INTERNATIONAL ASSOCIATION FOR PSYCHIATRIC NURSES

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"Agenda 2030: Repositioning Mental Health Care"

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University of Essex

Dedication
To JESUS THE CHRIST

The Way, Truth & Life
John 14:6

The Saviour
Matthew 1

The good shepherd
John 10

The true vine
John 15

The bright and morning star
Revelation 22

In HIM we live, move and have our being
Acts 17

"Behold I come quickly"
Revelation 3

Exploring the relationship between Locus of Control and the perception of the quality of mental health care experienced by Black and Minority Ethnic Community in the United Kingdom

Dr Stephen Joseph

The Context of the study – Black people and mental health

- There is a longstanding, well-documented history of racial disparities in mental health services
- The Care Quality Commission report (2013) shows persistent inequalities in mental health for BAME groups, and specifically those from African and Caribbean backgrounds.
- The Chief Medical Officer's 2013 report (Davies, 2014) shows that people from African and Caribbean backgrounds are more likely to be:
  - given a diagnosis of schizophrenia;
  - admitted to hospital via police intervention;
  - have higher rates of detention under the Mental Health Act;
  - experience the harsher end of treatments such as control and restraint;
  - and less likely to be offered more socially oriented interventions.

The Context of the study -2

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- There is also extensive research into the inequalities in mental health for Black and Minority Ethnic (BME), particularly African and Caribbean (A & C) communities (Care Quality Commission, 2014; Crisp et al, 2016; Keating, 2016);
- “Stalled cycles of recovery.” (Bhui & O’Hara, 2014; NHS England, 2016; Robinson et al, 2011)

The Context of the study -3

- However, there are no clear-cut explanations (Department of Health, DoH, 2013), or strategic direction towards reducing such inequalities (Crisp et al, 2016).
- This study explored this issue from a different perspective by addressing the dearth of enquiry into possible connections between unexplored concepts as a possibly useful explanation and action model towards addressing the inequalities relating to A & C mental health

UK Context-Health Inequality (2022 Report)

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- **the over-use of coercive mental health treatment under the mental health act for Black Caribbean and Black African groups**
- **increased rates of mental illness for Black Caribbean and Black African men**
- **systematic persecution from psychiatric services and criminal justice systems**
- **these groups much more likely to be subjected to coercive treatments such as involuntary admission to mental health wards, Community Treatment Orders and violence from state systems.**
- **Black patients in the UK are also subject to more intrusive treatments, such as injectable anti-psychotics**
- **are less likely to be offered talking therapy for severe mental illness.**
- **the under-use of specialist mental health services by South Asian (Indian, Pakistani and Bangladeshi) groups (NHS Race & Health Observatory, 2022)**

Aims of the Study

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- To explore the challenges from the ambits of the tension between care and control in psychiatry
- To apply the concept of perception of control to explore possible answers to the current reported poor mental health experiences, profiles and negative outcomes of the subject population, (see locus of control article- Joseph & Keating, 2021) in references) and
- with a view to arriving at some suggestions to improve the current status – from service user perspectives, and
- To identify how services across all sectors (statutory, non governmental/voluntary) can be developed to better support the community.

The Conceptual Framework - Locus of control (LOC)

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The concept (LOC) refers to

- the extent to which individuals perceive the level of control they have over events in their lives,
- this in turn, plays a role in determining their responses to various occurrences and situations (Rotter, 1966; Strickland,1978; Declerck et al, 2006; Wallston, 1992; Joseph & Keating, 2023).
- Individuals are placed on either an ‘internal’ or ‘external’ spectrum in locus of control.
- LOC is a continuum rather than a static location- influenced by factors

The Conceptual Framework - Locus of control (LOC)

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- Individuals who believe that their actions determine what they receive fall within the ‘internal’ spectrum
- those who believe that what happens to them is determined by external or environmental factors, over which they are unable to exert any influence, are considered to have an ‘external’ locus of control (Rotter, 1966; Strickland,1978; Declerck et al, 2006; Wallston, 1992).

Study design

- Qualitative design
- Data collection with mental health service users of African and Caribbean (A & C) origin
- All participants based in South London
- Conducted via in-depth face to face engagement:
  - One-one interviews (x 10) - six female and four male
  - Two focus group sessions (14 x services in total- sixteen male and female)

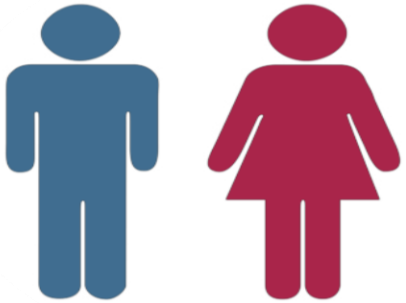

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Table 1. Demography of study sample

One-to-one interviews x 10				Focus groups x 2		
Variable	**Results**	**Percentage**		**Variable**	**Results**	**Percentage**
Gender				**Gender**		
Male	**4**	**40%**		Male	**6**	**42%**
Female	**6**	**60%**		Female	**8**	**58%**
Age	**Range**	**Mean**		Age	**Range**	**Mean**
	36-58	**47**			**32-55**	**43.5**
Marital status				**Marital status**		
Single	**9**	**90%**		Single	**13**	**93%**
Married/cohabiting	**1**	**10%**		Married/cohabiting	**1**	**7%**
Ethnicity (self-described)				**Ethnicity (self-described)**		
Caribbean	**6**	**(60%)**		Caribbean	**9**	**64%**
African	**4**	**(40%)**		African	**5**	**36%**
Employment status				**Employment status**		
Employed	**0**	-		Employed	**0**	-

Analysis of Data

- Analysis of the data was conducted following an idiographic approach
- In line with the Interpretative Phenomenological Analysis (IPA) procedure (Smith et al, 2012).

Findings…

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Superordinate Themes	Subordinate themes
1.Perception of Control-meaning	1.0 Taking important decisions 1.1- On everyday matters 1.2 — Regarding mental health 1.3- Spirituality in taking decisions
2.Perception of Levels of Control in relation to mental health experience	2.0 Levels of control- mental illness triggers 2.0.1 — Stress factors 2.0.2 - Identity challenges 2.1 Different levels of control-services experience 2.1.1 Admission process and hospital experience 2.1.2 Level of control- contradictory post discharge Experiences
3.The role of culture in LOC	3.1- Significance of culture in identity and LOC 3.2 Significance of family in culture and LOC 3.3 Perception that their culture was being ignored in respect of diet and other support for self-care in hospitals 3.4 Low perception of African and Caribbean ethnicity and cultures by mental health services
4. Experiences of Care and Control in Mental Health services	4.1 Coercive practices 4.2 Lack of consistent care 4.3 'Earning' discharge 4.4 Personal needs not being met.
5.Suggestions for improving experience for African and Caribbean clients	5.1 Staffing by African and Caribbean, including senior roles/models 5.2 Professionals to show interest in the culture of African and Caribbean people 5.3. Listening to ideas of clients and their family members 5.4 Post discharge support 5.5 Community approaches 5.6 Clients approaches

Findings...focus for this presentation

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1.Perception of Control- mental illness triggers	1.0 – Stressful factors 1.1 - Identity challenges
2.Perception of Different Levels of Control in relation to mental health experiences	2.0 Admission process and hospital experiences 2.1 Levels of control 2.2 Contradictory post discharge experiences

Table 2 - Superordinate and subordinate themes emerging from the results

Stress factors as mental illness triggers work, society/racism, etc

"From work…. It was a strain. I used to do a lot of hours, used to start at 7 in the morning and finish at 9 at night and it's catering and it's constant…..all the time". (Alison, 1-1)

"…..it lead to the breakdown… umm….I was doing a lot of hours and I wasn't eating well and um…it was a constant thing of worrying all day and you don't realise the pressure. I'm still shocked that I'm still here". (Carla, FG2)

Stress factors as mental illness triggers work, society/racism, etc…

“ “But the major thing that really, really sent me over the edge…remember racism and prejudice based on culture and belief……. just doesn’t start at one point. It starts from the year dot, it’s continuous; and it breaks you down and it breaks you up inside and it mashes up your head…. he phoned my friend and she came and got me in the pub, and I stayed in bed for about 2 weeks in her house and that was the real start of what I call my breakdown. That was it from there and from there I had to go and see a psychiatrist, the doctor came and took me to the psychiatrist…”. (1-1)

“… I had a lot of racism, I had a lot of racial problems and erm…..I had a lot of anxiety. I suffered from anxiety from a young age”. (1-1)

“Well my reaction was gradually erm... frustration and annoyance and stress and erm...gradually.....leaving the post”. (1-1)

Stress factors as mental illness triggers work, society/racism, etc…

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"Well I actually feel that if I had have been a white British...I would have made it because ...I know and I know that because I was there. So I erm..I feel that based....I was denied an opportunity based on my skin colour". (FG2)

"Well essentially my mental illness has been caused by predominantly traumatic events in my life. Bullying at school, mistreatment by mother's neighbours and stuff like that …" (Dwayne, 1-1)

"Well how I was brought up, the way I was brought up; because I had so much abuse…racial abuse..I would come in crying to my family saying "someone called me a blackie or a nigger" or something like that. I used to have terrible things said to me" (Brian, FG1).

Loss of identity

"Well I was a very confused person, I had no identity; I didn't know my identity and I was controlled. My people and the authorities controlled me, I had no say, I had no say". (1-1).

"I felt it was very important for me to formulate my identity but at the time I was half in half out in terms of my own mind because I was struggling with mental illness at the same time and I didn't know it you know". (1-1).

"It's very difficult you know, you know I have got two degrees in my time. One in law and one in biomedical science, which I didn't complete for various reasons, because I became ill or gave up for various reasons. So what I'm trying to say is I'm not stupid. So it's really difficult to find facilities who really cater for me you know, in terms of my identity, my interests, you know they were trying to be nice to me but I remember they were talking to me like a child you know? I was 38 years of age. People are affected differently and people react differently you know" (1-1).

Differences in perceptions of control – pre, during and post hospital experiences

"The first time they put me in hospital they took me in there in my underwear… they wouldn't even me let me put my clothes on when they came. They just kicked the door down and just rushed in and they just started talking all this rubbish about all these things I didn't do…… Then I was in the shower with the door kicked off and I said to them "well if you're going to take me away I expect you to let me put my clothes on and you can take me away. They took me out of the place in my underwear, put me in the unit, took off my underwear, gave me an injection, I fell asleep and woke up on the ward…." (1-1).

"On my admission to the mental health hospital, which was some years ago now I had no control over it, I had no say in it at all. A short excerpt from my story is that I was at my mum's place having dinner and she called the doctor in to examine me, the police came and they took me in the ambulance to the mental health hospital. I didn't have a say in it all, everything happened so fast and the mechanism that was in place was that I didn't have a say in it and to this day I'm still trying to have a say in it even though it all happened a long time ago. So what I'm doing now to help with this …interview um…is of benefit to me as well …. to speak up about what happened to me you know …. and for someone to say well this is awful or this is good or this is something you know? ….I had no control". (1-1).

Differences in perceptions of control – pre, during and post hospital experiences

"…decisions were made for me and the only way I could influence them is by....is by...well, basically agreeing to what had been said and then coming back and saying my opinion on what that decision was. So, I did learn to....I didn't really challenge any decisions because that wouldn't have helped the situation I don't feel. I was better off trying it, coming back and saying why I agreed with it or disagreed with it". (1-1).

"I had no say in the medication they forced me to take. I was like a baby because of the medication which I called a spiritual strait jacket." (FG1)

".. I had no control of my life when I was in hospital and decisions were made for me and I had to do that but power came in for me when I made the decision that I'm not staying in hospital. "I don't know what's going to happen, what's going to take place, I don't want to stay in hospital, I want to go home" I tried as best and I could and see the outcome..." (1-1).

Post hospital experience – contradictory levels of control

"Well obviously I feel that I've found myself now and my identity and I feel that I'm able to speak up a bit more for myself now and things like that and they can't dictate to me….they can't control me. They used to be able to do that in the past" (Jane, FG1).

"…but I ….with the boredom that's actually built up over my life over the years um….you still need someone talking to you, you still need someone that's normal ummm..making sense for you. You still need all that, you don't know what's sensible really, you don't know what's sensible". (Dwayne, 1-1).

"It sits on you and stirs you up um… it's just hard talking about it because you're not that far from it…it's not like it happened, it took place and you get over it. You can't really get over it because there's so many things going on, so many things attached to it. From home to hospital it's different, just to…just to….I have to walk around the streets just to make sure, just to know… I'm around my place….I'm by myself that I'm not with people like I used to and I find I get tired but you know it needs to be…it needs to be with people that can explain" (1-1).

"Oh yeah, I feel as I'm pretty in control yeah, yeah….Erm….with my mental health, with my physical health to a degree. I mean there are certain things that will come up with my physical health that it's just natural and wear and tear as they say. My housing situation is under control, my financial situation is under control. My day to day living is under control" (Carla, FG2).

Post hospital experience – contradictory levels of control

"To a degree I'm in control and in part I'm not in control because like I said it's this medication. If I come off this medication I'm scared. I don't know what would happen to me so I feel that I am controlled by the system to stay on the medication and to another extent I could try to come off the medication slowly with the help of the professional people…..and see what happens". (Carla, FG2)

"To a degree that I am and to a degree I feel that I'm not because I'm on medication now permanently and I feel like I'm not in control and not in charge because I feel that the medication is in charge of me". (Tim, FG2).

"To be in control of one's life, we can live from day to day …maintain our house if we've got one, maintain our life, maintain bills erm....maintain mental and physical health. Be able to socialise, be able to interact, be able to stand up for oneself when we need to, be assertive, be confident and let the doctors and the mental health team….to be able to make them aware of who we are and our capabilities and needs and things like that and that we are in control".(FG2).

""After such a long time in that place, having no control I felt….um….I was mad. I wasn't able to think about getting back. I've been brought this way and what am I going to do, what am I going to do? I don't know anyone, I just don't know. I expected to be in more with doctors and stuff like that but um…it doesn't seem to work that way" (1-1).

Post hospital experience – contradictory levels of control

"…. I mean, I was not in control, couldn't get any more career, and the psychiatrist, as I have said, those bloody tablets she gave me half killed me anyway. And, I ended up like a bloody zombie on benefits". (FG2).

"Because you know just as any healthy you know mentally stable person can be all sorts of different people they seem to be putting all the mental health sort of down route to this kind of average and it's not going to be…I mean most people are just not going to be shop cashiers or whatever when they're, when they're well. They're going to be creative people or constructive people or social and there doesn't seem to be any option other than get well". (FG1).

"…so again going to a psychiatric hospital yes you're mended you're well, you're given all the support and the psychological help and you're on the right balance of medication but if those stressors are still in the community, unless you have developed coping mechanisms or a way to accept that or deal with it you're always going to be fighting against it and end up ill or you are just going to become subdued and accept what's happened so it doesn't seem like a win, win situation". (1-1).

Post hospital experience – contradictory levels of control

"You have to claim benefits and in order to claim benefits …and in order to claim benefits you have to comply with job centre, you have to comply with your GP, you have to go to the GP and the psychiatrist to get the letters to support your claim…you have to do everything otherwise you just end up in trouble". (FG2).

"That's it. Just get well and once you're a little bit well, once you have a little bit of control it's like "ok, go to the job centre, there are the jobs there so go and mess up your life…" and then you're back to square one". (FG2).

"Well I am dependant on the government for my finance, for my benefits and I'm dependant on the government for my medication which I need. So, society plays a big interference in my life…". (1-1).

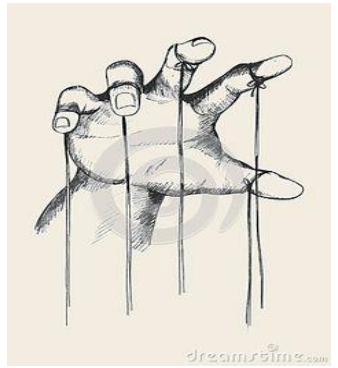
"…but I also think that not feeling any control kind of keeps it perpetuating further because yes in a lot of ways I do feel ummm kind of control or are or kind of at the mercy of others. I mean because kind of you know I mean I live in…I'm on benefits, I'm on supported housing and so you're kind of living on somebody else's money and somebody else's property. It's like you know…that in order to live…" (FG1).

Barriers to recovery

- Lack of ongoing support
- Depersonalised services
- Unsafe environments - relationships, location (i.e. going back to previous ‘life’), cultural response
- lack of personal safe spaces – to talk/open up
- Lack of meaningful activity – activities valued by the individual
- Being ‘frozen in time’

Social isolation

Loss of control



Lack of recovery: *"frozen in time"*

I need to get the support to learn how to unlock, not unlock…release the baggage….But I'm just afraid where that might lead. Could I manage it? If I can't which way will I go

Previous associations and hegemonic masculinities

Medication

Social recovery

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- Varied meaning – some common features:
  - Control – sense of agency
  - Hope – optimism about the future
  - Trust – regaining trust in others/self
  - self-management – managing daily living
  - Healing – physical and mental health – reflexivity/balance
  - off-medication
  - Re-negotiating identity/masculinity
  - ‘social inclusion’ – work, family, socialising
- Motivations – reasons for wanting to ‘progress’ (i.e. family/children)
- Pathways – availability/sequence of care and support

Emerging understandings of being human

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If, I could give any advice to anybody, I'd say the strong thing to do, the manly thing to do as such, is to seek help. The weak thing to do is to hide it.

I've dropped the macho act and I mean I don't wanna have to be the Mr Macho, she didn't marry me because I'm a Mr Macho, you know what I mean

Frank Bruno, that boxer guy, you know he done mental health issues, didn't he?

Focus on men's experiences? Masculinity and recovery

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So, I'd definitely say, you know, associate yourselves with people who support you….you might have a friend that's … Mr Hard Man, and he believes that he shouldn't seek help, or they believe he shouldn't seek help. They believe he should brush it under the carpet…no disrespect but you don't need people like that around….

Recovery and re-negotiation of identity

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I learnt to love myself and also be around positive people, positive energy…

The old friends I used to have, how do I overcome that barrier? How do I get past it or through it? It is by slowly distancing myself from them. That's the only thing. I think anybody would have to do that .

Built my life around mental health now, so I go to the groups and the away days, and things like that…Whereas before it used to be a bit of a party, going out, raving, you know, it took a toll on me…

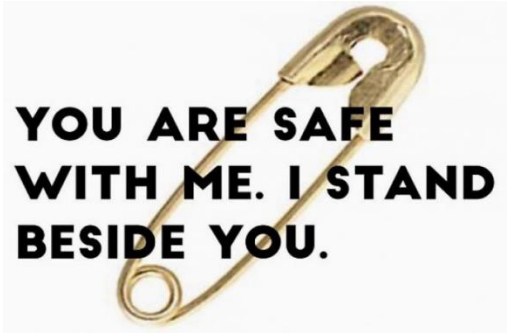
What's needed to re-negotiate identity

Safe spaces

Practical help

Authentic relationship

Enjoyable and meaningful activities



That's the other thing about he men's group, I like. Everybody here would support. They seemed to know when you was not feeling too good, or you were going through a bad spell….That's what I like about the men's group. When I got into it I really like it

Tailored safe spaces

No disrespect to other races, but you know, Jewish people understand Jewish people more than an Islamic person, do you know what I mean. An Islamic person understands an Islamic person more than a Black person. A Black person understands a Black person more than a white person…

You know the NHS is just going to provide you with a … person that don't really care about you

Alienation from mainstream services

Enablers to recovery

- Safety
  - Spaces to talk; not stigmatising institutions (i.e. medical, family) and community
- Meaningful, positive activity
- Routes to ‘social inclusion’ – to be less isolated
- Personalised/life course/holistic – taking account of the ‘whole’ person, personal needs/preferences
- Joined-up/triangle – communication between stakeholders
- Continuity of care – i.e. from the same professionals
- Socio-cultural approaches – ethnicity, gender

Conclusions

- Recovery is a process – support/services needs to reflect this – be appropriate for service users in different stages
  - i.e. interventionist to start, progress to support role
  - i.e. one-to-one, progress to groups
  - i.e. social activity, progress to volunteering (to employment?)

- Service users may not come from a ‘safe’ environment (i.e. culture, gender norms), returning to the same environments may not support recovery - how can we provide safe spaces??

- Service users do not need to make every decision/do everything they want (i.e. come off medication) – but need to feel part of a conversation

Today's questions

1. Focus on location of this conference and other parts of the world?

2. What are the messages of the findings for Africa and other regions?

Literature Review, Methodology; Data collection; Analysis

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Research Findings

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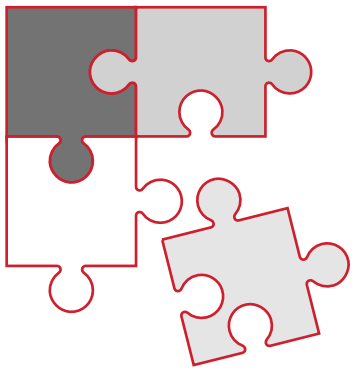
Analysis of existing
(a)Practices
(b) Policies in similar contexts >> Identifying Implementable Policy Options



Addresses Inequalities in Mental health Care

Improve Mental health outcomes

Today's questions- focus on location of this conference?

What are the messages of the findings for Africa?:

1. Practice?
2. Policy?

Controlling My Life? : How to Achieve Positive Mental Health Outcomes for Minority Ethnic Communities from Their Own Perspectives

https://www.amazon.com/Controlling-My-Life-Communities-Perspectives-ebook/dp/B0968PL58Z/ref=sr_1_1?crid=5B0IPUEQ1H47&keywords=stephen+Joseph+controlling+my+life%3F&qid=1686747984&sprefix=fe+improving+mental+health+for+minority%2Caps%2C8786&sr=8-1

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