Conceptualisation of recovery from psychosis: a service-user perspective

Lisa Wood,[1] Jason Price,[1] Anthony Morrison,[1,2] Gillian Haddock[2]

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[1]Greater Manchester West Mental Health NHS Foundation Trust; [2]University of Manchester

Correspondence to Gillian Haddock (Gillian.haddock@manchester.ac.uk)

Aims and method There has been much uncertainty about the concept of recovery in psychosis. The aim of this paper is to conceptualise recovery, through service users' descriptions of their recovery stories. A qualitative approach (interpretive phenomenological analysis) was used to guide interviews and analysis of data.

Results Eight service users were interviewed about their recovery from psychosis. Data analysis revealed four superordinate themes: 'impacts on mental health', 'self-change and adaptation', 'social redefinition' and 'individualised coping mechanisms'.

Clinical implications Data indicates that multiple dimensions of recovery are all important to individuals when considering their subjective experiences of recovery from psychosis. Recovery can only be conceptualised by the person making the recovery journey and treatment outcome measures must reflect this individuality.

Declaration of interest This paper outlines independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research.

As a result of government policies and the National Services Framework[1] the concept of 'recovery' has become an increasingly discussed topic within the mental health field and is an important concept for mental health service providers and policy makers. However, its definition has never been explicitly formulated. This is of concern because of its current influence on research and clinical practice.[2]

The definition and measurement of recovery in mental health has been approached in differing ways. Some people have simply outlined recovery by singular factors such as symptoms, relapse rates and functioning.[3,4] Others have considered it to be a long-term process incorporating hope for the future, rebuilding self and rebuilding life.[5] Davidson *et al* outlined recovery as two superseding models: one that incorporates recovery as symptomatic and the other that adopts a sense of well-being regardless of symptoms.[6] Others have described recovery as a set of internal and external conditions.[7] In light of this diversity, it is important to explore what the term recovery means in order to prevent misunderstanding and misapplication. Within the domain of psychosis, recovery has traditionally been regarded as predominantly about symptom alleviation.[2] This definition has been widely adopted in clinical and randomised controlled trials (RCTs) of psychological therapies (e.g. cognitive–behavioural therapy)[8–10] and medication.[11,12] As RCTs are used as the benchmark for effective treatments for psychosis in National Health Service (NHS) and Department of Health policies and guidelines, symptom alleviation is clearly an important factor in relation to defining recovery in current services. In addition, symptom alleviation is important to recovery as psychotic symptoms have been shown to cause much distress, debilitation and reduction in social functioning.[4,13]

Further support for symptom change as an important indicator of recovery is illustrated by the number of psychometrically reliable symptom outcome measures that have been developed. Outcome measures such as the Positive and Negative Syndrome Scale (PANSS),[14] the Brief Psychiatric Rating Scale (BPRS)[15] and the Psychotic Symptom Rating Scales (PSYRATS)[16] are commonly utilised illustrating the dominance of symptom alleviation as an indicator of recovery. Other outcomes have also been frequently used. For example, relapse reduction has been used as a measure with regard to recovery.[17] Relapse often includes assessment of reoccurring symptoms, rehospitalisation rates and remission times.[18] Assessing relapse allows clinicians to identify periods of symptom stabilisation and thus periods of recovery. There has also been a long-standing interest in assessing quality of life as an indicator of recovery in psychosis.[19] Quality of life integrates objective and subjective indicators, a broad range of life domains and individual values.[20] Studies have predominantly examined aspects such as independent living and employment,[21] e.g. using the Quality of Life Scale (QLS).[22] Similarly, functioning has been used as an assessor of recovery, e.g. Global Assessment of Functioning (GAF).[23] Quality of life and functioning are often assessed along with symptom outcome measures in RCTs and treatment studies.[24]

Collectively, these approaches to recovery have defined the term as a multidimensional outcome, although its

dimensions are usually quantified and assessed individually. Although this approach has given great insight into recovery and impact of treatment, it does not represent the multidimensional and complex picture that has been highlighted by some service users. For example, some research has highlighted that recovery has also been considered as a process, which incorporates a range of personal and social factors.[25]

A meta-analytic study of recovery research from a service-user perspective identified five clusters of important factors different to those already outlined.[26] First, personal and self-empowering processes were highlighted as significant. This included taking control of one's life and developing a positive self-identity.[27] Second, recovery was identified as a motivational process, incorporating items such as generating hope and being active in one's own recovery.[28] Third, developing one's own competences, including making sense of mental distress and seeking knowledge was highlighted.[5] Fourth, making changes in the direction of social and community participation was highlighted as important, such as accessing social support, including support from other service users.[29] Finally, incorporating resources from the environment was deemed imperative, including accessing mental health services and voluntary support services. Further factors have also been identified from service-user research. One dominating factor is the need for individuals to overcome their experiences of psychiatric treatment and medication. This may involve aspects such as overcoming social isolation, stigma and discrimination.[5] Furthermore, the effectiveness of medication, appropriateness to the individual and side-effects have been shown to be important.[2,25,30] Spirituality and religion have also been recognised as relevant, as a coping mechanism or an explanation for an individual's experience.[30]

Collectively, the term recovery has been defined in a diverse manner dependant on an individual's perspective. A vast number of approaches have been outlined, but there is still uncertainty about what factors contribute to the construct of recovery, and whether recovery is related to symptom change or not. Studies to date have not taken an all encompassing approach to recovery, and have constrained their focus to either symptom alleviation or the idiosyncratic recovery process and its impact on life. This current study aims to alleviate this uncertainty by adopting an inclusive approach in further scrutinising what factors are important to this multidimensional concept. This study explores people's subjective experiences of recovery and, in particular, the relationship between recovery and symptoms. Interpretative phenomenological analysis was used to elicit data from participants because of its person-focused nature. Interpretative phenomenological analysis is concerned with the individual's understanding and interpretation of their own personal experiences.[31] It assumes that people are self-interpreting beings; therefore the researcher attempts to interpret the participant's experiences from the participant's perspective. A semi-structured interview schedule was utilised in order to elicit individual's personal views on recovery from psychosis. This facilitated the discussion of specific recovery topics such as symptom change and issues that affect recovery, but also allowed for flexibility in people's personal experiences; a method highly suited to interpretative phenomenological analysis.

Method

Participants

As interpretative phenomenological analysis studies are conducted with small sample sizes, usually with a minimum of five or six participants,[31] recruitment was conducted until a minimum number of participants was met and until the team felt that saturation of themes was achieved. The inclusion criteria were: experience of psychosis within the past year (i.e. delusions and/or hallucinations); aged between 18 and 65; and in contact with mental health services. Exclusion criteria included: not being able to speak English; not able to give informed consent; and having taken part in other research within the past 6 months. A variety of statutory care providers across Greater Manchester West NHS Foundation Trust were approached for suitable participants.

Design

The study utilised a semi-structured interview approach and focused on the participants' subjective experience of recovery in psychosis. The schedule was developed by a clinical psychologist and service-user researcher (G.H. and M.K.). Service-user-led research[5,26] and symptom-focused literature[2,3,8,14] were scrutinised in order to generate relevant themes. Discussion with a service-user group generated further interview themes about personal background, experience of symptoms, recovery and impacts of symptoms. The interview schedule was piloted with three service-user researchers and went through several changes to ensure that it reflected the diverse views on recovery apparent in the literature. The final version included the following headings: information on initial contact with mental health services; background on personal experiences; current experiences; what they felt had changed over time/recovery; how they feel they have changed (i.e. personally, emotionally) over time/recovery; ways of coping; impacts and changes to their life.

Procedure

Early intervention services, assertive outreach teams and community mental health teams were approached about recruitment for the study. A total of 75% of interviews were conducted by a service-user researcher. All interviews were audio-recorded and transcribed verbatim by a service-user researcher (J.P.) and research assistant (L.W.) in order to help familiarise them with the data.

Analysis

Interpretative phenomenological analysis was the analytical device used, as it is well suited to the exploration of subjective experience.[31] A core concept of interpretative phenomenological analysis is that the analyst should become immersed in the data.[31] Tapes were listened to and the transcripts read through a number of times. Both

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the first and second author analysed all the interviews independently, and, after multiple readings, extracted pertinent themes. All the themes were then finalised by the authors. The fourth author (G.H.) acted as a mediator where there was any disagreement with regard to themes.

Results

Eight people were interviewed (six males and two females), with an age range of 24–35, and all had experiences of delusions and/or hallucinations within the past 12 months. Six were recruited from early intervention services and two were from community mental health teams. Overall, 132 themes were generated from the interviews by the authors. Overlapping and repetitious themes were identified and, where it was agreed by consensus, these were removed. The remaining themes were then further discussed, resulting in some being identified as reflecting the same concepts as others. This allowed a further fine-tuning, resulting in 50 clear themes that were representative of the expansive concourse. The final 50 themes broadly covered 8 areas of recovery: symptoms, emotional aspects, the self, behaviour, services and support, coping mechanisms, social functioning and occupational aspects. From these broad eight themes a logical grouping of four superordinate themes emerged.

The four superordinate themes were described as: 'impacts on mental health', 'self-change and adaptation', 'social redefinition' and 'individualised coping mechanisms'. These themes were underpinned by change, highlighting that recovery is a process, not an end-point. The first theme was defined as 'impacts on mental health' because of the importance placed on symptom change by interviewees. The second theme, 'self-change and adaptation' was defined by the negative changes that participants felt had happened following experiences of psychosis. The third theme, 'social redefinition' represents the social changes often associated with psychosis. The final theme 'individualised coping mechanisms' is representative of the way that people chose to cope and overcome their experiences. These themes each had two further subthemes that consisted of smaller themes (Box 1).

Theme 1: impacts on mental health

All participants interviewed discussed alleviation of symptoms and/or negative emotions as key to their recovery. They discussed specific changes in symptom characteristics as well as changes in their emotional state.

Box 1 Interpretative phenomenological analysis: key themes, subthemes and further themes of aspects important to a change in recovery.

Impacts on mental health

Reduction in symptoms of psychosis
- Preoccupation with experiences
- The content of experiences
- The frequency of experiences
- The duration of experiences
- The loudness of voices
- The origin of the experiences
- Perception of experiences
- Amount of distress
- Conviction

Emotional change
- Overcoming depression and low mood
- Feelings of happiness and enjoyment
- Overcoming anxiety and stress
- Overcoming anger and frustration
- Changes in the amount of emotions experienced

Self-change and adaptation

Personal change and belief
- Positive self-beliefs
- Redefining who you are
- Feeling less vulnerable
- Overcoming embarrassment
- Regaining personal freedoms and rights
- Having a positive outlook for the future

Behavioural change
- Improvements in sleep
- Energy and lethargy
- Motivation for change
- Reduction in self-harm and suicidal ideation
- Regaining independence
- Changes in drug and alcohol use

Social redefinition

Occupational change
- Stable living conditions
- Job seeking and maintaining employment
- Financial stability

Relationships and social behaviour
- Being less withdrawn and isolated
- Finding the ability to trust others
- Taking part in meaningful activities and hobbies
- Developing and depending on relationships with friends and loved ones
- Increasing social activity
- Overcoming being judged and stigmatised

Individualised coping mechanisms

Support and treatment
- Benefits of medication
- Benefits of therapies
- Peer support
- Support from loved ones and/or friends
- Receiving help from the mental health services
- Concerns over the side-effects of medication
- Importance of spirituality/religion

Understanding and control
- Help-seeking with experiences
- Recognising the early signs of becoming unwell
- Being able to cope with experiences
- Understanding your experiences and/or diagnosis
- Feeling empowered over your experiences
- Having control over experiences
- Thinking clearly about experiences
- Having control over own thoughts

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Reduction in symptoms of psychosis

All participants considered a change in symptom characteristics as important to their recovery. Therefore, psychiatric-based indicators of recovery were found to be important to those people interviewed.

> 'They're not as aggressive as they were when they were really bad . . . they were really, really nasty and they used to really upset me but they're not as bad anymore . . .' (Reflecting the importance of the subordinate theme of 'the content of experiences'.)

Emotional change

Affective and emotional changes are often associated with experiences of psychosis. For the people interviewed, this was a significant factor when considering their experiences.

> 'It was definitely the most difficult time I've ever experienced, and I've had depression, on and off, since I was 14 maybe. But it [the depression that coincided with the psychosis] was far worse than that.' (Showing the importance of 'overcoming depression and low mood'.)

Theme 2: self-change and adaptation

Experience of psychosis was shown to have great impact on one's self. The themes illustrated the importance of overcoming psychosis and being able to regain self-identity.

Personal change and belief

Interviewees described negative self-belief and negative personal change since experiencing psychosis. Their previous self wanted to be redefined in spite of current experiences.

> 'I feel better about myself now, the voices used to make me feel like a rubbish person, they made me feel like I wasn't worth anything, now I can control this I feel better about myself.' (The theme 'positive self-beliefs' was key to personal change and belief.)

Behavioural change

The research also identified a number of behavioural changes; participants expressed the importance of motivation, independence and changing harmful behaviours.

> 'I think I'm over most of it you know, but I think there's still little things, like a routine of looking after myself, which can sometimes suffer . . . sometimes my appearance can get quite bad.' (Illustrating that self-care is key to subordinate theme 'regaining independence'.)

Theme 3: social redefinition

Mental health problems were shown to have a direct impact on an individual's social role. Redefining and reconciling their social circumstances was frequently spoken about in all interviews.

Occupational change

Changes in finance, work and living arrangements were acknowledged to be great stressors. A return to optimal functioning in these areas was identified as a struggle but something that people were keen to tackle.

> 'Not having much luck getting a job at the moment, which is quite frustrating really.'

> 'I was in lots of debt and it was stressing me out.' (Illustrating the subordinate themes 'job seeking and maintaining employment' and 'financial stability' as being main occupational issues.)

Relationships/social behaviour

Social isolation, the breakdown of social networks, judgement and stigmatisation is often common with mental health experiences. It was important to interviewees to rebuild these networks and relationships to assist in recovery.

> 'One of the main things [that made me feel better] is the support that my family gave me really, although it was strained at times, after a while, not at first but after a while they would understand what I was going through.' (All interviewee's supported the theme 'developing and depending on relationships with loved ones'.)

Theme 4: individualised coping mechanisms

Developing an individualised coping mechanism was considered important to all people interviewed. By accessing support and treatment, people were able to assist their recovery. Furthermore, gaining insight and understanding was also shown to be important.

Support and treatment

Support and treatment is of great importance to those with mental health experiences. Interviewees had diverse views about what support and treatment they found beneficial illustrating the individuality in appropriate support and treatment.

> 'And [care co-ordinator] has been a great help, you know working through everything . . . and the team [were helpful].' (Subordinate theme 'receiving help from the mental health services' was important to some interviewee's recovery.)

Understanding and control

Understanding and coping with experiences was highlighted by all interviewees as important to their recovery. However, each individual had different approaches and found a range of things helpful.

> 'I would have to think something rational and take control of my own beliefs and it was really empowering.' (This quote reflects the need for subordinate theme 'having control over experiences'.)

Discussion

The findings from this study highlight the multidimensionality of the recovery process in psychosis, and that this does include a role for symptom change. There appears to be four main aspects that are important to consider: impacts on mental health; self-change and adaptation; social redefinition; and adapting an individual coping style. These factors were shown to be important to all those interviewed. The varied emphasis that the interviewee's placed on change within these four areas indicates that recovery may not be considered merely an outcome with clear cut differences between being recovered and not being recovered. This supports the notion that recovery is an ongoing process, consistent with previous literature.[25]

Nevertheless, participants found symptom alleviation to have a major bearing on their recovery and this highlights the importance of considering symptoms within the recovery process, and as an important indicator of outcome from treatment. However, these findings also highlight that

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recovery is much broader than symptom alleviation alone. Improvements in psychotic symptoms may be important to recovery, but only in conjunction with a range of other factors. Furthermore, the findings in relation to the need for change within symptoms may indicate that although full symptom alleviation or removal may be important for some service users, for others, changes in the nature of the symptoms may be just as important. For example, recovery may mean the continued presence of symptoms but without their negative impacts. Clinicians should consider this when working with service users by working more holistically and being mindful of the importance of other social and psychological factors.

The emotional impacts of having psychosis were also identified. The effects on depression, anxiety, anger and frustration illustrate that emotional change is also important to consider. Psychotic symptoms are often concomitant with these aspects and measured accordingly (e.g. PANSS)[14] so more importance may need to be placed on these areas. Anger and frustration was highlighted. This may be of particular interest as it is often not considered in typical outcome measures within trials or services for psychosis.

Another aspect that was the highlighted as important to recovery was self-change and adaptation. All people interviewed identified a change to their character, personality and identity. For example, they were less confident, less energetic and less motivated. Most people found that they no longer were able to do the things they used to do, i.e. hobbies and activities. Rebuilding identity and character understandably plays a key part in recovery, as outlined in previous service-user-led research,[5] and should be considered as main factors with regard to therapy and research.

A major area of recovery that was also common throughout the themes was the social impact of psychosis. Most participants found that their financial stability, living arrangements and employment status were affected by having experienced psychosis. This highlights the continued need for social relationships and issues that affect social behaviour to be considered when developing services with regard to recovery. All interviewees spoke about a decrease in social activities, an affect on their relationships with friends and loved ones and feeling isolated. Social activities are measured briefly in such measures as the PANSS,[14] as social relationships are in the GAF,[23] but are often otherwise ignored in terms of published research. This current study and other previous service-user research has shown how important developing social networks and activities are in regard to recovery (e.g. Pitt *et al*,[5] Chadwick)[27] but they are often not being considered in enough detail by large quantitative studies (e.g. Kuipers *et al*).[32]

Implications

This research illustrates the importance of understanding recovery from a holistic perspective that incorporates personal factors as well as symptoms. It highlights that future research scrutinising recovery, treatments and therapies should be examined more expansively. Symptom alleviation should be considered alongside other important factors such as social and personal change, and individualised ways of coping.

Conversely, this research also highlights that symptom alleviation is important and should not be underestimated. All participants highlighted symptom change as an indicator of their recovery, and change in symptoms was often accompanied by alleviation of distress and personal change. Within the recovery movement, the importance of symptom alleviation for many people can often be lost when considering other factors; an emphasis still needs to be placed on this. Therefore, it may be desirable to develop an assessment tool that incorporates these themes in order to allow a broader, recovery-focused approach to the monitoring of symptoms and the impact that such experiences have on life.

Strengths and limitations

One strength of this research is that the majority of the interviews were carried out by a service-user researcher. Literature has shown that the interviewer's power and positioning play an important part in the interviewing procedure.[33] As the service-user researcher had shared experience with the interviewee, it could be expected that richer, more detailed information may have been elicited. This has been illustrated in other service-user-led studies about recovery[5] and impacts of diagnosis.[34] This strength may also be a limitation. The service user's personal experiences will have influenced the direction and data extracted by the interview process.

A further limitation to this study is the young sample from mainly early intervention services. Their experiences of mental health and its services may not be representative of those who have had longer-term mental health experiences and engaged with differing services. Furthermore, the imbalance in gender may also have a confounding effect. With only a small number of female participants, their views may not suitably represent the overall population.

It can be concluded that recovery is a multifaceted process that incorporates symptoms, social factors, personal adaptation and development of individualised coping mechanisms. These four factors should not be considered as mutually exclusive but factors that coexist. Furthermore, recovery is idiosyncratic and dependent on personal definition so the importance placed on these outlined factors can differ across individuals. It is therefore important to consider all themes outlined in this research to ensure individual recovery is focused on within future services and research in psychosis.

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About the authors

Lisa Wood Research Assistant, **Jason Price** Service-user Researcher, RECOVERY Programme, Psychology Services, Greater Manchester West Mental Health NHS Foundation Trust, **Anthony Morrison** Professor of Clinical Psychology, School of Psychological Sciences, University of Manchester and Greater Manchester West Mental Health NHS Foundation Trust, **Gillian Haddock** Professor of Clinical Psychology, School of Psychological Sciences, University of Manchester, UK.

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