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Ethnic Minority Older People, Histories of Structural Racism and the COVID-19 Pandemic

Jenny Hewitt and Dharmi Kapadia

Key points

- Older ethnic minority people are more at risk of exposure to the COVID-19 virus and to the social difficulties exacerbated by the pandemic due to longstanding inequalities in housing, health, employment and resources. These inequalities are (both historically and today) largely structural in nature.
- Older ethnic minority people have been deeply affected by isolation as a result of lockdowns associated with the COVID-19 pandemic. The loss of social spaces, like those provided by voluntary, community and social enterprise (VCSE) organisations, have been felt acutely by racially minoritised people in later life, who often use social spaces as a means of accessing cultural connection, support, and advice and information. The lack of digital access for some ethnic minority older people, coupled with language barriers for others, has further hindered their ability to maintain social connections and access resources and information.
- Vaccine hesitancy is much more complex than has been painted by media discourses. The majority of older ethnic minority people featured in our study had accepted, and indeed had received, the vaccine but described friends and family members in their community *feeling distrust* of the government's motives, *making historical associations* with eugenics and testing done on ethnic minority people, and *feeling insulted and misunderstood* by the racialised messages being conveyed about the reasons for vaccine hesitancy.

Ethnic minority older people: What has COVID-19 taught us?

The COVID-19 pandemic, which swept the world in 2020 and continues to do so, has had a devastating effect for ethnic minority older people (Kapadia, 2021), many of whom already had poor health. Yet there has been very little investigation into why the impacts have been felt so acutely among this group. We know already that in the UK, older ethnic minority people are among the most excluded groups in society, due to experiences of racist discrimination and disadvantage that have accumulated over the life course (Stopforth, 2021). Further, the deficit of research specifically focusing on ethnic minority older people has a detrimental effect on the ability to create effective policy solutions for this demographic (Bécares, Kapadia and Nazroo, 2020). The differences in health outcomes for the ageing ethnic minority population are stark and undeniable (Bécares, 2015; Evandrou et al., 2016). Ethnic minority people have up to three years' lower life expectancy, up to seven years' lower healthy life expectancy and worse health-related quality of life compared with their white counterparts (Watkinson, Sutton and Turner, 2021; Wohland et al., 2015). Health outcomes in recent decades have been consistently poor for Pakistani and Bangladeshi people. They have the worst health out of all ethnic groups at almost every stage of the life course. But older age is where the ethnic inequalities are starkest, with Pakistani and Bangladeshi people displaying levels of poor health up to twice as high as those of the white majority group (Kapadia, 2021).

Recent research, conducted by Public Health England (2020), gives us some indication about the distrust that older ethnic minority people feel towards health services. This affects the confidence that ethnic minority groups have about statewide public health interventions such as the COVID-19 vaccination programme. Experiences of structural inequalities and racism across the life course interact with the impacts of loneliness and isolation caused by successive lockdowns

and shielding. The combination of these factors may have exacerbated ethnic minority older people's existing sense of distrust and subsequently dangerously decreased their willingness to have the COVID-19 vaccine.

In our research project, conducted as part of the COVID Race Inequalities research programme of the Centre on the Dynamics of Ethnicity (CoDE), we explored ethnic minority older people's experiences of racism and discrimination throughout the life course. Through in-depth life history interviews, we aimed to understand how people's life chances had been affected by discriminatory experiences, and particularly by their interactions with state institutions such as education, health and immigration services. We also asked our participants about how they had been affected by the COVID-19 pandemic. We interviewed 19 ethnic minority older people aged 61 to 95, from January to May 2021, on Zoom or on the telephone. The participants referred to in this briefing have been given pseudonyms in order to protect their identity.

In this briefing we use the qualitative data collected during our research project to show (1) how isolation stemming from the pandemic restrictions has affected older people's wellbeing as well as quality of care in health and social care services, (2) the vital role that has been played by VCSE organisations in providing a lifeline for ethnic minority older people and (3) the underlying experiences and reasons behind distrust of the vaccine and health institutions more generally.

Isolation and its damaging effects

Experiences of isolation and loneliness have been deeply felt by many sectors of society. For ethnic minority older people this can be understood in a number of ways: through the loss of community supportive social spaces, the exclusion caused by a lack of digital access and language barriers, and the difficulties faced particularly by older ethnic minority women, who may be less likely to speak English confidently or know how to access wider sources of support. Our study revealed that during the lockdowns, many older ethnic minority people intensely felt the loss of support which would usually have been accessed face to face through informal community groups, VCSE community groups and other communal organisations. Participants reported a loss of shared cultural understanding, which in turn caused linguistic misunderstanding when seeking support from health services, as well as stark reminders of the 'othering' experiences they had experienced previously upon arrival to Britain (and subsequently) as racialised media discourses began to circulate.

So that lockdown is affecting really badly, especially women because they really want to meet sisters and their mothers and parents. So what they really need is five days of wellbeing training in their language, and if that is provided – which I am providing at the moment to about 10, 12 different groups across the North West, and that's helping, and people are coming forward.

Erjan, male, Pakistani, aged 65

This sense of isolation was intensified during instances of hospitalisation due to COVID-19, as exemplified by a recent study of Somali people admitted to hospital during the pandemic (The Anti-Tribalism Movement, 2020). Unable to communicate with staff, they feared dying alone, and could not rely on family members to communicate on their behalf as they were often admitted alone. The participants in our study reported confusion and mixed messages about the pandemic from local authorities, the news, their own community and religious groups, and communication with family and friends in their countries of origin. One of our participants spoke of elderly community members being afraid to seek medical support in case their customs around death were not respected:

The way the information has been disseminated, the way they keep on changing their mind, the way there has been no reassurance about people of different faiths, for example, to say 'if you die and you're a Muslim you will be buried as a Muslim although we may not have your family, we have an agency ... and they will take care of [that]' – that has not been provided.

Nahla, female, Moroccan, aged 61

The experiences of miscommunication transcended religion and language barriers, arising as cultural misinterpretations too. Evelyn, a Jamaican participant aged 65, described how the loss of her informal community group had impacted upon cultural misunderstandings. One elderly member of the group described herself to a health practitioner as 'me soon dead', a phrase that is interpreted in Jamaica as meaning 'all will be well in the end'. Instead, this comment sparked stressful mental health interventions from health services in the belief she was at risk and suicidal.

Communities' integral knowledge of individuals and their stories can be pre-emptive and protective in situations where older community members are isolated and their circumstances potentially misconstrued.

The struggles of older carers

For older ethnic minority carers of family members, the requirement to shield the vulnerable also restricted the carers' lives, impacting on mental health and wellbeing and on access to supportive services. Our research highlighted a silent suffering of ethnic minority carers which has largely been ignored in recent research and media discourses. In our study, Graham, an older Jamaican man, explained how difficult it was to care for his elderly mother with dementia, both during the pandemic and before it.

I'm sixty-four and I literally, from say February or March of last year, I've been a prisoner in isolation, incarcerated in isolation. People talk about getting back to normal, I was thinking the other day it was right at the point where I was thinking they've been writing about normal ... I bet there aren't a lot of people that will want to go back to my normal, back to normality,

whose normality? You wouldn't want to go back to my normality. My normality is being to drive around outside with Mum in the back of the car usually ... look at that joy that I'm missing – I don't think so.

Graham, male, Jamaican, aged 64

Older carers look after not only elderly family members but also younger family members. Another Jamaican participant described the intergenerational transmission of hardship that had affected his children and subsequently his grandchildren. This had resulted in serious mental health issues for his granddaughter, who lived with him and whom he cared and provided for. He explained the struggles they had to access appropriate mental health services for his granddaughter:

Now she's got a sleeping problem so she had to give up work. Like she doesn't sleep through the night, now she's sleeping there now. She wake up in, when she come back she will be sleeping until now, 5 o'clock. Not natural that, not natural ... because she's trying to get them [mental health services] to help her and ... and when she talk to them they say that is not for their department, that is for different department.

Weston, male, Jamaican, aged 84

These insights into the narratives of pressure, complicated by duty and societal expectation, indicate a need for further understanding of the challenges of older ethnic minority caring roles within families, and how these have been greatly exacerbated by the pandemic.

For older ethnic minority people in care homes, who are at a greater risk both of dying from COVID-19 (Care Quality Commission, 2020) and of dying from the virus at a younger age (Care Quality Commission, 2021), their isolation was worsened by lack of visits, and their fear was heightened by the knowledge that the outcomes for many of their demographic were considerably worse. These concerns exacerbated poor health and wellbeing immensely, as demonstrated here by one of our participants, recounting the situation of one of her elderly female friends, herself unwell, prevented from caring for her son, who was in residential care with Alzheimer's disease:

She now has these moments where she feels sad at what's happened, at her being ill and her son not being there to look after her. Instead he's in a nursing home. And the fact that COVID has made it so difficult, because before COVID, from time to time they'd be able to pick him up and he'd come home and spend the day with the family, and the other extended family members would join.

Evelyn, female, Jamaican, aged 65

VCSE organisations as a lifeline

The COVID-19 pandemic has illustrated the crucial role played by VCSE organisations and campaigners in ethnic

minority communities. This work has continued throughout the crisis, adapting to the restrictions on social contact, in order to continue offering advice, bereavement support, mental health services, support for those experiencing isolation and trusted places to access information about the pandemic. Despite this, these organisations have not been provided with sufficient additional financial support and resources. The Ubele Initiative describes how 9 out of 10 small ethnic-minority-focused VCSEs could not sustain themselves beyond the initial first few months of the pandemic due to a lack of reserves (Murray, 2020). Deeper work is imperative to understand the reasons behind the reliance of much of the UK's ageing minority ethnic population on VCSE organisations, and behind the lack of strategic state support for the work they do. Such organisations are a vital connection in otherwise under-served communities already identified as broadly distrustful of direct state intervention.

The simple failures in communication due to insufficient materials providing health information have also been a fundamental flaw in the government's attempts to engage and protect older ethnic minority people (Chaudhry, 2021). VCSE organisations have done their best to reach out to communities, but isolation and lack of resources have made this difficult. This inevitably creates a reliance on friends and family members for resources as well as information about health, which leaves older ethnic minority people open to the possibility of receiving misinformation and becoming isolated without support. Our participants commented:

Now again, in Asian culture people they have different needs, linguistic needs, then mostly it's a [visual] culture, so they need some image type things on publicity and awareness materials.

Erjan, male, Pakistani, aged 65

People who do not speak English tend to rely on third-hand delivered information and that's where the misinformation I think tends to be, and becomes very problematic in managing it.

Nahla, female, Moroccan, aged 61

Our research uncovered VCSE organisations doing their best to step in and provide basic resources such as food and crisis communication management when family members were taken into hospital, and to dispel misinformation about COVID-19. If the ongoing critical role of VCSE organisations in creating a dialogue between communities, research done about them and policy is ignored, ethnic minority older people are left at risk from misguided, ineffectual resource allocation at a time of increased vulnerability.

'Vaccine hesitancy'

Media discourses centring on 'vaccine uptake', and more specifically 'vaccine hesitancy', among the ageing ethnic minority population have at times blamed ethnic minority groups for not wanting to have the vaccine rather than

focusing on structural and historical reasons underpinning anxieties around the vaccine. Our research showed that older ethnic minority people have a genuine concern about health services' motivations regarding the vaccine, due to previous harmful racist research and treatment:

How dare you, how dare anyone, say to a person of colour, 'You're being stupid for not wanting to take the vaccine, the COVID vaccine'? ... And these people, their history is laden, is a montage of mistrust and they have the right to say, 'No, I'm not doing that because I don't trust you'.

Graham, male, Jamaican, aged 64

Despite this, many of our participants had already been vaccinated or had decided they would be vaccinated, which is in direct contrast to media reports of ethnic minority older people being much less likely to take up the vaccine. The reasoning behind getting the vaccine for one participant was that many white people were getting vaccinated, which went some way to attesting to the safety of it and dispelled some of the fear around medical harm being inflicted on ethnic minority groups, although this was not the case for members of their social network:

I know originally the white race used the black race to test all sorts of medication and this and that, which some of them still do now ... But then, I said to them, 'This one is quite different'. When you go to where the vaccination is you see more white people taking it. But I don't know why some of them still have that ... these stories have been handed down. And especially if you work some places you will still notice that some new drugs are being tried on ethnic minorities or some type of treatment.

Femi, female, Nigerian, aged 77

Distrust of state institutions

Distrust of state institutions and health services has been shown to connect to life course experiences of disadvantage and racism, as well as significant historical narratives of medical racism and violence (Nuriddin, Mooney and White, 2020). Campaigners have cited the government's failure to respond with specific protection of overexposed ethnic minority people, when this was first called for at the onset of the pandemic, as a contributing factor to the subsequent hesitancy in vaccine uptake. This subsequently reinforced a lack of care towards ethnic minority people during the pandemic, and understandable distrust emphasised by the knowledge that the government could have done more. Concerns connected to confidence in the vaccine's suitability (e.g. the risk that it may contain forbidden products or may be 'tested' on ethnic minority communities) were not understood or adequately addressed by local and national government agencies.

Our research showed that the failure to target support and services towards ethnic minority people suffering

disproportionate losses and exposure to the virus may be a significant factor in the lower uptake of the vaccine among ethnic minority people aged 80 and over (OpenSAFELY Collaborative et al., 2021). Among our participants, there was resentment that a situation that could have been addressed through resource allocation and recognition of fears was inferred to be due to false claims around genetic differences among ethnic groups:

And the thing is that when this pandemic [happened], the ethnic minorities were in the front. They are the frontline and that's why many of them died with no proper protection, you know. So they know the reason why and they keep saying it's because our DNA is different or something. It's just that there was a lack of protection and they were put in the frontline. That's it.

Femi, female, Nigerian, aged 77

Key recommendations

The following recommendations are made with explicit reference to the lack of attempt to address ethnic inequalities arising from the COVID-19 pandemic, which is evidenced by the lack of depth in statutory reports (e.g. Public Health England, 2020). This is despite previous recommendations (before and during the pandemic) that have sought to tackle racial inequality in the UK, and that would also support the formulation of strategies to respond to the specific barriers and concerns raised in this briefing.

These recommendations are immediate and imperative actions to begin to address the unacceptable chasm between the negative outcomes for older ethnic minority people in the UK in this crisis and those of the wider population:

- 1. Produce and implement a national race equality strategy.** The persistent disadvantage that ethnic minority people face in the UK requires national action. A dedicated race equality strategy is required from across government departments (e.g., Department of Health and Social Care, Department for Levelling Up, Housing and Communities), including a clear plan as to how ethnic minority older people will be helped to recover from the effects of the pandemic, and how ethnic health inequalities will be tackled in order to prevent the worsening of these inequalities in old age. Additionally, UK ageing policies need to include solutions to the inequalities faced by ethnic minority older people; recent policies such as 'The Grand Challenges' neither sufficiently acknowledge ethnic inequalities in older age nor contain specific actions to address them.
- 2. Close the ethnicity data gap.** Ethnicity data reporting must be truly mandatory in all official and statutory statistics and data monitoring. In

order to be accurate and more precisely reflect the experiences of ethnic minority groups, disaggregated categories (e.g. Pakistani, Bangladeshi, Indian, Other Asian) should be used instead of overarching ethnic categories (e.g. Asian). National populations surveys must also be reviewed in order to ensure data are collected for ethnic minority older people to enable robust statistical analysis. Further, the topics that are asked about in these surveys should be relevant to the lives of ethnic minority older people (e.g. ask about racist discrimination over the life course). Funding future research that aims to understand experiences of racism over the life course and structural barriers would better contextualise the inequalities faced in later life.

3. Address the digital divide for older ethnic minority people.

Targeted training and resources for people to improve their digital literacy skills

are welcome. The onus should be on statutory agencies to ensure that they provide information in a variety of formats which are both easily accessible by ethnic minority older people and easy to understand.

4. Establish permanent infrastructure and funding streams to support VCSE organisations.

VCSE groups have been at the forefront of supporting ethnic minority communities, yet many operate on short-term funding with limited human resources. National and local government should integrate many of these VCSE organisations into statutory services to a greater extent and provide dedicated streams of national and local funding for them to operate on a long-term basis. In addition, work is required by the government to establish better working relationships with large, national VCSEs, in order to work with them effectively to regain the trust of ethnic minority older populations.

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