Service users' views of a self-help pack for anxiety

Abstract

Background - Despite some evidence for the effectiveness of self-help approaches and their recommended use in recent NICE guidance for anxiety and depression, more research is needed into service users' views of self-help materials and their effectiveness in different service settings, including self-help groups.

Aim – To obtain the views of a group of mental health service users who attended a self-help organisation of a) a self-help anxiety pack, b) the impact it had on their coping and c) the impact on them of the user consultation exercise.

Method - The views were obtained through focus groups using a semi-structured interview schedule and were then subject to qualitative template analysis.

Results - The emergent themes included recommendations for improving the pack by making it briefer, more readable and less technical. Other clear themes were the value of working with the pack as a group and concerns about individuals being able to make use of the pack without support and guidance. The implications of these findings for the development and implementation of self-help approaches for mental health problems and research with community based self-help groups are discussed.

Conclusions – Service user views of self-help approaches can inform the development of effective and acceptable materials and clarify the support required to make effective use of the material.

Service users' views of self-help anxiety pack

<u>Introduction</u>

Self-help approaches have become increasingly popular in recent years in the form of books, CD Roms, internet based resources and self-help groups. These approaches have the potential to empower service users and provide them with more accessible interventions (Wright, 2004b; Lewis, Anderson, Araya, Elgie, Harrison et al., 2003; Richards, 2004). They also have the potential to provide more cost effective interventions. Self-help is a service development and research priority in mental health in the UK and guided self-help is recommended in recent NICE guidance for mild to moderate anxiety and depression (NICE, 2004a,b) as part of a stepped care model. In a stepped care approach relatively low intensity interventions are provided initially and more intensive, costly interventions provided only if required (Lovell, & Richards, 2000). Self-help, or self management, approaches are also important in that they increase self efficacy and self reliance and provide a range of options that can be accessed more easily. This is important in view of the lack of availability of therapists and the consequential long waiting times. Self-help materials can also be used at any time, need not interfere with work of family commitments (Lewis et al., 2003) and are important in increasing patient choice in mental health services. Although NICE guidance recommends self-help for mild to moderate mental health problems, self-help approaches should also be considered in other settings such as secondary care and the voluntary and community sector where there are many self-help groups for people with mental health problems. Lewis et al (2003, page 3) pointed out that "self-help groups are interesting and potentially important methods of delivering self-help interventions", and that there has been little evaluation of self-help materials in self-help groups. The need for more research in this area involving service users has also been highlighted (Wright, 2004a; 2004b).

Self-help approaches can encompass a range of approaches, including strategies people use in their everyday lives, self-help and support groups that have little or no involvement with

Service users' views of self-help anxiety pack

statutory services or professionals and professional led self-help technologies such as workbooks and CD Roms, most of which are based on cognitive behavioural therapy (CBT). CBT has been found to be effective for a range of psychological problems, particularly anxiety and depression (Department of Health, 2001). Areas covered by CBT based self-help material often include understanding the cognitive model, understanding the nature of the anxiety and depression and the relationships of thoughts, feelings, physiology and behaviour, self monitoring, cognitive and behavioural strategies and relapse prevention. Self-help interventions can be provided in a range of settings, with different amounts of professional support, and with different amounts of information, ranging from relatively brief booklets to more comprehensive workbooks. Workbooks require active engagement, some self assessment and working to achieve goals using self-help strategies.

The Lewis et al review recommended more qualitative research into service users' views of the accessibility, ease of use and perceived benefits of self-help materials. This is very important to ensure such material is acceptable, accessible and effective. It is not only important to develop material based on well established approaches such as CBT but to present it in accessible ways. Feedback from service users is required to help clarify the amount of guidance needed to make use of such material. The importance of service user involvement in research in the NHS has been advocated in policy guidelines since 1999 (Department of Health, 1999) and there is increasing evidence of such involvement in mental health research (Telford and Faulkner, 2004). This can involve various roles, ranging from advisory roles, providing their views as research participants and as primary researchers (e.g. Rose et al, 2003; Trivedi & Wykes, 2002; Faulkner & Layzell, 2000). In this study service users express their views as research participants. A service user's experience of distress and mental health service usage brings a perspective to research that could not otherwise be achieved (Townend & Braithwaite, 2002). Service user involvement in the research process

Service users' views of self-help anxiety pack

may also contribute to improving their self-belief (Davis & Braithwaite, 2001). Several papers have commented that service users who participated in initiatives welcomed the opportunity to be involved and that their self esteem improved as a result of their contributions (Barnes, 1997; Sheppard, 2000). The findings of other surveys and interviews with patients are also in support of this (Lord, Echocka, Czarny et al, 1998).

This study sought the views of service users attending a self-help group for people with mental health problems of a CBT based self-help pack for anxiety. The study has the following aims:

1. To involve service users in the evaluation and revision of the anxiety self-help pack.

2. Evaluate the usefulness of the self-help pack for service users with anxiety problems who attend a self-help group.

3. Evaluate the impact on service users of being involved in the evaluation and revision of the pack.

4. To make recommendations on how the self-help pack can be revised and developed to be more user-friendly.

Service users' views of self-help anxiety pack

Method

Design

The research was qualitative and involved conducting focus groups with mental health service users attending DASH (Depression Anxiety Self Help) to obtain their views of the self-help pack. The groups were conducted using a semi-structured technique incorporating a series of questions initially derived from the research objectives.

The Self-help Pack

The self-help pack was called "Working to overcome anxiety". It consists of a 110 page book and contains sections on understanding anxiety, physical effects of anxiety, recognising anxious thinking, dealing with our anxious thinking, effects of anxiety on mood and behaviour and dealing with setbacks. A professionally recorded relaxation exercise was included and available as a tape or CD.

Focus groups

Focus groups were chosen as the method to obtain the service users' views. Focus groups are a method that allows the exploration of the views people hold about particular issues and have been widely used and developed in health service research since the late 1980s. They are seen as being very effective in the development and testing of new services as they allow for the identification of factors that service users find important (Smith 1995). Focus groups can yield information about an issue, or raise an issue that has never been considered in relation to the topic at hand. In this study the service users were already attending an ongoing group so adapting this group to a focus group for the purposes on the research made sense.

Participants and sampling

The research was conducted in Huddersfield, with service users from DASH. DASH is a self-help group with charitable status. It receives referrals of people experiencing mental health problems from NHS professionals such as psychiatrists, psychologists, community

Service users' views of self-help anxiety pack

psychiatric nurses, occupational therapists, the local crisis team and general practitioners. Other referrals are accepted from Job Centre Plus (non Job Seekers Allowance and Disability Employment Advisers teams), Womenspace, other voluntary sector groups and self referrals are also accepted. All service users attending DASH have significant problems with anxiety and/or depression and many have enduring problems requiring longer term support. Some have other diagnoses such as schizophrenia and bipolar disorder. DASH is funded by South and Central Huddersfield Primary Care Trusts and Kirklees Social Services, and with short term project funding from a range of charitable foundations.

Sampling was purposive in order to address the research objectives. A sample of seven service users were involved, all being recruited from the existing 'health group' of DASH who met weekly for support and to discuss various health issues. The sample included those members (service users) who attended this group and agreed to participate in the study.

Recruitment of participants and procedure

The first stage involved making contact with DASH to determine feasibility and to agree the broad outline of the proposal. The existing 'health group' of DASH agreed to work through two sections of the self-help pack over 6 weeks (three weeks for each section), supported by their group facilitator (IS). It was agreed that views of the pack could best be obtained if the service users spent some time working on and discussing the material and trying out the strategies suggested. A research assistant employed by the South West Yorkshire Mental Health NHS Trust attended two of these meetings (the third and sixth) for feedback on the self-help material to inform a revision of the pack. Members of the health group were given an information sheet and consent form and asked to return it within 2 weeks if they wished to participate in the research. Those giving positive consent were seen again as a group by the researcher to discuss the research further and to arrange the focus groups. Seven service users agreed to participate in one of two focus group discussions to discuss their experience of

Service users' views of self-help anxiety pack

working with the self-help pack, its usefulness and their views on being consulted. One group was held with four service users and the other with three. The focus groups took place on the premises of DASH, facilitated by a research fellow (MM) who had experience of conducting focus groups, individual interviews and qualitative analysis and had not been involved in the development of the self-help pack. Sessions were audio taped and lasted approximately one hour.

The interview schedule for the focus groups was structured to explore the following issues:

- How useful the material was to service users.

- The layout and clarity of the self-help pack.

- What service users had learnt from the pack and what they been able to put advice into practice.

- How they felt about being consulted on their views.

- Recommended changes to the pack.

- Any other points raised by the service users.

The study was given ethical approval by the local research ethics committee and all participants gave informed consent.

Data Analysis

The data was analysed using the template analysis technique (Crabtree & Miller, 1999; King, 1998). The essence of this approach is that the researcher produces a list of codes (a template) representing themes identified in their textual data. Some of these will usually be defined *a priori*, but they will be modified and added to as the researcher reads and interprets the texts (King, 1998). Thus, the template organising style involves coding a large volume of text so that segments about an identified topic (the codes) can be brought together to complete the interpretive process (Crabtree & Miller, 1999).

Service users' views of self-help anxiety pack

Both King (1998) and Crabtree & Miller (1999) regard this approach as occupying a middle ground between content analysis (Weber, 1985) where codes are predetermined and analysis of their distribution is via statistical methods; and grounded theory (Glaser & Strauss, 1967) where there is no *a priori* definition of codes. Advantages of template analysis includes the fact that it does not involve a lot of prescriptions and procedures (King, 1998) and its consequent flexibility enables it to be modified to suit the needs of a study in a particular area.   A code manual or coding scheme which serves as a template for organising the data can be developed in a number of ways ranging from a reliance on predetermined codes, generally based on understandings from prior research of theoretical considerations, to the development of codes only after some initial exploration of the data has taken place (Crabtree & Miller, 1999). However, a common intermediate approach is to develop at least a few predefined codes, which are refined and modified during the analysis process (Crabtree & Miller, 1999; King, 1998). King (1994) identified the interview topic guide as a good starting point for the development of the template and this approach was used in this research.

Results

Focus group views

The account of the analysis of the data has been summarised into coded themes using template analysis, drawing illustrative examples from the transcripts.

1. Positive and negative points of the self-help pack **–** Participants were asked to highlight what they thought had been positive and negative aspects of the self-help pack for them. The general consensus amongst participants was that they found that working on the self-help material more beneficial when they worked on it in a group session than by themselves or at home:

> *"We only really understood the material because we worked as a team and with a member of staff from DASH".*

Service users' views of self-help anxiety pack

Participants also found that working in a group with other service users experiencing similar problems was in itself very motivating and more enjoyable:

> *"We were in group, found that good because people there were in the same position, so it made it more fun".*

More than half of the participants stated that the information in the self-help pack had given them an insight into their mental health problems:

> *"It is useful because it gives an insight into one or two new ways in helping you".*

> *"…you recognise what is happening to you as you have read about it".*

2. Most useful/least useful sections of the pack - Participants were asked to give their views on which parts of the pack they had found most useful and least useful. Both positive and negative comments were made:

> *"The quizzes caused me anxiety, so I didn't like them and didn't find them helpful…irrelevant tasks and questions".*

> *"I have very little concentration, so I found the diaries and worksheets tedious and didn't want to fill them in".*

Participants also highlighted the positive aspects of the pack and emphasised how the information provided was helping them to recognise their anxiety and the different ways of dealing with it:

> *"The diaries were the best, you can write stuff down and go back to it, erm maybe one day you have a bad day and then you can go back and look at the diary and say to yourself, how can improve on that".*

> *"…well erm, I suppose the helpful thing is the pack explains just what is going on and being able to understand what is happening to you…so if I have another anxiety attack it will be something I can click with and I will be able to do something about it".*

Service users' views of self-help anxiety pack

Participants identified other good examples from the self-help pack:

> *"…the diagrams and illustrations were very good, I can remember things from the illustrations because they stick in my mind…"*

> *"I found the handouts quite interesting; there was a lot of useful information in the handouts and the quizzes and questions made you think about what was happening to you and you reflect on things that have happened and try and see if you can apply the techniques to your situation".*

3. *Layout and clarity of the self-help pack*

Some participants expressed their concerns about the amount of information that was presented in the pack, and cited that in order to make it more appealing to people it would benefit from being shorter in length:

> *"The pack in general is very good, it has a lot of useful information in it and it can help you…but I think it should be cut shorter because there's a lot of pages and a lot to take in. If it were cut shorter it would look better and we would be more encouraged to want to use it…at the moment it's too big and puts you off…"*

> *"I think it would be better if everything was in bigger print and we would prefer more illustrations and it should be shorter".*

The general consensus held by most participants was that the self-help pack might be more useful if it were easier to understand, less technical language:

> *"It was heavy going…way over my head, found other sections easier and the language too, this was too clinical and over the top…it needs to be in plain language…easy for academics to understand".*

> *"The questions were laughable, erm…does not help and I know a lot of self-help but all this information goes out of the window when you are actually having a panic attack…its too much information…"*

Service users' views of self-help anxiety pack

> *"Too technical, not in lay-language and I found 1ˢᵗ two sections of the booklet easier".*

> *"Parts one and two were useful but it seemed to go downhill from part three…it just got too technical…another thing was that we were trying to cram too much in a short space of time.".*

> *"Needs to be in simpler language, so we can understand it better".*

> *"What I found when doing the questions and tasks, was that some of the words were difficult…needed a bit more explaining to me, like 'recognising anxious thinking and automatic and anticipatory' (reads from sections of pack), the language was too difficult to understand".*

4. Training - Another interesting issue raised by the participants was the need for appropriate training and advice and more support to help work more effectively with the information that was given in the self-help pack. The concern raised was that because they had not had sufficient time and tuition to work through the different sections of the pack, they were not able to maximise the full benefit from it:

> *"There was nothing specifically wrong with the pack, even the language wasn't bad really but I think what was needed were things explained to us, we should have had more time and more tuition".*

5. Effectiveness of the self-help pack in managing anxiety - The service users were asked about the impact of the pack and what they had learned from it.   Most reported that working through the self-help pack had had a number of benefits and had found it helpful in coping with day to day difficulties:

> *"It helped me with my breathing and it helped me to recognise when my anxiety was coming on, so I knew what to do and it gives you confidence and makes you feel better when you know how to deal with your anxiety. I find the pack gives you a good*

> *insight, like if this happens again at least you know what is happening and perhaps if you know what's happening it isn't quite so frightening. I mean, I have a condition that goes a long way beyond anxiety, I find the big thing that keeps me together is insight into what's happening and insight into all the strange things you experience…and then you are able to bring yourself round to some sort of reality again".*
>
> *"I sort of coped better, it has been helpful. It has helped me in dealing with people and everyday life and positive thinking…I think, you know it has taught me that by doing things bit by bit and not trying to do lots of things at once has helped me cope".*
>
> *"…not getting things out of proportion and knowing how to relax whenever you get agitated. It has helped me in meeting people, given me confidence in getting out more, it also gives you confidence in doing stuff, like art etc.".*
>
> *"We had a trip at DASH…on the canal boat I got anxious but I did refer to the techniques mentioned in the book and it helped my anxiety".*

Although service users were positive about the self-help material they did however place a great emphasis on the importance of prescribed medication. One service user reported that without medication the self-help material was useless on its own.

6. *Self-help group* - Another issue that emerged were the positive comments about DASH. All respondents stated that they appreciated the high level of support they received from the service and this had helped them cope better with their anxiety:

> *"DASH as an organisation is super because it certainly keeps you out of hospital and you cope better when you talk to people and met people. Everyone is in the same boat, it's a nice atmosphere and nobody judges you".*

Service users' views of self-help anxiety pack

7. Views on user participation - Several service users commented that they had welcomed the opportunity to be involved and that their self-esteem improved as a result of their contributions:

> *"This whole experience has helped us learn to deal with things better and given us the self-confidence. I mean before this I would never have wanted to talk to anybody and wouldn't have taken part in a group discussion, so this makes me feel good".*

One of the participants in the focus group acknowledged that a cultural divide exists between service users and primary care practitioners and commented that using service users to provide feedback about services was a very good idea:

> *"We feel positive about this…we have been through this so our views are needed, so people can understand…we need to build on this. It's nice to be included and have our views listened to and put forward".*

The general consensus from all participants was that this was a genuinely positive effort to include service users as equal members and they felt that their views were being considered in defining their own health needs and in shaping services:

> *"Its good you asked us for our views on the pack…it's a good idea because you need feedback to know what people need".*
>
> *"…yes would like to be involved in other research in the future but not into something as heavy as this".*

9. *Recommendations for revision of the self-help pack -* Participants were asked to give their views with regards to ways in which the self-help pack could be improved. Although a number of these issues have been discussed previously, this section highlights specific recommendations made by participants. On the whole participants were very supportive of the self-help anxiety pack and saw it as a valuable tool. A number of recommendations for further change were made by participants to make it more user-friendly. The majority of the

service users suggested that the self-help pack should be shorter and include more *'illustrations'* and the language should be made *'simpler, so it is easier to understand'*. Participants also suggested that the pack should be printed using a larger font to make it easier to comprehend. There was also a consensus for this group that working through the pack *'should be a group activity and not left to individuals to work through by themselves'*.

Discussion

This evaluation sought service users' views of a CBT-based self-help anxiety pack for credibility, understandability and helpfulness. The majority of service users evaluated the self-help pack positively but with constructive critical comments. This suggests a healthy degree of honesty and openness. There was consistency in the views expressed and the data collected provides evidence that the self-help material had made some beneficial impact on users' self-help strategies, consistent with other research using the same material (Lucock, Padgett, Noble, Westley, Atha, et al, 2005). There were critical comments about difficulties understanding the self-help pack, and recommendations that it should be shorter, easier to understand and with less technical language. The negative comments are important in that they point to possible adverse effects of self-help material if they are considered too demanding for service users, particularly those that may have problems with concentration and literacy problems. In addition, requiring participants to work on the self-help material in the group session with the facilitator worked well for the majority of service users. They clearly benefited from the support of the group, the facilitator and their fellow group members and this enabled them to make better use of the material.   They were also more likely to engage with the self-help material if they were motivated and enjoyed the various tasks and exercises. Another theme arising from the data suggested the need for some general training and awareness amongst health and social care staff, so they are more equipped to deliver the self-help material effectively and support service users in making use

of it. In the context of a mutual support self-help group, with the right training and experience service users should be able to facilitate other service users in working with self-help materials.

The information gathered, along with other feedback on the pack from service users and professionals, has been used to improve the self-help pack.   A consistent concern from the various sources of feedback has been that the pack can be too much for one person to work through without support. This has been addressed in three ways, by revising the format of the pack so it does not appear so intimidating, by reducing the content to some extent and by reviewing the amount of support required to use the pack effectively. The six sections are also available as separate documents. It seems likely that with any self-help material there will be different levels of support required for different individuals. In a related study of the effectiveness of the same self-help pack in a routine psychological therapies service, although there was evidence of its effectiveness overall and significant goal attainment for some individuals, others reported their concentration problems made it difficult to take in the information in the pack (Lucock et al, 2005).

In considering the views of the pack, it is important to consider the type of service users taking part in this study. DASH supports a significant number of people with more enduring mental health problems requiring ongoing support. Although all have anxiety and/or depression problems, some also have diagnoses such as schizophrenia and bipolar disorder and are more characteristic of service users seen by secondary care services. It seems likely that individuals seen in primary care with milder and more transient mental health problems will be more able to benefit from such self-help material without so much guidance.

This study supports a number of key conclusions and recommendations about the use of self-help material:

Service users' views of self-help anxiety pack

1. Self-help materials can be used effectively within self-help groups and group support is likely to enhance the benefits gained.

2. Self-help materials should be developed that are easy to understand, with minimal use of technical jargon.

3. Self-help materials can be over whelming to some service users so care should be taken to present it in an understandable and acceptable format.

4. Care should be taken to consider the amount of support required to make use of self-help materials.

5. Consideration should be given to training professionals to enable them to support service user's use of self-help materials and of service users in mutual support groups.

6. Research that seeks the views of service users can be a very positive experience for them.

In their review of research evidence about self-help interventions for people with mental health problems, Lewis et al. (2003) reported there are examples of innovative models using self-help materials within self-help groups but there was little research in this area, nor of research into self-help groups per se. This study is an example of research into this important area and illustrates how such research can help develop appropriate self-help materials, clarify the type and amount of support needed to make use of such materials and their role in self-help groups. There are also benefits to service users, from the self-help material itself and through the positive impact of consulting them on their views.

Service users' views of self-help anxiety pack

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Service users' views of self-help anxiety pack

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Service users' views of self-help anxiety pack

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