Problems with ‘Recovery’

Diana Rose, PhD
Professor of User-Led Research
Service User Research Enterprise (SURE)
IoPPN
King’s College London

Overview

- User-valued outcome measures
  - Findings from a nominal group
  - Patient-generated PROMs
- A case study of N=1 – how not to do recovery
- The danger of the ‘too dependent’ argument
- Why I’m not over the moon about recovery

The Service User Research Enterprise (SURE)

- Located at the Institute of Psychiatry, King's College London
- Biggest psychiatric research institute in Europe
- Generally thought to be very conservative
- Warned in no uncertain terms when went there
- But quite positive about user-focused research
- SURE is meant to be collaborative but we frequently do the user-led components of large studies

Nominal Group for Outcome Measures (Crawford et al, 2011)

- Nominal group a consensus technique
- Measures valued by service users
- Collected ~20 outcome measures commonly used in research for depression and psychosis
- People with the diagnosis rank the measures
- Median and range calculated
- Bring back to group to discuss
- Final ranking produced

Findings for the psychosis group

- Neuroleptic side effects scale ranked top
- Social functioning measures disliked
  - Normative
  - Is this true of recovery measures also? E.g. social capital
- Wellbeing measure that had some user input was valued
- Recovery star did not have high ratings

Outcome measures in RCTs

- RCTs are the 'gold standard' because they are neutral – no values enter in
- But values enter into the outcome measures
- What clinicians and researchers think is important may not be what service users think a good outcome
- Patient Generated-Patient Reported Outcome Measures (PG-PROMs) focus on the latter

PG-PROMs

- A participatory method for generating outcome measures entirely from the perspective of service users
- Participants AND researchers share experience of the treatment or service being evaluated
- User-LED research though may be embedded in larger studies

Recovery in the Bin

- Want nothing to do with outcome measures – user-generated or not
- Will never tell you what really matters to people
- Pilgrim calls for ‘near practice ethnography’
- We don’t know what is going on in services – fidelity measures and manualised interventions don’t capture it
- Some is clearly ‘re-branding’ but novel practice can only be elucidated by observation

A story: N=1

- Woman admitted to ‘recovery house’
- Hypotension due to chlorpromazine led to falling through a glass door and sustaining facial injuries
- Psychiatrist – can’t be left on her own – needs “nursing”
- Previous admission to acute ward three weeks before

The task

- One regular medication runs out
- Recovery staff said she must visit her GP to get refill as this is what she would **normally** do
- Despite there being a psychiatrist on staff
- It is a 20 mile round trip by public transport (with serious facial injuries and tearfulness)
- GP is furious
- She takes taxis mindful that not everyone could afford that in this situation

The reaction

- Recovery worker and woman chat
- She is in tears, task was traumatic
- Reaction of recovery worker – “but you got the medication, you achieved the goal”
- All the recovery workers are psychology graduates

The resolution

- You can’t be vulnerable in this ‘recovery’ house
- You have to be normal
- She left
- I know – it was me

Not research – rhetoric!

- The argument that service users should not be "dependent" on services
- The argument that all service users should get a job
- The argument that 'traditional' day services promote dependency
- All this in the context of savage cuts is dangerous in my view
- The 'recovery' narrative risks justifying cuts in service provision and making people feel guilty if they can't measure up – just one more thing that service users can't do

From social recovery to personal recovery

- Recovery started out with the user movement – peer support and *groups*
- Now is individualised, normalised and psychologised
- Fits with neo-liberalism and late modernity
- Fits the white middle classes
- Population differences in acute wards and the recovery house

Goals

- Recovery discourse says person must define their own goals
- But not just any goal is permitted
- Goals that fit with mainstream society
- Once again neo-liberalism and normalisation

You get the message – I'm ambivalent about recovery

- How can you object to hope – you can't, I don't
- But from the results of much research in SURE the world – and the world of mental health – can be a cruel place
- A recovery focus can turn into neglect leaving service users feeling abandoned
- A liberating discourse can become a disempowering one

Difference

- Our society is intolerant of difference
- The recovery response to this seems to be to ‘normalise’ difference
- A different response would be to accept and embrace it
- The LD field leads the way here

Conclusion

- Should not be thought that user-led research is tantamount to recovery research
- In some cases it will be
- But in some cases they will be at odds
- In my case I want to produce knowledge from the perspective of marginalised people
- This will elucidate problems as well as solutions