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## **On personal epiphanies and collective knowledge in survivor research and action**

**Diana Rose**

### **Abstract**

This paper starts by reflecting on the nature of memory as the paper relies on the memory of the author. It speaks to what seemed an 'epiphany' when understanding of mental distress was radically reframed but then argues that this 'epiphany' was not a moment but embedded in personal and social history and that the journey it started is still unfinished. The paper reflects on the tradition of Patient and Public Involvement (PPI) in research and argues that whilst an important move the prominence of method in mainstream mental health research means that patients and the public are constrained in the impact they can have. The paper then moves to consider some conceptual and epistemological issues and ends with arguing the importance of peer support in both theory and practice but without romanticising this innovation

**Keywords:** user-led research; patient and public involvement; memory

### **Prologue**

As this collection concerns reflexivity and mental health research I should start by situating myself in the present. I am writing, or at least drafting, this lying on my bed in a mental health crisis house. It is a model of what crisis care should be, everybody should have it and to maximise that stays are short. It is Wednesday morning and discharge is Monday. I have been here 9 days. I died in Rio de Janeiro and they brought me back to life. I was in ITU for 3 weeks and for the first week in a coma on life-support and I have lost two weeks, I remember nothing. Experts opine that this can cause PTSD. I had that already so it's a compound and another diagnosis to add to the list. I remember nothing but tiny fragments for two weeks and somehow this has spilled over and I trust no memories at all. Consequently I have no identity, there is no narrative left. I left myself in Rio and am a ghost, worse, the undead, roaming the banks of the river Styx, unquiet.

Why am I telling you this? Because this article is partly historical so relies on memory and at least a semblance of narrative cohesion. So we shall see how we get on, I have an Endnote library and fragments of survivor history and present formations and praxis. But also if you are kept, unknowingly, alive by machines and then emerge from that it puts a certain prised spotlight on the nature of memory and so of stories. So, it will be charged with bias. Not generalizable. I never claimed to be 'representative' only, within survivor and academic spaces, to 'represent'. We know there is a crisis of representation so maybe that is a fitting end to this prologue. It will, however, inflect what follows.

### **Introduction**

This article begins by recounting and situating a specific experience that at first seemed to reconfigure mental distress for *me*, as an individual. It is a (re)-counting as memory always casts and recasts 'events' in light of present and long-past concerns (McCauley, 1995). The tradition of oral history, focussed as it was on recovering the stories of silenced groups, also moved from a conception of those stories as in some sense unproblematically factual (Vansina, 1972), to a notion that they were in some way constructed (Tonkin, 1995). Today this is framed as a concern with 'narrative' which is situated within the 'linguistic turn' and always sees memory and the resultant narrative as socially situated and constructed (King, 2000, Roberts, 2006, Taylor, 2006). This approach to history or to qualitative data generally has been applied to health and illness (Sharf and Vanderford, 2003, Fredriksson and Eriksson, 2001) and specifically to madness (Hubert, 2002, Kalathil et al., 2011, Voronka et al., 2014). The perspective has been critiqued from within medical humanities (Woods, 2011), as leading to an entirely unbounded accounting of 'events' (Warhol and Lanser, 2015) and also, in terms of madness, as querying interpretations of stories by scholars who have not themselves experienced madness (Russo, 2016 ).

### **The epiphany**

An epiphany is a moment when time and perspective change. But there is a 'before' and an 'after' of this moment and so since I shall emphasise this, the questions of memory and of history, arise immediately. I have actually told this story twice before in print (Rose, 2014b, Rose, 2016). It concerns my first meeting in a user group. I didn't know what a user group was. I had just lost my job in a polytechnic teaching social psychology, anthropology and one of the first courses in 'women's studies' except we called it 'The Sexual Division of Labour' as we were fundamentally Marxists though deeply critical of both theoretical and practical ignorance / ignoring of the position of women in Marxist writing and Left practice . I had experienced distress since 1971 and managed to hide it pretty well until in 1984 all erupted and the union (also Marxist) arranged a medical retirement two years later. I had read a review of Judi Chamberlin's *On Our Own* (Chamberlin, 1978) and my reaction was horror that anyone would 'confess' to such experiences and put themselves out there as a mental patient. I did everything I could to hide my distress, which today would be framed as fear of stigma (Faulkner, 2017a) and so in retrospect it is amusing that I have now read nearly everything Judi Chamberlin wrote and she is a hero. That is an instance in which the present can inflect as well as override the past.

But back to the meeting which my partner found advertised in the London magazine *Time Out* and encouraged me to go along. It was not user-only (which meant nothing to me anyway), there were family members, social workers and people from local voluntary organisations. I also saw for the first time what long-term use of neuroleptics and specifically tardive dyskinesia could amount to as there were people who had spent their lives in the local old asylum (I had been there for shorter periods) and speaking was nearly impossible for them with their swollen, distorted tongues. And in this mix a woman stood

up and recounted experiences so close to mine – of wounds being stitched up without an anaesthetic, of being accused of attention-seeking, manipulation and time-wasting, of being thrown out of the ED without treatment. All these epithets and conduct I had heard and experienced and I more or less believed were true of me, but for this person it was nothing less than an abuse of her civil rights. This was my ‘epiphany’ and although it was certainly a life-changing moment it was not a matter of ‘scales falling from my eyes’ because my eyes were already open to such an account. I had been an activist, feminist, trades unionist, involved in the anti-Apartheid struggle. The language made sense, it just needed some inflection. In fact, it needed rather a lot of inflection as Left politics in the between the early 1970s and mid-1980s paid no attention to madness. But part of this new language was the recognition that my distress was no longer a matter of individual pathology but something shared with others, a counter-language and practice that could be learned from others and a new and ongoing knowledge collectively grounded. That was the centre of my epiphany. That the focus on the individual as the bearer of pathology, shared differently but equally by psychiatry and psychology, is the lie which subtends both.

### **The ramifications**

Despite being an academic, I did not immediately grasp for the literature but I did get involved. Through ten years of lying sometimes 24/7 in front of my gas fire, of going to the Day Hospital or being an inpatient, of being told I should never work again because it would ‘bring on a relapse’ and finally of getting the most deadly boring job but in a disability organisation, it was this journey, this movement that was not linear but had many loops and turns, it was this that sustained me. I got involved in organisational politics round the final closure of the local asylum (well documented in (Bell and Lindley, 2005) and especially (Campbell, 1985 (2005)), particularly housing and support in a way not so different to what was then happening in Canada (Church and Reville, 1989) and also in support groups for coming off neuroleptics where we made arguments that well pre-dated those later put forward by critical psychiatrists (Moncrieff, 2008). And we put those understandings into action. None of this went down well with local managers and psychiatrists but by 1988 we had *The Griffiths Report* (Griffiths, 1988) which prefigured the *NHS and Community Care Act* of 1990 (HMSO, 1990) and laid a duty on local providers to consult with their publics about provision for disabled and elderly people in the community. Mental health service users were organising long before this but the law confers a certain legitimacy even if implementation is deeply troublesome (Barnes and Bowl, 2001, The Survivors History Group, 2012). We fought battles with officialdom and long before such interactions were framed in terms of ‘violating normative behaviour’ (Barnes, 2009, Rose et al., 2016), we endured managers and clinicians interpreting our anger as signs of relapse or as the outbursts of ‘unrepresentative’ users who were either sicker than usual or more articulate than usual (you could not be both) (Rose et al., 2002). This is now legendary.

I got involved also in the self-harm network and this was more personal although still very much a collective, in fact social endeavour in the sense of sociability (Pembroke, 2005). Meetings were held in people's front rooms and there was always plenty of chocolate. Until that time I had thought I was the only person in the world who cut their arms at the behest of voices telling they were evil and needed punishment. But in these meetings long sleeves were no longer necessary and the understanding that you were not alone, not a freak was a comfort beyond words. So my epiphany was not just a cognitive or emotional moment, it led to new understandings and new forms of support, the opportunity for quite conventional forms of organisation if unusual in their content as well as direct action (Curtis et al., 2000). It was the start of a journey, one that has not ended and never will. And I have probably told it 'wrong' but that is the nature of memory. It also was not really the 'start' as previous activism and thinking made me receptive. It is not an 'origin' story (Wright, 2004). It is but a credible version.

### **And so to research**

But I always wanted to do research again, just thought it impossible. In their introduction to this special issue, the editors write: “? How, if at all, do personal experiences of mental ill-health enable critical reflection on the conceptualisation of mental health and illness in contemporary social science - as well as in society writ large?”. I hope the above makes it plain that however distressing and sometimes outrageous my 'experiences of mental ill-health' were and still are, they were never purely personal, my reflections on them were socially grounded in collective knowledge and action, in other words amenable to social science conceptualisation in some form at least. This collective action did not just change the 'interpretation', it changed the experiences themselves. Once re-interpreted, a phenomenon changes even if some elements prove stubbornly resistant and unshiftable. To adapt a phrase from Sandra Harding (Harding, 2004): “madness is achieved not assigned”. 'Achieve' may seem a strange word for such catastrophic experiences, but Harding means it politically. Women were not feminists waiting to emerge from the head of Zeus, feminism was a result of collective action and political struggle. I see a parallel in the rise of user / survivor activism, research and knowledge production which takes different forms and varies globally (Menzies et al., 2013, Bereford et al., 2010, Russo and Sweeney, 2016, Staddon, 2015, Faulkner, 2017b, Rose, 2017, Davar, 2013). I have examined this in a recent article in detail (Rose, 2017) and the debate between Angela Sweeney and Dr Christmas is also instructive (Christmas and Sweeney, 2016).

But I rush ahead of things. To go back in time to that user group – Camden Mental Health Consortium was its name and it was closely linked to Survivors Speak Out (SSO) and Mindlink. Together with an NGO we conducted a set of interviews with people who had experienced acute care in the old institution and also the new provision in a community hospital. We, the interviewers, had also experienced both. The results were not straightforward in that green space was missed and the new provision more boring in a day-

to-day sense but the freedom (the ward was not locked) to explore the city and to be close to relatives and friends (not everybody had them) was much appreciated. And the junior psychiatrist was someone who is now a famous psychoanalytic psychiatrist, the nurses were enthusiastic so the 'treatment' was entirely different. It was a small piece of work and would not today count as 'rigorous'. But it was published in 1988 (CHMC and GPMH, 1988) and together with work by Viv Lindow in Bristol (Lindow, 1994) probably constitutes one beginning of user-led research in England.

But to the mainstream this was the oddest thing. I am told the report was discussed at a seminar at the Maudsley Hospital and the primary response was bafflement. This was a time of fundamental policy change – deinstitutionalisation – happening in parallel in the UK and USA, happening differently in Italy (Scheper-Hughes and Lovell, 1987) and to be followed in different ways and at different times in many other places. Which is not to say such institutions no longer exist, far from it, and they are standard but sparse in the Global South. But this massive policy change provoked a certain set of concerns and a standard way of researching those concerns. The concerns themselves were negatively framed – murder, violence, jail and homelessness on the part of people 'decanted' (I don't think they thought of us as fine wine though) – more or less in that order. In the USA the McArthur Foundation tracked thousands of discharged individuals (Zelevnik, 2001) and in the UK there was a large Randomised Controlled Trial with 'community living' as the intervention and hospital residence as 'treatment as usual' (Muijen et al., 1992). The outcome measures were as above. In other words these negative events were enumerated using quantitative designs and required no contact with the people they were ostensibly about. In fact, it seems the idea that ex-inmates might have something to say was not considered because after all their speech is meaningless, isn't it?

This difference in approach, in method and in what is paid attention to laid the foundations for what people like me (and of course I claim no privilege here) were to continue to do, however variously. It was a reclamation. But again it has not been a linear, progressive or consistent endeavour, neither am I telling a teleological story. The two programmes of work carried out in NGOs in London in the second half of the 1990s, though not the same, had this at their core – what is the voice of service users here (Faulkner and Layzell, 2000, D., 2001) as well as how are we to conceptualise this (Beresford, 2002, Beresford and Wallcraft, 1997)?

But I did not know this at the time. I had a job – at one time unthinkable. I was completely committed to change and there was no distinction in my mind between research and politics although at work we had to refer to it as 'policy'. And there was not complete and comfortable agreement amongst all those involved – I was more than once roundly condemned for including quantitative methods in my work. On the other hand, I made friends then that exist centrally in my life to this day and to return to the Prologue for just a minute are key to how and if get myself back.

Another significant moment started when a group of people, mostly from BME communities, started work on the relation between black people in the mental health system and those charged with their care, a piece of work called *Breaking the Circles of Fear* (Keating et al., 2001). I was quite shocked to learn of the treatment especially of young black men at the hands of psychiatry, a situation that has got progressively worse and equally coerces or abandons other intersectional identities (Fernando and Keating, 2008, Cook et al., 2014, MIND, 2009). This has been conceptualised in terms of structural racism and the privilege of whiteness (King, 2016, Metz, 2010). The people on *Circles* were my friends.

But as I prepared a project that I was to leave to others to do, the experience was different (Wallcraft et al., 2003). We convened a Steering Group and determined it would be 'diverse'. The first meeting was a slap in the face for me when someone told me I must be racist because I am white. This threw me totally, someone who had always conceived herself as anti-racist. But it made me think. Did I stop the Springboks rugby game in Aberdeen until the light faded and the game could not be completed from a position of privilege – a white university student? Certainly I was brought up by a xenophobe – did that lurk in me? Even when our flat in central London was the local headquarters of ZANU-PF, did I really understand those politics or just feel excited by the turmoil and the conversations? I didn't feel privileged as a working class woman but maybe I was missing something here? I resisted, then thought about it and still do thanks to some remarkable people. The user movement in Britain and the 'community' of user researchers is, after all, predominantly white (Kalathil, 2010). Reference to structural racism is crucial, but not enough. We research the plight of Black people in the system but not our own positioning there and what it might include or exclude whether deliberately or inadvertently. Doing user-led research throws up uncomfortable issues that fit easily with social science frameworks, or at least social science re-cast as critical theory. Who exactly do we represent and what is representation here (Hall, 1997a, Hall, 1997b, Collins, 1986)? Why are we not examining whiteness (Doane, 2003)?

### **Patient and Public Involvement in Research**

And now for a necessary interlude. As I have said repeatedly, neither history nor the memory of it is linear and the right moment for a discussion does not follow a pre-set timeline. The interlude is necessary because what happened had a huge influence on user-focused research in England and beyond and recent changes have also consolidated some things but prompted others to break boundaries. In 2006, the National Institute for Health Research (NIHR) was created as the main funding body for research in the NHS in England. Its grounding was *Best Research for Best Health (Health, 2006)* a document that embedded the idea of Public Involvement in Research and which came to be called Patient and Public Involvement (PPI) in Research. It also set up or built on topic (condition) – specific networks and one of these was the Mental Health Research Network (MHRN) which made an early and strong commitment to PPI in saying that projects would only be admitted onto the

network portfolio if they demonstrated the inclusion of PPI. At first this was to be overseen by an independent service user group (SURGE) but this failed. There was an ongoing tension that is prescient for the rest of this piece and constituted a tension between PPI conceived as influence on the research process (Trivedi and Wykes, 2002) and conceived as user-controlled research (Beresford, 2002). This is to put a complex issue very simply but there was another facet which prefigured things to come. The MHRN was committed to PPI but *within* the academy and the opposing call for user-controlled research included research and knowledge production in spaces outside that institutional structure. It included research done in NGOs but it prefigured a recognition that the Anglophone model of empirical research is not the only way of producing knowledge and developing these other ways at least needs the inclusion of survivors from other disciplines such as the humanities, history, cultural studies and social sciences but probably often needs to be conducted away from academic spaces altogether. Examples are work on our own modes of support (Faulkner and Kalathil, 2012) and especially the reconfiguring of ‘interventions’ critiqued by some white academics and survivors (Harper and Speed, 2012, Rose, 2014a, McWade, 2016) by Black participatory research (Kalathil et al., 2011).

I don’t know why it took me so long to re-alise that in the Hearing Voices Network and the Self-Harm Network and in discussing eating distress we had actually been creating new knowledge. It was not just any old idea, it was to some extent codified and it was certainly shared (Pembroke, 1994, Pembroke, 2005, Campbell and Rose, 2011).

As promised, this is not a linear narrative so let us return now to the MHRN. From 2008, PPI was coordinated by Service Users in Research (SUIR) and it was very successful. A paper published in 2014 demonstrated that nearly 400 people in England publicly identified as service user researchers and many were attached to the MHRN (Patterson et al., 2014). But in that year the MHRN was disbanded and most of what it would have done was taken over by an NGO but in reduced terms.

I have written extensively about PPI and much of it is a story forged in retrospect, thus tidied up and more coherent than it was (Rose, 2018). I am not inventing this analysis, I don’t remember in detail the moments when things changed my opinions. I remember the summation so will just note the strengths and weaknesses of PPI, particularly in the MHRN. The strengths included bringing service users into the academy who would previously never have set foot there. They were admitted because of a certain expertise – expertise by experience. The plan was that they would be involved in all stages of the research from design to data collection, interpretation and dissemination. The first is beginning to happen (Robotham et al., 2016) and the second is almost commonplace although often user interviewers are accompanied by a professional. I don’t know quite what is thought would happen if service users were left alone with an interviewee but maybe things have not changed much from the late 1990s when keyworkers refused to cooperate with me on grounds service users were too vulnerable (read emotional) to do this and would not be



able to respect confidentiality. Interpretation has always been a difficulty and not only in mental health (Oliver et al., 2008) although the value of collaborative qualitative coding that involves service users has been made clear (Sweeney et al., 2013). Dissemination should be easy but is often tokenistic especially in terms of public events such as conferences. In addition, service users can comment on documentation such as information sheets and consent forms to ensure they are comprehensible to 'ordinary' service users.

So what are the weaknesses of this form of PPI? I have indicated some already – the emphasis on mainstream methodology and on academic spaces, both of which became clear to me as constraints on what could be said and known. But let's revisit some of this. There has been a concern with the *impact* of such endeavours spearheaded by a statement by Dame Sally Davies then Chief Executive of NIHR (Staley, 2009). However, it has proved incredibly hard to demonstrate any impact on the actual results of research (Staniszewska et al., 2011) or even to systematise the knowledge accumulated (Minogue et al., 2005, Telford and Faulkner, 2004, Brett et al., 2014). Some argue that this is not the issue at all, that there is an ethical imperative that people whom research is meant to benefit should have a say in how it is conducted, a position most extensively argued in France (Callon, 2009).

But maybe there is a reason for why it is so difficult to demonstrate 'impact', and that reason is structural. As I have said, nothing changes in the methodology of this mental health research. Service users are to be involved in every stage but each stage, and much of its detail, is set in stone. The methods are RCTs or big data analyses or complex evaluations following MRC guidelines which allow a small role for 'process evaluation' (ie qualitative work) but where quantitative methods reign supreme (Campbell et al., 2000). In my view, quantitative methods have a place but I have sat in too many meetings where the supremacy of the confidence interval or p value was so obviously rendering invisible crucial aspects of the research to rest content with this approach. To think that we are going to represent the 'perspectives' of service users by carrying on with RCTs that almost always have tiny effect sizes and huge heterogeneity is almost laughable. The current preoccupation with 'personalisation', in my view is driven by this problem.

In fact, the only time my work has ever had 'impact', defined as both creating new knowledge and being taken up by NICE (!), is when the methods have been radically altered in such a way that the voice of service users subtends the work rather than being an add-on. Such was the case with our ECT review which violated all the rules of a systematic review but nevertheless influenced NICE Guidelines (Rose et al., 2003). I also happened with an outcome measure which started rather than ended with the collective views of service users on acute psychiatric care (Evans et al., 2012). Incorporation into NICE Guidelines is not my primary objective but is one way of making a difference. In 2002, more than 11,000 people had ECT in England, in 2015 it was less than 3,000. I count this a victory. Others count it a scandal.

It is possible to be passionate about methods. To understand that is to see that what undergirds the bulk of mental health research today is the belief that method is the royal road to truth. If you get the method right, the results will speak for themselves. I have written about the shenanigans involved here elsewhere in a forthcoming paper but would just refer the reader to Bruno Latour (Latour and Woolgar, 2013) and Steven Shapin (Shapin, 2010). Science itself is social through and through, it is not neutral. This claim undergirds the privilege of method in medical and mental health research but it does not stand up to scrutiny. When our research is criticised for being biased or anecdotal (read qualitative) or plain unscientific, the objection is that it is coming from a collectively-generated position, produced by a marginalised groups with a standpoint that includes the political. This is in my view more honest epistemologically and so more justifiable than any claim to universality and neutrality.

### **It wasn't all a rose garden**

Public narratives tend to emphasise the positive unless they are the narratives of the wounded and I guess I could have written one like that too (Brown, 1995). I have written this almost as if I know what's what and as if I have been situated in an environment of closeness, support and agreement. In a sense, the second is more the case than the first, but of course there were disputes, sometimes bitter and personal. I am not talking here about disputes with non-survivor academics although those certainly happened and still do. I mean we disagreed amongst ourselves. There's nothing unusual in that, especially amongst excluded communities who have been silenced and are speaking up for the first time. But we were, after all, mad people and for me at least, this does not just amount to Szasz's 'problems of living' (Szasz, 1974) nor simply the side-effects of medication although these can be profound. So, I found it hard to contain my irritation when someone who was taking the minutes of a meeting needed every detail spelt out, every i dotted and t crossed, all to be literal and taking hours excluding only the nuances! This is a mild example but also more than the political differences I had with some in SSO, it is an issue of how we respond to madness itself. I have encountered it as a manager and did not handle it well but felt I had to protect (not physically) the other researchers who shared the office. I am not certain that we respond well to the kind of madness that is hard to empathise with even whilst I think that having been both high and suicidal I can understand better than most professionals what a person is experiencing. This is the basis of peer support but what if, to put it bluntly, the peer you wish to support is irritating the hell out of you or making you want to run a mile. Our response is often guilt that we feel this way. Of course, everybody, all groups, get angry with each other and it's a fine balance whether someone is acting in a crazy way that drives us crazy or that we are so super-sensitive to not pathologising that we beat ourselves up for rejecting behaviour that occurs all the time everywhere, we just happen to be in user / survivor contexts.

In any event, my narrative of activism and research was shot through with these kinds of dilemmas and arguments and the formation and reformation of groups that contested each other's positions. You will note that there are no references in the last paragraph and that is because these issues are rarely written 'in the raw'. The very act of writing and superlatively academic writing bleeds this of its passion and its anger and converts it to the contours of 'debate'. This is changing with blogs and other social media outlets but there seems to be a ban on passion in knowing. And yet that is exactly what we are doing. It is, in fact, what everybody does but in many instances (and here is my only reference to psychoanalysis) it is repressed. I am not advocating constant rows, just acknowledging the silliness of that social psychological triad: cognition, emotion, behaviour – from Gordon Allport (Allport, 1954) to Graham Thornicroft (Thornicroft, 2006) we have half a century of stigma theory built on the assumption these are separate

### **Conclusion**

There is no conclusion. This is a recounting and an accounting and in another space or another time it would be different although I hope not completely so. It is neither origin story nor telos. To return to the Prologue with which I started, about half of this paper was written when I was in a psychiatric facility and preoccupied with the belief I was a ghost, had left myself on the street in Rio where my heart stopped and would never get myself back again. I almost have, although not completely, retrieved my 'self', thanks largely to some people who figure in this recounting and who will know who they are. But the crisis house was usually a quiet and supportive space, an oasis in the desert that is current mental health services in England, and I am lucky enough to be able to pay for some therapy. Existence continues still in parallel worlds some of the time so as well as being necessarily partial, the story, even the arguments here, are perhaps are slightly haunted.

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