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Title: Recovery: what mental health nurses and service users say about the concept of recovery

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This is post peer review pre-print version of the paper published as
doi: 10.1111/j.1365-2850.2011.01776.x

The definitive and final version of this paper can be accessed via the link below

Accessible summary

- This qualitative study investigated the subjective experiences of recovery in mental health with service users and mental health nurses.
- Data from two focus groups were analysed and found differing perceptions of how mental health services are delivered and the barriers that are seen to hinder the implementation of a recovery philosophy.
- The main findings of the study are that recovery is a difficult to define concept and remains a challenge for both this group of service users and nurses.

Abstract

This study presents a thematic analysis of focus group talk to examine what recovery in mental health means to service users and nurses. Data were collected from two focus groups, one group of service users and one group of nurses. The service user group (n=6) were adults with previous or recent experience of inpatient mental health services. The nursing group were registered nurses (n=5) of various grades and experience currently working in inpatient mental health services in one region of the UK. Thematic analysis using Krueger’s (1994) framework led to four themes being developed. These were, ‘understandings of recovery’, ‘semantics’, ‘therapeutics’ and ‘a journey’. Whilst the recovery concept wasn’t new to either group the understanding of recovery was vague and contradictory.
Keywords: recovery, multiple perspectives, focus groups, qualitative, inpatient settings
Introduction
Following a number of major reviews (SCMH, 1998, MIND, 2000, DH 2002) a core challenge for mental health services in the UK has been to improve the standard of acute mental health in-patient care. In-patient services have been frequently criticised by service users (McGeorge & Rae, 2007) and a disheartened workforce (Hardcastle, 2007).

One way of positively influencing inpatient mental health care is to build on notions of recovery and focus on a mutually acceptable language that encompasses hope and therapeutic optimism (Lester & Gask 2006). There is vast literature on the topic of recovery (Deegan, 1988, 1992, Anthony 1993, Coleman, 1999, Young & Ensing, 1999, May 2000). There is, however, lack of research which considers how the perception of recovery compares between staff and service users.

The literature on recovery indicates some contrasting perspectives on its meaning and concept (for example see Mead and Copeland 2000; Lieberman and Kopelowicz, 2002). Campbell et al (2008) argued that the service user perspective on recovery will differ from that of the professional who has given the diagnosis and the service provider attempting to implement a recovery philosophy of care that is driven by policy. However, there remains little evidence of the range of agreement and disagreement between nurses and service users on the terms ‘recovery’.

The aim of this study was to explore different perspectives of service users and mental health nurses with regard to the concept of recovery and how it fits within mental health services

The Study
Ethical approval was granted by the local research ethics committee. Information sheets regarding the nature, purpose and requirements of the study were given to potential participants who were asked to contact the lead researcher if they wished to participate. Signed consent was obtained from all participants who were reassured that they would remain anonymous in reporting of the study. The focus groups were audio-recorded and to maintain confidentiality these recordings were securely maintained and destroyed after one year. Data was collected through two focus groups each lasting one hour which took place by arrangement at a local drop-in centre and a day hospital. Open ended questions guided the discussion, for example, what does the word recovery mean to you? and, what do you think it would take for a recovery approach to work in local mental health services?

The service user group (n=6) consisted of participants who were over 18 years of age, and had previous or recent experience of inpatient mental health services and were currently attending a local day centre. The nursing group were registered nurses (n=5) of various grades and
experience, currently working in inpatient mental health services. These details are summarised in the findings section below.

The data provided by the participants underwent a rigorous process of analysis and interpretation. Audio-recordings were listened to a number of times and transcribed by the lead author. Framework Analysis (Ritchie & Spencer 2002) was used to manage the data as this involves a number of distinct interconnected stages. The five stages consist of familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. Analysis involved going through the data, reading the transcripts and annotating them to identify particular areas of analytic interest. The transcripts were read and re-read before noting key ideas. Field notes were referred to when utterances were unclear on the recording.

The data was displayed on a table (Kruegar 2000) to classify and identify themes from the quotes. Two hard copies of the transcript were made one being a working transcript. The working transcript was colour coded to separate them into the two groups. Questions asked during the focus group were written on separate pieces of paper. The quotes were then cut and lifted from their original context and re-arranged and placed with the relevant question asked in the focus group. These were arranged so that service user quotes were one side of the paper and the nursing quotes on the other identifying similarities and differences. For example:

| What does the word recovery mean to you? | “I think recovery is returning back to the frame of mind that you were in prior to getting better” (N1: 13) | “getting better” SU1:13[...better yeah SU2:14] |

Once familiar with the data the data was coded and an initial thematic map of the data was developed. It is at this inductive driven part of the process that Boyatzis (1998) stresses the importance of clarity in what type of insight is being sought and why. To this end the data was coded initially using the utterances of the speakers as the source of coding. Following this initial coding the themes were grouped and using an inductive approach themes were identified in relation to their links to the data collated rather than making the data fit into an existing framework (Braun & Clarke 2006). The aim was to build a detailed and exhaustive category system of issues raised in each group and to link these together. Categories were then examined in the light of the research questions and specific areas of analytical interest. This process led to four central themes labelled ‘understandings of recovery’, ‘semantics’, ‘therapeutics’ and ‘a journey’.
Analysis of the findings of our study are reported under each thematic heading below.

**FINDINGS**

Details of participants are summarised in tables 1 and 2.

**Table 1. Nursing Group**

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Gender</th>
<th>Age range</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse 1</td>
<td>Male</td>
<td>40 - 50</td>
<td>30 years</td>
</tr>
<tr>
<td>Nurse 2</td>
<td>Female</td>
<td>50 - 55</td>
<td>35 years</td>
</tr>
<tr>
<td>Nurse 3</td>
<td>Male</td>
<td>30 - 40</td>
<td>15 years</td>
</tr>
<tr>
<td>Nurse 4</td>
<td>Female</td>
<td>20 - 30</td>
<td>4 years</td>
</tr>
<tr>
<td>Nurse 5</td>
<td>Female</td>
<td>30 - 40</td>
<td>25 years</td>
</tr>
</tbody>
</table>

**Table 2. Service Users**

<table>
<thead>
<tr>
<th>SU 1</th>
<th>Gender</th>
<th>Age range</th>
<th>Diagnosis</th>
<th>Contact with mental health services</th>
</tr>
</thead>
<tbody>
<tr>
<td>SU 1</td>
<td>Male</td>
<td>40 – 50</td>
<td>Bipolar Affective Disorder</td>
<td>22 years</td>
</tr>
<tr>
<td>SU2</td>
<td>Male</td>
<td>40 – 50</td>
<td>Anxiety/Depression</td>
<td>2 years</td>
</tr>
<tr>
<td>SU3</td>
<td>Female</td>
<td>30 – 40</td>
<td>Depression</td>
<td>4 years</td>
</tr>
<tr>
<td>SU4</td>
<td>Female</td>
<td>30 - 40</td>
<td>Bipolar Affective Disorder</td>
<td>15 years</td>
</tr>
<tr>
<td>SU5</td>
<td>Male</td>
<td>30 – 40</td>
<td>Not given</td>
<td>3 years</td>
</tr>
<tr>
<td>SU6</td>
<td>Male</td>
<td>20 – 30</td>
<td>Bipolar Mood Disorder</td>
<td>5 years</td>
</tr>
</tbody>
</table>

*Understandings of recovery*

This theme consisted of two main categories related to contrasting views of medical knowledge and knowledge of the concepts of recovery.

All participants had difficulty in articulating what recovery meant to them and its application to mental health. Two service users described it as getting better and recovering something that
has been lost. This is similar to the nursing group where two participants described it as, returning back to the frame of mind you were in prior to being ill.

“You you’ll never function hundred percent like you used to” (line 60 SU4)

“two things, that expectation of one hundred percent is not realistic and I would say recovery is being able to maintain regular whatever that is, its not up and down, its on a level and being able to maintain that level society may say that’s unrealistic or realistic recovery you may need to settle for a certain percentage” (lines 64-68 SU5)

There appears here to be a concern that expectations of recovery may place an extra burden on users of services including shifting responsibility to individuals and perhaps away from services. This picture is further complicated by a determination to move away from medical models of ill-health as illustrated by Lukoff (2007) who elaborates that it is the person who is the object of recovery not the illness.

Notions of recovery implicitly suggest a medical model for some authors (Whitwell 1999) while others (Anthony 1993) attempt to shift the concept towards more everyday concerns. This suggests that nurses need to be clear themselves of what shared understandings exist as the medical definition of returning to ‘a former state of health’ may lead to service users not being able to consider themselves ‘recovered’ under this definition (Andresen et al. 2003). One nurse participant constructed recovery as akin to recovering after surgery.

...”I think the use of the word you know means when you’re in health recovery phase. In the recovery phase after surgery or some sort of rehabilitation or something like that. has some sort of medical connotation like a recovery room after having surgery it does fit into and is pertinent to mental health really I understand but different from that ...really” (Lines 26 -30 N4)

The nursing group tended to construct recovery as a technocratic or even mechanistic event orchestrated by workers to the benefit of patients.

“Are we recovering people or are we fixing them because they have broken down. We are taking them out of their original problem, a breakdown, and bringing them into hospital but then what do we do? (Lines 40-42 N3).
This was followed by an experienced nurse constructing a problem-centred version as recovery that appears to use a deficit model of medical intervention as a primary explanatory source.

I personally quite like the concept of recovery really I see it more as identifying the problem the person is suffering from and recognizing the problem and what can be eh…provided to them to help them help them self that’s how I see it that’s my views on the term recovery. (Line 43 -46 N1)

It is not surprising that both groups were uncertain in trying to clarify the meaning of recovery. A medical model of recovery may be seen as overly negative using terms of diagnosis, symptoms, and illness (Ragins 2003). The implication is that acceptance of a medical approach to mental illness is necessary; “if you don’t see yourself ill in the first place, how can you recover” (Crowson & Wallcraft 2002 p 249). Crowson and Wallcraft (2002) however argue against recovery being led by professionals or using compliance as a proxy measure.

The pressures of the day-to-day demands described by the nurses were in contrast to the perceptions of the service user group. Two participants’ who felt left alone on the ward perceived staff as too busy in the office or not doing anything

“do you know in there are staff just standing around [SU1: are there?] doing nothing “(line 97 SU4)

“They stay mostly in the office in the staff room or wherever, not in the ward itself” (line 121 SU6).

This construction of staff raises issues regarding communication, partnership and the nurse-patient relationship. It reflects earlier concerns that inpatient settings are formalising divisions between those receiving services and those providing them rather than collaborating towards a central goal (SNMC 1999). One view is that recovery requires a shift from staff who can be seen as distant and remote to an approach similar to that of coaching and guiding (Robert & Wolfson 2004).

The importance of understanding the concept of recovery is well documented (Barker, 2003 Chadwick, 1997, Deegan, 1988 & Anthony, 1993). Indeed, without this understanding there will continue to be a struggle to embrace the delivery of a recovery-oriented service in mental health. It is evident however that there is more than one understanding of recovery, that these may sometimes be idiosyncratic and that accomplishing a form of shared understanding is crucial to achieving mental health service-facilitated recovery. Negative perceptions of severe mental
illness have made it difficult to talk credibly about working towards recovery, dampening the hopes of service users and carers. (Allott & Loganathan 2002)

In this study a participant in the nursing group referred to recovery as
“...returning back to the frame of mind that you were in prior to being unwell that is near a normal life” (Line 13 – 14 N1).

This version of recovery aligns recovery with medical understandings and is sharply contradictory to Deegan’s (1996) version which indicates that ‘to be normal’ is not part of the recovery process. Recovery for Deegan and others is about embracing life and questioning the negative stereotyping of diagnosis and psychiatric labels. Recovery is not a one-off process and people with mental illness will experience varying degrees of recovery at any given time (Davidson et al 2006).

The implications of mental ill-health mean that shared understandings of the condition and how it should be responded to are crucial to help to off-set long-term exclusion, discrimination and reduced civil liberties. The effects of mental illness were summed up by one service user as follows;
...you got your car you got your life you got your nice job and the next thing it’s all gone and it can happen to anyone. (Line 241 – 243 SU2)

The loss described here goes beyond that of health, to include other major losses that touch every aspect of life. This implies that recovery is a process not a place and understandings of it must address what was lost, rights, roles, responsibilities, decisions, potential and support (Jacobson & Curtis 2000). One participant described his negative experience in the work environment

“I was employed by one employer I wont mention the name but I stayed there for 3 months working quite adequately and then all of a sudden one guy found I had been in and he told my boss and my boss said I hear you have been in and I said yes what’s that to do with the job and he said oh I’m giving you your cards, just for being in hospital, it stinks doesn’t it” (line 270 – 274 SU4)

Participants in both groups did appear to have shared understandings of recovery as being more than a one-off event and saw it as a longer process.
“To me it’s a process ... its not short term recovery, for some people it might take a long time and I mean they may need rescuing on the way. then it's not just a one-off.” (line 53 – 55 N2)

“Yea but the thing is I have been in there so many times and been ill as you know so many times when I am in a manic state its pointless talking to me when I am in a really depressed state its pointless talking to me yea you know but then of course you come out of it you can see that little bit of…and they can help you but you gotta have someone with their head on like” (line 105 – 109 SU).

Piat et al (2009) appears to support the need for this shared understanding and indicates some ground that can be built upon to establish common approaches to recovery describing recovery as a long-term process, and a gradual step-by-step process.

Semantics
Closely allied to understandings of recovery is the use of language to describe recovery and its processes. Earlier we noted that language is used to align or distance speakers from particular constructions of recovery. Here we explore a little further the semantic representation of recovery as it appears that this also illustrates claims to ownership of the term itself and how it ought to be deployed. Two of the participants in the service-user group found the word recovery difficult to associate with mental health and getting better and believed that it wasn’t about the word but the support that was received. One service user stated that some people were ‘dead’ against the word, and not enough information was available on the subject. We believe this indicates some problems with imbuing the term with specific professional meanings which mask the disparities in understandings of important participant groups. For example;

“but I mean its their job isn’t it the nurses and whatever to use that word recovery coming from higher above you know but with service users the poor devils they are not getting that are they” (Line 320 – 322 SU).

We asked the groups to suggest alternatives but they both struggled, using words such as ‘spectrum’, ‘half-recovery’, ‘cycle’, ‘pathways’ and ‘resume’. The word ‘spectrum’ was described by one service user as the colours of blues and reds, one day you feel blue and one day you feel red and full of energy and that every day is different.

The phrase ‘half-recovery’, suggested by one service user was immediately dismissed by another claiming that it wasn’t a proper word. However this construction acknowledges that many service
users never feel fully recovered and that recovery varies greatly from one person to another (Sullivan 1994).

“its not the word really to be honest with you it’s the support given people working with you I mean the word is irrelevant really and its what’s doing the thing it’s the staff the money it’s the people out there that do it, could be anything, the word is rubbish but its actually getting it there, getting it sorted” (line 307 – 310 SU3)

One participant in the nursing group suggested the word ‘resume’ as an alternative word linking it more to recovering after an operation rather than being associated with mental illness, the participant saying “the terminology is …strange (N3). Nurses at ground level appear uncertain of their role in relation to recovery and there was a sense that the concept has been imposed on the profession who, despite rhetoric to the contrary are challenged by notions of therapeutic optimism.

O’Hagan (2001) articulates some concerns in particular that the word recovery for service users implies returning to their normal state of health, when, in fact many feel they have been changed by the experiences they have gone through. Other service users disregard the need for recovery as they feel that either they do not have an illness in the first place, or are able to live with the fact that they do. O’Hagan notes that some providers criticise recovery as being “esoteric nonsense … hard to grasp and … lacking in evidence base” (2004, p. 1). Piat et al (2008) declared that in a recent Canadian study most recovering service users were not using the word recovery to talk about their experiences.

Therapeutics
A common theme in our data was reference to relationships between nurses and patients particularly in relation to inpatient settings. The concern here appeared to be related to differing organisational and therapeutic imperatives and the ‘fit’ between these and the concept of recovery. Four of the nurses highlighted the difficulties they experienced in adopting the idea of recovery with the reality of the everyday pressures and task-oriented routines of inpatient settings.

“its not really very therapeutic people going on and off the ward…in terms of allowing people to grow and recover” (line 116 – 117 N5)"
“I don’t know, people can be very disturbed patients that need a lot of attention you know and then there are other patients which are quieter you know and perhaps have had a lot of problems you know and need a bit more time you know staying in their bedroom for a long time and you have to wait until they want any intervention”(line 118 – 121 N4).

The nurses talking here still appear to see recovery as something nurses do to patients and not something that is a process made up of different components supporting our previous points about differing understandings. Moreover therapeutic relationships and the environments in which they flourish would seem to require a more collaborative version of recovery in which both partners contribute, rather than one assuming the lead.

A mixed method study by Higgins et al (1999) identified a number of significant issues that may interfere with the development of a recovery culture within an acute inpatient setting. This study suggests patient dependency and increasing intensity and diversity make it difficult to maintain a safe and therapeutic setting, limiting the time available for nurse-patient interaction. The use of constant and special observations and the diversity of the client group within acute inpatient settings was alluded to by both nurses and services users in our study. The difficulty here is how a recovery concept can be applied within the current environment of acute inpatient settings, which may be providing little more than ‘custodial care’ (Mental Health Act Commission and the Sainsbury Centre for Mental Health 1997). It has been suggested that rather than nurses having limited skills in engagement and nurse-patient interactions, it is instead a consequence of working in a demanding and medically dominated arena (Moore 1998). Rather than shared understandings of recovery it appears that both nurses and patients have differing sets of priorities. One example of this is highlighted by Dodd’s & Bowles (2001) who describe ‘formal observation’ as a typical example of a medically prescribed intervention, which is frequently a ‘drain’ on nursing resources.

The importance of staff support and the opportunity to talk about experiences has also been identified in an Australian study by Happell (2008) which indicated support as one of a number of strategies key to promoting recovery but support also being attributed and valued as a sign of respect. Peplau (1952) described mental health nursing and the ‘nurse-patient relationship’ as practice based, and valuing human beings who are individuals worthy of respect with rights, responsibilities, needs and beliefs. It has been suggested that this ‘interpersonal relationship’ described by Peplau is now an outdated approach in this era of case management and brief interventions (Gournay 2000). There is however emerging evidence that it is the quality of the relationship, not the intervention that makes the difference (Hewitt and Coffey 2005).

A journey
Recovery has been depicted as a journey along a hard path that not everyone will wish to follow (Coleman 1999). Deegan (1988) has also noted it is a journey or process and not a destination or cure.

Although each person’s journey of recovery is unique to them commonalties appear. There was some shared understanding from groups in describing recovery as a journey in one form or another, ‘not a straight road’, ‘it’s a journey isn’t it ’a long and winding road’. The following quotes illustrate the pattern of the conversation in the service user group.

“Facilitator: some people have used the word discovery instead of recovery what do you think about that”

“what, like discovering something? [discovering a new self SU2]” (line 283 SU1)

“Pathways I would have said pathways I would have because we all take different paths!(line 284 SU3)”

The nursing group used the analogy of a journey or travelling to describe the recovery process. One of the nurses who had been qualified for more than 30 years started the conversation but was quickly followed by most of the group who appeared to pick up on this theme:

“its interesting that you think of recovery to hear you think of recovery in that way as in recovering from an operation I never thought of it as a short term condition I have always thought of it as a long term condition, its quite interesting ..now that you’ve said it I’ve obviously looked a recovery as yes it’s a long road  (N2)“ as you say it sometimes takes time”.(N3) It’s a journey isn’t it”(N5)“yea yea its more of a journey I mean”(N2) “it’s a long and winding road”(N4) Line 67 – 75).

What appeared evident was the flow in the conversation when using this term to describe the recovery process and the consensus on the journey of recovery. The acceptance that they [service users] “don’t get better don’t get back to what they were like before (N3)” but also the association that this isn’t exclusive to people who use mental health services as suggested by another of the experienced nurses “that’s the same for all of us really” (N5) [N3 yea] regardless of whether we have problems [N3] none of us can be where we were 10 years ago” (line 87 -88).

This suggests movement in thinking on the concept occurring even within the confines of this short group and perhaps also indicates potentially fruitful avenues to explore in future work in this area.
Implications for practice
Systems like people, do not change easily. Lewin (1958) recognised that traditional behaviour needs to be challenged before new behaviour can be successful. However, it is the degree of positive involvement of those affected by change that will have the greatest impact. Both groups were interested in the idea of recovery and keen to express their views. It was the lack of information, training and working in rigid task-oriented systems that created frustrations. Whilst the recovery concept wasn’t new to either group the understanding of recovery was vague and contradictory with a lack of information highlighted as an issue. Implications for practice fall into four key areas:

- A shift is required towards working collaboratively in the planning of care, engagement and the use of language that inspires hope and positive expectations of recovery.
- Creating an optimistic positive approach to all individuals who use mental health services.
- The move from medically-oriented services to viewing mental illness as more than a biological phenomenon with access to a broader range of interventions.
- Joint training and education for service users and nurses on recovery.

Mental health services need to focus more on personal outcomes rather than organisational performance outcomes and have a clear vision of what their expectation of recovery is for mental health.

Conclusion
Despite the extensive literature on recovery there remains ambiguity around its concept and the practicalities of its implementation in acute mental health services. It is apparent from this small study that there are contrasting views of recovery but also areas where agreement can be found.

The main limitation of the study is that the sample is small and findings cannot be generalised. Nonetheless, both groups comprised of varying ages and experiences, and were able to express views that were consistent with wider knowledge on recovery. Further studies in this area could address how shared and contrasting understandings are enacted in practice settings. There also appears to be some real opportunities for shared training and education of service users and nurses on the possibilities implied in a recovery approach that this study has only just begun to discover.
References


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