SOCIAL PSYCHOLOGY SECTION

ANNUAL CONFERENCE (virtual)

27 AUGUST 2021

A rational case for mad researchers in Social Identity Approaches to Health: an autoethnography

Jones, L., Kellezi, B., Marriott, M., Stephenson, C.

Background: User-groups have argued the diagnosis, 'Personality Disorder', is harmful, however, these voices are largely missing from mainstream academia. The Social Identity Approach to Health (SIAH) has demonstrated group-based processes can help or harm wellbeing. Given psychiatric diagnoses are, by definition, group-based, SIAH provides a useful theoretical framework to explore user-group concerns. This paper aims to demonstrate how inclusion of researchers with experiential knowledge of living with mental illness/distress can benefit both theoretical development and society more broadly.

Methods: The classification, exploration, and treatment of psychiatric diagnoses has arisen within a Western, Positivist, framework, and from positions of relative social advantage. Within this framework, deficits are situated within the individual rather than society. Objective methodologies are considered the 'gold-standard', whereas experiential knowledge, particularly of those labelled 'mentally ill', is devalued and contrasted against ideas of rationality and reason. SIAH carries different underlying philosophical assumptions to Positivism, presenting opportunities to develop more inclusive methodologies aligned with this. This paper uses SIAH as the underlying theoretical framework combined with the positioning of 'survivor researcher'. Autoethnography is used to discuss the value of experiential knowledge within research.

Findings: Researchers with lived-experience of mental illness/distress can offer valuable insights in shaping research questions and designs. Shared social identities of researchers and participants is theorised to support research participation of under-represented groups. The above offers opportunities to hear voices of devalued groups and to expand SIAH theorising.

Discussion: Inclusion of underrepresented and historically oppressed groups as survivor researchers has implications for research, practice, and society.

Introduction

Hello everybody, my name is Lauren Jones and I am a 'survivor researcher' at Nottingham Trent University. I have just completed the first year of my PhD under the supervision of Blerina Kellezi, Clifford Stephenson and Mike Marriott.

The primary question I am exploring in my thesis is whether some mental health diagnoses are more harmful than others, in people who have experienced trauma. My theoretical framework is the social identity approach to health. This is combined with the positionality and values of survivor research. Today, I am making a rational case for the inclusion of mad (or survivor) researchers in social identity approaches to health.

I would just like to thank my fellow presenters who have kindly turned on their cameras because I was feeling anxious about delivering this presentation; seeing some friendly faces helps.

Overview

This is the overview of what I'll be discussing today. It will be a whistlestop tour but slides and transcript can be provided.

Please be aware, I will be discussing some emotive themes, including reference to severe mental illness and suicide. If you are likely to be affected, then please look after yourself and stop listening if needed.

Knowledge and power

The western, biomedical model remains the dominant framework used to view and treat mental illness in the UK. Underlying this framework is Positivism, which is based on the premise that the world exists independently of our knowledge of it.

Epistemologically, this is linked with objective methods and ideas surrounding objectivity and reason. Foucault argued that within this framework, 'reason' or the ability to be rational, are essentially the opposite of madness.

The implications for people labelled mentally ill are that knowledge of our own experiences is delegitimised compared with other types of knowledge. This delegitimisation of people as "knowers" has been called epistemic injustice. It occurs within research, practice, judicial, and other social settings, and results in disempowerment.

Knowledge of people with mental illness has historically been subordinated to researchers and clinicians in relative positions of power and privilege.

White, western, educated, wealthy men without severe (or at least declared) mental illness have been the ones to decide: which questions to ask, how to ask them, how to interpret data, and how and where to disseminate findings. Traditionally, they have also decided what is ethical, what constitutes mental illness, and subgroups of mental illness, and how to treat them. I say this acknowledging my own privileges which I will discuss more later.

Cartoon slide - PD in the bin

Assignment of a mental health diagnosis, by-definition assigns an individual group-based membership. Some service-users and user groups have argued the diagnosis 'personality disorder' is harmful,

stigmatising, and ignores social contributors of distress. These voices – this knowledge - is typically missing from mainstream academia, going back to problems highlighted in the last slide.

Survivor Research

Survivor research is a developing field, closely aligned with the survivor movement and mental health activism.

As such it tends to challenge. It challenges: the individualism of biomedical approaches to mental health, social power imbalances, including academic elitism, and ideas surrounding knowledge.

Survivor researchers have lived-experience of surviving mental illness, trauma, and/or the mental health system.

Our experiential knowledge is seen as a valid and legitimate source of knowledge and becomes a central component of the research. Researcher positionality and reflexivity are used to increase transparency and interpretability but also to add to the overall knowledge which is produced. We argue that user-led mental health research from the standpoint of an underprivileged position is needed to enhance knowledge production, and to improve outcomes for end users of this research.

People who have experienced trauma and mental illness have often experienced harm by people or institutions in relative positions of power. Survivor researchers, including me, have found that shared identification with participants has supported recruitment in 'hard to reach' groups. Social identity theory provides a theoretical explanation for these findings.

Social Psychology is well placed as an ally to survivor research and we can benefit each other. On Wednesday, Linda Tropp gave an excellent overview of its historical dedication to social change. The field recognises that social factors, including trauma, and social identities, can affect mental health, and it already values experiential knowledge of participants in qualitative studies.

To build on this, experiential knowledge of trauma and mental illness can advance the field, not only in the role of 'the researched' but also from more equal positions of power. I thank the BPS for the opportunity to speak here today, and my NTU supervisors who have supported my madness.

Ok, now for the hard part.

Autoethnography

I first experienced depression and anxiety as a young teenager. For 15 years, these ebbed and flowed across a full spectrum of severity. Most of this time, I was on psychiatric medication prescribed during 10-minute GP appts. I was fortunate and able to attain academically, I got a BA and an MSc, I qualified as a speech therapist and went on to specialise.

Following several stressors, including a particularly difficult GP encounter, my mental health spiraled. I was white, educated, middle class (at least on paper), and a healthcare professional in the NHS working in a mental health trust. Despite these privileges and despite trying, it was impossible to access support.

Trying to access help, and this being repeatedly denied, eroded my self-worth, reinforced my belief that I didn't deserve support [*become emotional here]* and left me feeling broken and without hope. I eventually made the decision to end my life and then attempted to do so.

I was briefly given a working diagnosis of 'personality disorder (unspecified)'. This confirmed my longstanding belief that I was the problem. My personality - my 'me' was wrong. Finally, a trauma-informed psychiatrist diagnosed me with, complex post-traumatic stress disorder. This trauma diagnosis changed my view of myself from being inherently disordered to my symptoms being the result of something which had happened to me. The diagnosis also had practical implications, allowing me to receive treatment for the underlying problem, my trauma. After, now, 16 years, this started my recovery, which has been long, far from linear, and is ongoing. I have friends who weren't so lucky. [*became emotional here and had to pause*]

During my recovery, I saw an advert for a paid peer researcher position in research into the CHIME model of Recovery. 'Lived-experience' of mental illness was listed as essential. Seeing this shifted my lifelong view that my mental illness was something to hide. For the first time, I saw my experiences could be of value. This benefited my recovery through how I viewed myself and my experiences in relation to the world, and provided hope of different, accessible career options.

[*laughed*] I didn't get the position, but subsequently became fascinated by research into personal recovery. This concept was alien to me both as a mental health patient and as a healthcare professional in rehabilitation. I was able to find, interpret and apply this research to my own recovery which helped further. But I was only able to do this because of my own privileges and prior education. It takes about 10 years for research to reach practice. This then only aids those who can access services. It is vital that research about people with trauma and mental illness is made accessible, readable, and meaningful beyond academic bubbles. In mental health, this can literally save lives.

We know from social identity research that we classify people into us and them. I became acutely aware of this a few years ago when attending an academic Recovery conference, which I did wearing several hats, including mental health advocate, and learner. Academics were doing their best to equalise power dynamics, highlight benefits of peer researchers, and improve outcomes for people like me. I was loving it.

I then became aware of a small but definite backlash; to the conference, the people within it, and the concept of recovery. This backlash was from people with mental illness, who I therefore considered peers. I went home feeling confused and deeply conflicted. It's probably not surprising as you have just seen me cry, but I actually cried to my husband afterwards saying, "I don't want to pick a side".

My researcher identity and mental health advocate identity were both important but suddenly felt incompatible. [*gestured unbalanced scales*]

Mental illness disproportionately effects people from lower socioeconomic backgrounds, and can also result in loss of earnings. I had bought my £300 ticket to the conference on a credit card as a gift to myself for being discharged from my CPN. There was no discount to make it more accessible. My peers' critiques were online, they were not part of the conversations taking place. The research was about us, but dissemination was largely without us and this divide increases 'us' and 'them' - I encourage conference

providers to reserve free places for those without academic or financial privileges but with valuable experiential knowledge; so that they, and social psychology as a field, can benefit from this.

I discussed the experience afterwards with a friend diagnosed with BPD. Her symptoms and history were similar to my own, the only difference was really diagnosis. I asked her what she thought about the word 'recovery'. She considered this then replied, "I don't like the word recovery; I can't recover from me". In this context, she saw no distinction between her personality disorder and her self.

[Ran out of time to discuss this section due to tears earlier]: Since I reached crisis, I completed a psychology MSc. and now work in a lived-experience capacity supporting people who are unable to access adequate mental health support. Most have a history of trauma which remains unaddressed. Over 88% people diagnosed with BPD, now EUPD (who are often women) have a history of complex trauma. People with this disorder can 'disengage' from mainstream services, or worse

Conclusion

My lived experience, and in-group membership within trauma and mental health communities has shaped my research question. I have reason to suspect that different psychiatric diagnoses have different effects on identity, conceptualisation of illness and recovery.

The voices of lived experience, particularly of those labelled mentally ill, are given less value and less power in research and practice.

User group critiques exist but are typically missing from mainstream academia.

To improve theoretical development, we must ensure we aren't missing voices of marginalised groups. Social psychology is in a unique position to understand group dynamics. Shared identification of researchers in groups labelled ''hard to reach' can support participation and bridge the gap between 'us' and 'them' through shared identity processes. Research discussions, such as those occurring in this conference, remain limited to a privileged few. We need to explore who is missing and take practical steps to make access to knowledge more equitable so we can all learn, including from each other.

I'm fairly used to talking about my experiences in my work. The emotional demands of this are something I have to manage carefully. I feel fortunate to be here today but have found deciding what to talk about particularly emotionally challenging. The main issue for me has been time and what feels psychologically safe to include within this time. Considerations around flexibility, including time restraints in talks given by survivor researchers may benefit future inclusion.

Thank you for listening.