Title: 'Technically well, but not really': carers' constructions of recovery from psychosis

Abstract

Background: The recovery movement has become highly influential in research and services for people who experience psychosis. However the precise meaning of recovery from psychosis is contested, and there are concerns that the language of the recovery movement may be co-opted to serve other priorities.

Aims: To investigate carers' constructions of the meaning of recovery from psychosis.

Method: A qualitative study, using synthetic discursive psychology to analyse transcripts of semi-structured interviews with seven carers recruited from an Early Intervention in Psychosis service, where recovery approaches were practised.

Results: We found medical accounts of recovery to be highly influential used both frequently and as a key reference point, even when describing alternative, non-medical accounts of recovery. Such alternative accounts of recovery in the data were fragementary and participants tended to use such accounts to signal some kind of trouble or disruption.

Conclusions: Explanations of the objectives of recovery approaches cannot escape comparison with a medical repertoire of recovery. Such explanations may benefit from illustration using personal accounts of recovery that contain concrete detail. Creating conditions of safe uncertainty around the meaning of recovery may be an important aim for clinicians and services.

Declaration of interest: None.

Keywords: Recovery, Carers, Psychosis, Discursive Psychology

Main text

Introduction

The principles and practices of the recovery approach to mental health care have become part of the mainstream of mental health policy and research (Slade et al., 2012). The prominence of the recovery approach represents very significant progress for a movement that originated in the 1980s from first person accounts of recovery from psychosis (eg. Deegan, 1988). Nevertheless efforts to realise the aspirations of the recovery approach face a number of obstacles (Slade et al., 2014), not least disagreement and misunderstanding about the precise meaning of the term recovery (Roe et al., 2007). The study reported here sheds light on the understanding and usage of the term recovery in practice by carers of people who have experienced psychosis. Carer accounts of recovery have not been widely investigated despite their importance in the recovery process (Leamy et al., 2011).

Uncertainty about the precise meaning of a recovery approach can be traced to its interpretive origins. In order to differentiate this approach from the traditional medical focus upon symptom remission, definitions of recovery feature at their core highly idiosyncratic personal elements. Deegan's seminal paper (1988; p.57) refers to recovery as "a process, a way of life, an attitude that is inherent in everyday challenges." Anthony's (1993) influential definition describes recovery as the development of new meaning and purpose, which enables the reconstruction of an identity beyond illness. However the potential flexibility in meaning in these definitions also creates the potential for the mis-appropriation of the recovery approach.

There have long been concerns that services and professions might co-opt the language of recovery to serve other organisational and professional purposes (Buchanan-Barker & Barker, 2008). For example there is evidence that some practitioners interpret recovery in the light of organisational concerns to reduce costs or meet targets (Le Boutillier et al., 2015),

and at least one service-user movement in the UK has emerged to protest against what they regard as the coercive use of the recovery model (Recovery in the Bin, 2016).

One significant attempt to resolve this difficulty in a concrete way is offered by Leamy et al. (2011) in a systematic review and synthesis of published descriptions and models of the recovery approach. They propose a conceptual framework comprising thirteen characteristics, five processes and five stages - arguably a solution that is comprehensive and potentially measureable, but potentially unwieldy as a means of communicating an important idea. We wished to investigate how this ambiguity and tension in the use of recovery language might affect the practice of the recovery approach in predominatly medically-orientated services. Specifically we were interested in how the term recovery is used by carers of people with psychosis, whose views and experiences of the recovery approach have been reported only rarely.

Relationships, such as those with carers, are generally considered to be crucial for the recovery approach (Tew et al., 2012; Thomas & Rickwod, 2016). Close personal relationships are already a well established focus for psychosis research due to long-standing work on the role of expressed emotion and communication deviance in relapse prevention (eg. O'Brien et al., 2006; Pilgrim et al, 2009). Recovery focussed research has identified a particular role for relationships in instilling hope and self-confidence (e.g. Topor et al., 2006; Roger et al., 2008) as well as in developing new social roles and meaning in life (Leamy et al., 2011). This significance of close personal relationships means the absence of carer and close other perspectives in the recovery research literature is an important omission. There are significant questions for practice that research needs to address such as how can close relationships that promote recovery be supported and harnessed, and what might obstruct such relationships?

One study of the recovery approach using survey and focus group methods with carer participants found considerable differences in interpretation of the term recovery (Parr, 2009). Some participants understood recovery as an absence of illness and others described in terms familiar to the recovery approach such as new meaning or purpose. Of particular relevance is the finding that different definitions of recovery elicited strong psychological responses: "For some people [recovery] is a term that is controversial and does not feel appropriate for their experience, for others it suitably conveys the promise of a better life, a life lived with mental health problems" (Parr, 2009, p.23).

Given the institutional and clinical importance of the recovery movement, potential disagreement and discord arising from the meaning of recovery, and the potential significance of carers in the recovery process, we set out to investigate the use of recovery language by carers of people with psychosis. We adopted the methods of a type of discourse analysis, known as synthetic discursive psychology (Wetherell & Edley, 1999).

This kind of analysis provides a detailed map of the ideas that influence individuals' interpretations and behaviour, how they overlap or contradict eachother, and how they are used in practice.

Such methods lend themselves to the study of social psychological processes, such as helping relationships and recovery in mental health, where the aim is contested or confused (eg. Mackinnon & Murphy, 2016).

Method

Participants and ethical approval

The study received ethical approval from a National Health Service (NHS) research ethics committee. The study sampling strategy was purposive. We recruited participants with direct experience of caregiving for people with psychosis and exposure to a recovery-based

approach so that our interviews would be as relevant to the research topic as possible. Potential participants were therefore recruited from a multi-disciplinary Early Intervention in Psychosis (EIP) service within an NHS Trust in the East Midlands region of the United Kingdom. This service provides multi-disciplinary mental healthcare, aiming to broadly follow a recovery approach, to people experiencing a first episode of psychosis between the ages of 16 - 35, for up to three years. The service follows EIP service standards set out in guidance for the NHS in England (National Institute for Health and Care Excellence, 2014) such as a commitment to offer psychological and family interventions and to address social inclusion, whilst maintaining a hopeful outlook for the possibility of recovery. The service works with carers as well as service-users and potential participants were approached in the first instance by NHS workers, who had been briefed about the study. Mental health workers in the team were asked to review their caseloads to identify carers who might be potential participants and to have an informal discussion about the study and provide them with an information sheet.

Eight carers were approached to take part by NHS workers and of these seven contacted the lead researcher and agreed to participate. The decision to approach eight carers was a product of two considerations. Our principal aim was to collect highly relevant examples of talk about recovery that could be intensively analysed and this was met after seven interviews. This focus, rather than simple number of participants, is the basis for the 'information power' of discursive qualitative studies (Malterud, Siersma & Guassora, 2016). We were also guided by the practice of published discursive psychology analyses of in depth semi-structured interviews on mental health topics which drew on similar sample sizes (eg. LaFrance, 2007; Liebert & Gavey, 2009). Demographic characteristics of the participants are summarised in table 1.

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Data collection

The study used data from semi-structured interviews conducted by the lead researcher, a 26 year old female trainee clinical psychologist who has a previous interest in recovery approaches. The interviewer was not known to the participants prior to the interview, and neither of the research team had worked in the service from which participants were recruited. All interviews took place in the carers' home and were audio recorded. Their length ranged between 45 and 90 minutes. They were transcribed by the lead researcher using a simplified version of the scheme developed by Gail Jefferson (appendix A; Potter, 1996). Interviews were aimed at eliciting a range of talk around recovery and the experience of caring for a person with psychosis, rather than narrowly soliciting views on the recovery approach. They were guided by a schedule which included a range of questions addressing the following three topic areas: 1) the person's current caring role; 2) initial reactions to the person they care for developing psychosis; 3) the participant's hopes for the person with psychosis' recovery in the future. The interview schedule was not used restrictively, and the interviewer was able to engage with participants using further comments or questions to explore their accounts. The data reported here therefore includes both direct responses to researcher-led interview questions on recovery and participants' comments related to the topic of recovery made at other points in the interview (Seymour-Smith, 2008). The use of contrived research interviews to gather data for discursive analysis has attracted some criticism from discursive psychologists who prefer to work purely with naturalistic data (eg. Potter & Hepburn, 2007). However, unlike recordings of naturalistic talk, retrospective interviews afford researchers the opportunity to explore participants' accounts. This is an

important advantage for synthetic discursive studies investigating the wider discourse surrounding an issue (Griffin, 2007).

Analysis

Synthetic discursive psychology draws elements from conversation analysis (CA) and post-structuralist informed discourse analysis (Edley, 2001). It explores how both the available wider discourse, and the local conversational context, shape talk about a particular issue. In the context of the analysis reported here this means we sought to map the variety of ways in which recovery is talked about in the data and the potential implications of these variations. Margaret Wetherell and Nigel Edley suggest three features that might appear in a synthetic discursive analysis (Wetherell, 1998; Edley, 2001). Interpretive repertoires are the frameworks of language and meaning that participants draw upon to make sense of experience. Ideological dilemmas (Billig et al., 1988) are contradictions or differences between interpretive repertoires that might be used by participants to make a particular point, or position themselves in a particular way. Finally subject positions refer to the social identities that people are able to adopt by talking in particular ways.

Practically, the analysis followed four overlapping steps. First, the data corpus was read through in its entirety and re-read. Second, recurring patterns of talk that might form interpretive repertoires were identified and possible repertoires were refined during a process of comparison of instances. Third, subject positions that participants occupied within the data were identified and their links to particular interpretive repertoires scrutinised. Fourth, ideological dilemmas were identified, highlighting relationships between interpretative repertoires. The analysis was completed primarily by the first author. The second author assisted with the analysis of interpretive repertoires, subject positions and ideological

dilemmas. He is a clinical psychologist with experience of work in community mental health services, and in the use of discursive methods in qualitative research.

Analysis and Discussion

Below we describe and discuss three key findings from our analysis of all seven interview transcripts. These findings are illustrated here using four extracts from the interview transcripts. These extracts are accompanied by an analysis of the text, and a wider discussion of the implications of each finding. The first finding we report is the content and usage of a medical interpretive repertoire of recovery that was heavily used by participants. Second, we show how alternative interpretive repertoires of recovery were often heavily dependent upon a dominant medical repertoire in order to be made sensible. Third, we describe how the use of these alternative repertoires by interview participants was often an occasion for highlighting trouble or concern. In each extract the interviewer is named as Hollie (lead author) and the participant is given a pseudonym.

The medical interpretive repertoire we report below appeared in some form in every participant's interview. This repertoire constructs recovery from psychosis in broadly medical and categorical terms as involving medical treatment and leading to the absence of symptoms and a restitution of the person back to health. This is a common construction of recovery from many kinds of ill health, following the 'restitution narrative' of illness (Frank, 2013) where the purpose of recovery is to return to one's previous state of health. This construction of recovery has been found specifically in the context of psychosis by recovery by Noiseux et al. (2010) in their research into perspectives held by service-users, professionals and families on the process of recovery in psychosis services.

In many cases participants did not adopt this repertoire in a straightforward manner. Instead they used this repertoire to discuss the problems of such a restitution narrative in psychosis.

For example extract 1 is taken from a point in the interview where Isla is discussing her partner's recovery from his first episode of psychosis, and she uses the term 'technically well' to draw attention to apparent shortcomings of a medical construction of recovery.

Extract 1

1   *Hollie:* and do you feel more pressure around that time because there is less support

2   *Isla*:   so I was finding it <u>really</u> hard I was <u>really</u> stressed [Hollie: mm] you know our baby

3   wasn't sleeping (.) you know I was very stressed but because he was

4   technically well we didn't really have any support from professionals (.) at

5   that point

6   *Hollie*: so it sounds as though when (partner's name) would become well maybe in some

7   ways your stress would [go up]

8   *Isla*:   [yes absolutely] certainly that first year that was the case [Hollie: yeah] yeah

9   <u>definitely</u> (.) the worst times for me were when he was <u>technically</u> well but (.) not

10   really yeah

Isla introduces the phrase 'technically well' on line 4, repeating it on lines 9-10 in response to Hollie's question, adding clarification: "<u>technically</u> well but (.) not really". This term seems to characterise the apparently precise symptom-bound nature of the medical interpretive repertoire of recovery whilst drawing attention to the limits of such a view, although Isla does not elaborate on these limits in detail. This juxtaposition of 'technical' approaches from how things 'really' are creates a risk of positioning professionals aligned with a technical approach as distant from the real concerns of service users and their families.

Extract two arose in the early stages of an interview with Sue. At the point where the extract occurs Sue is in the course of explaining the high level of trust she feels for her child's EIP

team. Sue talks up the shortcomings of a medical interpretive repertoire of recovery as a way of justifying her trust.

Extract 2

1 *Hollie* so your initial experience it sounds as though it was quite refreshing to have that

2 different approach to things

3 *Sue:* I think it was really and er (.) but keep in mind you know they talk about what were

4 our early responses to this and {inhales} and I think I think (.) being a nurse and being

5 a doctor in general nursing general practice we sort of wanted boxes ticked we wanted

6 to sort this problem out and get on with it [Hollie: right] (.) and if that meant taking

7 pills for the rest of your life you do it [Hollie: mm] and (.) the the early intervention

8 approach was not (.) obviously he was on medication but they were (.) they were (.)

9 they were saying (.) do not do not look for a label [Hollie: right] do not look for a

10 label (.) with the passage of time see what happens (.) I found that a little bit upsetting

11 at first because I thought I never want this to happen again a and I was slightly

12 annoyed when one of the EIP workers said [Hollie: yeah] 'you know he may have a

13 few more of these episodes but he will manage it better' and I thought 'what an awful

14 thing to say' (.) but as it turned out they couldn't have been closer to the [truth]

15 Hollie: [right]

On line 5 Sue orients the interviewer to her professional role as a nurse, and her partner's role as a medical doctor, connecting the account of her initial hopes for her son's recovery that immediately follows with these professional medical identities. Sue's account includes several components derived from a medical interpretive repertoire of recovery. It constructs recovery as systematic -getting 'boxes ticked' (line 5) - and requiring compliance - 'if that meant taking pills for the rest of your life you do it' (lines 6-7).

At the local conversational level Sue uses a change of footing (Edwards & Potter, 1992) over the course of the extract to first align herself with a medical repertoire of recovery and then distance herself from it.   Sue's identification of herself as a nurse on line 1 acts as a footing, accounting for the defensive reaction she describes when a health professional challenges a medical approach on line 9. Sue's account of her reaction escalates, from finding the advice 'a little bit upsetting' (line 7) and being 'slightly annoyed' (line 8) to a stronger 'what an awful thing to say' (line 10). Sue then resolves this escalating tension in her account by changing her footing and endorsing the health professional's advice (lines 10-11). This switch follows the form of an 'X then Y' construction described by Wooffitt (1992). A detailed recounting of a set of circumstances ('X') is used as a means of building the credibility of an account of an unexpected event that follows ('Y'). The credibility of the 'wait and see' approach to recovery that Sue endorses at the end of the extract is contingent upon the detailed account of a previously sincerely held medical view.

This analysis has two implications for understandings of the wider discourse surrounding recovery from psychosis.   First, to break with a medical interpretive repertoire of recovery appears to invite trouble, evident in this extract in Sue's description of her indignant reaction to the suggestion of a 'wait and see' approach. A troubled relationship with the term recovery was also reported by Parr (2009) also found evidence of trouble with the term 'recovery', with some participants suggesting it is does not apply in the context of psychosis, and others explaining they'd had to undergo a lengthy process of accepting a different understanding of the term.   Second, accounts using alternative interpretive repertoires of recovery appear dependent upon the of use a medical repertoire as a constrast, in the manner of an ideological dilemma (Billig et al, 1988). However in our data we found the medical

interpretive repertoire that forms one end of this dilemma appeared far more detailed and

coherent than the alternative repertoires of recovery that appear at the other pole.

We use the following two abstracts to develop our analysis of how participants indicated

trouble arising from the movement through this ideological dilemma towards an alternative

repertoire of recovery. In extract 3, during a discussion of weight gain due to antipsychotic

medication, Lynda refers to a 'hard' process of 'accepting'.

Extract 3

1   Hollie [and which was to go]

2   Lynda [and whether is <u>revisable</u>] you know (.) if the weight gain is revisable well then you

3   sort of think ok but (.) somebody said something (.) em (.) somebody said something

4   (.) em (.) one of these one of the EIP meetings for carers I did go to that is about (.)

5   you have to <u>consider</u> that they're never going <u>to be</u> the same <u>person</u> as you thought

6   they were going to be (.) [Hollie: mm] (.) and its <u>accepting</u> that (.) [Hollie: mm] is the

7   hard thing (.) really I suppose and think maybe that I have got to <u>accept</u> that that's not

8   gonna happen [Hollie: mm] you know it's not going to go back to that (.) this person

9   that you thought she was

10   *Hollie*: so in a way that comment did that start to get you [thinking about]

11   *Lynda*: [yeah the future and that if I could <u>accept</u> that] (.) then we can move on to something

12   else and maybe I could support her <u>better</u> by not trying to get her <u>back into</u> the person

13   that that she was (.)

Lynda describes how she came to 'accept' that a restoration of her daughter to 'the person

that you thought she was' (lines 8-9) is unlikely. Such 'restitution narratives' of illness

(Frank, 1997) have been found to be restrictive, locking people to previous selves and

identities (eg. Smith & Sparkes, 2004). Lynda's account portrays difficulty in moving away

from such a narrative, through her use of hedging (Myers, 1989) to signify a lack of certainty

about this acceptance process.. Examples of hedging include frequent hesitation in lines 3-7

and thinking aloud on line 7 - 'really I suppose and think maybe that I have got to accept'.

On line 10 the interviewer responds to this trouble by offering a comment that invites some

resolution by focussing the conversation upon Lynda's responses to the dilemma she

describes. Lynda's offered resolution on lines 11-13 contains further hedges and is very

general 'we can move on to something else'.

A similar account of moving away from a restitution narrative is apparent in the interview

with Isla, shown in extract 4.

Extract 4

1   Hollie: was there at that time when you described a turning point was there a change in your

2   expectations or your understanding of what was [happening]

3   *Isla*:   [yes] yes so (.) my initial expectation was (.) this is an illness the doctors will give

4   him medicine and he will get better [um] em (.) and I think at that point it was when I realised

5   medicine alone is not going to make him better (.) [Hollie: mm] em and (.) they they were

6   telling us then that he was always going to have episodes [right] (.) em (.) so I was thinking

7   (.) if he is always going to have these episodes we need to know how to make how to how to

8   make how to live with it (.) yeah

Isla refers to her expectation that her partner's recovery would follow a restitution narrative

initially before realising this would be unlikely. Isla then starts to develop an alternative

account, but with little specific content on lines 7-8. Isla's account of the alternative apporach

to recovery is characterised by an emphasis on what she needs to know, rather than what the

alternative consists of, and positions her as uncertain and tentative.

This analysis suggests that there are few conventionally available linguistic resources

available to carers to supply non-medical accounts of recovery (Tay, 2011), and such

accounts are hedged with uncertainty. This reflects a wider concern arising from recovery movement, that recovery is so deeply personal that it defies definition (Barker & Buchanan-Barker, 2010).

Conclusion & Clinical Implications

We found a medical interpretive repertoire of recovery was drawn upon extensively by participants. This broadly frames recovery as the systematic resolution of symptoms, requiring the compliance of the person with medication regimes, with an aim to return to life as it was before psychosis occurred. Importantly, even when participants presented alternative accounts of recovery these were deeply intertwined with a medical repertoire. Finally, participants commonly appeared to have a significant stake in a medical account of recovery, showing 'trouble' when describing how it had been challenged or movement towards an alternative account of recovery.

We identify three clinical implications of these findings concerning both the involvement of carers in recovery focussed care, and recovery based care more generally. First, explanations of the objectives of recovery may require comparisons with a medical repertoire of recovery in order to be comprehensible. Second, challenges to a medical repertoire may well elicit significant opposition, given the stake that some carers appear to take in such restitution narratives. Clinicians may wish to consider how to offer a place of safe uncertainty for people with psychosis and carers in their life who are troubled by a move away from a restitution narrative (Mason, 1993). Finally, clinicians and services should consider promoting access to multiple personal accounts of recovery. Collections of such accounts are readily available (eg. Scottish Recovery Network, 2016). The aim should be to provide a variety of concrete embodiments of recovery that are optimistic but do not follow a restitution narrative. These might provide a resource to people with psychosis and their carers to

develop ideas of possible future selves. Attempts to systematize the meaning of recovery such as that by Leamy et al. (2011) may provide a solution for research, but this kind of technical and arguably unwieldy taxonomy is unlikely to be suitable for the public communication of recovery ideas.

This paper represents one of the first investigations of carer understandings of recovery. The intensive analysis of rich semi-structured interview data has enabled us to go beyond straightforward descriptions of attitudes towards recovery to map the conflicting ideas informing talk about recovery and how they are used in practice. However this approach has a number of limitations. Semi-structured interviews are contrived, and the study of more naturalistic talk about recovery by carers, service users and professionals, whilst difficult to collect, would address this weakness and potentially inform specific advice on the conduct of recovery conversations. The intensive method draws on data from only a smalll sample of participants from one specialist service. Participants were largely female and parents. This may reflect the EIP setting of the research because this profile of participants is similar to that found in to larger studies of caregivers of people with first episode psychosis (eg. Jansen et al, 2014). It should be noted that the recovery approach applies to a much wider range of mental health conditions and caregiving relationships than are reflected in the sample studied here, and we should be cautious about assuming these findings might transfer to other services, persons with other kinds of mental health problems and their caregivers.The study explores the processes of talk about recovery rather than specifying the level of agreement with, or understanding of, recovery ideas amongst carers. Further research using more extensive qualitative or quantitative methods could address this weakness in two ways. First it could establish how transferable the findings are to other settings and places and second it could investigate any demographic or social characteristics associated with particular

approaches to recovery by carers. Finally, we suggest that techniques for improving the

communication of recovery ideas are evaluated in longitudinal studies.

Appendix A
Transcription guide, adapted from Potter (1996).
(.)	Short untimed pause
[Hollie:]	Brief interjection by named speaker, or overlapping talk
<u>text</u>	Word(s) emphasised

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Table 1: Demographic characteristics of participants

Participant pseudyonym	Age	Caring relationship	Diagnosis of person they are caring for	Occupation
1- 'Joan'	53	Mother	Bipolar Disorder	Surgeon (retired)
2- 'Emma'	31	Step-mother	Schizophrenia	Business ownder (part time)
3- 'Lynda'	57	Mother	Schizophrenia	Head teacher (full time)
4- 'Isla'	31	Wife	Schizophrenia	Teacher (part time)
5- 'Sue'	52	Mother	Bipolar Disorder	Nurse (part time)
6- 'Frank'[1]	64	Father	Schizophrenia	Business owner (full time)
7- 'Bev'	54	Mother	Schizophrenia	Employed (part-time)