

Mental Health, New Methodologies and Epistemology

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The work I am going to talk about is focused on user-led and collaborative research in mental health. This is not just because my expertise is in this area but because I think the field of mental health is different when compared to involvement activities for other groups of users and for the lay people involved in research in health, social care and public health. However, the second part of my talk – where I present new methodologies designed by SURE – is certainly relevant to other groups of consumers who wish to get involved in research.

First, a word about the Service User Research Enterprise (SURE) which is located at the Institute of Psychiatry in London. We are a team of ten people and have grown rapidly over the last four years. Most of have used or are using mental health services and our core aim is to do research from the perspective of the consumer of mental health services.

My talk falls into three parts. First, I will outline how mental health service users came to be involved in the field of research. Second, as I have said, I will present one of two new methodologies which we have developed at SURE. These are patient-centred systematic reviews and participatory research in a mental health context. I will give examples of the first of these and the papers by Angela Sweeney and Tanya Graham present the work on participatory research in a mental health context. Finally, I am going to tackle some theoretical questions around user involvement in research. I think that it is time to go beyond technical questions of method and try to develop some conceptual arguments which can function as the underlying philosophy or epistemology of what we are doing when mental health service users get involved in research.

The User/Survivor Movement

It is sometimes said that the user/survivor movement is the child of the consumerism which emerged, in the UK, with the latter stages of the

Thatcher government and developed with the Major government. Certainly, the movement grew exponentially at this time. It is estimated that the movement grew from 15 groups in the mid-1980s to over 700 today and consumerism certainly played a part in this. However, it is very important to note that the user/survivor movement pre-dates consumerism. In the mid-1980s there was plenty of activity and it was radical. The medical model was contested, psychiatry was criticised for being in breach of civil liberties and social care was dismissed as paternalistic. Why should mental health service users have organised like this, in advance of other patient groups? It was partly a borrowing from the civil rights movement from the USA which had some, although not much, influence on the English Mental Health Act of 1983. However, there is a more important reason. Mental patients are the only group in society who can have their liberty taken away when they have not committed a crime. Many saw this as an injustice and felt compelled to organise to combat it.

So the user movement in mental health pre-dates consumerism. Indeed, it may have lost some of its radicalism because of consumerism but the momentum existed beforehand.

User/Survivor Research

What does this mean for user involvement in research in mental health?

There were people with research skills in the movement and they were anxious to contribute by doing user-focused research. Indeed, many insisted on *user-controlled* research, not wanting to compromise themselves by working with professionals whom they did not trust. Starting in the mid-90s, there were many small local projects and two large programmes of work. Both of these were located in charities in the UK. One was the Strategies for Living programme at the Mental Health Foundation and the other the User-Focused Monitoring programme at the Sainsbury Centre for Mental Health. Both of these were/are user-controlled. This means that users control all stages of the research cycle.

With the possible exception of disability research, it is only in mental health that user-controlled research developed at that time and in this way and it is because user-focused research was rooted in the user/survivor movement. It took its research questions from the movement and its main aim was to elucidate the experience of mental distress and of receiving treatments and services as understood and experienced by service users. It was research by and with service users.

These research endeavours were not accepted by the mainstream research community. I will come back to some reasons for this at the end but basically we were accused of being biased, anecdotal and over-involved. Consequently, when we did publish, our reports constituted part of the 'grey' literature. It was impossible, until very recently, for user-focused research to be accepted for publication in the peer-reviewed literature.

In the past three years, things have begun to change for user-focused research in mental health. With more and more government emphasis on the 'expert' patient, our Department of Health and other funders have started to require user involvement at least at the stage of writing proposals if not in the entire research process. Indeed, my own institution, the Institute of Psychiatry, recognised the importance of user involvement in research when it set up SURE. The Institute is the most prestigious mental health research institution in Europe and hardly known for its radicalism. So this was no mean feat.

I do not mean in any way to criticise user involvement in research in other specialities. However, I think that user research in mental health has its own characteristics, that it is flourishing and that this is partly a result of the strong user movement in which we find our roots.

Developing New Methodologies

I now want to move on and describe one of the two new methodologies which we have created at SURE. This is patient-centred systematic reviews. I will describe this method and illustrate it using the example of electroconvulsive

therapy or ECT. The second new method is participatory research in a mental health context. This is the subject of the papers by Angela Sweeney and Tanya Graham at this conference. Both these methods aim to elucidate the experience of service users in relation to treatments and services and both rest on the assumption that people who use mental health services are 'experts by experience'. In other words, we are experts in our own experience of distress and in what it is like to be on the receiving end of treatments and services. Nonetheless, I think that both the new methods I am going to describe could be used in fields other than mental health.

Patient-Centred Systematic Reviews

Systematic reviews are regarded in mainstream medical research as the most scientific method for measuring the effects of treatments. The aim is to pool the results from a series of studies in order to calculate the average findings from these studies. They typically pool the results from a large series of randomised controlled trials – also judged to be the acme of scientific method. Their inclusion criteria for trials are very strict and they are all taken from the peer-reviewed literature.

Patient-centred systematic reviews also search the peer-reviewed literature. But this time it is for studies which have asked service users their own views on treatments and services. They are typically not RCTs but surveys or experiments. However, we also include other forms of data. We include the 'grey' literature – publicly available work but which hasn't reached the peer-reviewed literature. For patient-centred systematic reviews these will be reports authored by user groups or in collaboration with them. We include also first-hand accounts of the treatment or service in question and call these 'testimonies'. We have developed an innovative technique here by gathering testimonies in electronic form, for example, from the internet. Finally, the researchers for these reviews will have received the treatments or services themselves thus having 'insider knowledge'. In addition, there is always a Reference Group made up mainly of people who also have received the treatment or service we are looking at.

How do we analyse these data? We perform a meta-analysis on the peer-reviewed literature but also include in the meta-analysis the grey literature. So this part of the work is quantitative. For the testimonies we conduct a qualitative analysis using coding categories. The initial categories come from discussions in the Reference Group and these are supplemented by careful reading of the text. The qualitative analysis is meant to give richer information or to 'fill out' the quantitative data.

Consumers' Views on ECT

Let me illustrate this, briefly, with reference to our review of Consumers' Perspectives on ECT or shock treatment as I believe you call it in the USA. This was commissioned by our Department of Health and it was a commission not without controversy. As our review was taking place so was a meta-analysis of the efficacy and safety of ECT. The Department set up an Advisory Group to oversee the two studies. This was made up largely of senior psychiatrists and methodologists and most of them did not want our work undertaken at all – they stated that patients who objected to ECT were a vocal and angry minority who represented no-one but themselves. This reaction simply made us determined to do a good piece of work.

Now to the Review itself. As indicated, both the main researchers on this project had received ECT themselves and we also had a Reference Group made up of people who had received ECT plus a couple of user-friendly academics with qualitative research experience. I must stress that this was a collaborative project. A psychiatrist and a psychologist were also part of the team and they had specialised expertise in two of our main themes – memory loss and legal issues surrounding compulsory treatment in psychiatry. However, the main data collection and analysis was carried out by the user researchers.

Here is the information we assembled. 26 studies from the peer-reviewed literature where clinicians asked their patients about their experience with ECT. 9 papers or reports written by user groups or in collaboration with user groups also asking consumers what they thought about ECT. And 139 testimonies which we mainly assembled from the internet and a video archive.

The themes which our Reference Group thought important to look at were: perceived benefit; permanent memory loss; perceived coercion and emotional response to the treatment.

I will take perceived benefit as my first example as I can then refer to it later. We combined the peer-reviewed and the grey literature to find the average percentage of users who felt satisfied with ECT. As it turned out, this was a pretty meaningless exercise. Some clinical papers reported satisfaction rates as high as 90% and some user reports as low as 18%. The standard response to this would be that, because they were surveys of the groups' own members, the user reports were biased. But because we had been patients ourselves it seemed to us that something else was going on. We did some correlational analyses and discovered that a certain combination of methodological factors seemed to characterise clinical studies which reported very high satisfaction rates. In essence, these studies interviewed patients as soon as treatment ended, on the ward, the interviewer was the treating doctor and s/he asked a few simple questions. We had been in this position ourselves and argued that in these circumstances people would not want to cause trouble or might even say they were happy to get rid of the doctor who was asking yet more questions. Some people simply lied to avoid more treatments. The clinicians, of course, criticised the consumer studies on the grounds that they were biased but our own experience told us otherwise.

The qualitative analyses told us about why people did or did not feel satisfied with ECT. There were people who said it had saved their lives. But these were outnumbered by users who said it had been profoundly damaging. There were also those who made 'trade-offs', for example, that the side-effects were too serious for them to countenance it again. There were people who were so angered by their treatment that they wanted to take legal action and there were people who had joined email lists for support for what they thought was a negative treatment.

For our other themes, there was not so much difference between clinician-authored and consumer reports. On average, across all studies, about one third of participants said they had experienced severe and permanent memory loss as a result of having ECT. One person wrote movingly about how losing significant memories meant that she had lost a part of herself. Another expressed exasperation at not being believed or taken seriously by her psychiatrist when she complained of memory loss.

Again, consistently, about one third of those who had signed a form consenting to ECT felt that they had done so under pressure. So even though they had apparently consented they still felt that they had not had a choice. The qualitative data gave examples of this including being made to sign the consent form late at night after heavy medication and even a threat to have a mother's children put in to care if she did not sign.

So you can see that patient-centred systematic reviews include information that would not be admissible in standard meta-analyses. They also include qualitative as well as quantitative analyses and again standard reviews are strictly quantitative following a standard type of statistical analysis. Most clinicians would not see our approach as innovative but as being subjective and biased.

Nevertheless, our review had policy implications. It was used by our National Institute of Clinical Excellence (NICE) in their appraisal of ECT. NICE is a highly influential body which advises government. We also had an impact on criteria for compulsory treatments for ECT under proposed new mental health legislation.

Theoretical Issues

I want to turn now to some theoretical issues around user-led research. I have described two new methodologies but I cannot rest there. All research rests on underlying assumptions – philosophical principles which lie behind our work. These are usually implicit – certainly in mainstream work they are implicit as science believes it trumped philosophy when Enlightenment thought became established. However, science does rest on a philosophy

often, though a bit misleadingly, called positivism. I think it is time we developed our own philosophy, or to use another term, epistemology.

I can approach this by telling you a story from a conference I attended recently. This conference had a whole stream dedicated to user involvement in mental health research. This did not make everyone happy. The journalist invited to write up the conference said that the user stream was biased and subjective. Another delegate said to me personally that user involvement in research was just political correctness.

From what position were these two men speaking? There is an established hierarchy of methods in mainstream research. It is called the Cochrane hierarchy. Top of the list comes the meta-analysis and then the randomised controlled trial. I have already referred to this. Next comes the controlled experiment followed by observational studies. Bottom of the list comes expert opinion. So perhaps you can begin to see that our focus on expertise by experience and our admission of surveys and testimony data in systematic reviews means that, in terms of the Cochrane hierarchy, we are not scientific at all. Indeed, even though 'expert opinion' is admitted to the hierarchy we have to be clear about what this means. It means professional expertise and in mental health this will be psychiatrists. It is not meant to embrace the expertise of the consumer because this is not thought of as expertise at all.

Why does the Cochrane hierarchy take this form? It is because mainstream science believes that the scientist must take a neutral stance to the collection and analysis of data and that if this is the case then universally true knowledge will be the result. In contrast to this, the methods I have been describing are criticised as biased and subjective and our focus on non-neutrality of the observer is criticised as user researchers being over-involved with their subject. Qualitative research is also seen as 'soft' science if it is seen as science at all. In this way, the knowledge we produced can be undermined before we even start.

Just as there is a hierarchy of methods, there is also a hierarchy of knowledge produced from these methods. We can mention the medical model – although this term covers a multitude of sins – evidence based medicine and evidence based policy. All these rest on the neutrality of the observer, on randomised controlled trials and all are seen to generate universal truths.

By contrast, our emphasis on the non-neutrality of the investigator and expertise by experience is downgraded as valid knowledge. We are said to be biased, anecdotal and over-involved. This is particularly so in mental health as who wants to listen to a nutter?

I think that this hierarchy of knowledge is also a hierarchy of power. Dominant, powerful discourses shape the way we think about the world and how we act upon it. In mental health it is the psychiatrist and allied professionals who hold this dominant discourse. If a psychiatric patient is told they should never seek to work again they are likely to believe it. In relation to the working classes in the nineteenth century, Gramsci called this 'hegemonic' power. Maybe we see today such a dominance of hegemonic power that many cannot contest it.

Now we can consider some lessons we may learn from feminist standpoint epistemology. These feminist writers noticed that Enlightenment thought rested on certain oppositions: reason/unreason; culture/nature and intellect emotion. They argued that the first of these oppositions characterised male attributes and hypothesised that science was being conducted through a male lens and women were being excluded from science.

To take one example. In evolutionary anthropology, received wisdom was that language evolved in the activity of the hunt – a male domain. Donna Haraway then argued that language probably evolved in the interaction between mother and child. In other words, she turned received wisdom on its head.

From arguments such as this came the idea of feminist standpoint epistemology. Thinkers were no longer to be neutral – they took an explicitly feminist stance. Science then became political and a little relativist.

Ten or fifteen years ago no-one took feminist epistemology seriously. Now nearly all universities have departments of gender studies and some have chairs. I would like to see this happen with mental health but first we must push the argument a little further.

Certainly, some of these ideas could be applied to mental health. In terms of the Enlightenment oppositions referred to above we are characterised by unreason, closeness to brute nature and overcome by our emotions. But if we get rid of these Enlightenment ideas and engage in emancipatory research with no pretences as to the neutrality of the observer then I think we can truly forge new methods and a new theory for doing user-focused and collaborative research.

Nonetheless, feminist standpoint theory has its critics. The most commonly observed critique is that the theory is essentialist. That is, that it rests on assumptions about the *natural* attributes of women. I personally do not agree with this criticism but it is frequently voiced.

So now I want to introduce another theory, this time that developed by Foucault on the theme of madness. He argues that the mad have been the subject of powerful discourses and practises, largely by psychiatrists, for three centuries. So, again, we have allusions to the Enlightenment. However, Foucault is quite clear about power as he argues that this subjection has silenced the voice of the mad altogether.

My argument is that we need to reclaim our voice and this can be done sometimes through research. But this will not be easy as not all those oppressed by psychiatry rise up against it. Again we may borrow from Foucault and his idea of 'resistance'. This is a resolutely non-essentialist

concept as it refers to the range of reactions that may arise as a result of a certain configuration of knowledge and power.

So what are the possible reactions of psychiatric patients in response to the multiple ways in which psychiatry operates? Some accept its propositions and practices and in saying that I do not mean to be paternalistic as I did that for years myself. Some engage in little acts of resistance such as not taking medication – although, in fact, in the eyes of psychiatry non-compliance with medication is about the most rebellious thing a patient can do! Still others complement their doctor's advice by, for example, engaging in self-help and some go further relying purely on complementary medicine and self-help.

But some people entangled in psychiatry's web do struggle and they see this as political. These activities should be the roots of user research as I indicated at the start. If they are then user research may develop in an emancipatory way and make its contribution to the user movement.

Conclusions

We need to forge a philosophy for consumer research which values service users' experiences. We cannot uncritically accept the idea of the neutral observer in relation to the production of knowledge. We have a battle on our hands – we need to emphasise the importance of expertise by experience and not have this undermined by more mainstream ways of producing knowledge. We can adapt existing radical theories and ally ourselves with them and hopefully become activist scholars in the way that has been done by other marginalised groups.