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

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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
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.

- Gramsci’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 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
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.