A new self-management intervention for people with severe psychiatric diagnoses

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Abstract

Purpose – *The purpose of this paper is to describe the development and delivery of a self-management and peer support intervention for people with severe mental health diagnoses.*

Design/methodology/approach – *There was a gap in the provision of a self-management intervention designed and delivered by people with psychiatric diagnoses. In total, 24 people with the experience of severe mental ill-health took part in developing the model and course materials for a new self-management intervention. A three-stage intervention was designed: two-day training, six follow-up sessions, and on-going peer support.*

Findings – *Between 2009 and 2012, over six hundred participants across Wales were trained. In total, 35 of the new courses and 27 of the Bipolar UK courses have been delivered. Currently, 15 peer support groups are still meeting regularly and many people are receiving on-going support. At present, the effectiveness of the intervention is being evaluated; data are being collected at baseline, and at six and 12-month follow-up.*

Originality/value – *Most self-management strategies developed in the past have been focused on physical health conditions and developed and delivered by clinicians. This new self-management intervention is based on the needs and experiences of the target beneficiaries. It was developed and is being delivered by people who have a psychiatric diagnosis, and have come through the training themselves.*

Keywords *Self-management, Peer support, Recovery, Mental ill-health, Service users, Mental health services, United Kingdom*

Paper type *Research paper*

Introduction

Self-management in general refers to the methods, skills, and strategies by which individuals can effectively manage their own activities towards the achievement of their objectives. In health care, self-management refers to the interventions, training, and skills by which patients (service users) with a long-term condition can effectively take care of themselves, and are in direct control of the management of their condition. Self-management includes goal setting, problem solving, planning, decision making, and self-intervention, etc. Some evidence already suggests that a goal setting and problem solving approach may improve clinical practice and outcomes (Clarke *et al.*, 2009). Goal setting may also help to evaluate the effectiveness of a range of mental health services in meeting the needs of their service users (Sestini, 2010; MacPherson *et al.*, 1999).

Over the past three decades, several models of patient-centred care and self-management have been developed, although studies of their efficacy and effectiveness have only been conducted in recent years. The Stanford Patient Education Research Center has developed one of the most prominent programmes, offering evidence-based interventions for a range of chronic health conditions (http://patienteducation.stanford.edu/programs/). The programmes are designed to help patients gain self-confidence in their ability

to control their symptoms, and understand how their health problems affect their lives. However, the programmes are aimed at physical rather than mental ill-health, e.g. diabetes, cardiovascular disease and arthritis (Harvey *et al.*, 2008), and this approach has been much less widely used in mental health conditions. A pilot study focused on collaborative care planning and goal achievement for people with serious mental illness reported improved self-management and mental functioning at three to six months follow- up (Lawn *et al.*, 2007).

One of the first group interventions designed for people with psychiatric diagnoses was the Life Goals Program (Bauer and McBride, 1996). This psychoeducation is focused on improving disease management skills and achieving social, occupational, and quality of life goals for people with bipolar disorder. The intervention has shown to reduce weeks in affective episode and demonstrated functional and quality-of-life benefits over three years (Bauer *et al.*, 2006). More recently, a broader psychoeducation programme for people with bipolar disorder was developed: the Barcelona Bipolar Disorders Program (Colom *et al.*, 2003). This programme focuses on four areas: illness awareness, treatment compliance, early detection of prodromal symptoms and recurrences, and lifestyle regularity. All of these aspects have shown some efficacy previously (Colom and Vieta, 2004). A follow-up after two years has shown that the programme significantly reduced the number of relapses, increased time to reoccurrences (both depressive and manic), and decreased the number and length of hospitalisations compared with controls (Colom *et al.*, 2003). The long-term efficacy was maintained after five years (Colom *et al.*, 2009).

In the UK, Bipolar UK (formerly MDF the BiPolar Organisation), a national charity run by and for people with a diagnosis of bipolar disorder, has developed the first self-management training for people with bipolar disorder (www.mdf.org.uk/?o ¼ 56979). The important difference of this training from the above-mentioned psychoeducation programmes is that it was developed by and is delivered by people with a diagnosis of bipolar disorder. The programme is delivered in a group of 14 participants and two facilitators (both of whom have the diagnosis). It teaches how to recognise the triggers for, and warning signs of, an impending episode of illness, and how to take action to prevent or reduce the severity of an episode. The modules also include Coping strategies, support networks, action plans, strategies for a healthy lifestyle, and advance directives. Although the training is well regarded, it has not been formally evaluated.

Aims

The Mental Health Foundation (the Foundation) aimed to develop a stronger evidence base for self-management as an intervention for people with psychiatric diagnoses other than bipolar disorder. A review of existing self-management strategies revealed the absence of a coherent testable intervention for people who have regularly used secondary mental health services. The Foundation consulted a number of people who had been involved in generic self-management training. It was concluded that whilst generic training that included people with a range of long-term health conditions offered potential benefits, these were often not fully realised because people with a psychiatric diagnosis experienced discrimination and felt excluded from groups. In addition, discussions with people who had been involved as participants and expert patients suggested that these interventions were based on three key assumptions that are reasonably valid for many conditions, but do not seem to hold for people with some mental health diagnoses:

1. A reliable diagnosis which is agreed by patient and clinician.

2. An effective clinical treatment that helps the patient.

3. A reasonably constructive relationship between clinician and patient.

For example, for many people with a diagnosis of schizophrenia or personality disorders, one or more of these assumptions prove to be unreliable. It is worth noting that some of these assumptions break down for other long-term health conditions as well. In particular, we worked with an expert patient from an HIV/AIDS background who recognised these difficulties and offered significant experience, as well as support in developing an approach that did not rely on these underpinning assumptions.

Development

The Foundation decided to develop a new self-management intervention tailored to the needs of people with severe mental health diagnoses. The aim was to develop, deliver and evaluate a testable intervention. The proposal received significant funding from the 2009 Big Lottery Fund's Mental Health Matters funding stream for Wales.

In order to ensure that the intervention accorded with the needs of people who have used secondary mental health services, we chose a development model that had a high degree of service user involvement. The initial development took place at a four-day residential workshop in Cwmbran, South Wales. This workshop was facilitated by experienced ex-service users who were research and development experts. The event brought together 24 people who had used secondary mental health services in Wales; of these, two had been involved with Bipolar UK's long established self-management course, two had other training experience, 12 belonged to self-help groups, and eight had no previous connection to self-help or training. The majority had no previous training or self-management experience. The group as a whole was typical of the target group we wanted to benefit from the intervention.

The workshop participants recognised the essential importance of peer support in self-management. There is evidence suggesting that peer support for people who experience mental ill-health can have many benefits for their mental and physical health and wellbeing (Repper and Carter, 2011; Bates *et al*., 2008). The key conclusions from the development group were that the training needed to be goal-orientated, and needed to be followed by peer support. The model that emerged from the workshop was a three-stage intervention in the following format:

1. Two days of training with a focus on goal setting and problem solving.

2. Six half-day follow up sessions, usually fortnightly.

3. On-going peer support, at least monthly, for six months.

This set would be delivered to a group of ten to 15 people, and the whole series of sessions – from the two-day training to the last facilitated follow-up – would take about nine months to run. The inclusion of peer support as an additional component, alongside self-management, was incorporated to try to increase the long-term effectiveness of the intervention.

Once this initial design was converted into a draft training manual and participant materials, all materials were reviewed by a group of service users from North Wales. The materials were then adjusted for a real time pilot of the initial two-day training. This training was delivered in North Wales, by the facilitators of the workshop. The first pilot led to significant revisions, particularly on the volume of content; the schedule and materials were also adjusted for a second pilot. The second pilot was run in South Wales and was facilitated by two people who participated in the first pilot. The development process took about 12 months from the recruitment of the initial team to the completion of the second and final pilot.

Delivery

Recruiting participants took a great deal of effort. To promote the courses, we held local launch events, often in collaboration with a local service user group. The events drew a wide range of local people including mayors, community police, local companies and clinicians. These events also succeeded in encouraging people to talk about mental ill-health in public settings. We also contributed to a national campaign of Hafal, a leading Welsh mental health charity. This significantly increased the profile of our work and enabled us to reach a greater number of people than would otherwise have been possible.

We recruited an average of 20 people for each course; of these, typically a dozen would actually attend the first two-day training, and the final peer support group tended to include six to eight regular attendees. The dropout rate was lower where we were working with existing local groups, but there were no obvious indicators to suggest why some groups seemed more sustainable than others.

Between December 2009 and January 2012, 62 courses were delivered and 647 people trained across Wales. Of the total, 35 courses were the new courses developed by the Foundation which reached 320 people. A further 27 courses were commissioned from Bipolar UK, in order broaden the evidence base; these trained additional 327 people. This also enabled us to reach potential beneficiaries from an early stage and offer people a choice of courses.

The newly developed courses were entirely delivered by people who had previously been course participants (with the exception of the first pilot). This ensured that the facilitators had a good understanding of the materials and of the experience of learning self-management skills. It also enabled participants to identify closely with the facilitators, rather than perceive them as remote authority figures. It also offered encouragement for participants who wanted to go on to develop facilitation skills.

In order to support people to develop their training and facilitation skills, the workshops were, where possible, jointly facilitated by one person with more experience and a co-facilitator who wanted to build their training skills. This model allowed us to develop a team of approximately two dozen trainers. This group was divided into a North/Central Wales team and a South Wales team. The teams met as groups from time to time and we provided support and development to those who needed it.

Peer support

In order to keep peer support groups going over time, we aimed to establish the characteristics of a good peer support group, and identify the potential blocks to sustainable groups. The consultation was conducted in two stages: a questionnaire, and two consultation days. We developed a questionnaire with the aim of gauging ideas about what would make people want to attend a peer support group, what makes it successful, long-lasting, and what the barriers are to playing a full role in the group. In total, 176 questionnaires were sent out; of these 146 to self-management participant and 30 to other relevant organisations. We received 41 and eight responses, respectively. Building on the questionnaire responses, the two consultation days were carried out in South and North Wales (five and six participants, respectively). This process identified the following issues:

ʙ One (or ideally more than one) person needs to take responsibility for keeping a group going. This person (or people) should come from the group, not from outside the group.

ʙ The group needs to have a clear purpose: setting and reviewing goals was regarded as a good purpose.

ʙ Groups need to have agreed ground rules.

ʙ Groups need to have opportunities to share learning with other groups.

Currently, 15 peer support groups are still meeting regularly (out of our 35 courses delivered) with an average of six attendants. Many people who attended the Bipolar UK course are receiving on-going support and are part of their networks; however, the precise number is difficult to estimate.

Evaluation

The starting point was a desire to establish the effectiveness of self-management as an intervention for people with severe psychiatric diagnoses. An evaluation of the effectiveness of both types of delivered training is currently underway, and the following outcomes are being assessed: wellbeing, ability to function on a day-to-day basis, goal achievement, and cost-effectiveness. This is particularly important if self-management is to be offered as part of a service with statutory funding. We collect baseline data before people start the course, and repeat the assessment after six and 12 months, to allow long-term follow-up of the impact of the intervention. Baseline data have been collected and follow-up data collection is on-going.

Where next

The final half year of the project will see the collection and analysis of the remaining six-month follow-up evaluation data and the start of the 12-month follow-up. The results of the

evaluation will be reported in due course. Funding has now been secured to continue to support the peer support groups for the next three years; this will enable evaluation follow-up to be continued for a longer duration.

Recent developments in mental health care policy in Wales appear favourable to this kind of patient-centred intervention. The Mental Health Measure, Wales (2010) Act makes holistic care planning a statutory requirement. Together with Bipolar UK and Hafal, the Foundation is working to produce guidance to help people translate self-management plans into statutory care plans. This will enable people to take a more proactive approach to their own care plans. It will also encourage mental health and other professionals to ensure that services provided reflect the needs and goals of the people they are funded to serve.

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