Using Participatory Action Research to Tackle Ethnic Inequalities in Severe Psychological Distress

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Background

Persisting Ethnic Inequalities

Ethnic inequalities in severe psychological distress and its association with broader social disadvantage and care experiences have been documented for more than five decades (Bhui et al., 2018). Members of some ethnic minority groups, are more likely, than ethnic majority populations, to:
- ❖ receive a diagnosis of psychosis (Black Caribbean and Black African are five times more likely. Halvorsrud et al., 2019)
- ❖ experience coercive pathways to care (e.g. police and criminal justice system; detention under the mental health act (Halvorsrud et al., 2018)
- ❖ receive biomedical vs. talking therapies.

There is a strong correlation between multiple forms of social disadvantage (e.g. employment, housing, outcomes of educational achievements) and risks of both severe mental illness and coercive treatment (Nazroo, Bhui, & Rhodes, 2016). However, little is known about:
- ❖ processes underlying these inequalities
- ❖ how these disadvantages are experienced
- ❖ how they shape people's lives and interactions with mental health and other institutions, and
- ❖ what this means for service design.

Institutional Racism

Institutional racism has been drawn on to explain these inequalities, however, the processes of institutional, structural and interpersonal racism and how they constitute and reproduce one another has been under theorised (Nazroo et al., 2019).

Aims

- ❖ To address these gaps and inform policy development and practice through a participatory action research (PAR) approach

- ❖ To explore the life histories of ethnic minority people experiencing severe mental distress and those who work with them

- ❖ To improve service delivery for ethnic minority people

Primary Research Questions

1. How have racialised identities shaped experiences of severe psychological distress over the life course?

2. How does that relate to interactions with mainstream mental health services and other institutions (e.g. school, criminal justice system)?

3. How are these experiences of 'race'/ethnicity shaped by other dimensions of social identity (i.e. gender, class and generation)?

4. What are experiences of alternative forms of support beyond formal institutions?

Methods

Tackling inequalities: Politicising research

To explore these questions, an approach that can illuminate context, complexity, and contradiction is needed. Thus we adopted an in depth biographical qualitative approach embedded within Participatory Action Research (PAR).

PAR Cycle: Making Praxis

What is Participatory Action Research (PAR)?

Researchers and marginalised groups work together as colleagues with different skills to offer in a process of mutual learning throughout all stages of the research and strive to improve the lives of those involved in the research process (Cornwall & Jewkes, 1995). Key aspects and rationale for PAR include:

- ❖ an explicit political agenda for promoting social justice and transforming current practices or power structures
- ❖ 'democratizing' knowledge through co-production
- ❖ expanding focus from the individual to social-structural level
- ❖ constructing new meanings through reflections on action
- ❖ developing critical consciousness of researchers (what Freire called 'conscientization')
- ❖ drawing on many ways of knowing (epistemologies)
- ❖ seeking to transform reality "with" rather than "for" oppressed people
- ❖ a living, iterative process that cannot be predetermined

Participants

- ❖ 30 ethnic minority experts-by-experience and 10 experts-by-profession with diverse social identities and experiences with mental health services.
- ❖ Recruitment: multiple domains including ethnic minority community and mental health organisations, self-help volunteer organisations, service-user led organisations (e. g. Hearing Voices Network, National Survivor User Network: NSUN), faith-based and arts organisations.

Data Collection & Analysis

- ❖ qualitative individual face-to-face interviews (2-4 hours audio recorded & transcribed) adapting the biographical narrative interpretive method (BNIM: Wengraf, 2001).
- ❖ "Integrally psycho-societal, BNIM...facilitate[s] an integrative understanding of both the 'inner' and the 'outer' worlds of 'historically-evolving persons-in-historically-evolving situations'" (Wengraf, 2001).
- ❖ BNIM analysis emphasizes: the life history, the life story (how the story is told/constructed) and the relationship between the two.
- ❖ digital stories demonstrating key turning points from the interviews will be created
- ❖ these stories will be shown during focus groups with key stakeholders (experts-by-experience, carers, experts-by-profession, commissioners) adopting an Experience-Based Co-Design approach to identify policy priorities.
- ❖ Reflective field notes are used to provide greater context to the transcripts and promote critical self-reflection.
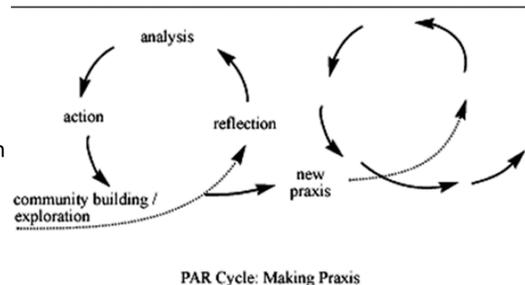
Initial Observations

Emerging Themes

Racialised identity

Sense of exclusion/othering

"...wanting to feel appreciated by people who are white y'know..." [Anila, identifies as mixed race (Bengali, White Czech) and bisexual]

"...just sort of because everyone else is white I just knew that I was different and sort of my mum would sort of make me aware of that of the fact that I was different." [Anila]

Intersections of gender, class & race

"I'd really like to be white." [Anila]

"I felt really ugly compared to all the rich white middle class girls". [Nia]

Pathologising racialised identities

"I sort of had like body dysmorphia. I suppose it's to do with the fact maybe that I look different to other people and obviously like ((audible crying)) that made me think that that I was like just ugly". [Anila]

"I don't, I don't, I don't like um sometimes I think that coloured people are called 'unwell' when they just react and just to a situation and they just get called unwell 'cause they're just making some noise or something when really nobody's bothering to look into why: they're making noise." [Ashraf, identifies as mixed race (Black African, White British)]

Interactions with Mental Health Services
Medical vs Psychological Therapies

"I think being in hospital made me ill rather than before hospital" [Pauline, identifies as Black Caribbean].

"It was the first time somebody sat me down and listened to me..." [Pauline on the first contact with a psychologist]

"Someone is saying y'know we think you need some support, we can support you. They're taking an interest but I find them unhelpful in the sense of when I'm stating my case saying y'know this medication is har:ming me or this medication may not be what's best for me ((yawns)). I NEED TO WORK, they wouldn't listen to me and um that's what I found really unhelpful (pause) because when I remember one time I was going for a job and then this guy was saying why would I wanna hire someone who's smacked up on medication (pause)... And so if they're not willing to give me a chance and give me a break from this medication so I can get employed, how is that helping me at all or how is that y'know how is that even benefitting me at all anyway." [Ashraf].

Lack of acknowledgement of the impact of intersection of racialised and other marginalised identities

"I knew how I was (read) how people perceived me um and put things onto me because of my race because of my gender and all of that so to not be allowed to bring that into the space and to have it medicalised was quite difficult really and made everything worse really ((pause)) cos I want to feel like a whole person in a space and I don't ((laughs loudly)) a lot of the time." [Nia, identifies as Black British, non binary and queer]