Navigating the mental health system: Narratives of identity and recovery among people with psychosis across ethnic groups

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ABSTRACT

There is consistent evidence that members of the black Caribbean population in the UK are more likely to have coercive relationships with mental health services, typified by high levels of police involvement and compulsory treatment. This research has relied upon a medical epidemiological framework that has enumerated differences in service use but failed to unravel the complex interplay of individual, social, and cultural factors that inform the pathway to care. The purpose of this study was to explore the journey through mental health services from the perspective of individuals from the black Caribbean and majority white British population to help understand variation in the use of mental health services. Individual interviews were conducted with 17 black Caribbean, 15 white British, and 3 non-British white people with psychosis as part of AESOP-10, a 10 year follow up of an ethnically diverse cohort of individuals with first episode psychosis in the UK. Thematic narrative analysis identified three overarching narrative categories: ‘losing self within the system’ narratives gave primacy to individuals’ identity as a chronic psychiatric patient with participants unable to break the cycle of service use; ‘steading self through the system’ narratives combined recognition of the value of psychiatry and its limitations with the ability to access psychological therapy and protect valued social roles; ‘finding strength beyond the system’ narratives challenged negative dominant discourses and emphasised social, interpersonal and intra-personal factors in recovery. We found variation in narratives across ethnic groups with ‘losing self within the system’ narratives most common, though not exclusive to, black Caribbean participants. Distress appeared rooted in social structures that disadvantage black people, and psychiatry appeared to be experienced as a further form of oppression, that initially provoked resistance and fear, and over time, resignation to the identity of psychiatric patient.

1. Introduction

Over the past 40 years, research on psychoses and ethnicity has focussed on the high incidence of psychotic disorder in minority ethnic groups, particularly among the black Caribbean population in the UK. Research has found that persistent inequalities exist in how individuals from minority ethnic groups access mental health care, highlighting higher rates of compulsory admission to psychiatric hospitals, and the increased involvement of police, among black Caribbean people with psychosis compared with the white British population (Bhui et al., 2018). However, in recent years, the narrow focus of this body of research has been criticised for an overreliance on a medical epidemiological framework that serves to enumerate differences in service use across ethnic groups, but fails to explain the causal mechanisms behind the observed associations, creating a static, one-dimensional model of pathways to care (Harrison, 2002; Morgan et al., 2004; Bhui et al., 2018).

To address these limitations, and elucidate why these disparities occur, the pathway to care must first be recognised as a dynamic social process involving an interplay of individual, social, and cultural factors. Here we can apply insights from sociological and anthropological studies of help seeking (Kleinman, 1980; Pescosolido and Boyer, 1999; Morgan et al., 2004). Viewed within this framework, ethnicity does not operate as a discrete category that can be neatly correlated with outcomes of interest, but as a complex set of historical and contemporary processes and disadvantages that shape how individuals experience the health system (Bhui et al., 2018). Kleinman’s Health Care System model (1980) played a key role in advancing understanding of how illness

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responses and interactions with health care are informed by the cultural framework in which individuals make sense of their experience. Kleinman coined the term ‘explanatory models’ to describe the notions that individuals hold about specific illnesses and their treatments (Kleinman, 1980). Kleinman proposed that these explanatory models, though fluid and changeable, are anchored in the social and cultural context in which they arise, which can contribute to discrepant clinical realities (socially legitimised beliefs, roles, relationships, and expectations around treatment) that in turn can impede health care (Kleinman, 1978). Understanding ethnic differences in the use of mental health services therefore necessitates an understanding of how people make sense of their experiences, how this changes over time, and of the norms and values that inform these explanatory models across ethnic groups.

Within the health field, interest in personal narratives has translated into a focus on illness narratives (Kleinman, 1988). The genre of illness narratives reveals how people construct narratives to help organise chaos into a coherent life story and reshape their sense of self in relation to the illness (Adame and Hornstein, 2006). Here narrative can be viewed not only as reflecting identities, but creating them (Bamberg, 2000). Categories have been proposed to capture the different types of illness experience and related concepts of self. The medical sociologist Arthur Frank (1993) distinguished between ‘restitution’, ‘chaos’, and ‘quest’ narratives that are used to structure and interpret stories over the course of an illness (Frank, 1995). The ‘restitution’ narrative de-emphasizes the patient’s self-identity, depicting a movement towards recovery of health through the power of medicine and doctors. Stories of ‘chaos’ lack a sense of a viable future as the self is lost among experiences of suffering and incomprehensible events. The ‘quest’ narrative affords the ill person an active voice, holding chaos at bay and meeting “suffering head on; they accept illness and seek to use it” (p. 115). Though providing valuable insight into the subjective experience of living with a chronic health condition, the applicability of these narratives across cultures has yet to be explored. Instead, commentators suggest they have been positioned as transcultural truths of human experiences, despite relying heavily on narrative research in high income and English-speaking countries (Woods, 2011; Llewellyn-Beardsley et al., 2019). Moreover, others argue that illness narratives are not simply a reflection of lived experience but a function of the interpersonal context, differences in social position between narrator and listener, and the broader belief system within which they are expressed (Murray, 2000).

Western society’s dominant medical meta-narrative provides an overall context in which personal narratives exist. Meta-narratives, or master narratives, can be defined as socially sanctioned ways of interpreting experiences that supress personal perceptions and dictate how to define the self (Sakalys, 2000). The language of the biomedical model, which defines distress in terms of mental dysfunction and disease, both describe and dictate how people conceptualise their own struggles (Adame and Hornstein, 2006). Crowe (2000, p584) writes that the process of psychiatric diagnosis reduces the experience of individuals to “a priori categories of normality and abnormality that reveal a strong gender, culture and class bias”. Critics have challenged the assumed universality/objectivity of diagnostic categories as a value judgement about undesirable beliefs and behaviour, articulated from a viewpoint of Western individualism (Szasz, 1974), that effectively marginalises individuals’ experience of mental distress and the social-political and cultural context in which it occurs (Thakker and Ward, 1998). Mental illness narratives reveal that a person’s identity can come to feel defined by his or her diagnostic label. These diagnostic classifications may enhance the perceived ‘groupness’ of people with mental illness and ‘difference’ from the population, leading to stigmatising ideas about (enduring) negative traits that may become internalised by the individual (Corrigan, 2007). Individuals from minority ethnic groups may be particularly vulnerable to a loss of identity if forced to adopt meanings and interpretations that conflict with their own experiences and culturally and materially shaped models of and responses to distress (Crowe, 2006).

Subsequently, narratives of emotional distress have been sought that provide an alternative to medical conceptions of mental illness, both mirroring and enabling a shift towards a recovery paradigm that emphasises empowering people to take an active role in shaping their own recovery and pursuing full and productive lives (Ridgeway, 2001). Sharing personal stories of mental distress has been central to the psychiatry survivor and service led user movements that emerged in the 1960s and 70s and has helped to build a sense of solidarity and hope among sufferers (Morrison, 2013). Narrative inquiry had helped to provide structure to these stories, supporting participants to sequence their experiences in temporal order, and identify themes and processes across them (Rhodes, 2014). Narrative approaches to mental illness have focussed on the potential disturbance to the self in psychosis. In a review of first person written narratives of madness, Adame and Hornstein (2006) identified three clearly defined types of subjective experience of emotional distress: ‘traumatic interruption’, in which the emotional crises felt foreign to the person’s usual sense of self, ‘purposeful suffering’ in which the person’s life was interrupted, but the experience become a catalyst for a personal revelation, and ‘continuity’, in which emotional turmoil was considered an ongoing part of life, or a person’s diagnosis is embraced as part of his or her identity (Adame and Hornstein, 2006).

Mad studies, the academic discipline that emerged around the survivor/service user movement, has increasingly focussed on using narrative research to investigate the experiences of individuals within recovery. Described as ‘sister paradigms’, narrative studies and recovery have been found to share 10 common emphases on meaning, identity, change and development, agency, holism, culture, uniqueness, context, language, and giving voice (Spector-Mersel and Knaife, 2018). A recent systematic review and synthesis of narratives of recovery from mental health distress (Llewellyn-Beardsley et al., 2019) challenged and extended Frank’s (1995) original typology, adding narratives of ‘escape’ from services or treatments experienced as damaging to those of ‘enlightenment’, ‘endeavour’, and ‘endurance’. They observed that recovery narratives could be characterised according to their positioning in relation to the clinical model of health with narratives of ‘recovery despite the system’ and ‘recovery outside of the system’ highlighting the role of inter-personal and social factors. The review also highlighted that narratives of psychosis were comparable in characteristics and emphasis to those of other forms of psychological distress, challenging the stereotype that people with psychosis lack competence or insight into their illnesses. Finally, however, they conclude that research into the narratives of more diverse populations is needed.

Despite recognition that socio-cultural factors influence experiences of illness (Kleinman, 1988), experiences of recovery (Spector-Mersel and Knaife, 2018; Tuffour et al., 2019) and how stories are told and interpreted (Hinton and Levkoff, 2000), we are unaware of any narrative studies that have sought to understand individuals’ journeys through mental health services from the perspective of those in minority as well as majority populations. In the present study, we use qualitative methods, and specifically narrative accounts that prioritise the perspective of individuals with mental illness over time, to gain insight into the social and cultural processes at work in shaping different responses to mental illness and interactions with mental health services.

2. Methods

2.1. Design

We conducted a qualitative study to explore the experience of living with psychosis and navigating mental health services among individuals of white British and black Caribbean ethnicity. The study was embedded in AESOP-10, a follow up study at 10 years of 532 individuals with first-episode psychosis that sought to investigate the course and outcome of psychosis across ethnic groups in the UK (Morgan et al., 2017). Our
approach was informed by work on narrative analysis, specifically experience-centred research that assumes that illness narratives serve a personal function, helping individuals to make sense of their illness and reconstruct identity around it. In this context narratives can reflect how someone feels about themselves and how they want to be seen by the listener (Ricoeur, 1991; Squire, 2013). Attention was also given to the role of the interview context in shaping the stories, specifically the differences in social positioning between the narrator and researcher (Murray, 2000). Thematic narrative analysis was used to examine the content of these long-term experiences at the personal level within and then across the individual accounts (Reissman, 2008).

2.2. Participants

Seventeen black Caribbean (BC), 15 white British (WB), and 3 non-British white (NBW) participants were purposively selected from the AESOP-10 sample to ensure roughly similar numbers of black Caribbean and white participants and to ensure a spread in terms of gender, age, and mode of entry into services (i.e., voluntary vs. compulsory) (see Table 1).

2.3. Data collection

Care was taken throughout the research process to stress that participation was entirely voluntary, the interviews confidential, and the decision to take part independent of any care that participants might receive. All interviews were conducted face to face in participants’ homes or at the research institution, according to individual preference, and typically lasted between 1 and 2 hours. Interviews were conducted by CM, a white male social scientist who was already known to participants through his involvement in data collection for AESOP-10. In the first instance, participants were asked to recall, in their own words, what brought them into contact with mental health services for the first time. Participants were then asked about their journey through services, from onset to present day, using broad, open ended questions to elicit detailed accounts, following “participants down their trails” to understand the role that the mental health system played in their lives (Reissman, 2008, p24). The interviewer used follow up questions to elucidate meanings and, where helpful, constructed a thumbnail sketch of service use to facilitate talk about specific events and places. The interviews were audio recorded and transcribed verbatim. Ethical approval was provided by the Joint South London and Maudsley and Institute of Psychiatry and Research Ethics Committee (Ref: 321/02) and written informed consent was obtained from all participants.

2.4. Data analysis

A thematic narrative analysis was undertaken through a process that consisted of five stages. First, the research team listened to individuals’ interviews, reviewed transcripts, and completed case histories that summarised the salient themes and progression of themes in each interview to encourage a case centred approach. Second, each interview was characterised as a whole by identifying the dominant tone of the narratives (Crossley, 2000), and the core narrative in each story was summarised as succinctly as possible (Mischler, 1986). Third, individual interviews were coded using NVivo 12 (QSR International, 2019) to create narrative themes. We sought to examine the relationship between themes and their progression within each individual account before making comparisons and searching for common experiences across stories. Fourth, we constructed a chart that included core narrative, narrative tone, and dominant narrative themes (identified as attributions and positioning in relation to the clinical model, diagnosis and recovery) to help manage the depth and breadth of data and explore patterns in participants’ experiences (see Appendix 1). Fifth, we developed a typology of narratives that characterised the stories broadly into three overarching groups that we present in the findings. Finally, we consider the meaning of these narratives in relation to prior theory in the discussion.

2.5. Commitment, rigour, transparency, and coherence

We used various strategies to raise awareness of our influence on the data, to ensure the completeness of data collection and analysis, and to produce an account that resonated with participants and readers (Yardley, 2000). For each interview, at least two of the three authors (VL, white British female, social scientist; CMc, white British female, former mental health practitioner and service user; GN, white Greek male, MSc student) independently developed case histories that were then amalgamated, and analysed transcripts, each recording reflections on dominant narratives and trajectories in analytic diaries, before meeting to compare and justify interpretations, referring back to the data in discussions. CM commented throughout on the extent to which the analysis resonated with his experience of conducting the interviews. VL continually checked emerging interpretations of common themes against the individual transcripts and looked for contradictory data, immersing herself in the participants’ accounts. We acknowledge that CM’s work exploring the social influences on the aetiology and outcome of psychosis and VL’s experience exploring illness experiences in older people across ethnic groups contributed to an awareness of the limitations of the medical model.

3. Results

An examination of narrative tone and narrative themes, including attributions and positioning in relation to the clinical model, diagnosis, and recovery (see Appendix 1), suggested that narratives, though overlapping and unique to each individual, could be categorised into three overarching groups: 1) losing self within the system; 2) steadying self through the system; 3) finding strength beyond the system. These categories were typified by certain patterns of experiences and beliefs (See Fig. 1).

3.1. Losing self within the system

Some narratives portrayed individuals as enmeshed within mental health services – as ‘losing self within the system’. Evident in the accounts of 11 black Caribbean, 3 white British, and 1 non-British white participant, these narratives conveyed a sense of disenfranchisement and ongoing struggle with participants seemingly unable to break the
cycle of service use. Victoria (BC) recounted the dates and circumstances of her repeat admissions with clarity, noting both the familiarity of life on inpatient units and the cyclical nature of these admissions, precipitated by alterations within the community during the “danger period” surrounding the anniversary of her mother’s death. Daniel (WB) also described a long history of service use in which periods of stability were punctuated by the erratic use of medication and hospital admissions. His despair at being unable to escape this cycle was evident: “I was so sick of being in and out of hospital and having to take tablets and feeling so down that I just wanted to die I think by then”. Medication had helped Kelvin (BC) to reduce his voices, and monthly visits from his Community Psychiatric Nurse (CPN) provided him with limited but regular social contact, yet his narrative, like many others in the group, conveyed a sense of hopelessness. Vivid memories of hunger pervaded his account; at best, he imagined life would remain the same, at worst, he feared a return to poverty, an experience fused with fear and paranoia in his mind. When asked if being poor could cause schizophrenia, he replied:

Yeah, definitely ... when they ain’t got money or no food or that, they start to do stupid things, like I’d come out my house at the door and someone, a neighbour would be going in his car and he’d say hello and I’d ask him if he can borrow me some money ... he said he ain’t got any you know. I didn’t know what to do. Sometimes like you say, it’s only hours before the Post Office opens for me to change the cheque, I’d get up from the bed and I couldn’t go in because I was so hungry and that, and I was shaking, and I couldn’t go out. (Kelvin, BC)

A recurring theme within this group was the narrative that doctors know best, and diagnoses had been made and accepted on this basis. Harrison (BC) described a lack of agency during his three inpatient admissions and contact with clinicians in the community. When asked how he would describe his problems he replied, “They say it’s schizophrenia...”, but appeared unsure of what that meant or what contributed to his relapses. A sense of resignation seemed to characterise these accounts.

I can’t remember, they did various things like blood samples, swabs and urine tests, I think they did all of that, and they said that the way they analysed me was that I had schizophrenia, because I’d been smoking cannabis, and I had a nervous disorder, because I’d become nervous, that’s what they said.

Interviewer: And what do you think, do you think you have schizophrenia?

That’s what they say, I don’t know, I don’t really know, I’m not really trained to say if I have or I haven’t, but that’s what they say. (Charlie, BC).

This was reflected to a degree in participants’ interactions with the interviewer. Darryn (BC) spoke with deference, commenting that his psychiatrist “knew what she was talking about, as do yourself”, while Laura (WB) invited a professional judgement on the diagnosis that she had been given, asking, “I’m manic depressed, do you think I am?” By contrast, a small proportion of narratives, notably among some black women participants with children, appeared guarded with emphasis placed on how well they were doing. Again, this seemed indicative of interactions with mental health professionals. At the end of one such interview, Denyse (BC) reflected: “I don’t know what madness is but ... I wouldn’t say anything, I’d let them [CPN] do the talking but I won’t contradict or say what I think if you know what I’m trying to say because whatever I say is not right but what they say is right so that’s why I don’t say anything.”

The narratives also revealed tension between accepting diagnoses and the need for treatment, and deeper beliefs that ‘schizophrenia’ and ‘psychosis’ signified madness. Daniel (WB) described his poor adherence to medication in these terms: “There was this ongoing conflict between am I crazy or am I not and I decided no I’m not, I’m going to do without this I’m going to get by without it, I’m not taking tablets because there’s nothing wrong with me”.

Stigmatising language was commonplace and Daniel recognised that his fear of being locked up in a “mad house”, or as Charlie (BC) put it in a “padded cell”, had prevented help seeking in the past: “I didn’t want to say
that I was hearing voices in case I got put into hospital and I was confirmed mad”. Narratives were frequently used by participants to distance themselves from other patients on wards who were characterised as “proper mad” (Abigail, BC). Though many appeared to resist these labels, there was a sense that some had come to define themselves in these negative terms. Victoria (BC) explained that she accepted that she had a mental illness because “I’m feisty, I’m too much of it, there’s something wrong with me, yes”.

Yet these narratives also put social circumstances and psychological scars at the heart of the distress experienced and participants spoke at length about experiences of financial insecurity, abuse, and violence. Darryn (BC) attributed his mental illness to “the pressures of life” including prison sentences that had precipitated periods of homelessness:

“That [prison] really shook me up because I lost my life then, I lost my flat, I lost all my furniture, I lost my clothes, I lost everything … If you can see all these [homeless] people and the general look on their faces, you can see that life’s taken its toll on a lot of people and it’s made them that way. Life’s made them that way, not that they choose to be because when you’re teenagers you couldn’t imagine having that change of life from being vibrant to maturity which is just dull and boring you understand because sometimes got hold of you and are you accepting that you’ve got a mental illness and the facts of life you know. (Darryn, BC)

Laura (WB) described how years of bullying at school and the sudden loss of her grandmother had induced an acute sense of fear that had never been addressed. After years of close contact with CPNs and four repeat admissions, she felt that her symptoms were now bearable, but that mental health services had let her down by failing to address the traumatic events in her childhood. Like others in this group, she had not accessed talking therapy and appeared to have little hope that she would receive support for these issues in the future.

3.2. Steadying self through the system

The narratives of 14 white British participants characterised mental health services as imperfect, but central to their recovery. The tone of these accounts was typically reflective with participants using the discussion to make sense of and/or educate the interviewer on how services had helped them navigate their mental illness. Psychiatry was characterised as serving a purpose that ultimately enabled them to move forward with their lives. Though flawed: medication helped alleviate symptoms; inpatient admissions kept them safe; diagnoses described their condition. Like others across the sample, experiences were attributed to the pressures of life including financial worries, work pressure, bereavements, traumatic events, and abuse. Around two thirds of this group spoke of the value they had derived from intensive work with psychologists, therapists, and/or counsellors that provided a space to reflect on emotions, thought processes, and past trauma. Following his first and only admission to an inpatient unit, Jonathan (WB) followed the advice of his psychiatrist and sought a psychodynamic counsellor whom he saw weekly for six years. He concluded, “It’s [perceived recovery] particularly to do with the counselling, particularly unearthing one or two key incidents in my past and starting to deal with the emotions that are attached to them that were quite traumatic in their own right, and it took me that long to get to what they were and start dealing with the emotions around them”. (Jonathan, WB).

Depression, you could say psychosis I suppose, if you wanted to get more clinical or you could use some of the names my neighbour calls me which are wonderful, nutter, madman, crazy, that kind of thing.

Interviewer: And what about your family how did they respond?

Actually I get on better with them now since the diagnosis than before, I mean for them it helps explain a lot of things, you know, and they’ve been pretty good about the whole thing, really. (Benjamin, WB).

Theses narratives tended to portray an upward trajectory in which individuals had a biological predisposition to mental illness but had now reached a stage where they were able to live well with their condition. Some put the experiences of mental illness firmly in the past, for example Oliver (WB) and Richard (WB), and Beth (WB) and Lydia (WB), who felt that their psychotic episodes had been precipitated by illicit substances and prescription drugs, respectively, and had subsequently been treated. Beth explained, “I’m over and done you know, it was something, was an episode something that happened, it was induced, drug induced, it was not … so … it shouldn’t have any bearing for future things”.

Often contained within this narrative arc were references to a residual inner strength or ‘survival mechanism’ that had given individuals the confidence they could recover. Reflecting on his experience of drug addiction and psychosis, James (WB) explained: “There was always a little candle in there still burning, it’s never blown out you know, it definitely inspired me to really make something of myself”. Similarly, for Beth (WB), Lydia (WB), and Christine (WB), continuing to bring up their children meant that an essential part of themselves remained intact: “I never lost my kids, I never stopped looking after them, I was always preserved, I was always sane, although the world would say you’ve lost the plot, you know”. Like others in this group, Christine likened recovery to an unpleasant journey that had ultimately enhanced her resilience. She concluded, “I think a lot of life’s painful experiences are like that, it moulds us, it shapes us, separates the wheat from the chaff, you know, I think it addresses a lot of issues that maybe you wouldn’t look at otherwise”.

Other participants in this group spoke about formal education or careers being disrupted but ongoing, providing an important anchor in their lives. Despite years of instability and periods of acute ill health, Christopher (WB), Lydia (WB), Sara (WB), and Beth (WB) obtained university degrees and teaching qualifications and continued to work with the support of family, friends, and employers. Beth (WB) was unequivocal that she needed to work during periods of depression and following manic episodes: “I had to, I didn’t give up work, I wanted to keep some normality in a way in my life”. There was recognition that recovery depended upon myriad factors including resilience, social support, and input from psychiatric services. Christopher (WB) concluded: “I would put it [perceived recovery] down to five things possibly, my Mum, my close friends, medication, the professionals and of course me, I have played a big part in me getting better”.

Most acknowledged the social and psychological dimension of their condition. Like others across the sample, experiences were attributed to the pressures of life including financial worries, work pressure, bereavements, traumatic events, and abuse. Around two thirds of this group spoke of the value they had derived from intensive work with psychologists, therapists, and/or counsellors that provided a space to reflect on emotions, thought processes, and past trauma. Following his first and only admission to an inpatient unit, Jonathan (WB) followed the advice of his psychiatrist and sought a psychodynamic counsellor whom he saw weekly for six years. He concluded, “It’s [perceived recovery] particularly to do with the counselling, particularly unearthing one or two key incidents in my past and starting to deal with the emotions that are attached to them that were quite traumatic in their own right, and it took me that long to get to what they were and start dealing with the emotions around them”. (Jonathan, WB).
3.3. Finding strength beyond the system

The final group of narratives explicitly rejected a clinical model of mental health. The tone of these accounts, evident among five black Caribbean women and one white British man, appeared critical, but also appreciative of the opportunity to share their story with the interviewer on what they had endured in the mental health system and how they had overcome it. Ira (BC) explained that her diagnosis of bipolar disorder had acted as a prism through which her behaviour had been seen, such that her candour and inclination to question treatment decisions were sometimes misconstrued as mania. She reflected that it had taken years to separate herself from this identity: “If you’re told enough times you believe it.” These narratives resisted the premise that mental health services played a decisive role in their lives. Contact was downplayed, as if inconsequential, and questions around the role of services in recovery were often dismissed.

Instead, narratives in this group served to normalise the experiences of mental illness through incorporating them as an inherent part of who they are and positioning them as an appropriate response to harmful interpersonal experiences and negative social circumstances. Ira (BC) concluded, “I don’t know one person where extreme outside stress really badly situations have happened, and it hasn’t affected them one way or another”. Patrick (oW) explained his condition in similar terms: “I feel acute responsibility, I feel I’m not being a good, I’m not being a provider, I’m not playing a role in life so what is mental illness, is it all the stress I’m experiencing”. These accounts also brought certain characteristics to the fore, as individuals explained their experiences in the context of being deeply sensitive, artistic, imaginative, deep thinking, or spiritual. Together these narratives asserted the importance of the social, psychological, and spiritual aspects of their illness and lives.

I wouldn’t put it in a doctor’s … I wouldn’t use the same language you would use for it … For me it was a spiritual journey, it was a massive spiritual journey, and yes you do need help on the way and you do occasionally need something to help you sleep or you do need protection, but there’s a lot of other things in the medical system that you don’t need … it’s [psychiatry] very sterile, a lot of it is very sterile and it is very clinical, and it’s a narrow perspective of life … If you’re trying to tell people that if they’ve had a broader experience then their life isn’t correct and they’re mad and they need drugs to not live that way, when actually a lot of people need to live that way and they need to go through this experience, and they don’t need to be told that there’s something completely wrong about them or be locked up? (Paula, BC). One of the things I need to do which is one of the things the psychiatrist never actually clocked on to, which is quite bizarre, is that I’m adopted, so that is like a very large segment of my life”. Therapists and counsellors had played an important role in helping individuals in this group to talk about painful emotions and experiences. Conversely, psychiatry was strongly criticised for neglecting these important aspects of individual’s lives.

4. Discussion

Participants’ accounts have been broadly characterised according to one of three narrative themes at a fixed point, several years after participants first entered mental health services. ‘Losing self within the system’ narratives gave primacy to individuals’ identity as a chronic psychiatric patient with participants unable to break the cycle of service use; ‘steadying self through the system’ narratives combined recognition of the value of psychiatry and its limitations with the ability to access psychological therapy and protect valued social roles; ‘finding strength beyond the system’ narratives challenged negative dominant discourses and emphasised social, interpersonal, and intrapersonal factors in recovery. We found variation in narratives across ethnic groups with ‘losing self within the system’ and ‘finding strength beyond the system’ narratives most common, though not exclusive to, black Caribbean participants. We did not target participants who self-described as recovered and the stories took different forms, encompassing ‘upward’, ‘up and down’, and ‘horizontal’ trajectories seen elsewhere within the literature (Llewellyn-Beardsley et al., 2019). Nevertheless, we found they provided valuable insight into the social and cultural factors that might hinder or enable people with psychosis to move towards living well and resist, or in some cases cast off, the role of ‘chronic patient’.

5. Methodological considerations

It is important that the data are discussed in the context of certain methodological considerations. We acknowledge that researcher preconceptions and identities inform the entire research process, contributing to the construction and interpretation of the accounts given. Both black and white British participants appeared to welcome the opportunity to share their experiences, and we have endeavoured to follow interviewee’s concerns. However, as white academics we remain hierarchically privileged outsiders (Squire, 2007) and there are limits on our understanding. There is a strong argument for including black voices in the research team and/or processes in future research, for instance, conducting Participatory Action Research to ensure that the research strategies are conducted collaboratively. Moreover, the research does not speak for those who may not have felt comfortable or well enough to participate in a research interview.

Participants did appear to derive value from taking control of their story in the research interview. Shlomith (2002) suggests that this act of telling is a way of reclaiming narrative order and keeping the chaos that can accompany illness at bay. Coupled with a cultural expectation for immediately I feel phew, it’s gone I’m not carrying it around anymore, the next thing I do I’ve got my incense on, I’ll have a bowl of porridge, something like that something wholesome and nutritional with a banana, have a bath and go back to bed, something as simple as that and I’ll feel much better. (Rebecca, BC).
5.1. Becoming a chronic psychiatric patient

‘Losing self within the system’ narratives were most common among black Caribbean participants. Narratives exhibited a high level of self-stigma that gave primacy to individuals’ identity as a chronic psychiatric patient (Corrigan, 2007). Previous studies have identified the weight of stigma attached to mental illness among minority ethnic groups (Kovandzic et al., 2011) with mental health problems provoking avoidance and discrimination in some black communities (Memon et al., 2016). High levels of police involvement and compulsory treatment are likely to exacerbate this fear and inculcate a sense of powerlessness in relation to mental health services (Bhui, 2018). Studies of recovery among individuals of black and minority ethnic origin have suggested that the stigma of mental illness may be accentuated by multiple intersecting disadvantages including the additional stigma associated with race, culture, ethnicity (Leamy et al., 2011). The narratives available to people who have serious mental health problems, who have been described as among the least powerful of minorities, are often negative, narrow, and/or written by others (Rappaport, 1995). People from minority ethnic groups and those with experiences of poverty, homelessness, abuse, and the criminal justice system may be even more vulnerable to oppressive master narratives that “inscribe their life stories with internalised and public expectations of failure, diminish- ment and lack of future possibilities” (Onken et al., 2007, p18). In this context, psychiatric services may not be experienced as therapeutic, but as a form of oppression that initially provokes resistance, and over time, acquiescence, and resignation to the identity of psychiatric patient.

5.2. Structural disadvantage

The influence of the psychiatric meta-narrative in the ‘losing self’ narratives was striking, revealing how the voice of those in emotional distress can become lost in the psychiatric discourse (Adame and Hornstein, 2006) and power structures. We found that participants often attributed their distress to social and environmental experiences, rooting it in precarious living situations, poverty, and fraught relationships, which in turn perpetuated the cycle of service use. This is consistent with evidence of socioeconomic disadvantage among the black Caribbean population in the UK, including higher rates of unemployment and higher proportions of persons living in low income households than in the majority white population (Khan, 2020) that are fundamental drivers of ethnic inequalities in physical and mental health (Hudson et al., 2013). Yet these experiences and attributions appeared marginalised as participants defined their mental pain in terms of the clinical diagnosis that they had been given and ostensibly deferred to doctors and medication to fix them. Though suggestive of Frank’s ‘restitution’ narrative, participants voiced little expectation that treatment would restore their health. Instead, a profound sense of hopelessness pervaded these accounts (Frank, 1995). Narratives conveyed a sense of despair that individuals could not escape their illness or their circumstances, which appeared inextricable in participants’ minds.

These findings highlight the importance of the wider socio-environmental context and the relevance of viewing recovery within an ecological framework in which characteristics of the individual, characteristics of the environment (such as opportunities), and characteristics of the exchange between the two (such as choice), interact to promote or hinder recovery (Onken et al., 2007). For example, the ‘steading self’ narrative, evident among some white British participants, provided examples of positive social circumstances in which family, friends, and colleagues supported individuals to maintain careers and formal education, which in turn, helped nurture a belief that they could recover. In quantitative analyses of data from AESOP-10, we found evidence of worse long-term social, clinical, and service use outcomes among black Caribbean compared with white British people with psychosis (Morgan et al., 2017). Crucially, various indicators of social disadvantage and isolation at first presentation were found to contribute to the greater likelihood of a continuous course of symptoms and low rates of symptomatic recovery. Taken together, the findings of our quantitative and qualitative analysis suggest that improving mental health not only rests upon alleviating symptoms, but on addressing wider social issues that can co-occur with and be compounded by mental illness, such as poverty and social marginalisation. According to the ecology framework set out by Onken et al. (2007), these social circumstances can deprive individuals of meaningful options for how they wish to live their life, stifling hope and the ability to act in self-determined ways. Critically, these experiences, for many black people, are rooted in structural disadvantages that pervade society and which psychiatry fails to fully address, as the things that matter most to patients are relegated to the periphery, to be addressed – if at all – on an ad hoc basis by allied professionals (i.e., social workers, occupational therapists, etc.). Further to this, psychological therapy was positioned as remote and unattainable in ‘losing self’ narratives, despite lives being enmeshed with psychiatric services. This is consistent with evidence that psychological therapy is less likely to be offered to black African and African Caribbean service users and may not be culturally appropriate or geographically accessible (Bignall et al., 2019). It is also possible that these participants did not have the same financial means to fund associated childcare costs, transportation etc. or private counselling or therapy as described in other groups.

5.3. Bridging the gap between social and psychiatric models of mental illness

In the ‘steading self through the system’ narratives, evident among white British participants only, mental illness was often attributed to an innate biological propensity, but one that was triggered by severe negative life experiences and adversities. These accounts seem to illustrate how medical frames of reference could be used to create a ‘self-protective narrative’, alleviating feelings of self-blame and shame (Peters et al., 1998). Participants recognised the utility of medication for managing symptoms but were unequivocal that their experience could not be reduced to psychopathology and biological treatments. In line with previous accounts of recovery in service users who combine biological and environmental attributions (Jacobson, 2001), participants sought ways to use the system as part of an overall strategy of self-management, trying a variety of providers and treatment modalities. Compared with ‘losing self’ narratives, ‘steading self’ narratives appeared more likely to give voice to the limitations of psychiatry and the value of accessing psychological therapies. This in turn seemed to help bridge the gap between social and psychiatric models of mental illness and avoid the conflict in clinical realities seen in other narratives (Kleinman, 1978). Another distinctive aspect of these narratives was the struggle to protect key aspects of identity and pursue valued social roles. Participants spoke of their need to continue in jobs or at university and the support that they received to do so. Arguably, maintaining a non-illness self-concept helped prevent entrenchment of the chronic patient role (McCay and Seeman, 1998). Individuals’ accounts of their inner belief that they would recover suggested a sense of agency that was absent from the ‘losing self’ narratives, which may have been augmented by external opportunities for positive change.
5.4. Reauthoring of experience

The ‘finding strength beyond the system’ narratives align with narratives of ‘quest’ that afford the ill person a voice to tell their own story, often centred around personal growth, in which medication and doctors are no longer the remedy (Frank, 1995). There are also parallels with narratives of ‘escape’ from the identify of chronic psychiatric patient and the belief system surrounding the medical model of mental health (Thornhill et al., 2004). Participants described their alienation from the framework that psychiatry used to understand and treat their mental health problems and of the gulf between this and the social, psychological, and spiritual dimensions of their illness. These narratives seemed to challenge and externalise negative dominant discourses through finding meaning and value within their own experience, for example in reclaiming a positive self-concept in which psychiatric symptoms exist as part of a creative or spiritual identity. Here, as in the ‘steadying self’ narrative, recovery involved integrating illness into the self-concept, so that it is seen as a part, but not the totality, of the self (Jacobson, 2001). As evidenced elsewhere in the literature, these narratives challenged the authority of the clinical model through suggesting that recovery can occur without the intervention of services (Llewellyn-Beardsley et al., 2019). Instead, emphasis was placed on social, interpersonal, and intrapersonal factors, such as nurturing oneself, developing coping strategies that promote health and wellbeing, and withdrawing from destructive relationships and environments. This reauthoring of experience has been identified as a pivotal task in the interpersonal, and intrapersonal factors, such as nurturing oneself, living well. We have drawn on an ecological framework that argues that logical, and spiritual dimensions of their illness. These narratives through finding meaning and value within their own experience, for example in reclaiming a positive self-concept in which psychiatric symptoms exist as part of a creative or spiritual identity. Here, as in the ‘steadying self’ narrative, recovery involved integrating illness into the self-concept, so that it is seen as a part, but not the totality, of the self (Jacobson, 2001). As evidenced elsewhere in the literature, these narratives challenged the authority of the clinical model through suggesting that recovery can occur without the intervention of services (Llewellyn-Beardsley et al., 2019). Instead, emphasis was placed on social, interpersonal, and intrapersonal factors, such as nurturing oneself, developing coping strategies that promote health and wellbeing, and withdrawing from destructive relationships and environments. This reauthoring of experience has been identified as a pivotal task in the process of personal growth and recovery (Onken et al., 2007). Though these narratives described a path to recovery, they also encompassed periods of distress and alienation from services, as participants sought to defend themselves against the role of the chronic psychiatric patient. It is difficult to identify specific resources or turning points, but one can speculate about the role of spirituality in these accounts, which may have helped to engender hopefulness, and the social circumstances, family networks, and opportunities available to those demonstrating ‘strength beyond the system’ narratives who were typically employed, living in their own home, and highly articulate. Forging a new life path rests upon the availability of resources (Rothman et al., 1996).

6. Conclusion

The aim of this study was to explore experiences of the health care system, yet there is also evidence in the narratives of progress towards living well. We have drawn on an ecological framework that argues that the process of recovery requires both internal and external resources to overcome psychiatric disability and the accompanying stigma imposed by society. The data suggests that distress among black and minority ethnic groups is rooted in social structures that disadvantage black people. Black participants appeared most vulnerable to oppressive master narratives and most likely to experience psychiatry as another form of oppression that did not address the sources of their distress. These findings underline the necessity of interventions that target social disadvantage in this population, including better access to psychological therapies, Individual Placement and Support for employment (Bond et al., 2013), and peer support for isolation. We suggest that to be optimally effective, a package of social interventions is needed across multiple domains to break the cycle of entrenched social disadvantage and disengagement that leads to worse outcomes, especially in those from black minority groups.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at [https://doi.org/10.1016/j.socscimed.2021.113981](https://doi.org/10.1016/j.socscimed.2021.113981).

Author contribution

Vanessa Lawrence: Methodology, Formal analysis, Writing – original draft preparation. Catherine McCombie: Formal analysis, Writing – Reviewing and Editing. Georgios Nikolakopoulos: Formal analysis, Writing – Reviewing and Editing. Craig Morgan: Conceptualization, Methodology, Data collection, Supervision, Writing – Reviewing and Editing, Funding acquisition.

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