User-Focused and Collaborative Research in Mental Health: Where do we go next?

Diana Rose, PhD

Service User Research Enterprise (SURE)

Institute of Psychiatry, King's College London

Overview

- Why mental health?

- A new methodology
  - Patient-centred systematic reviews

- Some theoretical questions

Locking us up

People with a mental illness diagnosis are the only group in society who can be locked up without committing a crime.

- User-focused research in mental health before other medical specialities

The User/Survivor Movement

- Sometimes said the movement is the child of consumerism – Thatcher and Major
- Certainly grew exponentially in this time
- BUT the user/survivor movement in UK pre-dates consumerism
- Early movement radical
- Borrowed ideas from civil rights in USA

The User Movement and Research

- Users in the movement with research skills
- Many small local projects
- Two large programmes of work in mental health charities in mid '90s:
  - Strategies for Living
  - User-Focused Monitoring (UFM)

Aim

- To describe the experience of mental distress and of receiving treatments and services

- But try to remain rooted in the user movement by taking questions and methodologies from it.

Developing new methodologies - SURE

- Patient-centred systematic reviews
  - The example of ECT
- Other examples
  - Participatory research in a mental health context
- Experts by experience – important but problematic concept

Mainstream systematic reviews

- The most 'scientific' way of measuring the efficacy of a treatment

- Pool results from a large number of studies – to estimate the effect more precisely

- Typically rely on randomised controlled trials – also the apex of the scientific method

- Strict inclusion criteria

Patient-centred systematic reviews

- Far more flexible in the data they admit
- Make use of peer-reviewed literature but only if it asks what users think about a treatment or service
- Include 'grey' literature as well – reports authored by users
- First-hand accounts or testimonies
- Researchers have received the treatment themselves – 'insider knowledge'
- Reference group largely made up of those who have received the treatment

Examples of Patient-Centred Systematic Reviews

- ECT
  - Controversial

- Ongoing – patient perspectives on new anti-depressant medication

Critique from the Mainstream

- Most mainstream researchers would say our method is biased, anecdotal and subjective.

- Biased: use of grey literature (unrepresentative)
- Anecdotal: qualitative materials
- Subjective: experiencing treatment ourselves

- But our ECT review did have influence:
  - NICE Guidelines
  - New Mental Health Act

- Also published in peer-reviewed literature

Theoretical issues

- New methodologies are one thing but we also need new theories
- What are the philosophical principles which lie behind the research that we do?
- Science says it trumped philosophy 300 years ago but not so – its philosophical principles remain implicit.
- So let's be explicit about ours.

The Cochrane Hierarchy of Evidence

- Meta-analysis

- Randomised Controlled Trials

- Experiments

- Observational Studies

- Expert Opinion

Expert Opinion: the Bottom of the Pile

- What is meant by expert opinion?

- Professional 'experts' deliberating on a topic.

- In mental health – psychiatrists

- Users' expertise by experience doesn't really count here either

Why Cochrane?

- Many reasons given by medical researchers

- The scientist must be neutral

- If this is so, it will result in universal ontological truths

- But also, psychiatric researchers wish to be part of the medical community

Implications of Cochrane

- It is from here that the critiques of bias, anecdote and over-involvement derive.

- Qualitative research is considered 'soft' science if it is considered science at all.

- So, the knowledge we produce can be undermined before we even start.

Hierarchies of Knowledge

- Hierarchies of evidence lead to hierarchies of knowledge:
    - Medical model (multi-farious)
    - Professionally-based medicine
    - Professionally-based practice

- All these rest on the neutrality of the observer, on randomised controlled trials and all are seen to generate universal truths

Knowledge and Power

- Hierarchy of knowledge is also a hierarchy of power

- Dominant discourses and practices shape how we think about and act upon the world.

- Gramcsi's hegemony

Non-Neutrality

- Does not mean that we impose our own views on our research participants

- All views by users must be included

- The aim is to make the user(s) voice, as elicited by user research, equal to the research of mainstream thought

Feminist Standpoint Epistemology

- Feminist writers have noted for some time that modern thought rests on certain oppositions:
    - Reason/unreason
    - Intellect/emotion
    - Culture/nature
- They say that the first of these are male attributes and that science likewise has a male slant.
- Women are marginalised from science or at least feminine attributes are
- So again, there is an argument that thinkers are not neutral. Feminists took an explicitly political stance and one that was a little relativist.

A standpoint epistemology for mental health

- Enlightenment oppositions referred to above easily applicable to mad people:
  - Unreason
  - Closeness to brute nature
  - Overwhelmed by emotions

- This is what has to be challenged theoretically as well as rhetorically

Problems with Standpoint

- Feminist standpoint epistemology has been criticised as essentialist

- It is the natural (essential) attributes of women that can produce new knowledge

Foucault and the Mad

- Madness has been subjected to the discourses of Reason and the Enlightenment for three centuries

- Thereby has madness been silenced and denied a voice

Finding a Voice: Not Essentialism but Resistance

- All who are oppressed by the psychiatric system struggle against it?
- No:
  - Some accept its propositions and practices
  - Some engage in little acts of resistance eg. not taking medication
  - Some engage in activities not strongly contesting the medical model eg self-help
  - But some do struggle and see this as political
  - Some of these are doing emancipatory research
  - Which does not mean that all user research is the same

The Category of 'Experience'

- Experience is never 'raw'
- Determined by conditions of existence which are always changing
- Even 'choice' – eg joining a user group – will change consciousness and not always in the way expected
- 'Experience' and 'identity politics' are problematic concepts which need to be theorised

Conclusions

- We need to forge a philosophy for research that values users' experiences
- This philosophy will deny the role of the neutral observer
- We can adapt existing theories
- We need to be open to criticism of our own central categories
- We can ally ourselves with existing radical thought.