**Contested understandings of recovery in mental health**

**Abstract**

Background

The concept of recovery is contested throughout the existing literature and in mental health services. Little research exists which gives voice to service user perspectives of recovery.

Aim

This paper explores how service users in two recovery oriented services run by the National Health Service in North West England. Service talked about recovery and what it meant to them.

Method

14 service users accessing these services took part in semi-structured qualitative interviews focusing on the concept of recovery. Data were analysed using an Interpretive Phenomenological Analysis approach.

Results

Service users talked about recovery as a dynamic, day to day process as well as an outcome; specifically related to being discharged from inpatient settings. A number of factors including relationships and medication were cited to have the potential to make or break recovery

Conclusions

The study highlights the continued dominance of the biomedical model in mental health services. Service users appear to have internalised staff and services understanding of recovery perhaps unsurprisingly given the power differential in these relationships. Implications for clinical practice are explored.

Declaration of interest

None

**Keywords:** mental health; service user experience; recovery; qualitative research

**Introduction**

Recovery is a contested concept within the arena of mental health, both between and within groups of service users, carers, professionals and policy makers (Pilgrim, 2008, p.295). Traditional ideas of recovery originate within the medical model of illness which seeks to identify the biological basis for symptoms. Once addressed through treatment, there is an assumption that the symptoms decrease and finally disappear; in essence the person recovers. As a concept, recovery is subject to many interpretations and is therefore appropriated in different ways for different purposes. Kraepelin, on the basis of his observations of patients, concluded that schizophrenia was a degenerative disease from which there was no recovery. Jaaskelainen et al’s systematic review (2013) of fifty studies concluded that one in seven individuals with schizophrenia met their criteria for recovery. However, despite the well-constructed systematic review there remain questions about whether the sample of patients included in the studies reviewed were more likely to focus on people with severe schizophrenia, whether the follow-up periods of the studies was long enough and whether the criteria for recovery applied by the reviewers were too stringent (Slade and Longden 2015). Implicit within the studies reviewed and the systematic review is the idea that mental health difficulties are located in the individual and recovery depends on the individual and is best measured by experts using a range of standardised measures or tools. This approach fails to take account of how recovery is defined by the person living with the experience, the fluctuating nature of mental distress and the impact of the wider socio-political environment on the individual’s wellbeing (Harper & Speed, 2012).

The service user movement, in its various forms, have tried to re-appropriate the term recovery in a way which is more meaningful to them. Recovery in the Bin (RITB), a user-led group for Psychiatric Survivors and Supporters, adopts the view that ‘recovery’ is a powerful concept that is used ‘to discipline and control those who are trying to find a place in the world, to live as they wish’, while trying to deal with their very real mental distress (<https://recoveryinthebin.org>). RITB suggests that the determinants of mental distress are to be found in families, communities, wider society, and social policies. In this context, recovery is not the responsibility of the individual but relies on the wider efforts of communities, social policies and society.

This paper contributes to the debate on recovery by exploring meanings of the idea of ‘recovery’ held by a group of forensic mental health service users at various stages of in-patient care.

**Recovery as a process and an outcome.**

Previous research has explored whether recovery is a process, an outcome or a combination of both (recovering then ultimately being recovered) (Liberman & Kopelowicz, 2005). If recovery is used as the desired outcome of a mental health intervention there may be issues for people who do not recover but who learn to live with their mental health issue. These service users may be perceived as ‘treatment resistant’ or in some cases even ‘non-engaging, ignoring the challenges of learning to live with a mental health issue and reinforcing the dominance of a biomedical approach.

Although divided in approach the more recent literature on recovery generally takes more of a ‘recovery as a process’ perspective. One systematic review mapped the various stages of recovery onto a trans-theoretical model of change (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011), suggesting a possible sequence in the recovery process. However, there was little consistency across the studies reviewed in the way in which the stages of recovery were conceptualised. Other studies have sought to identify common components of recovery and these include; hope (Andresen, Oades, & Caputi, 2003; Clarke, Lumbard, Sambrook, & Kerr, 2016; Leamy et al., 2011; Topor, Borg, Di Girolamo, & Davidson, 2011); connectedness (Clarke et al., 2016; Leamy et al., 2011; Topor et al., 2011); freedom (Clarke et al., 2016; Pilgrim, 2008; Roberts, Dorkins, Wooldridge, & Hewis, 2008) and choice/autonomy (Clarke et al., 2016; Leamy et al., 2011; Topor et al., 2011; Turner-Crowson & Wallcraft, 2002). Such elements are illustrated in the sample of definitions illustrated in Figure 1.

**INSERT FIGURE 1 ABOUT HERE**

**The nature of recovery orientated mental health services.**

Recovery-orientated mental health services are not new. However, the rhetoric accompanying these services often fails to match the reality of what happens in practice (Killaspy, Harden, Holloway, & King, 2005; Killaspy, White, Taylor, & King, 2012). For some individuals, the diagnosis and receiving of mental health services may have an impact on their lives and upon their recovery; Deegan (1993) reports the difficulties of having to recover from being labelled as ‘mentally disordered’ and Harper and Speed (2012) suggest that relationships with staff in particular are capable of making or breaking a service user’s recovery (Harper & Speed, 2012).

Slade et al. (2014) identify the ways in which mental health services rely on notions of clinical recovery (see figure 2 for the different ‘types’ of recovery) squeezing out alternative ways of seeing recovery such as those framed by the service user perspectives. The dominance of clinical recovery extends into the everyday worlds of work and leisure where recovery is viewed as binary. You need to have recovered to access paid work or be recovering to continue to claim benefits, but it is rare that you might be seen as fit to work while still living with particular mental health difficulties.

Research has identified areas in which mental health services can use recovery in a less stigmatising and more positive way. This could be achieved, for example, by adopting a strengths (as opposed to deficits) approach (Harper & Speed, 2012; Slade et al., 2014); encouraging service users to construct advanced directives and wellness recovery action planning (Copeland, 1997; Roberts et al., 2008; Slade et al., 2014); providing supported housing rather than detention when possible and through developing recovery colleges (Slade et al., 2014). Roberts et al. (2008) emphasise that it is possible for mental health services to be recovery orientated even when a service user is detained. They attempt to reconcile the perspectives of professionals and service users advocating clear communication with service users regarding the decision making processes and allowing service user’s choice whenever possible. Choice is defined in a number of contexts and not simply by presenting dichotomous alternatives.

**Recovery in the context of risk.**

Within mental health services there is very often an unresolved tension between a service user’s wish for autonomy and a professional’s need to limit the risk a service user poses to themselves or others. Society has become more risk averse, as evidenced by laws in place to detain without trial those who threaten societal norms (Beck, 1992). Risk assessment has become a central feature of public services and in particular of mental health services. In a UK study of decision making by Mental Health Review Tribunals, (Perkins, 2003; 128) identified the way in which the benchmark against which risk was measured was the worst case scenario. In the case of patients detained under the Mental Health Act this was usually harm to a member of the public. On the basis of the principal articulated by Myers (1997) that the more dire the consequences, the smaller the acceptable risk, Tribunals were observed to put the protection of the public before the rights of the person detained under the Act. Similarly, for any mental health service user embarking on the road to recovery, setbacks, mistakes or relapses (Farkas, Gagne, Anthony, & Chamberlin, 2005) often result in the imposition of restrictions on or removal of autonomy. Perhaps not surprisingly, risk assessment and management have been identified as ‘anti-recovery’ (Roychowdhury, 2011; 9) because recovery often involves taking action that might be defined as risky. While service users with a professional background have argued that taking risks is part of being human and that part of recovery includes experiencing the dignity of risk and having the right to fail (Deegan, 1992), professionals see themselves as accountable for risk taking and are often fearful of the implications of adverse events for them as professionals. Morgan (2016) suggests that by eliminating risk and not allowing service users to reap the benefit of risks, individuals are deprived of an essential aspect of quality of life which could in turn lead to risky behaviours.

Given the tensions and debates that exist in the provision and receipt of forensic services, this study sought to explore how a group of service users emerging from a period of detention viewed the concept of recovery and how well their concept of recovery fits with recovery-orientated services.

**Method**

**Setting and sample**

The study took place in 2013 in two recovery orientated services run by the National Health Service in North West England.Both services explicitly use a recovery based model and aim to promote social inclusion by aiding a service user’s transition into the community. The two services are highly integrated with many service users accessing both simultaneously; one is a step-down unit (SDU), the other is a social inclusion programme.

1. **Step-down unit (SDU)**

This male-only unit operates as a bridge between medium secure services and independent living in the community aiming to provide service users with the relevant skills needed for the next step in their care pathway. The stated aims of the unit were to facilitate clinical, personal, social, functional and safe recovery. Social recovery included (re)establishing relationships (platonic and intimate), community membership and social inclusion. This was facilitated by allowing service users unescorted community leave to engage in activities both on the unit and in the community as part of a positive risk management approach.

1. **Social Inclusion Programme (SIP)**

This programme is designed to help male and female forensic mental health service users in step-down or inpatient units who have gained leave. The purpose of the programme is to facilitate the service users becoming more engaged in meaningful activities in their local community. This could include undertaking an educational course or by joining an interest group. Based on the person’s individual interests, the SIP staff organise visits to relevant venues and may join them for the initial visit while providing support throughout their engagement. The duration of support varies according to individual needs but the SIP will gradually withdraw support over time with the aim of promoting service user autonomy.

The Recovery Star (MacKeith and Burns 2008) is a tool designed to encourage service users and mental health professionals to examine different aspects of a service user’s recovery. This measure is completed collaboratively at regular intervals to monitor service user’s experience with the service over time. The tool was designed to enable mental health staff to support individuals they work with to develop a better shared understanding of their recovery. It can also be used to plot a person’s progress and to assess the effectiveness of services (Department of Health New Horizons Programme, 2009). It was used as part of routine practice in both the SIP and the step-down unit.

All service users on the SDU or actively engaged in the SIP in January 2013 were invited to participate in the study and those who consented were recruited (n=14). The profile of respondents was similar across the two services. Overall the majority had a current diagnosis of Schizophrenia and all were White British aged between 20 and 42 years old. Nine participants were male. All but one of the SIP participants were living in community settings, including step-down units, supported accommodation and independent flats at the time and interviews were conducted in their homes. The one exception was a participant who had been recalled to and was residing in a medium secure unit (MSU) and the interview was conducted there. All the SDU participants were interviewed in the unit. All research participants had at some point been in secure mental health services.

**Data capture and analysis**

Qualitative one to one interviews were conducted by two research assistants. Interviews averaged 45-60 minutes duration and all interviewees were compensated with £10 cash for the time they had given. The interviews were based on a topic guide covering the participant’s experience of their care and treatment. Participants were explicitly asked “What does the term ‘recovery’ mean to you?” in order to explore their understanding of recovery. Interviews were digitally recorded and then transcribed. The respondents have been given a pseudonym to ensure anonymity.

An Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) approach was adopted for the analysis of the data. This approach specifies a number of analytical stages with a degree of flexibility in how these stages are implemented. The process began with data familiarisation with the data based on extensive reading of the text and jotting down of initial impressions and ideas. Descriptive codes were then attributed to each line of text. Reflection on these codes enabled themes then to emerge from the data, first in each individual case, then subsequently across cases and groups. Next, the descriptive analysis evolved into a deeper interpretation of the codes, focusing on the participant’s experience. This interpretation was collated and presented visually within tables to help clarify the relationships between themes and participants. The overall process was monitored through supervision by an experienced, senior qualitative researcher who encouraged further reflection from the researchers, including highlighting of potential areas of personal bias. NHS National Research Ethics Service approval was granted in December 2012.

**Results**

**1. Defining recovery**

All of the participants interviewed offered multidimensional definitions of recovery. These included ideas of recovery as a process as well as an end point.

*“ ...* *it’s about being in a better place than where I was when I was well and just sort of being happy and being able to see the changes and how much I’ve grown up and how I’ve accepted all the help and how it’s changed me into a different person. That’s how I sort of see recovery.” ‘Robert’, SDU*

This process of recovery involved developing a sense of the future without certain behaviours that were deemed by professionals to be harmful for their recovery (for example drinking alcohol or gambling) as well as undertaking activities to optimise recovery.

*“To see where you’re going... Like staying off drink and that... Keep complying with my medication, keep a healthy lifestyle.” ‘Paul’, SDU*

*“Staying well. Keeping on medication and keeping myself well.”’Eric’, SDU*

Despite lacking validation as a tool, the Recovery Star was frequently identified as a tool being used to measure their recovery.

*“I remember the Recovery Star, it is all that, social networks, families, family unit...” Thomas, SIP*

While service users knew that the Recovery Star was in use, they did not necessarily know how to interpret the scores. One service user when asked if a particular score was required in order to leave the unit, responded; *“I haven’t got a clue, I don’t know how it works.” (‘Eric, SDU).* There is a possibility that due to its importance to staff, service users recognised that the recovery star was important without really understanding how it could help them.

Service users suggested recovery was a state of being which needed to be maintained. This was reported to be achieved through living in the present and taking one day at a time. One respondent described this as *“I just plod on.”(‘Denise’, SIP)*.

Central to these ides of recovery was the concept of “*getting people back into normality.”(‘John’, SIP).* The majority of service users in the SDU associated recovery with getting out of the unit and being discharged. They reported understanding the need to provide staff with evidence of ‘being engaged in services’ as a way of progressing towards discharge. ‘Being engaged in services’ was framed in terms of ‘getting boxes ticked’:

*“I’ve done my alcohol groups, I’ve done my drugs groups, so I’ve got all them boxes ticked...It’s a bit of both sometimes you feel you have to do it just to get out and you just feel that you want to do it.” ‘Thomas’, SIP*

All service users reported the importance of complying with the requirements of the professionals in order to be ready for discharge– saying and doing the ‘right thing’ and avoiding the ‘wrong things’. Being given more freedom within the service and eventually being discharged were seen as falling within the remit of the staff and were defined as evidence of recovery:

**2. Responsibility for recovery**

The influence of the biomedical approach was evident in the majority of interviews with service users in the step-down unit. The psychiatrist was perceived to be the key decision maker in the service users’ care.

*“... I always get nervous round my doctor because he’s got like so much control over my life so it sometimes feels ... I think of loads of things to say then I just get dead nervous and forget what I was going to say and just end up saying half of it or something”. ‘Robert’, SDU*

In addition, service users were likely to attribute their progress to the staff rather than to their own efforts.

*“Staff from the [medium secure unit] they’ve done a magnificent job with me and I couldn’t have asked anything more from them and I suppose once I’ve spent most of my time on here [the step-down unit] I couldn’t have asked much more off these either.” ‘Robert’, SDU*

*“That’s your psychiatrists, psychologists, social worker team, they’re the more important teams, they keep an eye on things, OT and FST.” ‘Thomas’, SIP*

The relationships service users have with staff are clearly important, but it is surprising that the service users did not acknowledge their own agency in getting better. If relationships with staff are seen as the vehicle by which the service users are is discharged from a service there may be a danger that more effort is expended on maintaining good staff relationships than acquiring the skills that might be required to survive once discharged. Perhaps not surprisingly, despite lengthy periods spent as an in-patient, service users identified their relationships with staff as of greater importance than those with other service-users. While creating and maintaining sustainable friendships might be important for survival once discharged, attaining discharge was a more immediate and pressing goal and staff were seen as holding the key to discharge.

As identified above running alongside recognition of the importance of staff to their discharge was compliance with medication regimes. Many of the participants did not envisage a future without the continued need for medication. This suggests that, as with physical conditions such as Type 1 diabetes, participants saw their mental health difficulties as permanent but treatable. Medication generally, and the drug Clozaril in particular, was cited as important for recovery.

*“The mental disability has been overcome largely by the medication so we can forget about that...” ‘Harry’, SIP*

All apart from a couple of service users acknowledged and accepted the likelihood that they would be on medication for the rest of their life. One respondent recalled his previous attempts to come off medication:

*“... I’d get to the stage where I am today you know, where I think logically... My minds clear and I’d think ’I don’t need medication,’ but it was only the medication that was making me think clearly you know... get on in life really. The way I feel today, I know I need my med... I know it’s my medication that keeps me as well as I am today you know.” ‘John’, SIP*

**3. Expectations and the future**

Service users in the SDU could be described as being at a point of transition. While experiencing increased freedom and reconnection with the world outside the unit, it was clear that this only provided a limited basis for understanding what the future might hold. Service users had high expectations of what community living would be like. All except one of the SDU respondents assumed they would be receiving a high level of support in the community:

*“... at the end of the day when I get out I’m going into supported living so it’s like 24-hour support living, so I don’t really see the difference between being here and having loads of support and being in a flat and having loads of support. I don’t really see the difference.” ‘Robert’, SDU*

A number of service users who had been discharged previously reported how small the world of an in-patient service user is in comparison with life outside in the *“big world” (‘Paul’, SDU):*

*“I remember when I was upstairs in the [medium secure unit] and I’d not been out for years and then I come out and, whoah, it was like massive, it felt really big like but you get used to it after a while, it becomes normal after a couple of weeks. It’s so different isn’t it when you get outside, it’ll probably feel weird for a week or two and then you get back into the regime of living like. But everything seems big out there when you’ve not been out for a while. So when you get out there by yourself you’ll probably feel weird for a couple of weeks and then you get back to normal then.” ‘Eric’, SDU*

When this particular participant was asked if he felt worried about going back into the “*big world”* he responded *“I do and I don’t.” (Paul’, SDU).* Central to the concerns of this respondent was the level of support that might be available ‘outside’.

Other respondents were keen to demonstrate to staff their ability to administer their own medication and to structure their day and reported previous success living independently in the community prior to their admission. In terms of recovery, realistic expectations may be an important part in the transition from services into community life and will make it more likely that service users can cope with independent living effectively.

Throughout the interviews everyday activities such as walking and discussing books were talked about in the language of therapies administered by services. The *“reader group”* and the *“walking group” (‘Thomas’, SIP)* were all discussed in terms of therapeutic interventions rather than fulfilling hobbies that people adopt in everyday life.

While getting out of the SDU was the core concern for some SDU service users, SIP respondent’s highlighted different experiences and concerns; about their future in the community and the impact of their mental health difficulties on their ability to participate in work and relationships.

*“...I don’t want to go back to work too much... I’m stressed out, I’m 40 now and I’m burnt out... from being ill for so long, er... so just a bit of temporary work.” ‘Thomas’, SIP*

*“with the medication I’m on or maybe as a result of the illness, I’m not sure, but my concentration span and motivation span has been considerably reduced.” ‘Harry’, SIP*

*“Well you know,... you meet a girl for the first time you know … get to know them and that, tell them about my mental illness and some of them didn’t understand or they didn’t want to understand.” ‘John’, SIP*

Supportive relationships outside of the SDU were identified as holding the key to successful re-integration into the community. One individual acknowledged that his past history had jeopardised important family relationships to the point where he acknowledged that this was his last chance.

*“Well you only get so many chances before they sort of disown you because you just won’t listen or ... because I think when I was younger when I started offending I wouldn’t accept the help like so it was causing problems and that and this time I’m accepting the help so they sort of appreciate that I’m accepting the help and I’m trying to change things, do you know what I mean? So it’s sort of my last chance this time.” ‘Robert’, SDU*

Another service user explained the difficulties of maintaining a relationship with her child while in services, describing the SDU as a potentially threatening environment for her daughter:

*“She could do yes* [visit] *but .... With the ill people and that and if anything happens, no I wouldn’t want her to be here. Bringing her up in a bad environment.” ‘Eric’, SDU*

In the context of the service user’s recovery, these relationships had the potential to strengthen and enhance recovery as well as to threaten and undermine it. The extent to which individual recovery had been understood in the context of these relationships by staff was not clear from the service users.

**Discussion**

The findings of this study provide an insight into how participants talked about ‘recovery’. Participants’ understanding of recovery was heavily influenced by the views of staff and an acknowledgement of the importance of medication to their future wellbeing. Within the biomedical model, adherence to medication regimes was seen as a reflection of a service user’s insight as well as a means by which health could be restored. In order to be deemed to be recovering service users were keen to demonstrate an acceptance of the bio-medical model regardless of whether this actually fitted with their view of the world.

The importance of service user’s relationships with staff and how these can make or break recovery has been noted in the literature (Harper & Speed, 2012). Participants in this study emphasised the benefits of these relationships. This may reflect the power staff were deemed to have over a service user’s progress towards discharge. Perhaps more worryingly was the attribution of the service user’s progress to the efforts of staff since this seemed to override efforts exerted by service users to be discharged. Despite the recovery models adopted in the two services examined here, the responsibility for healing and progress seemed to reside with service users individually and the clinical professionals. Little effort appeared to have been invested in ensuring that family and friends featured as part of the service users’ preparation for life outside the service.

Participants completed assessments of recovery including the Recovery Star. Some defined their recovery entirely in terms of the items on the Recovery Star and the scores attributed to these items. This is worrying for a number of reasons, not least because the Recovery Star has previously been found to measure social functioning rather than recovery (Killaspy et al., 2012). This could suggest that service users have internalised professional’s definitions of recovery, rather than developing their own conceptualisation. Another interesting feature of the service user discourse on recovery was the absence of reference to ‘risk’. The University of Manchester’s 2014 National Confidential Inquiry into Suicide and Homicide by People with Mental Illness found that, between 2003 and 2013 in England, 2368 mental health patients died by suicide within the first 3 months after discharge from hospital. The peak time for risk of suicide was 1 week after leaving hospital. However, all the participants in this study were focused on staying well, returning to normal and avoiding readmission. It may be that the focus on recovery adopted by these services enabled service users to be positive about the transition from hospital to community. However, in the absence of any longitudinal data it is difficult to know how prepared these service users were for their life after discharge.

Critical research has proposed that, for service users to reclaim recovery as a meaningful concept for self-empowerment, it may have to be abandoned or reclaimed radically (Harper & Speed, 2012). In relation to this study, recovery had a number of dimensions: While it included keeping or feeling well, it also included being discharged; it included living in the community but it also recognised the need for continued support, and finally; it recognised the importance of professionals on the road to their recovery. Recovery was not a single state of being but a complex mix of the past, the here and now and, the future. In this context ideas of recovery will change over time and in relation to the circumstances in which people find themselves.

The study provides an insight into how forensic mental health service users view the concept of recovery. There are a number of factors which need to be taken into account when considering these findings. The interviews were undertaken with service users prior to their discharge. It is possible that at this time service users may have felt under pressure to present a particular view of recovery in order not to affect plans for their discharge. In addition while a service user research group was asked to consider and provide feedback on the research proposal during its initial stages they were not involved in data collection or analysis.

**Implications for clinical practice and future research**

The findings from this study have a number of implications for clinical practice. Firstly, it raises the issue of how goals of recovery are internalised by service users. Secondly, it has identified the potential for misuse of measures designed to monitor recovery, in this case the Recovery Star. Thirdly, it suggests that service users may need to feel more responsible for their own progress rather than attributing it to the work of professionals. The study also raises the possibility that many service users may not be adequately prepared to reintegrate into the community with high expectations of the amount of support that will be available. Service users may be better prepared for living independently in the community by accessing services like the SIP or the SDU with greater levels of freedom and autonomy.

Future research in this area could involve further consultation with service users and staff through, for example, focus groups with various groups of service users. These could provide an insight into how they believe mental health services could aid recovery and the findings could inform new recovery orientated services and guidelines.

**Conclusions**

This research was conducted with the aim of giving service users a voice to explore what recovery means to them. The findings would suggest that professionals and mental health service’s perceptions of recovery have been projected onto service users, indicating a reduction of this voice.

Given the nature of secure services and the extended length of time service users involved in the study have spent in these settings, it is perhaps unsurprising that service users have internalised professional’s perspectives of recovery. Within these therapeutic relationships there is an implicit power dynamic and as discussed above, decisions around discharge are ultimately made by professionals. In order for the concept of recovery to progress and be reclaimed by service users, a shared understanding must be developed between service users and mental health professionals.

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