorder protocol. Biological Psychiatry **41** 1165-1173.

Frank E, Swartz H, Mallinger A, Thase M, Weaver E, Kupfer D (1999) Adjunctive psychotherapy for biplolar disorder: Effect of changing treatment modality. Journal of Abnormal Psychology **108** 579-587.

Frank E, Swartz HA, Kupfer DJ (2000) Interpersonal and social rhythm therapy: managing the chaos of bipolar disorder. Biological Psychiatry **48** 593-604.

Frank E (2001) Interpersonal and social rhythm therapy. In : Fourth International Conference on Bipolar Disorder, Pittsburgh, USA.

Frank E, Swartz HA (2004) Interpersonal and social rhythm therapy. In: Johnson SL, Leahy RL (eds) Psychological Treatment of Bipolar Disorder. London: Guilford Press.

Gartner A (1979) The pro's con's and pitfalls of 'self-help' rehabilitation programmes. Social Science and Medicine **13** (A) 113-121.

Geertz, C. (1973) The Interpretation of cultures; selected essays, ix, 470 p.

George S (1998) Towards an integrated treatment approach for manic depression. Journal of Mental Health **7** 145-156.

Gitlin MJ, Swendsen J, Heller TL, Hammen C (1995) Relapse and impairment in Bipolar Disorder. American Journal of Psychiatry **52** 635-1640.

Goldberg JF, Harrow M, Grossman LS (1995) Course and outcome in bipolar affective disorder: A longitudinal follow-up study. Am J Psychiatry **152** 379-385.

Gonzalez-Pinto A, Gonzalez C, Enjuto S, Fernandez de Corres B, Lopez P, Palomo J, Gutierrez M, Mosquera F, Perez de Heredia JL (2004) Review article: Psychoeducation and cognitive-behavioural therapy in bipolar disorder: an update Acta Psychiatrica Scandinavica **109** (2) 83-90.

Goodwin FK, Jamison KR (1990) Manic-depressive illness. New York: Oxford University Press.

Gournay K, Ritter S (1996) The nurse's support role. Nursing Times **92** 44-45.

Gregory RJ, Jindal RD (2001) Ethical dilemmas in prescribing antidepressants. Archives of General Psychiatry **58** 1085-1086.

Griffiths KM, Jorm AF, Christensen H (2004) Academic consumer researchers: a bridge between consumers and researchers. Australian and New Zealand Journal of Psychiatry **38** (4) 191-196.

Hallensleben A (1994) Group psychotherapy with manic depressive patients on lithium: ten years experience Group Anal **27** 475-482.

Harrow M, Goldberg JF, Grossman LS, Meltzer HY (1990) Outcome in manic disorders: A naturalistic follow-up study. Arch Gen Psychiatry **47** 665-671.

Helgeson VS, Gottlieb BH (2000) Support groups. In: Cohen S, Underwood LG, Gottlieb BH (eds) Social support measurement and intervention: A guide for health and social scientists 221-245. New York: Oxford University Press.

Hill GR, Sheppard G (1996) Manic depression and the role of the mental health nurse. Mental Health Nursing **16** 18-20.

Hill GR, Hardy P, Sheppard G (1996) Perspectives on Manic Depression: A Survey of the Manic Depression Fellowship. London: Sainsbury Centre for Mental Health.

Hilty DM, Brady KT, Hales RE (1999) A review of bipolar disorder among adults. Psychiatric Services **50** 201-213.

Hoffman, C. (1978) Empowerment movements and mental health: Locus of control and commitment to the United Farm Workers, Journal of Community Psychology, **6**(3), 216-221.

Hossack A, Robinson J (2005) The treated sex offenders as 'paraprofessional' co-workers in the treatment of the sex offender. Journal of Sexual Aggression **11** (1) 103-113.

Jameson R (1998) A consumer's guide to mental health? Nursing Times **94** 21.

Jindal RD, Thase ME (2003) Integrating Psychotherapy and Pharmacotherapy to Improve Outcomes among patients with mood disorders. Psychiatric Services Nov 2003 **54** (11) 1484-1490.

Johnson SL, Roberts JE (1995) Life events and bipolar disorder: implications from biological theories. Psychological Bulletin **117** 434-449.

Johnson SI, Winett CA, Meyer B, et al (1999) Social support and the course of bipolar disorder. Journal of Abnormal Psychology **108** 558-566.

Jones SH (2001) Circadian Rhythms, Multilevel Models of Emotion and Bipolar Disorder – An Initial Step Towards Integration? Clinical Psychology Review **21** (8) Nov 1193-1209.

Jones S (2004) Psychotherapy of bipolar disorder: A Review. Journal of Affective Disorders **80** (2-3) June 101-114.

Jones SH, Sellwood W, McGovern J (2005) Psychological therapies for bipolar disorder: the role of model-driven approaches to therapy integration. A Review Article. Journal of Bipolar Disorders **7** 22-32. Blackwell Munksgaard, 2005.

Kahn, D (1990) The Psychotherapy of Mania, Psychiatric Clinics of North America **13**, 229-240.

Kanas N, Cox P (1998) Process and content in a therapy group for bipolar outpatients. Group **22** 37-42.

Karlsruther AE (1976) The influence of supervision on facilitative conditions on the psychotherapeutic effectiveness of non-professional therapists. American Journal of Community Psychology **4** 145-154.

Keller M, Lavori P, Coryell W, Andreasen N, Endicott J, Clayton P, Klerman G, Hirschfeld R (1986a) Differential outcome of episodes in illness in bipolar patients: pure manic, mixed/cycling, and pure depressive. Journal of American Medical Association **255** 3138-3142.

Keller M, Lavori P, Klerman P, Andreasen N, Endicott J, Coryell W, Fawcett J, Rice J, Hirschfeld R (1986b) Low levels and lack of predictors of somatotherapy and psychotherapy received by depressed patients. Archives of General Psychiatry **42** 458-466.

Keller MB, McCullough JP, Klein DN (2000) A comparison of nefazodone, the cognitive behavioural-analysis system of psychotherapy, and their combination for the treatment of chronic depression. New England Journal of Medecine **342** 1462-1470.

Kim EY, Miklowitz DJ (2004) Expressed emotion as a predictor of outcome among bipolar patients undergoing family therapy. Journal of Affective Disorders **82** 343-352.

Kripke DF, Robinson D (1985) Ten years with a lithium group. McLean Hospital Journal **10** 1-11.

Krumm S, Becker T (2006) User involvement in Mental Health Services Research. Psychiatrische Praxis **33**(2) 59-66.

Lam D, Wong G (1997) Prodromes, coping strategies, insight and social functioning in bipolar affective disorders. Psychological Medecine **27** 1091-1100

Lam D, Wong G (1999) The development and validation of the coping inventory for prodromes of mania. Journal of Affective Disorders **53** 57-65.

Lam DH, Jones SH, Haywood P, Bright JA (1999) Cognitive Therapy for Bipolar Disorder: A therapist's guide to concepts, methods and practice. New York, NY: Wiley & Son Ltd.

Lam D, Bright J, Jones S et al (2000) Cognitive therapy for bipolar illness: a pilot study of relapse prevention. Cognitive Therapy and Research **24** 503-520.

Lam D, Wong G, Sham P (2001) Prodromes, coping strategies and course of illness in bipolar affective disorder – a naturalistic study. Psychological Medecine **31** 1397-1402.

Lam DH (2002) Psychotherapy for bipolar affective disorder. Current Medical Literature **13** 1-4.

Lam D, Watkins E, Hayward P, Bright J, et al (2003) A randomised controlled study of cognitive therapy of relapse prevention for bipolar affective disorder – outcome of the first year. Archives of General Psychiatry **60** 145-152.

Lam D, Wong G (2005) Prodromes, coping strategies and psychological interventions in bipolar disorders. Clinical Psychology Review **25** (8) Dec 1028-1042.

Lam D, Wright K, Sham P (2005a) Sense of hyper-positive self and response to cognitive therapy for bipolar disorder. Journal of Psychological Medicine **35** 69-77.

Lam DH, Hayward P, Watkins ER, Wright K, Sham P (2005b) Relapse Prevention in Patients with Bipolar Disorder: Cognitive Therapy Outcome After 2 years. American Journal of Psychiatry Feb **162** 324-429.

Liberman, R.P. (1994) Psychosocial treatments for schizophrenia, Journal of Psychiatry: Interpersonal and Biological Processes, **57**(2) 104-114.

Liberman, R.P. and Corrigan, P.W. (1993) Designing new psychosocial treatments for schizophrenia, Journal of Psychiatry: Interpersonal and Biological Processes, **56**(3) 238-249.

Liberman, R.P. and Kopelowicz, A. (1995) Basic elements in biobehavioural treatment and rehabilitation of schizophrenia, Journal of International Clinical Psychopharmacology, **9** 51-58.

Lingam R, Scott J (2002) Treatment non-adherence in affective disorders. Acta Psychiatrica Scandinavica **105** (3) 164-172.

Lorig, K.R., Sobel, D.S., Stewart, A.L., Brown, B.L. Jr, Bandura, A., Ritter, P., Gonzalez, V.M., Laurent, D.D. and Holman, H.R. (1999) Evidence suggesting that chronic disease self-management programmes can improve health status whilst reducing hospitalisation, Journal of Medical Care, **37**(1) 5-14.

Mason P (1998) Users at the top. Mental Health Nursing **18** 28-29.

McLeod J (2001) Qualitative Research in Counselling and Psychotherapy. Thousand Oaks, CA: Sage.

Michalak EE, Yatham LN, Lam RW (2004) The role of psychoeducation in the treatment of bipolar disorder: a clinical perspective. Clinical Approaches to Bipolar Disorder **3** 5-11.

Miklowitz DJ (1998) Psychosocial approaches to the course and treatment of bipolar disorder. CNS Spectrums **3** 48-52.

Miklowtiz DJ, Frank E (1999) New psychotherapies for bipolar disorder. In: Goldberg JF, Harrow M (eds) Bipolar Disorders: Clinical Course and Outcome. Washington, DC: American Psychiatric Press 1999 57-58.

Miklowitz DJ, Simoneau TL, Sachs-Ericsson N, Warner R & Suddath R(1996) Family risk indicators in the course of bipolar affective disorder. In: Mundt C (ed) Interpersonal Factors in the Origin and Course of Affective Disorders. London, England: Gaskell Books.

Miklowitz DJ (1996) Psychotherapy in combination with drug treatment for bipolar disorder. Journal of Clinical Psychopharmocology **16** (suppl 1) 56S-66S.

Miklowitz DJ, Simoneau TL, George EL, Richards JA, Kalbag A, Sachs-Ericsson N, Suddath R (2000) Family-focused treatment of bipolar disorder: 1-year effects of a psycho-

educational program in conjunction with pharmacotherapy. Biological Psychiatry **48** 582-592.

Miklowitz DJ, George E, Richards J, Simoneau TL, Suddath R (2003) A randomised study of family-focused psycho-education and pharmacotherapy in the outpatient management of bipolar disorder. Archives of General Psychiatry **60** 904-912.

Miklowitz DJ, Richards JA, George EL, Frank E, Suddath RL, Powell KB, Sacher JA (2003) Integrated Family and Individual Therapy for Bipolar Disorder: Results of a Treatment Development Study. Journal of Clinical Psychiatry **64** (2) 182-191.

Mondimore FM (1999) Bipolar Disorder: A Guide for Patients and Families. London: John Hopkin Press.

Morris CD, Miklowitz DJ, Wisniewski SR, Giese AA, Thomas MR, Allen MH (2005) Comprehensive Psychiatry **46** (2) March-April 98-104.

Mueser KT, Hilton DW, Schaub A, Essock SM, Vogel-Scibilia, S (2002) Illness Management and Recovery: A Review of the Research. Journal of Psychiatric Services **53**1272-1284.

Ochocka J, Janzen R, Nelson G (2002) Sharing power and knowledge: professional and mental health consumer/survivor researchers working together in a participatory action research project. Psychiatric Rehabilitation Journal **25** 379-387.

Orosz, J. (Rev.), Miles, M.B. and Huberman, A.M. (1997) Qualitative data analysis: an expanded source book (review), Public Administration Review**, 57**(6) 543-549.

Palmer AG, Williams H, Adams M (1995) CBT in a group format for bipolar affective disorder. Journal of Behavioural Cognitive Psychotherapy **23** 153-168.

Patelis-Siotis I, Young LT, Robb JC, Marriott M, Bieling PJ, Cox LC, Joffe RT (2001) Group cognitive behavioural therapy for bipolar disorder: a feasibility and effectiveness study. Journal of Affective Disorders **65** (2) July 145-153.

Peet M, Harvey N (1991) Lithium maintenance, 1: a standard education programme for patients. British Journal of Psychiatry **159** 197-200.

Perry A, Tarrier N, Morriss R, McCarthy E, Limb K (1999) Randomised controlled trials of efficacy of teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment. British Medical Journal **318** 149-153.

Priebe S, Wildgrube C & Muller-Oerlinghausen B (1989) Lithium prophylaxis and expressed emotion. British Journal of Psychiatry **154** 396-399.

Prien RF, Potter WZ (1990) NIMH workshop report on treatment of bipolar disorder. Psychopharmacology Bulletin **26** 409-427.

Prien R, Rush AJ (1996) National Institute of Mental Health Workshop Report on the Treatment of Bipolar Disorder. Biological Psychiatry **40** 215-220.

Ralph RO (1999) The Recovery Advisory Group model of recovery (powerpoint show). Available: http://www.mhsip.org/recovery/.

Rea MM, Tompson MC, Miklowitz DJ, Goldstein MJ, Hwang S, Mintz J (2003) Family-focused treatment versus individual treatment for bipolar disorder: Results of a randomised clinical trial. Journal of Consulting and Clinical Psychology **71** 482-492.

Repper J, Perkins R (2003) Social Inclusion and Recovery: A Model for mental health practice. London, Bailliere Tindall, Elsevier Science.

Retzer A, Simon FB, Weber G, Stierlin HM, Schmidt G (1991) A follow-up study of manic depressive and schizo-affective psychoses after systemic family therapy. Journal of Family Process **30** 139-153.

Rose D (2001) Users' voices: The perspectives of mental health service users on community and hospital care. London: Sainsbury Centre for Mental Health.

Ryan, R. M. (1998) Commentary: Human psychological needs and the issues of volition, control and outcome focus, in Heckhausen, J. (ed); Dweck, C. S. (ed). Motivation and self-regulation across the life span, pp. 114-133. Cambridge University Press, New York, United States.

Sachs GS, Thase ME (2000) Bipolar disorder therapeutics: maintenance treatment. Biological Psychiatry **41** 39-47.

Salzer MS, Rappaport J, Segre L (2001) Mental health professionals' support of self-help groups. Journal of Community and Applied Social Psychology **11** 1-10.

Sang B (1999) The customer is sometimes right. Health Service Journal **19 August** 22-23.

Schortinghuis NE, Frohman A (1974) A comparison of paraprofessional and professional success with pre-school children. Journal of Learning Disabilities **7** 245-247.

Scott J (1995) Psychotherapy for Bipolar Disorder: An unmet need? British Journal of Psychiatry **167** 581-588.

Scott J (1996) Cognitive therapy for affective disorders: a review. Journal of Affective Disorders **37** 1-11.

Scott J, Garland A & Moorhead S (2001) A pilot study of cognitive therapy in bipolar disorders. Psychological Medicine **31** 459-467.

Scott J (2004) Treatment Outcome Studies. In: Johnson SL, Leahy RL (eds) Psychological Treatment of Bipolar Disorder. London: Guilford Press.

Seligman MEP (1995) The effectiveness of psychotherapy: the Consumer Reports study. American Psychologist **50** 956-974.

Shakir SA, Volkmar FR, Bacon S, Pfefferbaum A (1979) Group psychotherapy as an adjunct to lithium maintenance. American Journal of Psychiatry **136** (4-A) 455-456.

Sheppard G, Hill RG (1996) Manic depression: Do people receive adequate support? Nursing Times **92** 42-44.

Simon GE, Ludman EJ, Unutzer J, Bauer MS, Operskalski B, Rutter C (2005) Randomized trial of a population-based care program for people with bipolar disorder. Journal of Psychological Medicine **35** 13-24.

Slay, J.D. Jr., McLeod, C. and Johnson, J.N. (2001) Organising a collaborative healthcare system in a medical setting, in Cummings, N.A. (ed), O'Donohue, W. (ed) et al. (2001). Integrated behavioural healthcare: Positioning mental health practice with medical/surgical practice (pp. 95-120). xvi, 347 pp.

Soloman DA, Keitner GI, Miller IW, Shea MT, Keller MB (1995) Course of illness and maintenance treatments for patients with bipolar disorder. Journal of Clinical Psychiatry **56** 5-13.

Targum SD, Dibble ED, Davenport YD, Gershon ES (1981) The Family Attitudes Questionnaire: Patients' and spouses' views of bipolar illness. Archives of General Psychiatry **38** 562-568.

Thase ME, Bhargava M, Sachs GS (2003) Treatment of bipolar depression: Current status, continued challenges, and the STEP-BD approach. Psychiatric Clinics of North America **26** 495-518.

Tohen M, Grundy S (1999) Management of acute mania. Journal of Clinical Psychiatry **60** 31-34.

Van Gent EM, Zwart F (1991) Psychoeducation of partners of bipolar manic patients. Journal of Affective Disorders **21** 15–18.

Vieta E, Colom F (2004) Psychological interventions in bipolar disorder: from wishful thinking to an evidence-based approach. Acta Psychiatrica Scandinavica **422** 34-38.

Wahl OF (1999) Mental health consumer's experience of stigma. Schizophrenia Bulletin **25** 467-478.

Webb Y, Clifford P, Fowler V, Morgan C, Hanson M (2000) Company patients' experience of mental health services in England: A 5-trust service. International Journal of Health Care Quality Assurance **13** (6/7) 273-281.

Whittingham C, Parsons K (1999) The medical paradigm and service user's experiences. Mental Health Nursing **19** 20-24.

Wilson GT, O'Leary KD (1980) Principles of behaviour therapy. Englewood Cliffs, NJ: Prentice Hall.

Ward T, Brown M (2003) The risk need model of offender rehabilitation: A critical analysis in Ward T, Laws DR, Hudson SM (eds) Sexual deviances: Theoretical issues and controversies. Thousand Oaks, CA: Sage.

Warner R (1994) Recovery from schizophrenia: Psychiatry and political economy (2nd edition). New York, Routledge.

Williams, C. and Collins, A. (1999) Defining new frameworks for psychosocial intervention, Journal of Psychiatry: Interpersonal and Biological Processes, **62**(1) 61-78.

Woodbridge K, Fulford KWM (2004) 'Whose values?' A workbook for values-based practice in mental health care. London. Sainsbury Centre for Mental Health.

Yalom ID (1975) In: 2nd edition The Theory and Practice of Group Psychotherapy. Basic Books, New York.

Yin RK (1994) Case study research. Design and methods (2nd edition). Thousand Oaks, CA: Sage.

Zarate CA, Tohen MF (1997) Bipolar Disorder and Comorbid Axis I Disorders: Diagnosis and Management, cited from Chapter 6.

Scales used:

Mood: Internal State Scale – Bauer, Crits-Christoph, Ball, Dewees, McAllister, Alahi, Cacciola, Whybrow,1991

Empowerment – Sciarappa & Rogers, 1997

Coping: derived from FULL COPE, Brief COPE – Carver CS, Scheier MF, Weintraub JK, 1997

Quality of Life: adapted from WHO_QOL 100 items scale 1994a, b – WHO-QOL-BREF, 1996.

WHOQOL Group (1995) The World Health Organization Quality of Life Assessment (WHOQOL) Position paper from the World Health Organization. Soc Sci Med **41** 1403-1409.