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Title: Voice hearer's perceptions of Recovery; findings from a focus group at the 2nd World Hearing Voices Festival and Congress

ABSTRACT

Background

Mental health recovery has been referred to as a new paradigm. In English speaking countries it is clear that it has been able to influence the thinking of a range of stakeholders and has the potential to transform the perception and experience of service users, service providers and staff.

Aim

This study aimed to capture the views of attendees on mental health recovery at the 2nd world Hearing Voices Congress and Festival in Nottingham, England

Method

Using a qualitative approach a 90 minute focus group of 12 conference attendees was dual moderated by an academic and service user. The interview was digitally recorded and then transcribed by one of the researchers. Data was examined using thematic content analysis.

Results

Participants questioned how the word recovery translated internationally and how despite the terminology, that service providers and professionals were not listening to and that they do not understand service users.

Conclusion

A number of findings emerged from the focus group activity; the most striking was the call for emancipation from professionals. The focus group thought that recovery had been a start and had been able to serve a purpose. However the focus group members thought that the hearing voices community had already begun to move on.

KEY WORDS: mental health recovery, hearing voices, international, collaborative working.

Background

In the last decade the area of mental health recovery has been able to attract a number of commentators; as a result this has produced a 'burgeoning' recovery literature and a continued recovery discourse (Perkins and Slade 2012). In English speaking countries recovery has been identified as the 'guiding principle' for mental health policy (Slade et al.

2008; Lieberman et al 2008) with having challenged the so called 'chronicity paradigm' (Ramon et al. 2007). For some professionals the response to the recovery movement has been mixed (Mountain and Shah 2008; St John-Smith et al; Roberts and Hollins 2007; Holloway 2008; Shepherd et al. 2008). For service users, especially those with psychosis the concept has proved to be particularly important as it has been used to redefine their experience and to move service users from the position of passivity commonly associated with the patient role, to a role where they look to take control, self determine and to have a life that has meaning, purpose and potential (Deegan 1988; Kelly and Gamble 2005;Copeland 1997;Anthony 1993; Allott 2002; Amering and Schmolke 2009).

The Study
Aims

This study aimed to gain an insight into the conceptualisation of recovery from attendees at an international conference run by the Hearing Voices organisation, held in the UK October 2010.

Participants

Conference attendees included experts by experience and experts by profession from around the globe. It was estimated that 400 people daily attended the conference. The focus group was scheduled for the second day of the conference and had been signposted in both the conference flyer and the delegate pack on registration.

Method

The study used a non representative approach (convenience sampling). Therefore no attempt was made to be representative in the number and characteristics of the studies participants. Given that the conference was directed to people with experiences of hearing voices,. it was anticipated that the attendees would be able to yield some useful information and to offer a range of views and experiences on recovery. Four broad topic areas had previously been identified by the researchers and were used to inform the discussion in the focus group.

Ethical considerations

Ethical approval was gained for the study from the University of Manchester UK. The researchers took care to ensure that potential participants had been given sufficient notice of the research in the conference flyer and at a presentation by one of the researchers on the first day of the conference. Further information on the research was also included in the conference pack, made available to participants on the first day. At the beginning of the focus group the researchers went through the information sheet, and the ground rules for

participation e.g. confidentiality and respect to others. Before starting the group all of the participants were asked and agreed to complete a consent form.

Data collection and Analysis

The focus group was dual moderated. The researchers agreed that the service user would be seen to take the lead during the focus group. This was agreed as the impression of tokenism wanted to be avoided. Strategically it was also thought that this might serve the research questions more effectively and encourage the group to engage. It was decided that the other researcher (academic) would manage the focus group and ensure that it ran well (Stewart et al 2007). Given that a mixed focus group format was chosen, there had been a concern that between the participants, there may emerge a power imbalance. If during the group session this should occur, the researchers decided to use the dual moderator role to manage this. Given the authors' interest in exploring the perspectives of the participants and any perceived gaps, contradictions or difficulties; the researcher opted to look to the qualitative tradition and decided to employ a naturalistic approach to capture the relevant issues.

The focus group was digitally recorded and transcribed verbatim prior to thematic content analyses. Analysis was undertaken by one member of the team and the findings shared with the other members for confirmation and comment. Open coding was used to identify themes, categories or codes and was conducted 'in Vito' with a continuous comparisons (comparative analysis) identifying the same codes occurring elsewhere in the text (Straus and Corbin 1998). Over time, codes were merged (collapsed) into concepts then categories and finally themes (Strauss and Corbin 1998).

Results

Twelve conference attendees decided to participate in the focus group (Table 1). Findings from the focus group are presented using the themes extracted from the data analysis. Direct quotes from the group have also been used to structure the heading for each of the areas that have emerged. The characteristics of the group have been outlined in Box 1

Box 1.

Characteristics	
Gender	**Number**
Male	**7**
Female	**5**
Background	
Service user	**6**
Carer	**1**

Service user/professional	1
Professional	4
Country	
UK	8
USA	1
Denmark	3

The word recovery, potentially limiting and not always helpful

While for professionals and academics the meaning and definition of recovery continues to be returned to and debated (Collier 2010), it was clear that the group had a sense of frustration with how and by whom it was being interpreted and applied.

Subject 7 - 'I think the wrong thing about the word recovery, is that it is only used if you are mentally ill. I am not recovering from smoking and when I had lost 50 kilos I wasn't recovering from fatness.'

Subject 5 - 'I think it lends itself well to the engineering model of medicine. Where you have a person who is going to help you recover and that limits the process.'

However this view was not shared by the entire focus group and an alternative view was put forward by one of the members:

Subject 10 -'It's good to have a word that gives somebody who is actually going through a very traumatic period. I have a friend and think the word recover gave her some hope'.

Difficulty with translation and meaning of recovery

A number of already familiar alternatives to the term recovery were generated that were thought to capture the experience of service users and to have more meaning for example, discovery, hope, coping, making sense. Participants whose first language was not English suggested that the word 'recovery' had a number of limitations that were not only just about the meaning but also implied a cultural reference to its use. Almost a one size fits all approach a Mc Recovery, that might not fit in with or does not reflect the ideas, values and experiences of the person(s) but rather might be used to impose a new meaning that was unwanted .

Subject 2 -'It's a big problem in Denmark a lot of people in psychiatry did not understand it and it was from a foreign country and it was scary and they didn't know what it was, so it was a big problem.'

Subject 3 - It's harder to hijack discovery, by people led by that model of healing and where going to make you better. It encourages an atmosphere of exploration and development

There also appeared to be a concern that the context of the word implied a value base and perspective that was too limited and restrictive.

Voice 7 - 'I think that there is a danger; some versions are highly individualistic. The idea that on my own I can plough on and do all of things and recover in glorious isolation is complete nonsense'.

Being understood or listened to

The group identified that while in society in general things remained unbalanced towards people with mental health problems, they still felt let down by the mental health system. Specifically, this disappointment would manifest in the power relationship between them as the user of services and health professionals who were perceived as having control and subsequently the power. The ability to choose, self-determine and make decisions was returned to by the focus group members and was a well received theme. Key to discussion was how people (professionals) in services and positions of authority are perceived as behaving by service users and the view that service users have of their own status and standing in these relationships.

Subject 8 - 'One of our weaknesses is that those of us who have been in the system a long time have internalised its limits, don't feel that power, I think that we need to change the system or just remove ourselves from it'.

Subject 3 -'What we need is emancipation we have got to reclaim that power. It's not empowerment because that's been taken we need to be emancipated.

Subject 9 – 'We need to be in a state of revolution'

Subject 7 - 'I'm not in the same position as a psychiatrist. I think that we are too nice and that we need to be challenging.'

Frustration with Services

Participants were clear about their frustration and how service providers needed to look more closely at what they were doing and how they are delivering services that reflect the true meaning of recovery based values and competencies. This clearly seemed to link to the previously identified theme and generated the retelling of a number of experiences, which related to concerns about the future. This became a reoccurring theme the group found hard

to stay away from and consequently kept drifting back to as their frustration gained momentum:

Subject 7 - 'We now have all sorts of things that say they are recovery something or other .I remember being at a big NHS conference. The chief executive says "we're all in this together and we all want the same thing". That's rubbish! What you want is a good carer, a pay structure, a pension, professional status and all of the rest of it. I want to survive'!

Subject 3 -'Any idea that comes up or word you use is going to be hijacked and people are going to use it as suits them best. I think there is something about their preciousness about their professional autonomy. That destroys the relationship; the relationship and walking the journey together that's what's important.

Subject 4 - 'I think that the system needs to recover: To be creative not to just explain the new but to create something new'.

Subject 9 - 'I just want there to be decent psychiatrist around. I don't want a choice of whether to have magic beans or evidence based medicine. I'm a pretty informed consumer of mental health services. I want it to be clear what is the treatment the most likely to be effective and I want it to be available to me locally. I want it to be provided competently'.

The following captured some of the frustration

Subject 5 - 'The truth is that they don't know what they're doing, [professionals] so they have words to try and create some illusion that they know what they are doing'. 'I think that the problem is that they don't know what each other is doing, or themselves'

Some members of the group were particularly concerned as they thought that recovery had become associated with services and with professional self-interest; Roberts and Hollins (2007).

Subject 8- 'I do some professional development work for social workers and one of their greatest concerns is that they're in a sort of battle with the occupational therapists, that hijacked the role of being a recovery experts and they think that they should be the recovery experts'.

Subject 3 -'As a service user, I worked with an OT, a social worker who then does something completely different and then a nurse who says they're all a complete load of rubbish and there's nothing that they can do that the nurse can't do anyway'.

Discussion and conclusion

The study has identified that for some, that the mental health recovery debate remains. While the significance of the recovery model was not questioned the group thought that word recovery could be limiting and unhelpful. The significance of recovery's message of hope, resilience and optimism as a key part of the recovery paradigm for service user (Roberts and Hollins 2007) was not diminished or questioned. Clearly recovery has impacted on the

thinking and beliefs across a range of stakeholders and resulted in re- evaluation of received wisdom on what was acceptable and achievable (Frese and Knight 2009; Tierney and Kane 2011).

Recovery has been referred to by commentators as a complex multidimensional concept Onken et al., (2007) whose meaning has already attracted debate (Happell 2010; Meehan,et al. 2008; Frese and Knight 2009). Due to differing ways of understanding, this often means that there is not one shared definition but rather a multiplicity (Mountain and Shah 2008; Tilley and Cowan 2011). Meehan et al (2008) refer to the use of jargon and familiarity with an idea that may cause misunderstanding if confused with its everyday usage. The translation and meaning of recovery attracted some interest from the group, particularly for those whose first language was not English. While the exchange on this point was brief, the concern originated from an enquiry on whether the term translated into Danish and other languages. This wasn't just linked to the mechanics of translation but also its cultural meaning and point of origin. In effect the emergence of a one size fits all approach, which confines both the service user and professionals (Happell 2008;Piat and Sabetti 2012).

 (Not being understood and listed to by professionals and services caused clear frustration among the group, which at times reached the point of derision.). This was an element that was shared across international boundaries and was an experience that was not limited to one person or incident.. While anecdotal the experiences recounted served to illustrate the focus groups general feeling about how services and professionals had responded to the recovery model. Clearly the group thought that something was missing and that 'all kinds of services had just been renamed, rebadged or had rebranded themselves as recovery'. A view that was backed up by the groups experiences of mental health professionals as 'not knowing what

they are doing, what each other are doing' and in essence not appearing to value each other as mental health practitioners. This being something that some members of the group had seen played out in front of them when they came into contact with services.

It was recognised and acknowledged that recovery models and reasoning have been embraced in the UK by stakeholders from across the mental health arena. Given the changing landscape of health and social care in the UK, it is beyond the scope of the studies findings to establish if the rhetoric of services meets the lived experience of mental health service user. With members of the focus group consisting of service users, mental health professionals, carers and academics from the UK, USA and Denmark it seems clear that service users remain concerned about professionals, service providers and to question the balance of power. It was apparent that recovery represents a landmark in the rethinking of mental illness for service users; while recovery thinking has provided a tipping point, acting as an interim step towards empowerment, emancipation and citizenship. Perhaps reflecting the position of the US civil rights movement in the 1960 and 70s, the group' thought that what service users still needed was emancipation and that in terms of the recovery model, the hearing voices community had already moved on.

Limitations

The views and opinions expressed by the group may differ considerably from those less willing to participate in this type of activity and may not generalise to other service users or voice hearers or organisations. The study has a number of limitations that reflect and are inherent to the methodological approach taken. The research does demonstrate the partnership and collaborative working between service users and academics at the University of Manchester. The focus group was made possible by the organisational efforts of the service user without whom the opportunity would not have materialised.

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