A qualitative investigation of the process of personal self-reported recovery in mental health service users

Background:

Concept of personal recovery

There is evidence that mental health service users and the clinicians caring for them can have different ideas of what mental health recovery actually means, (Bonney & Stickley 2008, Perkins, 2001, Stotland et al 2008). Clinicians tend to focus more on remission of illness and prescription of medication, (Fawcett, 2007). In contrast, for service users recovery is an individual journey out of illness into a life of meaning, purpose and fulfilment, even in the presence of ongoing symptoms, (Deegan, 1996; Ng, 2008). For this, they need more holistic interventions aimed at facilitating this. We will call the service user experience of recovery: "personal recovery".

Importance of studying personal recovery

By definition, personal recovery is what is really important for service users in their recovery journey. It has yet to be fully described. It is not yet fully understood how it relates to the clinical assessment and course of illness. It is not well known what promotes or impedes it. In order for more people to experience personal recovery it is essential that the process is better understood. The eventual challenge is to find suitable interventions for those struggling with their personal recovery.

Links between personal recovery and spiritual well-being

Spirituality is defined as whatever gives meaning, purpose and hope in life, often involving the transcendent, (Barber & Wilson, 2014, Cook, 2004). It may or may not include a formal religious faith. There is much evidence for the importance of spirituality and the experience of spiritual well-being to service users, (Baetz,, 2009). Many qualitative studies have shown the importance of the more general issues such as meaning, purpose and hope in life, (the 'existential"), (Fallot 2007, Mohr et al 2011, Moran & Russo-Netzer 2016, Shiah et al 2015, Tsuang et al 2007, Unterrainer et al 2015, Warren et al 2015), and indeed well-being in these areas is one of the ways in which service users define their recovery, (McCabe et al 2007). A specific religion is also of great importance to many service users, (Borras et al 2007, Ho et al 2016, Huguelet et al 2006, Mohr et al 2012, Pargament & Lomax 2013). Many service users have unmet spiritual needs, both in the general and the religious sense, (Cook et al., 2012; Koslander et al., 2009; Pennybaker et al., 2016). Perhaps, then, some of the needs identified by the concept of personal recovery are spiritual in nature.

Measuring personal recovery

In order to investigate personal recovery quantitatively, a new self-report tool was designed, focusing on issues service users find especially important, and including spirituality and spiritual well-being, (Barber et al 2012). This, the Service user Recovery Evaluation scale, (SeRvE), with a shortened version for more routine use, (Mini-SeRvE), has now been developed and validated, (Barber et al 2012, Barber et al 2017). The principal investigator was a service user, working with extensive input from a research forum of 40 users in a scoping day, (Suresearch), and guided by a steering group of another 6 users meeting monthly. It can be said with confidence that these tools reflect the issues of recovery most important to service users themselves, ie. their personal recovery. Preference is for the Mini-SeRvE tool since as it contains only 15 questions, it is far more practical than SeRvE, (40 questions), for use with people with severe mental health problems, (Moeser et al., 2006)

Factor analysis of both scales confirmed the importance of existential and religious well-being for personal recovery and the priority service users place on positive issues rather than problems. For Mini-SeRvE specifically, factor analysis showed 3 clear factors, (existential well-being, religious well-being and mental ill-being) all correlating with each other to a moderate degree. A start has thus been made to describe the nature of personal recovery.

Different aspects of personal recovery

Using the 3 factors found in the Mini-SeRvE as the major aspects of personal recovery, we will now sum up what is already known about the issues addressed by each factor.

Factor 1: Existential Well-being, (EWB):
This factor embraces topics such as meaning, purpose, hope, self-acceptance, esteem and empowerment, ((Leamy et al 2011, McCabe et al 2007). Cross-sectional studies link these to good outcomes, both clinically and for quality of life, (Fukui et al 2012, Galanter et al 2011, Harris et al 2015, Huguelet et al 2016). Some studies suggest that existential well-being is a protective factor for developing depression and minor psychiatric disorders, (Maeselko et al., 2009, Volcan et al., 2003). Meaninglessness, in particular, is associated with all types of mental illnesses, higher severity of psychotic symptoms and poor recovery outcomes, (Glaw et al., 2017). Other studies have flagged up the crucial importance of hope, forgiveness of self and others, optimism and social issues for these associations.

Factor 2: Mental Ill-being, (MIB):
This factor includes common problems that service users face, eg. isolation, stigma, feeling others are against you, lack of motivation and agitation, (Barber et al., 2017). These problems have all individually been shown to be very important for service user recovery, (Barut et al 2016, Burke et al 2016, Freeman et al 2014, Lewandowski et al 2006). Qualitative evidence links problems in this area to negative outcomes from psychosis, (Happell 2008, Meijer et al 2009),

some service users even rating these issues as being more difficult for them than their psychotic symptoms, (Fusar-Poli et al 2014). The depression often seen accompanying all other kinds of mental illness may be a crucial issue here, (Lewandowski et al 2006, Nuraskin et al 2013).

Factor 3: Religious Well-being, (RWB):
An association between religion/spiritual belief and mental illness has been shown, (Bonelli & Koenig 2013, Koenig 2009, Larimore et al 2002, Moreira-Almeida & Koenig 2006), but there is conflicting evidence. Religious involvement tends overall to be associated with better mental health and better outcomes from mental illness. However, while some service users find their religion/spiritual belief to be helpful and comforting, others actually find it a source of confusion and distress, (Koslander et al 2013, Mohr et al 2004, Pargament et al 2000, Webb et al 2011). The reasons for this variation are at present unclear. Pargament has described it as positive or negative religious coping and has developed a short scale with which it can be assessed, the Brief Religious Coping Scale, (BRCOPE), (Pargament et al 2011). Positive religious coping has been associated with good mental health outcomes, while negative coping is associated with poor outcomes. Thus, religion/spiritual belief may have particular potential for influencing outcomes.

Proposed new study

It is clear that the separate issues raised in the 3 Mini-SeRvE factors need further investigation. Although there is a definite interaction between these factors, the correlations between them are by no means complete, and the causes and effects of changes within and between each individual factor are unclear. Comparing people with different diagnoses and different degrees of personal and clinical recovery is also necessary. A qualitative study is proposed to generate ideas about the mechanisms involved. This will be based on service users descriptions of changes in each of the 3 aspects of personal recovery identified by Mini-SeRvE validation, (EWB, MIB, RWB) and their ideas about how and why these changes occurred.

Aims:

To increase understanding of the whole process of personal recovery.
To study the nature of the relationship between the 3 identified aspects of personal recovery, (EWB, MIB, RWB), and any causal mechanisms that can be identified.
To create hypotheses as to why people vary so much in the extent to which they experience personal recovery.

Objectives:

To conduct semi-structured interviews with service users at a variety of stages of personal recovery and clinical illness.
These would:

Describe the time course and process of 3 aspects, of personal recovery (EWB, MIB, RWB), from the individual service user viewpoint.
Explore the relationship between these three aspects of personal recovery.
Use grounded theory to construct theories to model the process of personal recovery

Methodology:

Sample:

This would be a purposive sample of about 20 mental health service users. The first few will be chosen from people who are just about to be discharged, or who are attending their first outpatient appointment after a period of hospital admission. Participants would be initially chosen to from people who have indicated that their religion/spiritual belief is important to them. They will represent both those who are doing well and those who are doing badly with their personal recovery as scored on Mini-SeRvE. As the project enfolds, people with particular problems with any one of our three identified aspects of personal recovery would also be targeted. Comparisons may be made with people for whom religion/spiritual belief is of little importance to them. Depending on initial coding and results, participants with other particular characteristics, eg. clinical diagnosis, would be recruited to further test emerging theory. Inclusive criteria would be recovering from schizophrenia/other psychosis, bipolar disorder, major depression or anxiety state. Exclusion criteria would be under 18, cognitive dysfunction or learning disability, inability to speak and/or understand English.

Study design:

Potential participants will be identified from the caseload of the spiritual care team in Birmingham and Solihull Mental Health NHS Foundation Trust. As such, they will be likely to find spiritual and religious issues important, although many may have problems with these issues. They would thus be eminently suitable for investigating the spiritual issues which are such an important part of our concept of personal recovery.

Potential participants will then be approached by the research team, who will explain what it would mean for them to participate. They will then be given the opportunity to ask questions, and those who are agreeable will sign a consent form.

Having done this, they will then complete the Mini-SeRvE scale and the BRCOPE, give a self-rating of the importance to them of a religion/spiritual belief to them and undergo a HoNOS assessment from a clinician. They will be asked to give permission for the research team to have access to their medical records.
They will then undergo a semi-structured interview, in which the issues raised in each of the 3 subscales in Mini-SeRvE will be discussed, (existential well-being, persistent mental ill-being, and religious well-being). In particular, changes around these issues over time and the time course and extent of their overall

personal recovery will be explored. Participants will be asked to look back over past and current periods of illness where appropriate, and describe how they view the future. Clues as to why some people struggle so much with their personal recovery will be sought. After interviewing the first 5-10 participants, participants with specific characteristics will be selected for interviews to investigate emerging theories, (purposive theoretical sampling). Interviewing will continue until saturation of data is reached or 20 participants have been interviewed, whichever is the lesser. The interviews will be recorded live with permission from the service user.

Data analysis:

A transcript of each interview will be made so that coding can be more effectively carried out. These will be entered into a computer using NVivo software. The transcripts will then be subject to grounded theory analysis. Initial coding will be put into conceptual categories and this will enable theories to be generated about the processes involved in our 3 aspects of personal recovery. These will be related to the clinician's assessment and individual scores on Mini-SeRvE and BRCOPE. Theories generated will be further tested with purposive theoretical sampling.

Burdens and benefits of study on service user participants

Individual participants will be required to give approximately 3 hours to this project, both to complete the scales and to undergo a HoNOS assessment and a semi-structured interview. In addition, the interviews will be in depth and will address sensitive issues. However, some service users may benefit from talking about their experiences and having a chance to discuss these things with an empathetic listener. All interviews will be carried out by a peer service user researcher. In all cases there will be a trained member of clinical staff available during and after the interviews in the event that a service user is upset when talking about these issues. Financial re-embursement of £20 per participant will be given in addition to any travel and subsistence expenses.

Possible outcomes

This work could produce ideas about mechanisms involved in the 3 identified aspects of personal recovery. It might shed light on the way in which these interact with clinical illness. It could help us understand why some people seem to do much better than others in their personal recovery journey. This could lead to new interventions to promote personal recovery in our service users. In particular, it could highlight ways in which service users can be helped to find spiritual well-being, as one of the major issues involved, and thus inform the ways we practice spiritual care.

Sample questions for semi-structured interviews

We would like to discuss your personal well-being before, during and after your illness. This includes your sense of meaning and purpose in life, any mental difficulties you still have and how helpful, if at all, you find a religion/spiritual belief in your life.

1. Perhaps we could start by talking about how you feel your recovery is going. Do you feel that you are recovering? How is your life now?

2. What keeps you motivated and makes you get up in the morning? How has this changed since before you were unwell? Why do you think this has changed?

3. Do you have any mental problems such as feeling low, or isolated, or agitated? Is this worse than it was before you were ill? What do you think causes you to feel this way?

4. How important to you is your religious/spiritual belief? Do you find it helpful? What is helpful about it? Is this different from how it was before you were unwell? Why do you think this is?

5. How do you think your symptoms of illness affect your experience of recovery?

6. How do you now feel about your future?

Jo Barber September 2017

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