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Analysis

Making a difference: ethnic inequality and severe mental illness

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Summary

In this paper, we explore ethnic inequalities in severe mental illness and care experiences. We consider the barriers to progressive and cohesive action and propose ways of overcoming these. Clinical and policy leadership must bring together hidden patient voices, divergent professional narratives and quality research.

Declaration of interest

K.B. is Editor of the *British Journal of Psychiatry*, but has not played any role in the decision-making for this paper. K.B. leads and J.N. is a partner and K.H. a researcher in the Synergi Collaborative Centre.

Keywords

Ethnic inequality; severe mental illness; ethnic minority groups.

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In this paper, we explore the intractable problem of ethnic inequalities in severe mental illness and care experiences, and the common explanations. We consider the barriers to progressive and cohesive action, in both society and in professional practice, and propose ways of overcoming these. Inadequate research methods that fail to interrogate experience alongside survey or administrative data have contributed to a lack of compassion about what is at stake for those who experience severe mental illness and inequalities. We explore how societal processes including racism cannot be separated from the question of how to reduce ethnic and social inequalities and multiple disadvantages. Dominant and yet divergent professional narratives, and failure to learn lessons and build on past experiences, are products of social and psychological defences against the pain of noticing injustices. Individual and group political ideologies and power relationships are then enacted to sustain inequalities. Leadership and commitment to bring together hidden patient voices with divergent professional narratives and more precise research are needed to improve the health literacy on the evidence and motivate interventions.

Ethnicity and health inequalities

Members of some ethnic minority groups experience an increased risk of a first diagnosis of severe mental illnesses, especially psychoses. People in all ethnic minority groups – but most notably Black Caribbean, Black African and Black British people – with a diagnosis of severe mental illness experience higher rates of contact with the police and criminal justice system, more admission to psychiatric hospitals, less voluntary in-patient care and less primary care intervention.[1–4] Greater levels of criminal justice system involvement for Black Caribbean and Black African patients do not reflect reported violence or levels of substance misuse, nor delays in access to first-episode services.[5,6] Compared with other ethnic groups, Black Caribbean men and women are more often referred to specialist mental health services when recognised to have a mental health problem by their general practitioner, rather than being treated in primary care.[1] Some other subgroups are notably at a higher risk of compulsory treatment: women, older people, those experiencing social isolation, those lacking an advocate or general practitioner involvement and those facing multiple service contacts.[2,7–10] These trends may signal wider issues of disempowerment, lack of trust, social exclusion and a lack of political influence, evident most in ethnic minority groups but common in other patient groups who complain of exclusion and dissatisfaction with care. These complaints are heard in local patient groups and are rarely captured in the research or professionalised evidence.

There is significantly more use of the Mental Health Act (MHA) for some ethnic minority groups despite decades of investment in considering least restrictive options and alternative healthcare provisions.[11] Use of the MHA varies by providers and is higher in urban areas, with increased area deprivation and ethnic density. MHA use is especially high for Black Caribbean, Black African and Black British patients in the UK.[12,13] Aside from the commonsense notion that people would favour the least coercive and most empowering pathways to care that maximise autonomy (therapeutic choice), there are financial arguments for less use of the MHA and reducing tackling inequalities in the use of the MHA. The greater use of the MHA necessitates more use of in-patient beds, growth in legislative safeguards like tribunals, and more need for advocacy and quality standards in assessment and treatment processes. These additional demands have not been adequately included in cost models. So, reflecting the greater risk of compulsory treatment and the additional incurred costs, in a study in London, the cost of in-patient care for Black patients was 2.4 times that predicted based on population numbers. If the spending for Black patients was the same as the average across all groups in London, £76.2 million savings could be realised.[14] This report also indicated twice as much spending on Black patients compared with White patients on community services. If service use were the same for Black and White patients, a further £23.8 million would have been available for investment.

What explains inequality experiences?

Why should ethnic groups require more care through community, in-patient, forensic, and criminal justice services or by MHA use? Socioeconomic factors are likely to play a role in the increased risk of diagnosis of mental illness found for some ethnic minority groups. However, although poverty and social factors are often proffered to explain disparities in the use of care services and the MHA, it is important to note that adjusting for social factors does not fully explain the higher use of care services or rates of compulsory assessment and treatment in some ethnic minority groups.[15] Other factors are, thus, likely to be important. Furthermore, the statistical method

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of treating such factors as confounders obscures the ways in which social and economic risks are shaped by the ways in which ethnic identities are understood and acted on – meaning that within these statistical models we will be removing important, closely associated influences. This procedure reflects a poor understanding that ethnicity as a variable reflects a complex set of historical and contemporary processes and disadvantages, and is not only an individually embodied and discrete category of person. People do not live as adjusted versions of themselves, and one might question whether social adversity linked to race and ethnicity is, in fact, fundamental to the construction and experience of ethnicity, including the experiences in health systems. For example, social adversity, including discriminatory events and traumas, acts as the exposure (causal risk factor) and then also shapes these effects as well as emotional and behavioural responses, which can constrain the exercise of protest and expressions of power.[16,17] For example, the American Psychiatric Association's recent statement on racism and mental illness suggests that traumatic interactions can result in poorer self-esteem and internalised hatred, reflecting how adversity can undermine resilience and the ability to protest and protect.[18]

Cultural explanations

Sometimes explanations for differences in treatment are related to ethnic differences in beliefs, expectations and attitudes to mental illness, or to the nature of the illness (for example, whether it is experienced as an emotional, social or religious problem), which may deter help-seeking.[19] In addition, the way services are constructed, organised and run can systematically favour those who more closely fit these structures and processes, those who are familiar with how services operate and where professionals and patients share an understanding of the role of specialist mental healthcare.

Dynamic interactions between patient–professional and patient–health system take place in spaces in which systematic inequalities may emerge with no ill intent or obvious failings in practised standards of care.[2] Yet, to understand this we need a richer empirical evidence base built on patient experiences, to inform appropriate responses and accommodate the needs and priorities across diverse patient groups. Some patients present with unusual symptoms that include culturally shaped health beliefs or idioms of distress that may be misunderstood as being a physical disorder, if the metaphors used are of bodily functions. Alternatively, symptoms may be judged to be delusional beliefs if they seem to invoke supernatural forces or witchcraft. Also, explanatory models of distress may suggest to the clinician that difficult social and relationship strains should be the foci for remedy rather than mental distress being privileged for priority intervention. There are also differing thresholds for the willingness to express psychological distress across cultures.[20–22] In some instances there is under-recognition of mental illnesses; for example, in personality disorders,[22] when other interventions may be considered more appropriate, such as housing or social care or substance misuse services. These are certainly helpful, but the underlying distress or mental illness may not be identified precisely enough and thus interventions may not be offered. Cultural beliefs about illness, or explanatory models for the experience of illness around causes, consequences and expectations of treatment – held by both the patient and the clinician – will determine the motivation for, and types of help-seeking behaviours. These influence the clinician's impression about diagnosis and appropriate treatment, although the clinician's own cultural experiences and ways of relating to cultural and ethnic groups and their own ethnic identity will invariably influence what is noticed and what is overlooked.[23]

Systemic and structural influences

Various analyses over the years suggest that patients of Black Caribbean, Black British or Black African heritage experience a pattern of adverse pathways to care.[1,24] These findings have been sustained for over 30 years and more recent evidence suggests that similar inequalities might exist for patients in other ethnic minority groups. Despite the long period over which these inequalities have been documented, we have not seen effective actions or sufficient motivation to tackle them. Although there have been periods of public health and National Health Service action, these were time limited and insufficiently resourced or engaging, given the intractability of the problems, with no visible or sustained shift in ethnic variations in pathways to care.[25] Although interventions to improve care pathways are proposed,[26,27] there is little evidence that these are more widely adopted or implemented, or that these are being refined and evaluated nationally and regionally.

How can we explain these variations? Explanations for inequalities are likely to lie in trajectories starting with early-life experiences, school exclusions, a lack of educational opportunities and achievement and a lack of sustainable employment; some identity groups are excluded and disempowered, leading to social defeat and demoralisation; and some early-life social networks operate through fears, threats and domination, leading to crime.[28]

Language matters. Do we use the language of health inequalities and disparities or of racism and discrimination? Perhaps this is a false dilemma, as structural inequalities lead to discriminatory outcomes irrespective of whether discrimination is individually felt or noticed. However, the idioms in which these inequalities are explained and tackled either engage or disengage people across or within patient movements, professional disciplines and commissioning and policy circles. Language can be motivating if it resonates with experience; but it can be demotivating or produce opposition if it is perceived as dispiriting or attacking of ideologies and in that instance it can therefore perpetuate inequalities. Some agreement is needed on the vocabulary for any shared and cohesive effort.

Racism, prejudice and discrimination are frequently invoked to explain ethnic inequalities in health, social and economic outcomes. A systemic analysis is needed of how racism works in society and in organisations. Racism, prejudice and discrimination can take many forms, and are more openly expressed at times of austerity and political extremism (e.g. war on terror and Islamophobia in the USA, Brexit and hostility toward migrants in the UK and the growth of right-wing nationalist movements globally).[29,30] There is growing evidence showing the relationship between experiences of racism and discrimination and the risks of mental illness.[31–33] However, there is little empirical evidence that individual-level, conscious and prejudicial attitudes of clinicians act to disadvantage specific groups.[2] At least the complaints and reports of blatant behaviours and attitudes are unusual, given the greater emphasis on equalities policies and the growth of educational and developmental programmes. At the same time, the latest surveys of National Health Service care show that bullying, harassment and discrimination are not uncommon experiences in our workforce, and that senior staff and board representation is not commensurate with population demographics on ethnicity and race.[34]

Health professionals do need to hear views about discrimination, gender disadvantage, racism and all varieties of prejudice and respond constructively. Patients who feel disbelieved, where suffering is not understood or accepted, are unlikely to be at ease or willing to open up in conversation. This dynamic between the patient and professional is not likely to foster trust or the

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foundations for an alliance with balanced and respectful negotiations around treatment expectations.[35] Dismissing discrimination in general, and specifically racism as a subjective attribution not verifiable by objective measures, fails to recognise the degree of distress that racism engenders or the physiological and health effects of the experience of discrimination. Denial and non-recognition are important elements of the psychodynamic of racism and enactments of prejudice.[36,] The reality is that racism is not obvious nor easily detected in everyday life, and a fear of persistent racism in society has an effect on health even in the absence of direct violence. Interpersonal behaviours and communications may be seemingly innocuous, yet can signal prejudicial attitudes, a lack of trust, fear or avoidance. These microaggressions can lead to poor health and the effect can be felt by ethnic minorities, but are also felt by women experiencing disadvantage from any professional group.[37–39] Methods for assessing microaggressions are still being developed, yet their observation in practice needs only vigilance and a willingness to notice and discuss their intrusion into interpersonal and institutional life. Structural and organisational racism reflect broader conditions in which all varieties of racism thrive. Beliefs and fears about racism act as a mechanism by which coping responses are thwarted (statements like racism is not objective, for example), and only unhealthy coping is possible through either 'flight-or-fight' reactions or anger, which are harmful for health.

New paradigms

The explanations for disparities in pathways to care warrant inspection and critique so that we can progress to evidenced solutions to these longstanding and apparently intractable, complex and forever changing issues, also called 'wicked problems'.[24,40] The wider community, health and social systems, which reliably and predictably continue to generate institutional inequalities, need to be better investigated and targeted for intervention.

A challenge for all is that data have shown no change in patterns;[7,41,42] indeed, that was the reason the Count Me In census was ended, as no improvements were seen.[43] When perceived to be competing over scarce resources at a time of austerity, the rise of extremism and prejudice in the UK, USA and Europe may cause additional distress. It is regrettable is that we repeatedly fall foul of these privileged psychological and political processes that contaminate group thinking and leadership and promote specific types of political discourse that support economic exploitation, which means we end up manufacturing discriminatory policy. Attempts to remedy inequality and discrimination are then vilified and hampered by limited resources, lesser allocated priority and even assertions that tackling discrimination or inequality is undermining the social fabric of a race neutral or culturally blind society.

The indelible effects of racism, historical injustices and deprivation are not invisible to people affected by such experiences. This invariably leads those subjected to inequalities to express outrage and yet also perplexity at the silence. One response to this is that official policy language changes to silence mention of race and racism, as if a change of vocabulary alone removes underlying injustice and structural disadvantage. At some point there is an awakening or an incident and the search for the causes of health and societal inequalities reappears. One could argue that the Prime Minister's Race Audit (https://www.gov.uk/government/publications/race-disparity-audit) is an example of a sudden awakening after a period of silence, in the context of rising extremism, discrimination and growing inequalities. We anticipate a more thoughtful and progressive response for any future actions is needed rather than a reassertion of silence. Clinical, social and political leaders must be cognisant of these repeated historical and yet also contemporary patterns of responding to race relations.[45–47]

The lack of recent data works against an overarching commitment to tackle inequality or monitor progress of efforts. This loss of visibility and silencing is compounded by data that neglect the role of new and emerging ethnicities and identity groups. There is much hybridity of identities through which people experience the world and relate to others. In such a constructionist paradigm, we risk that ethnic inequality in pathways to psychiatric care is overlooked or neglected for fear that ethnic categories are too broad to understand causes of inequality and effect change. This can be most challenging when distress or inequality is felt through links to a deeper and more specific set of identities, rather than the race or ethnic label that is adopted in official statistics. This tension is also in flux, and different latent identity characteristics are activated at times of adversity or conflict, or when coordinating protest. The recent acronyms of BME and BAME (Black and minority ethnic) do nothing but classify large groups of people into categories that can never work for all people falling in those categories – just as race-based categories do not work in all circumstances, neither will ethnicity. Ethnic categories are devised and applied usually by those in positions of power, when there is a need for group data. Cultural categories are actually complex simplifications of collective and individual identities, related systems of shared beliefs, kinship systems and implicit behaviours.

Producing a consistent framework that tackles the macro or structural factors as well as the interpersonal and felt experience is challenging because the level of resolution or precision is invariably less when one level of analysis or felt experience is applied to the other. There is disagreement about how to transform health systems that generate race or ethnic inequalities without implicating individual interpersonal behaviours and prejudicial attitudes. The causes of inequalities are unlikely to be related to only a single protected characteristic such as race, gender, religion, age, disability or even non-protected characteristics such as poverty, unemployment or class; prejudices operate across these categories and can be felt in unexpected ways.[48] Inequality emerges because of combinations and clusters or intersectional sources of exclusion, disempowerment and sustained and deepening disadvantages that operate through and are sustained by power relationships.[49–52]

The wider influence of area deprivation, low income in families and impoverished localities (in terms of green space, lack of leisure facilities and safe shared public spaces, access to schools and healthier food, parental health literacy and employment opportunities) all produce poor health outcomes. In turn, these influences in urban environments can undermine mental health. In combination, individual or structural violence and discrimination lead to more traumatised and less confident, informed, resourceful and resilient communities. The combination of these factors with impoverished and unresponsive public services have wider significance, given the recent enquiries into how poverty and systems of failure appear to particularly impinge on the poorer, socially excluded, minority, migrant and voiceless sections of society. For example, when considering Grenfell or other public scandals, the sense of disempowerment at a structural and organisational level, permitting wealth and affluence to exist alongside Dickensian and neglectful public practice, is extraordinary. A minority experience is overlooked and left for those less fortunate to resolve through their own creative and desperate devices, rather than through politically engaged, optimistic and publicly supported enactment of citizenship rights and responsibilities. This is not to say that promoting the capabilities of those facing disadvantage is not important and essential, but structural disadvantage, unless tackled, will limit agency and capabilities.

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The future

This brief analysis shows that health inequality by ethnic group remains a real and ostensibly intractable challenge; professional opinions are divergent and coherence across sectors from policy, commissioning, management and clinical care is elusive. In part, this is because of the notion of race and race inequality immediately evoke latent notions of racism-related violence and hostility, failed science and impasse and discomfort among those trying to search for words to relate to another, less familiar cultural group. We fail to note the historical lessons, nor accept that inequalities can be generated by, and further compound social disadvantage and poor health; sustained inequalities lead to a lack of trust in public authorities and engender disempowered and pessimistic thinking. The Synergi Collaborative Centre (London, UK) is an independent centre of excellence that aims to marshal multiple forms of the research evidence, and curate it alongside the views of patients and the public to ensure that professional discourse is centred on what is at stake for them. We argue that disagreement, dispute and dissent reflect unseen and unheard perspectives, and we propose to not privilege the voices of larger organisations or familiar experts and instead gather lived experiences and hear hidden voices, which we argue hold clues for how health inequalities arise and are sustained, how racism operates and how we can empower people and communities to make best use of the cultural affordances and community assets at their disposal.

Motivating and engaging the powerful to act, and in directions that the powerless can be enriched and so the powerful give up their authority, is not a popular or well-rehearsed approach. This process is essential in health systems interventions, and leaders need to operate with a collaborative mind-set of sharing power. We propose that there is a failure of professional literacy and communications around race, not least because of its contentious historical legacy, but that this must not enslave future generations. We should be aware of the historical legacies that operate in the presence and structure of power relations, but we should also act to understand and reduce structural sources of inequality that set the context in which interpersonal enactments of inequality. A democratic, mature and equal society should actively tackle hostility and violence, and at the same time acknowledge and restrain microaggressions and the silence around injustices.

We are seeking ways of nurturing sustainable health systems that demonstrate collaborative leadership and greater importance attached to patient and public voices, including concerns about racism; and we need greater professional skills in emotionally intelligent and collaborative leadership and communication linked to race and ethnic inequalities in society and clinical settings. This approach is an important component of cultural competence. Cultural competence is not a finite collation of testable knowledge, rather it is a skill set that take time to master and requires developmental experiences that improve engagement with narratives of patients, sitting alongside evidence-based medicine and healthcare.

Conclusions

It is time to examine the multiple, often competing, value-laden narratives of what causes inequalities: exotic cultural idioms and explanatory models; service construction and delivery; and deprivation, racism and discrimination. We need to contrast the ways in which all of these can be conceptualised by personal, individual, family or cultural group, and organisational and structural agents of causation. It is right that we learn from the stories of patients in general and ethnic minority patients as these offer insights into how care systems fail, thus transcending the traditional but not unchallenged 'hierarchy of evidence' commonly associated with the medical discipline. The choice of methods should relate to our research questions and what we seek to explore; the 'gold standard' of randomised controlled trials cannot in isolation, by its design features, capture mechanisms or the richer and more in-depth patient stories to inform processes of service delivery and public health promotion.[53,54] This new form of science requires that we attend to the pre-verbal, the visual, the emotional and the less graspable aspects of ethnic inequalities and severe mental illness, and yet be prepared to provide a progressive and response set of options and conditions that match and overcome the inevitable resistances and anti-groups that align against such tenets.

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