Mental Health Qualitative Research Network

27 March 2014 meeting

Theme: Autoethnography in mental health research

Presentations:

Negotiating the swamp - constructing the subjectivity of a researcher mental health service user: Critical autoethnography, methodological questions and ethical dilemmas, Konstantina Poursanidou, Honorary Research Associate/Service User Researcher, University of Manchester

From lived experience to poststructural voice: Some methodological implications for the use of autoethnography in mental health research, Alec Grant, University of Brighton

“If this is an answer, then what is the question?” Using autoethnography as a basis for a doctoral research project, Simon Clarke, University Of Nottingham

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Negotiating the swamp - Constructing the subjectivity of a researcher mental health service user: Critical autoethnography, methodological questions and ethical dilemmas

Dina Poursanidou
MHQRN Meeting
London, 27 March 2014
My purpose in this paper

• Reflect critically on my search for an appropriate epistemology and methodology, as well as on my grappling with ethical questions and dilemmas, in the process of carrying out a piece of qualitative auto-ethnographic research

• The research in question has sought to explore the unremitting identity and other struggles implicated in the task of constructing and negotiating my double identity as an academic researcher and a mental health service user—a task full of complexities, challenges, contradictions and ambiguities
What I tried to do in my autoethnographic research

• Use my story to ask **wider questions** about the challenges and support/development needs of mental health service users actively involved in University-based mental health research; **using autobiography to inform critical social analysis**

• Use my lived experience as data to **problematise** mental health service user involvement in University-based research

• **The reality** of involving mental health service users in University-based research is a lot more complex, messy, troubled, and full of contradictions compared to **the respective rhetoric**

• A critical understanding of the manifold and complex ways in which **affective/emotional and socio-cultural dimensions of experience** interplay in shaping mental health service user involvement in University-based research

• My story/auto-ethnography first presented in June 2011; continually evolving, developing; reinvigorated through discussions with different audiences

• Not a coherent, consistent, linear, seamless and complete story

• A story characterised by contradictions, ambiguities, complexities, interruptions, fragmentation and open-endedness (Butler, 2005)
Looking for an Epistemology/Theory of knowledge

• ‘Using researcher subjectivity as an instrument of psychosocial knowing’ (Hollway, 2011)
• Privileging the concepts of intuition and emotional experience as knowledge tools
• Tolerating the absence of a consistent and linear story... tolerating muddle...allowing for imagination
• A theory of knowledge consistent with experiences radically outside rational language and discourse (e.g. madness; trauma); How to communicate the unspeakable/ineffable?
• Non-positivist, psychoanalytically informed theory of knowledge – Wilfred Bion
• An epistemology capturing the embodied, affective encounters that occur between subjectivity and socio-cultural life
A psychosocial framework of analysis

- A psychosocial framework of analysis ‘attempts to move from lesser (reductive: purely psychological or purely sociological) to greater understandings (more complex: recognizing both psychically unique and socially contingent elements) of social phenomena’ (Jefferson, 2008)

- ‘Conceptualizing the psychosocial subject non-reductively implies that the complexities of both the inner and the outer world are taken seriously. Taking the social world seriously means thinking about questions to do with structure, power and discourse...Taking the inner world seriously involves an engagement with contemporary psychoanalytic theorizing because only there, in our view, are unconscious as well as conscious processes, and the resulting conflicts and contradictions among reason, anxiety and desire, subjected to any sustained, critical attention’ (Gadd and Jefferson, 2007)

- Intrapsychic, intersubjective, institutional and macro societal/political and economic domains of experience

- Psychosocial influences that have combined in shaping my journey from Willow Ward back to academia
Looking for a Methodology

• Autobiographical material

*Critical autobiography as social science* (Church, 1995)

• *Autoethnography, Personal Narrative, Reflexivity-Researcher as Subject*  
(Ellis and Bochner, 2000)

• Personal, intimate, embodied writing

• First person voice

• Auto-ethnography connects the personal/self to the cultural/culture (Ellis and Bochner, 2000; Stone, 2011)
Why attracted to autoethnography? I

My attraction to autoethnography relates to the ability to see the complex interaction/interplay of the multiple dimensions of experience, i.e., intrapsychic/affective, intersubjective, institutional and macro-societal/political/economic, through looking at the interaction of self and culture. Perhaps seeing this complex interaction may be a step towards looking critically at and even going beyond (often unhelpful) dualisms such as individual/social, micro/macro, psychological/societal. Our biographies are inevitably social for example.
Why attracted to autoethnography? II

Using myself as an instrument of knowing and understanding ...
Making myself vulnerable...

With the conviction that

_Scholarship ‘that doesn’t break your heart just isn’t worth doing’_

(Behar, 1996, _The Vulnerable Observer – Anthropology that Breaks Your Heart)_
Methodological Questions I

• Personal narrative/history-reliance on autobiographical memory
• Traditional notion of memory: an individual archive of the past, stable over time
• Autobiographical memories as meaning constructions; shaped and defined by socio-cultural practices; in a state of constant flux; ongoing process of construction and reconstruction (Brockmeier, 2010)-How to capture/trust autobiographical memories in a personal narrative?
• What if autobiographical memory is overgeneralised and vague or absent? (trauma)
• "Memory is rarely accurate, but it is invariably true..."—Hughie O'Donoghue RA; emotional memory is invariably true
Methodological Questions II

• How to avoid being merely confessional, solipsistic and self-indulgent in the use of autoethnography and reflexivity? How to use autoethnography to inform critical social analysis?

• ‘Quasi-feminist—or ‘feminised’—forms of incitement to reflexive confession that are increasingly gaining favour within professional and higher educational contexts’ (Burman, 2006)

• Warning against ‘underestimating the speed and flexibility by which neo-liberalism absorbs and co-opts creative strategies—such as reflexivity—and returns them to old-style individualism’ (Burman, 2006)

• ‘Emotional geographies’ : ‘attempts to understand emotion—experientially and conceptually—in terms of its socio-spatial mediation and articulation rather than as entirely interiorised subjective mental states’ (Bondi et al, 2005)
Methodological Questions/Ethical Dilemmas III

• What counts as valid and legitimate research data - other than textual data in the form of interview accounts or patient records?
• What about verse/poetry/creative writing?
• What about visual data-photographic data, diagrams, drawings and artwork?
• What about data generated in communication through the internet/social media (e.g. email)?
• The ethics of autoethnography; To what extent can anonymisation work when others are heavily exposed in our personal narratives?
Data sources

- My reflexive research journal
- Reflexive notes from individual psychotherapy sessions that I attended as a client and where the challenges of being a researcher service user were worked through-including email communication with my psychologist
- Artwork and creative writing reflecting my struggle to make sense of my mental health crisis and recover
- Email communication with my psychotherapist and with other service user researchers/academics
- My mental health/care notes from 2009 (Jan-April)
- Informal conversations with other Service User Researchers
- Presentations and discussions of my continually developing auto-ethnography with different audiences
Language/Self-identifications/Identity politics

- Researcher Service User
- Service user? Used secondary mental health services from July 2008 to March 2013
- Consumer-Customer?

The neoliberal discourse/rhetoric of consumer participation in planning and evaluating services and in services research

Consumer choice, control and power

‘The consumer as king’ (Shaw, 2009)

- Psychiatric Survivor?
- Expert by Experience? Expert Patient Trainer; Service User Expert
Expert by Experience? I

I avoid identifying myself as an ‘expert by experience’ - a common label nowadays for mental health service users which I question. If I was to be called an 'expert by experience', what exactly would I be an expert on? On compulsory hospitalisation (sectioning) and how it can destroy one's confidence perhaps? But having had an experience of sectioning (my own experience) does not necessarily make me an expert on detention. It just means that I have lived through detention and I have the experiential/embodied knowledge that stems from that, so when I talk about detention it is not just on a cognitive/academic/theoretical level using knowledge that I have acquired from books, but on an affective, visceral, deeper level as well. Does this make me an expert? I am not sure...

Or would I be an expert on madness? But how can one be an expert on madness if madness is something that cannot be known and understood in its entirety, something that cannot be easily articulated? And are we not all experts through our experiences? if so, why would we need the presumed epistemological privilege of being a mental health service user to claim such expertise?
Expert by Experience? II

Furthermore, raw experience (embodied, affective/emotional experience) would not in my view be automatically translated into knowledge and expertise... I think raw emotional experience needs to be processed and detoxified and reflected upon in order to become available to thought, in order to become knowledge... so, experience does not equal expertise... On the other hand, I do recognise and value the collective experiential knowledge and expertise that emerges from the psychiatric survivor movement – but I would not call myself ‘an expert by experience’. Finally, apart from ‘experts by experience’ mental health service users often identify themselves as ‘Service User Experts’ and ‘Expert Patient Trainers’, in which case professionalised lay experts appear to use their mental health crisis/mental breakdown as a qualification; this is something I vehemently object to doing.

(From email communication with a service user academic in USA)
Language/Self-identifications/Identity politics II

• Distressed or disabled? Psychosocial disability (USA)
• Ex-inmate (Reville)
• Mad-identified (Reville)
• Mad Pride; Mad Movement; Mad knowledge and history
• Where is home?
  Academic Research or Psychiatric Survivor Movement?
Park House, North Manchester General Hospital

From Willow Ward to a research post: identity and other struggles

- Willow Ward: the culmination of my mental health crisis
- When I was detained in hospital, I was treated as somebody with diminished capacity and insight
- My care records covering the period of my detention in hospital (January-April 2009) portray me -among others- as ‘dishevelled, retarded, highly agitated and characterised by suicidal ideation, lethargic and far from mentally alert, incontinent, occasionally subjected to physical restraint and possibly needing ECT treatment due to treatment-resistant severe psychotic depression’
- All the above represented a huge blow to my confidence and a source of profound feelings of humiliation and shame, as well as a source of a deep sense of failure, unfairness/injustice and stigmatisation- all acutely disempowering emotions
- In a nutshell, my mental health crisis back in 2008-2010 and in particular my sectioning in 2009 were scarring, terrifying experiences whereby the very core of my existence was deeply shaken and all my certainties collapsed; therefore, the struggle to regain my confidence, return to academia and repair my life has been hugely challenging
Terror, A. Kubin

Feeling terrified in Willow Ward
Oppression, A. Kubin

Having my confidence crushed
How do you go from these states of mind back to academic research?
Psychosocial influences I

- Battling with low confidence, performance anxiety, perfectionism, self-doubt
- Difficulties with delivery on time and with team work; harsh criticism
- Colleagues’ lowered expectations of me; *unwitting prejudices*; delivery issues as ‘traits’; hard work to restore trust in my abilities
- What do colleagues see? The service user/somebody with a broken mind or the researcher?
- Because of my academic research background, not a *bona fide* service user
- Others protecting me from their frustration and anger; caring, sensitive people
Psychosocial influences II

- The wider neoliberal political and economic environment within which Universities operate
- Immense pressure to deliver within tight timescales
- Government cuts in research funding; a very competitive research labour market
- A succession of temporary, very short-term and part-time research contracts; linked partly to long term absence through sickness; financial uncertainty; obstacles as regards career progression (not entrusted with lead researcher roles; no time or mental space for writing for publication); unemployment
- Are Universities genuinely interested in service user/’mad’ knowledge infiltrating academia?
Psychosocial influences III

• Issues to do with career progression and support of service user researchers once in a job- even for the most qualified ones (we are given a job, ok, but can we progress and develop in it? how many service user researchers for example apart from Diana Rose and very few others get to be Principal Investigators in studies? how well are service user researchers supported and mentored in their jobs, ie given pastoral and academic support?)

• Issues to do with job security (given the uncertainty that researchers at large are facing due to serious job market challenges at the moment; people having very short contracts or just Honorary contracts where you do not get paid)

• All of these issues need to be taken seriously if we are to be talking about meaningful mental health service user involvement in academic research
Psychosocial influences IV

- External (structural; relational) obstacles to career progression
- Internal obstacles to career progression

Fear of relapse

Having to fight **critical, disempowering, internalised voices and messages** of mental health professionals

‘*What makes you think you can go from Willow Ward to a prestigious research job? You were very ill with psychotic depression, treatment resistant, possibly needing ECT! It can happen again!*’

- Driving myself to succeed: the desire to prove the medics wrong and reverse the prognosis; Righteous anger
- Manic over-compensation? A defensive response to my fears around relapse and to my feelings of grief around the losses my mental health crisis entailed?
Struggling with ambivalence

- **Ambivalence** towards my mental health crisis, service use and service user researcher role itself (huge losses and traumas/biographical disruption/bitterness and grief; opportunities for personal growth and transformation)

- ‘Madness as a dangerous gift’ - the lived experience of mental distress and mental health service use, as well as the knowledge stemming from that, may be an asset, something potentially positive and valuable in the context of mental health research, but at the same time represents something excruciatingly painful that at times I wish I did not have!
Recovery [©Daniel Saul-Making Waves]
What helped me in the journey from Willow Ward back to academia

• The critical importance of material and social conditions of my life (e.g. decent housing; financial support from my family; being able to afford cultural activities)

• Individual therapy sessions with a clinical psychologist (NHS) for 2.5 years

• Emotional support from my family, friends, colleagues

• Engagement with art

• Involvement with Asylum magazine and familiarising myself with the psychiatric survivor movement
Beginnings of recovery? Art in Willow Ward I
Beginnings of recovery? Art in Willow Ward II
Beginnings of recovery? Art in Willow Ward III
Beginnings of recovery? Art in Willow Ward IV
Art and beginnings of recovery?

Looking for something in a drawer yesterday I found 2 silk scarves that I painted when I was in hospital in 2009. the only meaningful activity on offer there was 2 hours occupational therapy per week; during these sessions I painted the scarves I found yesterday. I thought they are really nice and I remembered I felt proud of myself back then when I painted them. I guess I am amazed I managed to be so creative whilst being on really heavy medication and so demoralised. I am sending you some images of the scarves. I felt quite emotional finding the scarves. they are colourful with warm colours - a stark antithesis to my mood at the time...I remember I used to look forward to the occupational therapy art sessions when I was in hospital...perhaps the only thing I was looking forward to there...perhaps the art I was engaging in during these sessions reminded me of the possibility of another life, a life of freedom and joy away from the hospital where I was detained...perhaps the art symbolised the possibility of recovery for me back then... An example of the redemptive power of the arts when it comes to mental health recovery or the beginnings of recovery in my case?

From an email to my psychotherapist (8 February 2012)-Reflexive notes
Recovery from trauma- Memory and creative writing (START)

I have been in the A & E 3 times this couple of months – I am presenting as suicidal. I gave my story again and again – endless waiting in the lounge – together with my mother – who is and feels as lost as I am. Finally a mental health nurse or psychiatrist calls me in. I enter this tiny, bare room- a chair and an examining bed. I am asked about my symptoms. My despair is named ‘Symptoms’, nobody asks about my life, what may have happened to me – all very cold and clinical. One nurse says ‘Prozac makes people suicidal – go home and keep taking the tablets’, he said, ‘it is normal to feel suicidal with some drugs’. I wanted to be asked about my suffering, what brought me there, what it feels like to want to take your life, but no- symptoms and tablets and dosage. I decided I would not go to A and E again – not over my dead body!
Art and Recovery I (START)

Feeling terrified
Art and Recovery II (START)

Struggling to see the sun
Art and Recovery III (START)

Fun and excitement
NARCISSUS
Cheerful flowers, tossing golden trumpets in the breeze
Splashing yellow warmth, glorious picture in the Spring
“Look at me!” Your attention its quest is to seize
Cheerful flowers, tossing golden trumpets in the breeze
Triumphant in its song, enthusiastic to please
Movement and kale, its promise is to bring
Cheerful flowers, tossing golden trumpets in the breeze
Splashing yellow warmth, a glorious picture in the Spring

Dina Poursamidou
Art and Recovery V (START)

Celebration of Colour-Hope
Creative writing and recovery from trauma (START)

I do not want ECT!

loss of control

suffocate

restless

self-harm

Panic attacks palpitations, trembling and shaking

nameless dread?

unpredictable

angry, retaliating, swearing at the back of a police car

Afraid I may harm myself

Vulnerable depressed

stealing

lack of confidence

I am going to die?

anxiety

when is this going to end?

loss of freedom

cannot sleep

I want to escape

TERRIFIED TERROR

Terrified

Terror

I am restless

self-harm

Panic attacks palpitations, trembling and shaking

nameless dread?

unpredictable

angry, retaliating, swearing at the back of a police car

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stealing

lack of confidence

I am going to die?

anxiety

when is this going to end?
Reflections on art and recovery

Dina: I have got this material, which could be clay or could be mosaic tiles, that I can manipulate and form as I like and change... this gives me some hope that hopefully I can do that in my life too...if I can change the artistic medium, if I can change the clay, if I can form it the way I like, perhaps there’s a possibility of change to do with my mental health...I can change, my illness can change... There is this kind of link and symbolism that is very important...because doing art opens up this possibility of change which is vital for instilling hope and initiating recovery...

Reflexive notes from therapy session (15 October 2010)
Humour and recovery I - Depresso/Brick-
Transgression and rebellion?
Asylum: a sense of community

http://www.asylumonline.net
http://www.pccs-books.co.uk

Dina's Blog on Asylum, the Magazine for Democratic Psychiatry http://www.asylumonline.net/dinas-blog/
Epilogue: Ambivalence

Dina: there are people at Start who are brilliant in terms of their talents, but on the other hand, and that’s including myself, although I don’t think I’m brilliant artistically, but because of the mental health stuff they’re compromised in so many areas of their lives...they can’t work, they rely on heavy medication, they can’t travel in public transport, they’re restricted because of their mental health problems...I suppose I feel some bitterness around that because I feel it’s so unfair...and I think I feel that about myself as well...how much I’ve had to struggle to regain my confidence...I’m in the process of doing that, I haven’t done it...it’s just twice as hard if you’ve had that load of the mental health thing...I feel privileged that I’ve met these people but there’s a part of me that just feels bitter about the mental health thing...for me and for them I think...when I see how much people are compromised by it, whereas they’ve got amazing potential and talents...I don’t know, I’m not sure about it at the moment...whether having had a mental health problem has offered an opportunity for change and growth for me...

Reflexive notes from therapy session (June 2011)
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