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Working in Partnership to Develop, Implement and Evaluate a Skills Based Group for People with Bipolar Disorder/Schizoaffective Disorder

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Abstract

Aim: The present study involved collaborating with service users in the development, implementation and evaluation of a pilot skills based group intervention for individuals with bipolar disorder or schizoaffective disorder.

Method: The intervention was integrated into the service as an adjunct to current treatment regimes in three community adult mental health teams. Two focus groups were initially conducted with thirteen multidisciplinary team members in order to explore their experiences of working with individuals with bipolar disorder/schizoaffective disorder and to inform the design of the subsequent intervention. The second phase of the study involved working with service users. There were eight participants in the design group (seven of which attended two focus groups in order to outline the design of the intervention); nine participants in intervention only group and six participants in the treatment as usual group. Those in the design and intervention only groups were invited to receive the six week skills group intervention which was designed on the basis of the two focus groups conducted with the design group. In addition to drawing on the experiences of service users, the intervention drew on various manualised and internet based resources using experiential and didactic approaches.

Results: Qualitative findings indicated that service user involvement in service planning is crucial as they have a unique insight into services and their views may differ from that of professionals. Improvements in self-reported self-esteem and self-efficacy were reported by individuals post intervention during qualitative feedback sessions.

Conclusion: Future research is needed with a large sample size to examine if statistically significant gains are made and sustained and to further involve service users in decisions and facilitation of interventions.

Introduction

The majority of treatments available for individuals with bipolar disorder/ schizoaffective disorder revolve around antipsychotic medication (Emilien, et al., 2007).

Psychological impairments such as medication adherence, insight into illness, recognising early signs of relapse and coping mechanisms are not targeted by pharmacological interventions (Beynon, et al., 2008; Ghaemi, et al., 2004; Scott, 2001; Soares-Weiser, et al., 2007). However psychosocial interventions combined with pharmacological interventions empower an individual to become more involved in the management of their illness, leading to an improvement in their overall quality of life (Beynon, et al., 2008; Soares-Weiser, et al., 2007). In conjunction with this Emilien, Septien et al., (2007) citing research (Miklowitz, et al., 2003) found that psychosocial interventions such as CBT, family therapy and/or group interventions decrease the risk of relapse in individuals with bipolar disorder/schizoaffective disorder.

As with other groups of clients with chronic illnesses, clients with mental illness report a need for peer support groups to share experiences. With negative impacts on social life a significant factor in mental illness, this need for group interventions is becoming more apparent (Castelin, et al., 2010). Group based interventions enable members to share their experiences, learn from each other, gain new coping strategies, feel understood, realise they are not alone, reduce stigma, regain a sense of control and power, and establish more positive senses of identity and self-esteem (Downs, 2001; Meddings, 1998; Romme, Honig, Noorthoorn, & Escher, 1992). In addition the NICE guidelines (2006) state that clients, their family and carers should be encouraged to attend self-help and support groups as they may give information on early warning signs, types of treatment and side effects, and also provide support during crisis points.

Service User Involvement

Service user involvement occurs “when service users are meaningfully involved in decision making regarding their health, social care and treatment, and in the planning and delivery of healthcare services” (Health Service Executive, 2010; McEvoy, et al., 2008). It stems from the view that service users are the experts, rather than professionals in individual experiences of mental illness and the mental health services they are offered (National Institute for Mental Health in England (NIMHE). 2003; Svennevig, 2004). Service provider’s opinions and priorities are significantly different from those expressed by service users. (Svennevig, 2004). Barnes and Bowl (2001) gave an account of factors of importance for service users which include financial and relationship stability, and employment, while for service providers integration of services and management styles are of priority (Svennevig, 2004).

Hostick (1998) found that when giving the client a voice an “ideal service” became apparent. The main components of which consist of user/carer involvement in planning and monitoring services for all user groups, in addition to being provided a detailed health directory, clear and concise information of medical interventions, and availability of essential information via a newsletter (Hostick, 1998).

In conjunction with this NICE state that individuals with a diagnosis of bipolar disorder should be involved in making decisions about their care and treatment (National Institute for Health and Clinical Excellence, 2006). The NICE guidelines recommend that interventions for people with bipolar disorder should take into account their needs and preferences. In addition to this the Department of Health (DOH; 1994) have developed a report based on guidelines on a collaborative relationship between clients, mental health professionals and families in relation to an individual’s care plan, while also stating that the main focus for mental health nurses should be the person with a diagnosis of a mental illness.

A move toward a recovery focus and increased service-user involvement in Ireland has been also proposed by

A Vision For Change (Department of Health, 2006). Recommendations include service users being partners in their own care in addition to care plans being individual to each person and reflective of their needs and goals (Department of Health, 2006).

The process of recovery involves more than working with mental health services (Coleman, 1999; Wolfson, et al., 2009). Working together with other service users allows individuals to reach a maximum potential for recovery. Capturing the direct experience of a service user, and allowing them to take part identifying areas of need in services epitomises service user involvement (Wolfson, et al., 2009).

Service user involvement in the design stage of research is an innovative approach to gaining a more insightful knowledge of the field in mental health. Ramon (2000) also reported that this process leads to a greater understanding of lay perceptions of research in addition to a greater understanding of the lives of individuals with mental health difficulties (Faulkner, 2012). Actively involving service users in the research process is inclusiveness and plays a role in reducing the impact of stigmatisation on individuals with mental health difficulties. It has also been highlighted that an awareness of service user needs is essential for an effective service provision as their views may differ from what service providers perceive as important (Meddings, et al., 2011).

Previous studies such as Meddings, et al., (2011) have evaluated service user involvement and evaluation in hearing voices groups; however to date research among service user involvement in individuals with bipolar disorder/schizoaffective disorder is limited.

The present study worked in partnership with service users in the development, piloting and evaluation of a skills based group for individuals with bipolar disorder/schizoaffective disorder.

Method

The current study led to the development of a new group-based intervention to address the skills deficits associated with bipolar disorder. Initially there was a qualitative component to the study, which was aimed at designing a skills-based intervention. The second part of the study was a pilot evaluation of the research.

Participants

MDT Participants

Staff participants (n = 13; male = 7, female = 6) were all MDT members on two Community Adult Mental Health Teams. Several distinct professions were represented in the sample, with three psychologists, two psychiatrists, one social worker, one occupational therapist, three community psychiatric nurses, and three homebase treatment nurses agreeing to partake in the research.

Client Participants

Ultimately 13 client participants completed the study. Initially there were 22 individuals with a DSM-IV-TR diagnosis of bipolar disorder/ schizoaffective (18 participants = diagnosis of BPD, 4 participants = diagnosis of schizoaffective disorder), however a number of individuals dropped out during the course of the study due to various external reasons. The participants ranged in age from 29 to 68 years (M = 47.67).

Client Allocation to Groups

Participants were randomly assigned to one of three conditions: design group; intervention only group; or treatment as usual group. Participants in the design group (n = 9) were invited to attend a focus group in order to outline their needs in relation to designing a skills based group intervention. The intervention was then designed by the researcher and co- facilitator based on these identified needs. The intervention only group (n = 7) was also invited to attend a focus group which sought information about their satisfaction with services. The purpose of the focus group was to rule out familiarity contributing to group changes and thus was used only as a control method, which will not be analysed in the current study. Participants in the design group and intervention only group were then invited to partake in the programme in their local mental health service as an adjunct to their current treatment. Participants in treatment as usual group (n = 6) were offered the intervention pending outcomes from the study.

Stage One

Stage one consisted of a qualitative component comprising of separate focus groups with staff members and the key stakeholders (i.e. the clients) in order to design the main components of the intervention.

Design

The first phase of the study employed an exploratory design and consisted of four semi- structured focus groups. The first two focus groups were conducted with MDT staff members with a view to isolating dialogues regarding members' experiences of working with the skills deficits associated with bipolar disorder/schizoaffective disorder.

Two further focus groups were conducted with client participants (Design Group) in order to ascertain their needs and wishes in relation to receiving a skills based intervention. Based on the outcome of this initial focus group, it was decided to offer an additional focus group to the same participants.

The data from all four focus groups were analysed using thematic analysis (Braun & Clarke, 2006), which is a method for identifying, categorising, analysing, and reporting themes within qualitative data (Braun & Clarke, 2006).

Stage Two

The aim of this phase was to use the theoretical base and client needs as identified in the development phase to design the intervention and conduct a pilot study to test the procedure.

Design of the Intervention

The intervention was designed and conducted by the researcher and a senior clinical psychologist in a Community Adult Mental Health Service. The modules were based around client needs as identified through the planning focus groups conducted with the design group. The materials used for the interventions were collated from a number of sources specializing in the area of each module. As identified by clients in the design group during the planning focus groups, the group structure was a mixture of didactic and experiential learning, in addition to receiving handouts. Homework practice was also optional to individual clients as identified during the focus groups.

Stages of the Intervention

The six session intervention combined the theoretical basis from the literature reviews with the qualitative work from the focus groups. The components of the intervention were based on participant needs identified from two previous focus groups and materials used were predesigned from previous interventions. The intervention was delivered over six weeks, in two separate outpatient settings to accommodate clients from different geographical locations. Each session was two hours and 15 minutes in duration, with a 15 minute break halfway during each session.

Feedback Session

A feedback session in the form of a focus group was held in both locations on the seventh week. The purpose of the session was to verbally receive client's evaluations of the programme. The focus groups were audio recorded and transcribed verbatim. The content was analysed using thematic analysis as outlined previously by

Braun and Clarke (2006). A manual based on the exercises of the six sessions was also produced and provided to participants at the feedback session for reflection and learning beyond the programme.

Results

Focus Groups with MDT Members

Four main themes emerged from analysis of the focus groups: The first theme was the skills deficits associated with individuals, with the second theme addressing the impact of these deficits on daily lives. The third theme to emerge was the strategies that work to help individuals with these deficits, with the final theme capturing what resources MDT members feel that these individuals are needed to help them manage their illness more efficiently. A number of subthemes also emerged from each theme.

Skills Deficits

Participants across both MDT groups expressed concern in numerous areas of skills deficits associated with bipolar disorder. Difficulties with insight, acceptance, motivation and impulsivity were reported across both groups, while participants also reported that during depressive phases, persons with bipolar disorder particularly portrayed low self-confidence, self-esteem and anxiety.

Insight

Participants across both groups reported that lack of insight was extremely predominant in individuals with bipolar disorder. They reported that insight was imperative to overall engagement with services and acceptance of a diagnosis. One participant noted

“I think the first thing is, you know, the diagnosis itself, the understanding of bipolar affective disorder and what it’s all about, ...he or she has been diagnosed with this disorder but most of the clients would be seen at the OPD (Out-patient Department), they don’t even know their diagnosis is bipolar, they don’t know, they just ask them do they need, to be given medication.”

Acceptance

Participants reported that acceptance was linked to insight and individuals who were accepting of the life-long consequences of their illness were more likely to have greater insight into their illness. One participant captured this through the following statement

“You have the people who have partial or total insight, they will still have to come to an adjustment or an acceptance of having potentially a lifelong or a life-changing illness.”

Motivation

Participants reported that a lack of motivation was evident in particular during depressive phases with one participant noting

“the depressive phase probably brings up a whole other set of problems ... around motivation.”

Impulsivity

Participants described how impulsive acts impact on an individual’s quality of judgement. One participant reported *"part of the impulsivity or the impulsive, so that's why they would go into drugs and alcohol over-opportunistic ideas and grandiosity or, you know, there's being impulsive so, and that's actually, they don't have, you know, the judgemental swing in appearance, they kind of, they can't sort of manage their impulsivity."*

Self-confidence

Participants reported that during the depressive phase issues with confidence and self-esteem were likely to emerge more so than in a manic phase. One participant reported

"the depressive phase probably brings up a whole other set of problems, you know, around motivation and confidence, help seeking behaviour, you know, if somebody is significantly depressed... that they would seek help or to even attend work, or attend to relationships and often impaired concentration and stressed."

Self-esteem

Difficulties with self-esteem were identified as a component of depressive episodes and also during periods of stability. One participant reported

"usually somebody who is in a depressive phrase, they have low self-esteem."

Anxiety

Participants also reported that anxiety was related to issues with confidence, which in turn impacted on an individual's social functioning.

"Anxiety and avoidance, I suppose there would be a fair amount of that. People lose their confidence in themselves so they don't kind of engage in the things they would have before and they don't, sometimes they don't manage their anxiety very well."

Impact on Daily Lives

Secondly, participants reported that deficits in bipolar disorder have a significant impact on an individual's daily functioning. They reported that clients have a tendency to become socially isolated as a result of their deficits and community stigmatisation. They also reported that difficulties with insight can lead to readmissions and maladaptive anxiety management techniques include avoidant strategies.

Social Isolation

Participants linked social isolation to feeling stigmatised by members of society as a result of people being unwell in the community. One participant noted

"I'd say with some people too, like, locally here, it's kind of still a bit stigmatised, that if they are diagnosed, they have to present to the site of the psychiatric hospital or they may be admitted, either voluntarily or involuntarily .....that suddenly they are doing their own thing insightless, not aware of the diagnosis and the next thing, they may be facing admission.

Re-admission

Participants made associations between an individual's level of insight and number of admissions. One participant reflected the following

"You would see them being admitted again two or three times, some, you know, sectioned, and the penny still doesn't drop sometimes."

Strategies

During the focus groups, a number of common themes around strategies that were successful when working with individuals with bipolar disorder were identified. These include psychoeducation on the illness and symptoms and psychosocial interventions including anxiety management, problem solving approaches and support groups.

Psychoeducation

Psychoeducation was seen as one of the most prevalent strategies used across the service.

"It's important I mean that they have a real level of understanding about the condition and what the diagnosis means to them and how they can maybe process or formulate it in their mind or you know."

Psychosocial Interventions

Interventions varied across professional groups, with one common theme; they were a vital element of the service for individuals with bipolar disorder. One participant summarised this

"Certainly people who adhere to certain psychosocial interventions seem to have better outcomes."

Resources Needed

In relation to resources that would assist individuals in managing their difficulties, participants reported that peer support and group interventions in addition to formalised psychoeducation would be beneficial. In relation to interventions the participants also identified the therapeutic relationship as being a significant element in contributing to change.

Peer Support

Peer support was identified through group interventions, with participants reporting a willingness from clients to take advice from others in similar positions. One MDT member reported

"it's much easier to accept it from someone else who has been through it than it is from professionals."

Formalised Psychoeducation

Participants identified a need to formalise their daily interactions with clients, in particular when giving them information around their illness

"there's always an argument for formalising what we do informally, like a lot of what I discussed, we do informally, you know, there is no actual template you know, and maybe that's what they are looking towards, say, in coping with that group of patients, but maybe something more formalised around the psycho-education and the materials used that can manualise stuff."

Group Intervention

Group interventions were described as being of benefit to service users. One MDT member reported

"The other thing, probably within groups, with people particularly with bipolar particularly .....I run anxiety groups myself, like there is value in that as well. .....then I think that people would find it very beneficial."

Therapeutic Relationship

A positive therapeutic relationship was identified as being crucial to client engagement in services among all MDT member *"it's nearly an age-old cliché, the therapeutic relationship is hugely important and I suppose there's always sorts of angles on the therapeutic relationship but it's a kind of an unestablished one – without any meaningful relationship, no meaningful therapy can take place."*

Planning Focus Groups

The themes which emerged from the analysis of the planning focus groups are described in this section. They are organised into four parts. Firstly, the participants' views towards being part of the design phase are described. Secondly themes related to stigma of having a mental illness are discussed. The themes related to the content of the group reported, which are divided into eight subsections and integrated into how the skills groups were designed are discussed in the third section. Lastly the practical aspects of the group design are explored briefly.

Views towards Being Involved in the Design Stage

Innovative

Participants reported that being involved in the design phase of the intervention was a progressive and innovative initiative. They viewed this as being a vital part of service integration with one participant noting

"I think it's a very fundamental part for me ...it's the fact that we're designing it ourselves ... with the professional backup as well".

A Positive Step

Participants also reported that they felt being involved so early on in the design process was a positive aspect which would be beneficial to all parties concerned, as learning from others in similar situations is often the best experience for developing an awareness of symptoms and management strategies One participant in particular noted

" We're the ones who have the answers I think in many ways...I have learnt a lot myself, this is really what I would love to do, you know, in, ... I'd love to actually help people ... it's like a step towards it because I do know I have a lot of stuff to contribute".

Participants were excited about the idea of belonging to a group where members shared an aspect of their identity. They attributed it to having a unique insight that professionals were not able to gain and identified it as something that has been lacking nationally. Participants were eager for the group to become permanent with one individual reporting

"I feel that what's important for me in this group here is that I'm meeting other people of similar ... like as such, and I think just the chance to express my feelings or my thoughts about this is very important, ... talking to somebody that actually understands what I am going through rather than talking to a brother or a sister or a friend that doesn't understand the feelings and I think that's why this group for me is very important."

Stigma

The second theme that was identified in the data relates to the concept of stigma. Participants also spoke of the stigma attached to having a mental illness and its effect on their relationships with others.

"I think we ought to... acknowledge that there is still a stigma attached to mental illness, although the stigma is decreasing."

Content of the Group Intervention

The overall aim of the initial focus group was to seek information from participant about what skills they wanted to learn in a group intervention. To gain this information, clients were invited to participate in a second focus group and were asked about their experiences of living with the difficulties of bipolar disorder/schizoaffective disorder. Main themes were identified in the participant narratives, each of which will now be discussed in turn.

Finding my Identity

Who am I and what is my Illness?

Participants spoke about wanting to be distinguished as a person first and foremost, rather than being identified as an illness. One participant noted

“For me, it’s coming to terms with the illness and then finding the confidence to be able to say that’s the illness, that it’s not me”, while another agreed with this sentiment, stating a factor of importance was “ recognising your own mind and whether you need help or whether you can cope on your own.”

Assertiveness

Assertiveness was identified as a key skill which participants wished to develop during the intervention. There were a number of components to identifying assertiveness as a skill in need of development. In particular, a difficulty that became apparent was the participants need to trust their own experience especially when it comes to speaking to doctors about their medication. Another element of the assertiveness skill was that participants reported a need to find their voice, and gain confidence when speaking to others in particular professionals In relation to identifying assertiveness as a module of need during the intervention, one participant reported that assertiveness was a deficit among individuals with bipolar disorder which leads to other difficulties with managing their illness

“I think a lot of things come under it and assertiveness with your psychiatrist, assertiveness with people throughout the day that you meet in your work and your relationship, I think that’s a huge problem in bipolar is that you don’t deal with issues as they come and they build up and then it drives you into a high.”

Finding my Voice

A particular difficulty which was apparent among participants was their need to be able to trust themselves and find their voice in particular when speaking to professionals about the treatment they were receiving. Participants identified feelings of intimidation over having a mental illness and one participant noted

“I get there’s an issue with psychiatry and mental illness for a lot of people, and psychiatry can be quite intimidating to some people with a mental illness.”

Empowerment

Participants associated identified becoming assertive as a source of empowerment which would help them manage their illness effectively in conjunction with professionals. One participant reported

“It’s all about us ... being more empowered about our illness and owning our own illness as opposed to somebody else saying, “You are this, you do this”, you know, and it’s a kind of a negotiation and not a dictation, you know.

Recognising Triggers and Early Warning Signs

A common theme among participants was the need to recognise symptoms of their illness in order to promote relapse prevention. In addition, a need to recognise triggers and manage them effectively was identified. One of the first points in the focus group with regards to content was made by a participant, who reported

"Well I suppose anybody, people say that anybody who is suffering from any condition, the first thing is to recognise their own condition, and when a mood is going high or when it's going low, and then being, not being inhibited, or not being afraid to ask for help."

Side Effects of Medication

Viewpoints were strong around the side effects of medication with one participant noting "you could cure the illness and kill the patient."

Food Cravings

Food cravings were a contributor to distress among all participants in the group who were receiving pharmacological interventions which they wished to receive help with during the intervention.

"Well, if you could help us on the food cravings, it would be great."

Wanting an Alternative to Medication

As previously reported participants receiving pharmacological interventions were in distress around its side effects. A common point made throughout was that participants either wanted to manage their illness without medication or as little medication as possible.

"I think the issue of medication seems to be very important to everybody in here, whether you agree with taking it or if you don't take it, I think it's definitely a huge issue that needs to be discussed a bit more."

Relationships with Friends and Family

During the course of the focus group, participants also identified that family and friends play a significant role in their lives. Views alternated between family and friends being affected by episodes of depression and mania, to friends and family not fully understanding the illness.

Impact on Family and Friends

There was recognition among participants of the impact their illness had on their relationships with others

"It's tough on friends as well, you know, because they don't have the proper training ... it's a big pressure on friends, because I know that I put my, you know, not deliberately put my friends through a lot with particularly the highs, but they don't have any formal training, and it's rough on them."

Lack of Understanding

Other participants were of the view that friends can sometimes jump to conclusions and over-identify their personality with their illness. One participant, for example, reported that

"my position is that my friends now wouldn't have known me all my life, ... It is very difficult, because they're only getting to know, ...it can be a con because you feel like saying, "No, I'm not heading for a high, I'm fine... they're just picking one point out."

Coping Strategies

Participants were eager to identify strategies they used to stay well, in addition to learning new strategies from each other. Different strategies were exchanged during the focus group, with one participant giving their views on the importance of diet *"it's very important to eat because when you eat you actually slow down your system. Those little things I found for me."*

Others also gave advice on relaxation skills "Relaxing in the bath is good for you, isn't it, it is, and you have the candles and things like that." "I would read at night to help me wind down."

Motivation

And finally, participants identified motivation as a skill they wished to develop during the intervention. Motivation was linked to being able to have a structure to the day in addition to being a key skill in maintaining a state of well-being. One participant reported that an important factor they would like to acquire from the group as follows

"I think for me to stay motivated. I'm great when I have structure to my day but when my structure goes; I find it hard to motivate myself, so I think skills in that way would help me a lot."

Practical Aspects

Participant views were also asked around practical aspects of the skills group, such as timing, location, length of sessions, and structure of sessions. As there were two groups running, in two different counties participant needs were different and there were some constraints to what the service was able to offer due to other clinical demands. Overall participants were initially of the view that a non-clinical setting would be best if the group were to continue, with one participant reporting

"I think to encourage people into groups as such and for the future, it's to move it away from medical institutions as such ... it's very clear everybody around this table is quite sane, do you know, even though they have an illness, it's not, we're not crazy."

In addition, participants outlined their desires in relation to having other professional input in the group and the use of materials and homework. An overall feeling emerged of wanting to have a choice of whether or not to have homework, and wanting a psychiatrist in to listen to their views, however, there were different agendas in relation to the aim of having psychiatry input with participants reporting

"I think it would be good, certainly if they brought in a psychiatrist" ... I think I'd like for them to listen, open their eyes and take on board, you know, from our perspective as a user."

Feedback Focus Groups

Two feedback focus groups were conducted at the end of the six week intervention in order to provide a qualitative evaluation of the group. The feedback sessions were held in the same location as the intervention and thus the focus groups were a mixture of participants from both the experimental and control conditions. Four main themes and a number of subthemes emerged from the analysis of the groups.

Evaluation of Group

Participant narratives suggest that their overall view of the group was positive. Specifically, this favourable evaluation was explored according to three separate subthemes: the content of the group; participant attendance rates; and the perceived benefits of the group.

Content
Participants were asked about their feelings around the content of the modules and the materials provided. One member reported

“I liked when you do the actually specific things that you, that you could learn and that you could apply to your life.”

Participants also spoke about the experiential element of the skills training and the benefits of this practical approach, with one participant reporting

“You weren’t just getting things off your chest or anything. You know, you were actually learning something good, so that was very good.”

In particular, the participants described the assertiveness module as being extremely beneficial as they experienced being treated with equal importance as others and professionals. One participant stated

“I thought the assertiveness was very good, and just you could actually take home something from it.”

Another participant also spoke about the impact of the assertiveness module on his/her self-esteem

“I think that the module on assertiveness, I think that was good because I would have a very... feeling of low-worth... and to say they are just as equal to anyone else on the road.”

In relation to the materials provided, participants reported finding them beneficial and easy to read. One member spoke about the simplicity, yet effectiveness of the materials, stating

“I thought that ... the information that was, the information that had been given out was very useful stuff, ... you could spend a long time in a bookshop or in a library ... you wouldn’t find it as concise as that, so I thought that was really, very valuable.”

Another participant shared a similar view, stating
“there was a lot of quite positive advice given out about practical things like handouts or something that we could relate to as well and go back over and revise ourselves.”

Finally, others spoke about the second module, which discussed practical ways that clients could recognise early warning signs of relapse. One participant discussed how she found the traffic light system a beneficial way of recognising periods of stress, which was an area of need in her life

“the traffic lights system, that was really good and knowing your symptoms and watching out for new symptoms and stuff, that would be something I would have always, would have loved.”

Benefits of the Group
Both groups spoke about the skills they had developed as a result of the intervention. Some individuals recognised changes in themselves, however, were unable to give specific examples. One member captured this experience nicely, explaining

“I find it very hard to quantify... something has changed ... I think that you pick up things without realising it, like, you know.”

Other participants were able to distinguish particular modules which they felt were of significant benefit to them. As previously mentioned, the assertiveness module was a common theme which participants noted as being particularly beneficial outside of the group. One participant commented on the effects of learning that everyone has equal rights during the assertiveness module and explained

“I view myself a bit differently, just from the point of view that we have rights and entitlements to feel a certain way, and be a certain way and act a certain way, and I kind of took that on board a good bit and, you know, that helps and the assertiveness, ... So I have used that really, those two things, like, about, say, my rights, that I have as a person, I think, rights and also that as a person, you know, to be assertive and not sort of take a backseat.”

Participants also spoke about belonging to a group and sharing experiences with others who understood or had gone through similar things. One participant spoke about the motivation that the group gave her to get up and what the group meant to her

“I liked coming into the wee group on a Friday morning. It would give you somewhere to go on a Friday morning, a bit of focus and that, and I surprised myself that I was able to get out of bed and be in 15 minutes ahead of myself and I could do it if I really tried.”

Another was more specific of the sense of belonging that was felt as a result of being a member of the group

“I just thought it was helpful to be sort of in a group with people that went through it, had some idea of your bad brain or where you were coming from, you know, that had similar struggles to you and, it’s not something I have ever experienced before, so that was nice, just to feel a bit understood.”

While predominantly positive, participant evaluation of the group was also realistic. For example, several participants spoke of their awareness that the group was only a part of their lives for a limited period of time. In addition, one member discussed an understanding of the need to be engaged with the group material in order to experience the benefits

“My expectation at the start, what it was, I know that what works great with all groups or anything, is the old cliché that applies, that what you put in something, you get out of it.”

Another participant agreed with this belief, however, also appreciated that the group only represented a part in their recovery plan, acknowledging his/her own role in the maintenance of mental health wellbeing

“I’ve gained the knowledge that we all have to help ourselves, like, I mean we can’t rely on the health professionals to solve problems which we should be solving for ourselves”.

Service User Involvement

Participants were asked about their feelings towards being involved in the design and implementation of the group. In addition, those participants that were in the control group were also asked similar questions in an effort to understand their beliefs about user involvement. Reflecting these two distinct discussions with both groups, two subthemes were identified that address the issue of service-user involvement: Being Involved at the Design Stage; Not Being Involved in the Design Stage, both of which will be discussed in turn.

Clients’ views of being involved in the design stage of the intervention were all positive. For all participants it was a new experience and something they had not been familiar with. One member reported

“I had never participated in anything like this before, so I, it was all new to me, I had no experience of dealing with this thing before... it worked pretty well.”

Another member offered an anecdote to which he felt was similar to being involved in the initial stages of the group design explaining how the more people involved in the design stage the more comprehensive the intervention

“there was an old man up our way who used to say that two heads were better than one, even if they were cabbage heads... if you got more suggestions ... I could think a lot different than you.”

What Next?

There was a general feeling of sadness among all participants about the group ending, with one member simply saying “I feel a bit sad actually” in relation to ending the six week intervention.

All participants were eager for the group to continue from the initial planning focus group. Those assigned to the control group also reported during the feedback session an interest in continuing. For example, one member noted

“I would love for something to follow on from this.”

Although participants were all in agreement that they wished for the group to continue they were unsure in what format. There appeared to be a general agreement that the groups should continue to have a structure, with one participant explaining

“I think the focus would be good, ... just to focus on the skills, would be good.”

Finally, participants were keen to contribute to the planning of future groups with one individual stating

“ would need to have the recipients’ input too.”

Discussion

The objective of the current study was to involve service users in the development, implementation and evaluation of a skills based group for people with bipolar disorder/schizoaffective disorder.

Evaluation of focus group conducted with MDT members

The first phase of the current study was to explore the experiences and understanding of MDT members of the skills deficits associated with bipolar disorder/schizoaffective disorder. Overall, analysis of the focus groups indicated that MDT members were in agreement that skills deficits were apparent during all stages of illness and had a significant impact on the outcomes of treatment. Supporting previous research of Malhi, et al., (2007) and Beynon, et al., (2008) MDT professionals reported that prominent deficits consisted of difficulties with insight, social skills and confidence, which they felt in turn impacted on an individual’s daily functioning and interactions with others.

One theme which emerged throughout the analysis was the relationship between insight into illness and motivation and engagement with treatment services. Insight was defined by participants as having an understanding of the illness, inclusive of an awareness of vulnerability during episodes of depression and mania as well as recognising the need for treatment.

MDT members spoke about therapeutic alliance and its importance in assisting individuals with developing insight, alongside a strong sense of social support. Suto, Murray, Hale, Amari and Michalak (2010) emphasised the significance of therapeutic alliance as reported by clients in their motivation to engage with interventions.

In agreements with Suto, et al., (2010) MDT members reported that interventions were limited in their effectiveness without a positive therapeutic relationship.

Although it is evident in the current study and the literature (Cerit, et al., 2011; Steffany, Fredman, Jerrold, & Rosenbaum, 2004) that skills deficits are a prominent feature of both bipolar disorder and schizoaffective disorder psychosocial interventions remain secondary to pharmacological interventions in the treatment of bipolar disorder and schizoaffective disorder (National Institute for Health and Clinical Excellence, 2006; NCCMH, 2010). However, despite pharmacological treatments being the first method of choice among mental health services, it was evident in the current study that MDT members were aware of the need yet limited availability of psychosocial interventions.

MDT members also explored the impacts of psychological and psychosocial difficulties on daily functioning skills. The main themes emerging were based around social isolation and the stigma attached to same, avoidance management strategies and rates of re-admission were also described. As with previous research (Brohan, et al., 2011) MDT members reported that rates of stigmatisation remain high in society despite legislation in place against discriminatory practices (Vázquez, et al., 2011). In support of previous research (Cerit, et al., 2011; Perlick, et al., 2001) (2001) MDT members noted that difficulties with stigmatisation were managed through social isolation and avoidance of social situations. .

Rates of re-admission were also noted as a significant difficulty among MDT members, with associations made between levels of insight and admission rates. As previously reported impaired insight was a primary theme among the analysis of group findings. Braw, et al., (2011) corroborated with this view reporting that insight was also present among individuals with bipolar disorder and schizophrenia during periods of stability.

MDT participants also explored their views and experiences of group interventions for bipolar disorder and schizoaffective disorder. There was an agreement with the current literature (O' Connor, et al., 2008) that clients were more likely to benefit from advice from fellow peers as opposed to professionals due to power imbalances existing among professionals and clients. Clients were also reported as feeling a greater sense of validation and belonging. MDT members were also in agreement with Suto, et al., (2010) that group interventions allowed individuals to share experiences and feel more accepted in society thus leading to a possible reduction in rates of stigmatisation.

Tse, Doughty and Briston (2004) also reported that group interventions are successful in allowing clients to find support, acceptance and understanding when sharing their personal life experiences with others who have encountered similar feelings.

Evaluation of planning focus groups conducted with service users

Phase two of the study involved meeting with service users to involve them in the design of the intervention and gain an understanding of the views and experiences around service user involvement.

The service users were initially asked about their views of being involved in the design stage of the intervention. In support of A Vision for Change (Department of Health, 2006) guidelines service users initial views were based on the positivity of being given a forum to voice their experiences of having mental health difficulties and their experiences of mental health services to date. As Faulkner (2012) described service users emphasised the importance of their experiences being not only heard by professionals but acted on as they have a unique insight into their mental health difficulties that professionals do not have access to. They also had an awareness and agreement with the ethos of service user involvement based on the belief that they were the experts in the their experiences of mental illness and availability of mental health services (National Institute for Mental Health in England (NIMHE). 2003; Svennevig, 2004). With regard to research conducted by Svennevig (2004), service users also highlighted their differing opinions in treatment options and effectiveness in comparison to service providers.

Although government guidelines (Department of Health, 2006; National Institute for Health and Clinical Excellence, 2006; NCCMH, 2010) have been established around the necessity of service user involvement in all stages of service planning, service users generally acknowledged that the current research was their first opportunity to becoming actively and meaningfully involved in service development.

Designing Intervention

Defining the components of the intervention was the main aim of the planning focus groups. The intervention was based solely on the service user needs and wishes as defined during the focus groups and relevant materials for individual sessions were obtained from various sources. The process of outlining the modules for the intervention occurred over both focus groups. Initially clients discussed their experience of having a diagnosis of bipolar disorder/schizoaffective disorder. Similar to qualitative research conducted by Proudfoot, et al., (2009) who explored factors associated with a receiving a diagnosis of bipolar disorder service users highlighted side-effects of medication, difficulties distinguishing early warning signs from personality aspects, recognising triggers, experiences of receiving the diagnosis, stigma, loss of a sense of self, uncertainty about the future, fears of relapse and lack of assertiveness as areas they needed help with. Facilitators prepared for the second focus group through encapsulating the highlighted areas into six modules. The second planning focus group was based around refining the intervention and ensuring it captured the areas of need as identified in the previous focus group.

A common theme among the services users was an experience of being misdiagnosed or a significant lapse in time before receiving their diagnosis. Consistent with this Hirschfield, Lewis and Vornik (2003) reported that misdiagnosis is a common feature among bipolar disorder.

Bipolar disorder and schizoaffective disorder have been described as complex illnesses with a varied course among different individuals, which leads to a challenge in effective interventions (Emilien, et al., 2007). Involving clients in the design of the intervention was an effective method of managing some of these challenges.

An emerging theme throughout the analysis was wanting to develop a sense of belonging and to share aspects of identity. In association with Fudge, Wolfe and McKevitt (2008) service users noted during the initial focus groups satisfaction of a unique experience of being heard and a forum to share similar experiences with others, while also feeling listened to by professionals.

Service users also used the focus group as a forum to discuss the stigma they had experienced to date which was in line with Brohan, et al., (2011) who reported that one in five individuals have experienced a level of stigma in society. Individuals noted experiences of being stigmatised by society and hoped the group would assist in reducing this. They were eager to share experiences of stigmatisation and were open to seeking advice from each other on ways to manage it. Despite the focus group being a new experience to the majority of the participants their interactions during it were supportive of previous research highlighting the need for group interventions as a resource for individuals with mental health difficulties to seek peer support (Castelin, et al., 2010).

Comparison of MDT focus groups to service user focus groups

Service users were eager to voice their opinions on the content of the group intervention and described it as a new and innovative experience. To date the research in service user involvement in designing interventions is limited. Meddings, et. al., (2011) however designed a hearing voices group with the aid of a project worker who had experienced mental health difficulties. The study highlighted the importance of engaging service users in the consultation process as their views may differ from professionals. In this regard the current study found differences in opinions of difficulties associated with bipolar disorder and schizoaffective disorder between professionals and service users. Most noticeable professionals were unaware of difficulties with assertiveness among their client base. In line with this the research to date (Akiskal, et al., 2006; Stanghellini & Raballo, 2007) has highlighted an over-assertive role taken on by individuals with bipolar disorder which is inflated during episodes of mania. The assertiveness module was highlighted as a significant need among service users; however it was an area that needed clarification during the design phase. Service users openly expressed grievances over not being listened to by the mental health service. There was also awareness among the group facilitators of service users being able to state their grievances with the service, however being unable to articulate them in a meaningful and effective manner. The role of the second focus group was to clarify areas such as these in order to provide an intervention that met the service user needs. The concept of assertiveness was explored during both focus groups and clients agreed that this was an area of deficit which would allow them to convey their messages in a meaningful way without violating their own rights or the rights of others. In the qualitative evaluation of the group assertiveness was outlined as a major contributor to improvements in self-esteem and self-efficacy.

In another comparison of the MDT focus group to the service users, professionals did not appear to have an awareness of service user’s grievances with professional’s inability to listen to their needs. A theme of the need for service user involvement in services did not emerge during the MDT focus groups, again highlighting the importance of service user involvement.

Evaluation Focus Groups

Overall the evaluation of the intervention was positive from all participants with individuals describing the content both enjoyable and educational. Service users particularly valued assertiveness skills to help them convey messages in a meaningful manner and strategies to recognise when they are becoming unwell. Services users also reported finding strategies to cope during a crisis beneficial, and sharing and being taught strategies by other members which is similar to previous qualitative findings of Meddings, et al., (2011) who evaluated service user satisfaction of a hearing voices group and also found that participants valued other professionals giving talks to the group. Again mirroring Meddings, et al., (2011), and Wykes, Parr and Landau (1999) participants had self-reported improvements of self-esteem and self-efficacy.

Service users also explored the least beneficial parts to the intervention. As with previous research (Meddings, et al., 2011) reported negative aspects of the intervention were individual to each person. However, unlike Meddings, et al., (2011) services users did not report dissatisfaction with the content of the groups. Instead the location of the groups which was in a clinical setting and the attendance/dropout rates were reported as negative aspects by various individuals although these views were not expressed by all members.

All service users reported that that they would recommend the group to others, they were also eager for the group to become a permanent feature of the service. Members emphasised the importance of sharing experiences with each other, while also learning something new. One member in particular placed an emphasis on facilitators needing to encourage future participants to commit to the group during the initial stages as they may not believe it will benefit them. Meddings, et al., (2011) also found that group members placed an emphasis on sticking with the intervention in the beginning stages in addition to being able to share experiences with peers.

The focus groups also highlighted the value service users placed on the supportive network of the group and its contribution to improved aspects of psychosocial functioning which is supportive of Yalom and Leszcz (2005). As Meddings, et al., (2011) reported service users cited feelings of belonging and de-stigmatising the experience of having mental health difficulties as a benefit of the group.

Evaluation of Service User Involvement

In proportion to previous research service users involved in the design phase of the intervention reported an increase in self-esteem and social functioning as well as feeling valued and equal to professionals (Health Service Executive, 2010; McEvoy, et al., 2008). The high overall rates of satisfaction with the intervention are reflective of Hostick (1998) and may be indicative of giving the service users “a voice” and a forum to not only share their views but act on them.

Although those not involved in the design phase reported satisfaction with the content and overall ethos of the intervention this may have been due to modules selected by their peer group. Comparison of the MDT focus group to the service user’s indicated that modules of significance such as assertiveness as noted by service users may not have been included in the intervention without their input. This in turn is reflective of previous research highlighting the unique insight service users have into experiences of mental health and mental health services (Faulkner, 2012; Service User Research Group England, 2005).

In terms of service evaluation of service user involvement a better alignment of the needs of individuals and society have been outlined which is the basis of service user involvement (Health Service Executive, 2010; McEvoy, et al., 2008). Additionally service user involvement increased awareness from the service providers around the needs of their clients and the overall efficacy of the intervention. Service users also noted a high rate of satisfaction around the group facilitators which may be reflective of their involvement in the design leading to feelings of empowerment which is consistent with the literature (National Schizophrenia Fellowship., 1997; Svennevig, 2004).

Limitations

There were a number of methodological limitations in the present study.

Sample

One limitation was based on the small sample size of the group. The sample was also heterogeneous in terms of years since onset, education, etc.

Conclusions

Qualitative feedback from group participants indicated that service user involvement and group interventions that promote a forum for sharing experiences with others can result in improvements in self-esteem, self-efficacy and assertiveness. Facilitator enthusiasm and the new experience of service user involvement may also have contributed to increases in self-esteem and self-efficacy. Empowering individuals to become more involved in the maintenance of their mental health difficulties was also noted. Qualitative information indicated that all participants who completed the intervention found it beneficial and those assigned to the design group felt valued.

The study also contributes to the limited research conducted on service user involvement in service planning in particular in Ireland.

Future Research

It is recommended that future research explores service-user involvement in a larger sample size in order to effectively analyse changes across all three assessment periods and to highlight possible changes in self-esteem and self-efficacy after empowering service-user involvement. Qualitatively evaluating changes following each stage and including service users in the selection process of assessment domains and in analysis of the intervention as recommended by Faulkner (2012) would also be beneficial. An additional role of including service users in the facilitation of groups in order to promote peer support and increase empowerment is also emphasised.

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