

'It's possibly made us feel a little more alienated': How people from ethnic minority communities conceptualise COVID-19 and its influence on engagement with testing

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Tushna Vandrevala¹ , Lailah Alidu¹, Jane Hendy², Shuja Shafi³ and Aftab Ala⁴

Abstract

Objectives: The cultural beliefs, practices and experiences of ethnic minority groups, alongside structural inequalities and the political economy play a critical, but overlooked role in health promotion. This study aimed to understand how ethnic minority groups in the United Kingdom conceptualised COVID-19 and how this influenced engagement in testing.

Method: Black (African and Caribbean) and South Asian (Indian, Pakistani and Bangladeshi) community members were purposefully recruited from across the UK. Fifty-seven semi-structured interviews were conducted and analysed using principles of grounded theory.

Results: We found that people of Black and South Asian ethnicity conceptualised COVID-19 as a disease that makes them visible to others outside their community and was seen as having more severe risk and suffering worse consequences, resulting in fear, stigmatisation and alienation. Views about COVID-19 were embedded in cultural beliefs, relating to culturally specific ideas around disease, such as ill-health being God's will. Challenges brought about by the pandemic were conceptualised as one of many struggles, with the saliency of the virus contextualised against life experiences. These themes and others influenced engagement with COVID-19 testing. Testing was less about accessing timely and effective treatment for themselves and more about acting to protect the family and community. Testing symbolised a loss of income, anxiety and isolation, accentuated by issues of mistrust of the system and not being valued, or being treated unfairly.

Conclusion: Health communications should focus on counterbalancing the mistrust, alienation and stigmatisation that act as barriers to testing, with trust built using local credible sources.

Keywords

ethnic minority, COVID-19, testing

Introduction

The global COVID-19 pandemic has highlighted the scale of health and social disparities between populations within and across countries. The complex interaction of ethnicity, migration status, religion and socioeconomic disadvantage influences exposure to SARS-CoV-2 (from now referred to COVID-19) and has profound consequences for ethnic minority groups (EMGs). The pandemic is considered to discriminate, inflicting a disproportionate burden of illness and death across EMGs in the UK^{1,2} and disproportionate mortality among EMG health care workers.³ These outcome disparities have been attributed to the intersection of minority ethnicity with low socio-economic status, employment in

¹Centre for Applied Health and Social Care Research, Faculty of Health, Social Care and Education, Kingston University and St George's University of London, Kingston-Upon-Thames, UK

²Brunel Business School, Brunel University London, Uxbridge, Middlesex, UK

³Mass Gatherings and Global Health Network, London, UK

⁴King's College Hospital and University of Surrey, Royal Surrey County Hospital NHS Foundation, Guildford, Surrey, UK

Corresponding author:

Tushna Vandrevala, Centre for Applied Health and Social Care Research, Faculty of Health, Social Care and Education, Kingston University and St George's University of London, Penryn Road, Kingston-Upon-Thames KT1 2EE, UK.

Email: t.vandrevala@sgul.kingston.ac.uk

occupations with a greater risk of exposure, geographic disparities in health care availability, extended household composition and an increased incidence of comorbidities linked to poor COVID-19 outcomes.⁴ Ethnic minorities make up a significant proportion of front-line public-facing jobs, such as health care and social work, placing them at greater risk of exposure.⁵ In addition, for those on low incomes, absence from work because of illness or vulnerability can have significant implications for earnings and workplace transmission, highlighting the difficulties in engaging in testing and self-isolating.⁶

Strategies for living with the continuing threat of COVID are highly dependent on the uptake of testing for early diagnosis and to contain spread. Existing evidence has documented a lower uptake of health screening^{7,8,9} and testing for contagious disease in ethnic communities and among migrants. Studies in the USA have indicated a low testing uptake by migrants^{8,9} and a systematic review of migrants in high-income countries suggest that they may be concerned that COVID-19 treatment is chargeable, or that seeking care or putting themselves forward for testing could mean losing their job or be deported.⁶ Even where testing and treatment are free of charge, concerns remain that this does not mitigate barriers to accessing timely diagnosis and treatment: minority ethnic groups may be late presenters to health services¹⁰ and face multiple barriers,¹¹ presenting only where necessary due to concerns around immigration status, mistrust, lack of knowledge of the health system and uncertainties about entitlements to access health services.⁷ EMGs can lack knowledge and awareness of COVID-19, putting them at risk of the spread of misinformation.¹² Fatalism, belief in God and illness being attributed to external factors, or focus on familial risk rather than individual risk can act as barriers to testing for communicable diseases in EMGs.⁷

In order to develop a more targeted and inclusive public health response we need a better understanding not only of how specific cultures and income levels conceptualise COVID-19, but also how EMGs may conceptualise COVID-19 differently than the UK majority ethnic group, and how this conceptualisation influences engagement in testing. Health behaviour and behavioural change models usually focus on individual level factors that predict intention to engage in health protecting behaviours, such as testing and often do not account for specific sociocultural and socio-structural factors. In particular, the conceptualisation of health behaviour as being the result of an individual decision-making process does not account for the group identities of community and family and of the wider system in which EMGs can be positioned as outsiders. Hendy and colleagues proposed a theoretical model to explain the readiness of EMGs to engage in screening, highlighting the relationship between external factors and the EMG, which may provide

support or create stigma, and that between the EMG and the individual through which there may be a gain or loss of self-efficacy.⁷ This study draws on this model to explore how EMGs conceptualise and understand COVID-19, taking into account social, cultural and lived experiences, and how these understandings impact on willingness to engage in testing.

Method

We used a qualitative design, using a constructivist perspective, in which participants are viewed as creators of their social world, which the researchers subjectively interpret.^{14,15} Meanings and interpretations participants attach to their own experiences are acknowledged and grounded in specific social, historical and cultural contexts.

Participant recruitment

Participant recruitment was facilitated by an established network of existing contacts and wider project partners. Network partners were involved in charities and community organisations, faith organisations and women's centres with high levels of attendance by Black and South Asian people across England. Initial contact was made via email and telephone with key individuals from a range of organisations, who then invited their members on our behalf. We encouraged prospective participants to contact us directly to arrange an interview. The researchers are members of UK Black (African and Caribbean) or South Asian (Pakistani, Bangladeshi and Indian) communities and are therefore 'insider researchers' who share common knowledge, a common identity and some common life experiences with study participants, which facilitates meanings and trust within study participants' world.^{13,16} The insider status of the researchers as members of UK EMG communities helped create an environment in which participants felt they can freely express themselves.

We aimed to recruit participants from a range of socio-economic backgrounds, with differing cultural, philosophical and religious backgrounds and different occupations, ages, and health statuses. We set eligibility criteria as 18 years of age or older, from a Black (African or Caribbean), and South Asian (Pakistani, Bangladeshi and Indian) background, possessing the ability to comprehend and speak English to a sufficient level in order to understand instructions; ability to sign a consent form; and availability to be interviewed using videoconferencing tools (Microsoft Teams, Zoom and Skype) or telephone. First and second-generation migrants were included. A small number of stakeholders were also included. Stakeholders were defined as people embedded within the ethnic community groups above (and sharing the same ethnicity) and working with communities either formally (public health and allied health

professionals) or informally (community leaders, faith leaders and advocates).

Data collection

We used semi-structured interviews to ensure that core questions were asked of all participants while providing scope to explore relevant but unanticipated domains of experience and reflection. Interviews were conducted between August and December 2020 (lasting 45–80 min), by a researcher from the African community who was culturally and linguistically equipped to understand the target population using videoconferencing ($n = 47$) or telephone ($n = 10$). Participants were given a £25 Amazon voucher for their time.

The interview guide explored a list of topic areas using open-ended questions and prompts and was frequently annotated or moderated during the progression of the study.¹⁴ Interviews explored perceptions in which the COVID-19 pandemic had affected or influenced respondents and members of their communities. Questions iteratively developed as ideas emerged and addressed issues relating to how participants conceptualised the pandemic in their lives. We explored the impact of the disease, perceived effectiveness of guidelines and messaging, and facilitators and barriers to engaging with various health protecting behaviours such as hand washing, social distancing, social isolating and testing. In this paper, we specifically report data relating to their willingness to engage with testing for COVID-19.

After 57 interviews, the research team agreed that data saturation had been achieved, with no new significant insights emerging. The recordings were transcribed verbatim.

Data analysis

Our analysis was based on the principles of grounded theory, following distinct first-order and second-order phases.¹⁷ The first phase initially involved gaining a familiarity and understanding of the literature and context on health inequalities and COVID-19. It then moved on to an in-depth reading of the interview transcripts and recording observations about participant's experiences in the form of 'memos' (clustering together common themes). To complete this clustering, we then conducted axial open-coding, clustering the common themes into higher order categories. For the second order stage of analysis, we focused on moving beyond the one-dimensional clustering of themes and categories to focus on theoretical and relational links within the data. We reflected on a number of complex, intertwined contextual, psychological and societal interactions that overlaid our data structure. Drawing on our previous work and theory development around accessing health screening we organised these more relational interactions into three levels: the individual, the family and a system/societal lens.¹⁷

Our process of analysis was made transparent and coherent by interactive use of individual reflective notes (summaries of our memos and thoughts of what occurred), written down independently by three researchers and discussed in a series of group meetings. For example, we discussed how major issues of visibility and stigma interacted with each other and the impact of this (i.e. on feeling othered). We then collated our earlier memos and reflective notes and explored dynamic, intertwined relationships through the group analysis of key themes, achieving consensus through group discussion.¹⁷

Results

Twenty-eight participants identified as Black (African and Caribbean) and 29 from a South Asian background (Indian, Pakistani and Bangladeshi) (Table 1). While we acknowledge the diversity of culture and experience within this group, the purpose of our study was to distinguish between EMGs and the larger white majority UK population. For the purpose of this study, EMGs were analysed with the primary purpose of looking for commonality as a single group while taking account of specificity of differences within different ethnic groups. Seventeen stakeholders were also included. Study participants were more highly educated than the general population, due to our including stakeholders; influential individuals highly involved in community support (health advocates, leaders of community and faith-based organisations), so able to give us an in-depth view in relation to COVID-19 issues within their community.

Table 2 presents the first order concepts, second order themes and aggregate dimensions that we identified in our data. In the following, we report on four aggregate dimensions or higher-order categories: alienation and stigmatisation; self-efficacy; burden/struggles; and political and system-level mistrust.

COVID exacerbates visibility and stigma

Participants revealed that the narrative adopted by the media and the UK government in highlighting the disproportionate impact of COVID-19 on EMGs had made others outside their community aware of their contributions to society as frontline workers, working in the National Health Service (NHS) and other important and essential caring services.

It changed the way that other people saw us. I don't think that it changed the way we saw us. We knew that we were working hard at the butt end of racism. We knew that it is members of our community who were supporting the NHS, keeping the carer infrastructure alive in this country. We knew all of these things about ourselves. What happened with COVID is it forced other people who didn't see us, to see us, all of a sudden. (*Jamaican, Male, 58*)

Table 1. Study participant characteristics.

Characteristic	Number of participants (%)
Gender	
Male	20 (35)
Female	37 (75)
Age	
18–30	16 (28)
31–40	14 (25)
41–50	10 (17)
51–60	12 (21)
61+	5 (9)
Ethnicity	
African	19 (33)
Caribbean	10 (18)
Indian	11 (19)
Pakistani	9 (16)
Bangladeshi	8 (14)
Level of education	
GCSE(s)/O-level(s)	0 (0)
A-level(s)/AS-level(s)	0 (0)
Diploma (HND, NVQ Level 4 or 5, etc.)	5 (9)
Degree	39 (68)
Postgraduate degree/postgraduate diploma	13 (23)
Employment status	
Employed	44 (77)
Unemployed	13 (23)
Migration status	
Born in the UK	17 (30)
Born abroad	40 (70)
Contracted COVID/Suspected	
No	49 (86)
Yes	8 (14)
Know of anyone with/died of COVID	
No	10 (18)
Yes	47 (82)

Participants expressed that the new visibility highlighted socio-economic and health inequalities that already existed, and which in the current pandemic had manifested into disproportionate negative health outcomes for EMGs. Participants were acutely aware of the intersectionality of their ethnicity with other factors: that their pre-existing health conditions, co-morbidities, occupations (increased exposure), living arrangements (i.e. multi-generational households) and cultural values and norms put them at ‘additional risk’ of adverse outcomes; they expressed fear, anxiety and loss.

I work in the hospital - it is really frightening knowing that you are going into work and you don't know what to expect. (Zimbabwean, Female, 26)

I think minorities are the ones that are working in the frontlines or doing the jobs that people don't want to do. Then I guess I'm more at risk in a sense. (Djibouti, Female, 19)

We are mostly, I would say in service sector ... more or less front-line staff, working on buses, trains or catering industry or taxis or in hospitals. You are more likely to get infected. (Indian, Male, 31)

Participants said that the COVID-19 guidance and messaging had favoured a ‘white collar’ privileged position that did not reflect the reality of many in the community.

Yeah, a number of these measures are kind of very much aligned to a particular category of people to work from home and not many people have that benefit or privilege to work from home. I think it's a white collared mentality to feel that everybody would be able to work from home. It becomes a challenge for those who work outside their home to be able to do it and have an income. Most immigrant families aren't that privileged. Most of us are in dirty, demeaning or deadly jobs. (Jamaican, Female, 61)

Table 2. Data structure.

First order concepts	Second order themes	Aggregate dimensions
The contributions of ethnic minorities to the economy and work force in the country was made known	Visibility	Alienation and stigmatisation
We knew that it is members of our community who were supporting the NHS		
It has forced other people who didn't see us, to see us	Risk	
Existing socio-economic and health inequalities made visible		
We have been told a lot of ethnic minorities are dying from COVID-19	Othered	
We have more underlying issues		
We work on the frontline	Cultural and religious beliefs	Self-efficacy
We live together as a family and take care of our older ones		
Fear mongering headlines in media	Fear and stigma	
Isolation is difficult because of some of our housing situation		
I just feel like I'm more of a problem, rather than a help	Misconceptions	
We are doing the jobs that people don't want to do		
Racism is more overt with white vigilantes attacking people who are Muslims	Knowledge	
People don't want to be seen as weak or vulnerable		
Mentality of just firming it and hoping for the best	Mixed messaging from the government	
If it's your time, it's your time		
It's God's will	Protecting family and community	
I think there's a lot of disproportionate numbers of ethnic minorities being affected by COVID-19		
Fear of catching coronavirus at test centres	Saliency	Burden/struggles
People back home are not getting it		
Religious theories about coronavirus	Economic consequences	
We are immune to it		
Faith and prayer will protect us	Mistrust in health system	Political and system level mistrust
Not knowing how to book a test		
I can get COVID if I go to get tested	Mistrust in the government	
COVID-19 messages don't apply to me		
Mixed messages on COVID-19 since beginning of pandemic	Mistrust in the system of testing	
Family is really important		
I do not want to put my family at risk		
People are dying from other illnesses other than COVID-19		
We have gone through worst experiences than COVID-19		
We have come through civil war		
How is food going to be put on the table for the family		
Worried about last meal		
Who will provide for the family if we have to isolate ourselves for 14 days, that's two weeks of wages who's going to support that		
We work in the gig economy, self-isolating is unlikely with mild symptoms		
Forced to isolate with severe symptoms		
My data will be used to check on my immigration status		
As a black person I will be treated differently not be given the priority		
I don't feel valued by the NHS		
I will die if I go into hospital		
Attention and resources not given to ethnic minority communities		
The government changed the rules around meeting the night before Eid		
They've made it so clear to only get tested if you have symptoms		
The process of booking a test is complicated		
Test and trace system is just another way to monitor people's lives		
My data will be used to check my immigration status		
Assurance that testing will not affect my legal status		
It should come with some assurance that this is not going to expose anyone to the home office		

NHS: national health service.

Black and South Asian participants believed that the discourse around being ‘disproportionately represented’ also implied being ‘disproportionately responsible’ for the spread of the virus, and they were in some ways being ‘blamed’ for spreading COVID which they felt had increased alienation and stigma.

I think somehow there’s always this narrative that we’re the other. COVID, obviously there’s research and statistics showing that our communities have been affected far more greater than white counterparts. And so, that’s another problem to us, if that makes sense ... We have COVID, and nobody else seems to have it. And we’re the ones that are spreading it around. (*Pakistan, Female, 22*)

Participants stated that COVID made them visible to others outside their community, but this was often attached to blame, stigma and othering. This perception of stigma can lead to fear and, in turn, reduce the likelihood of engaging with testing and a growing sense of alienation.⁷

Self-efficacy as an antidote to fear and stigma

COVID is embedded in cultural beliefs about illness among EMGs, particularly related to an intersection with religious beliefs, where illness was seen as a sign of weakness or vulnerability, and participants expressed the stigma that a diagnosis of COVID-19 could bring.

I think there’s also a sense of stigma in the Somali community, when it comes to illness and diseases, people don’t want to be seen as weak or vulnerable. So, I think there’s also that mentality of just firming it and hoping for the best, and not wanting to be seen as suffering from COVID-19. (*Somali, Male, 27*)

In some cultures, particularly those that may be intertwined with Christian or Muslim religious beliefs, illness was considered as a sign from, or the will of God. Such an attribution frames the illness as unavoidable or unable to be eradicated unless God decides to intervene, with people having little or no influence on the impacts, or outcomes of the pandemic.

We are deeply religious people, and they say, whatever you behave, will be. If it’s your time, it’s your time. (*Somali, Female, 40*)

People say Allah knows why this is happening. (*Bangladeshi, Male, 65*)

Coronavirus is punishment from God for disobedience. (*Pakistani, Female, 45*)

This fatalism can lead to a lack of preventative behaviours and self-efficacy.⁷ The sense of lacking agency was further intensified by the EMGs’ misconceptions about COVID-19; namely, that ‘*people back home not getting it! We are immune*’. This strong fatalistic narrative was accompanied by theories that God was intervening. Faith and prayer were offered as strategies for protection from the effects of the pandemic.

The pastor would encourage us to pray that nobody is going to die of coronavirus and we return back to church safe and alive. (*Ghanaian, Male, 35*)

Study participants (Black and South Asian) did not conceptualise testing as a means of seeking timely treatment to protect themselves. The main motivation to test for the virus was to avoid the spread to other family members or their community. Participants from the Black and the Asian communities mentioned their strong family ties and the need to protect the family. This salient point was often expressed as a strong motivator for the community to participate in testing and other protective behaviours.

You know Africans have always been family, family is really important you don’t want to infect anyone. (*Cameroonian, Female, 58*)

I do not want to put them at risk because me being young might be able to cope better and they might not be able to cope as good as I would. (*Indian, Female, 23*)

It was evident in the data that high levels of fear and anxiety around COVID-19 and its impact led to a lack of self-efficacy to engage with the process of testing, with fear of catching COVID-19 at a testing centre salient.

Because I do feel as though there’s probably a level of stigma [to go to the testing centre]. I even heard one person telling me, even by going to the test centre, you’re increasing your likelihood of getting coronavirus, because everyone there probably has coronavirus. So, even though they had symptoms, they were very reluctant to go, because they were worried that they might not have it, but by exposing themselves to people at the test centre that have it, that they themselves will catch it. (*Ivorian, Female, 29*)

Participants also stated that members of the community may lack the necessary knowledge and skills required to access the testing-booking system, with limited information technology skills and access to smart devices.

Struggles and the burden of being a migrant

Some of our participants viewed the COVID-19 pandemic as ‘one of many battles and struggles’ they face. In some cases, the COVID virus was constructed as ‘small and inconsequential’, in terms of surviving different forms of hardship, especially in those with recent migration experiences.

I hear even some people were saying, we came through civil war, this is nothing for us. (*Somali, Male, 27*)

Study participants were often more concerned about the economic consequences of the pandemic than falling ill from the virus. Providing for their families was the most important ‘duty’, with testing and having to isolate not considered important or relevant for those who needed to worry about providing.

People are worried not just about Covid-19 they are worried about their last meal. Some people will not want to say they have Covid-19 because they have to isolate. That means less income. (*Nigerian, Female, 45*)

In EMG cultures, the man is often perceived as the main bread winner or provider for the family, so gender is an important intersectional consideration related to testing. Where incomes are uncertain, and the threat of job loss very tangible, the loss of income from having to isolate and the financial burden of this acted as a disincentive towards testing. The struggle to provide basic needs for subsistence outweighed the need to strive for safety (for something which might or might not happen). Perceptions of testing were closely tied to views on isolating.

If the man is the breadwinner within the household, financial circumstances as well would be a problem. The financial burden is a problem. If we have to isolate ourselves for 14 days or whatever days, that’s two weeks of wages. And who’s going to support that? And I think that probably is one of the key factors as well. (*Bangladeshi, Male, 36*)

It’s because the implication of having a positive test and isolating, as well as the people around you. If you are the breadwinner, then it’s going to be difficult, isn’t it, to isolate and not work and get paid. And there is also a proportion of our people not in high skilled jobs, illegal immigrants, not having the right to stay, and all that, are likely to play down their symptoms, and not go for tests and isolate, because then, how is food going to be put on the table for the family? (*Ghanaian, Female, 58*)

Genesis of mistrust and its impact

The theoretical model proposed Hendy and colleagues emphasises the role of trust in the health care system for the

take-up of testing.⁷ In our data, participants expressed fear and anxiety about falling sick and being treated poorly by the National Health Service (NHS).

If I get sick what will my situation be? What is the priority. That is what I think, why am I less privileged or will I be equally treated the way other ethnic groups are treated. I am very anxious. I don’t want to get sick. (*St Lucia, Male, 40*)

They think that if you end up in hospital, you will be dead. There are some people who think they would actually deliberately kill you if you go to hospital ... You aren’t prioritised. They would just let you die. (*Indian, Male, 83*)

Participants drew on their previous experience, with some concluding that the government and the health care system had failed to prioritise their health, and the health needs of their community, with historical issues of mistrust brought to the fore during the pandemic.

Some participants were likely to avoid booking a test because of privacy concerns. They said that the lengthy questions asked before one could book a test and the information required would be used to monitor them, track their immigration status and would be shared with the home office, resulting in deportation.

I think to motivate people to go for tests, it has also come with some assurance that look, this is not going to expose anyone to the Home Affairs or anything like that. And the essence of the health care team is not to expose anyone to immigration or something like that. (*Ghanaian, Female, 58*)

Their suspicions and mistrust about testing permeated to the NHS COVID-19 smartphone application, which was perceived as a system to monitor their lives.

I don’t know one person that tested as track and trace [NHS COVID-19 app]. This tracing is it just people in general rather than with Covid. It’s all control, really. (*Barbados, Female, 59*)

Participants noted that the government had intentionally brought about rules and guidelines without considering their specific needs.

It was literally introduced in the evening before Eid and everybody was feeling really like, they’ve just done this because it’s Eid tomorrow and they don’t want us to mix. And then the policing, I think they’ve always felt overly policed, as it is. And now it’s like, ethnic minorities have bigger families and they’re more likely to be breaking the rules. And people are getting reported and I think they feel overpoliced in that regard. (*Pakistan, Female, 30*)

None of our 57 participants suggested that they would consider COVID-19 testing as a means to access timely and

effective treatment. What is evident from our data is that government messaging around testing (and its focus on symptomatic testing) did not encourage study participants to put themselves forward for testing.

I guess because the government, especially the NHS, sorry, because they've made it so clear to only get tested if you have symptoms, and because of their symptom list some people don't fit into that. So they don't want to waste the NHS money and time and go and get tested. I am one of those people that will not go to get tested probably as well unless I actually felt I was on my last legs or something like that, to me it feels like a waste of NHS time and money as well. (Pakistani, Female, 24)

Discussion

This study aimed to understand how EMGs conceptualise and understand COVID-19, taking into account social, cultural and lived experiences and how these understandings influence willingness to engaging with testing for the virus. It is crucial that public health professionals understand EMG perceptions, needs and concerns related to prevention and testing of COVID-19 so we can design and implement specific, culturally relevant, useful and trusted interventions. The landscape of COVID-19 testing and uptake in the UK have changed at incredible pace, with the focus shifting to asymptomatic (mass) testing in December 2020. However, the findings from this study are likely to remain relevant, demonstrating that understandings of COVID-19 are embedded in cultural beliefs, economic concerns and long-standing issues, which are not transient.

Our findings highlight that people from EMGs found that an emphasis by the media on the disproportionate representation on COVID-19 mortality and illness made them more visible. This visibility made them feel stigmatised, blamed for COVID-19-related exposure, mortality and spread. Furthermore, the primary concern for Black and South Asian people is to provide for their family, rather than the threat of COVID-19, and this impacted on their engagement with testing. Participants talked about being 'forced to self-isolate' if they had severe symptoms. Isolation was perceived as something they were not able to do rather than something they were unwilling to do. They would be unable to isolate due to their immediate need to provide for their families, and it was thus easier not to engage in testing. Cultural and religious beliefs about illness and COVID-19 and misconceptions about COVID-19 self-efficacy led to high levels of anxiety, fear and loss. Perhaps the most salient finding was the lack of individual self-efficacy among participants, with not one participant stating that they would use COVID-19 testing to access timely and effective treatment for themselves. COVID-19 was embedded in a political system of mistrust and COVID-19

messages seem to reinforce historic racism, discrimination and mistrust.

Our findings draw attention to perceived 'narratives of blame' used by politicians and media, with people from EMG reporting being stigmatised and alienated during the COVID-19 pandemic.¹⁸ Where concerted efforts to control and prevent the risk were required of everyone, EMG perceived that they were positioned to pose an extra risk to society and were therefore more responsible for the spread of the virus. The emphasis on race as a risk factor, portrayed in media and by the government and policy makers appeared to exacerbate the blame, stigma and alienation experienced by study participants. This suggests that communications need to place less emphasis on race or ethnicity and explore wider social determinants of health.

Existing approaches to test for COVID-19 infection in the UK take insufficient account of the complexity many minorities face, such as loss of income and the struggle of living on the poverty line, when asked to take the test. In the absence of material support in the form of income and adequate room for people to self-isolate, many EMGs will not adhere to self-isolating protocols due to practical issues rather than any lack of motivation.¹⁸ As countries move into the next stages of the pandemic, symptomatic and mass (asymptomatic) testing is likely to be emphasised and there is an urgent need to avoid viewing testing and self-isolating as separate protocols and work to fill the gaps participants in our study identified.

When faced with the threat of stigma and fear as a result of a global pandemic, individuals are likely to consider psychological resources at their disposal, such as self-efficacy; the belief that one has the ability to act to manage a potential threat.¹⁹ Behavioural change theories have consistently emphasised the importance of self-efficacy, rather than community-efficacy or familial-efficacy beliefs. Our study found that participants were motivated to test to protect their families and their communities, in contrast to protecting themselves. This strongly suggests a need to shift emphasis from individual self-efficacy to collective efficacy, that is, pushing the belief that groups can work together to achieve an intended outcome.²⁰

A key finding was that for EMGs, COVID-19 was embedded in a political system of mistrust, and the strength of this mistrust across the health care. Disease outbreaks and pandemics can expose and exacerbate long-standing health inequities, systemic racism and marginalisation. Recent studies from the US have highlighted similar issues of mistrust in health care and government among African Americans,²¹ with decades of racism, marginalisation and discrimination isolating communities and making them particularly vulnerable and susceptible to COVID-19.^{22,23} To our knowledge, this study is the first to emphasise the impacts of this historical mistrust on the UK systems for COVID-19 testing, tracing and isolating. It is vital that

consistent efforts are made to work with community champions and leaders during and beyond the pandemic to start to shift and reframe beliefs, towards a more positive narrative that positions institutions such as the NHS as being equally welcoming and available for everybody.

Our study has highlighted the saliency of sociocultural and socio-structural determinants for COVID-19-related health-promoting behaviours. Concern for economic consequences is important in predicting protective health behaviours and the promotion of self-efficacy may not be particularly useful. Much traditional theoretical framing of behavioural change fails to appropriately focus on the power of the family and collective community and to fully appreciate the influence of these factors (both positive or negative).²⁴ We highlight the role of social connectedness and integration²⁵ and the systemic factors that are of particular relevance to EMG and migrant groups. Therefore, there is a need to develop pragmatic, culturally embedded models of health behaviour that provide complex, multi-layered contextual, cultural and socioeconomic granularity, specifically relevant to living with this modern-day pandemic.

In tackling misalignment between public health and EMGs, we need to focus on communications that counterbalance mistrust, alienation, and stigmatisation and work to actively build faith in these methods using local trusted sources. There is a need for access to clear, accurate, targeted and visible educational materials from authentic and trusted local sources.

Conclusion

COVID-19 test, trace and isolate systems are seen by public health and government officials as fast and effective ways to control the spread of the coronavirus. Our study suggests that EMGs may face barriers specific to their context, and that are not necessarily present in the wider UK community. It is imperative that future testing initiatives and public health programmes amend health behaviour communications, models and support systems to reflect this differential context.

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ORCID iD

Tushna Vandrevala  <https://orcid.org/0000-0002-1140-8445>

References

- Office for National Statistics. Coronavirus (COVID-19) Related Deaths by Ethnic Group, England And Wales: 2 March 2020 To 15 May 2020. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbyethnicgroupenglandandwales/2march2020to15may2020> (2020, accessed 15 February 2021).
- Public Health England. Beyond the data: understanding the impact of covid-19 on BAME groups. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf (2020, accessed 15 February 2021).
- Dhillon P, Breuer M and Hirst N. COVID-19 breakthroughs: separating fact from fiction. *The FEBS J* 2020; 287: 3612–3632.
- Iacobucci G. Covid-19: increased risk among ethnic minorities is largely due to poverty and social disparities, review finds. *BMJ* 2020; 22: 371.
- Kerwin D and Warren R. US Foreign-born workers in the global pandemic: essential and marginalized. *J Migr Hum Secur* 2020; 8: 282–300.
- Hayward SE, Deal A, Cheng C, et al. Clinical outcomes and risk factors for COVID-19 among migrant populations in high-income countries: a systematic review. *J Migr Health* 2021; 3: 100041.
- Hendy J, Vandrevala T, Ahmed A et al. Feeling misidentified: understanding migrant's readiness to engage in health care screening. *Soc Sci Med* 2019; 237: 112481.
- Guttman A, Gandhi S, Wanigaratne S et al. *COVID-19 in Immigrants, Refugees and Other Newcomers in Ontario: Characteristics of Those Tested and Those Confirmed Positive, as of June 13, 2020*. Toronto: ICES, 2020.
- Kim HN, Lan KF, Nkykyer E et al. Assessment of disparities in COVID-19 testing and infection across language groups in Seattle, Washington. *JAMA Netw Open* 2020; 3: e2021213.

10. Potter JL, Burman M, Tweed CD, et al. The NHS visitor and migrant cost recovery programme—a threat to health? *BMC Public Health* 2020; 20: 1–9.
11. Noori T, Hargreaves S, Greenaway C, et al. Strengthening screening for infectious diseases and vaccination among migrants in Europe: what is needed to close the implementation gaps? *Trav Med Infect Dis* 2020; 7: 101715.
12. Doctors of the World. An unsafe distance: the impact of the COVID-19 pandemic on excluded people in England. <https://www.doctorsoftheworld.org.uk/wp-content/uploads/2020/07/covid19-brief-rna-report.pdf> (2020, accessed on 15 February 2021)
13. Ahmed A, Vandrevalla T, Hendy J, et al. An examination of how to engage migrants in the research process: building trust through an ‘insider’ perspective. *Ethn Health* 2019; 8: 1–20.
14. Payne S. Grounded theory. In: Coyle A and Lyons E (eds). *Analysing Qualitative Data in Psychology*. London: Sage, 2007, pp. 65–86.
15. Kidder LH and Fine M. Qualitative and quantitative methods: when stories converge multiple methods in program evaluation. *New Directions Program Evaluation* 1987; 35: 57–75.
16. Ogilvie LD, Burgess-Pinto E and Caufield C. Challenges and approaches to newcomer health research. *J Transcult Nurs* 2008; 19: 64–73.
17. Gioia DA, Corley KG and Hamilton AL. Seeking qualitative rigor in inductive research: notes on the Gioia methodology. *Organ Res Methods* 2013; 16: 15–31.
18. Reicher S and Drury J. Pandemic fatigue? How adherence to covid-19 regulations has been misrepresented and why it matters. *BMJ* 2021; 18: 372.
19. Bandura A. *Social Foundations of Thought and Action*. Englewood Cliffs, NJ: Prentice-Hall, 1986, pp. 23–28.
20. Cho H, Li W, Cannon J, et al. Testing three explanations for stigmatization of people of Asian descent during COVID-19: maladaptive coping, biased media use, or racial prejudice? *Ethn Health* 2021; 26: 94–109.
21. Bateman LB, Schoenberger YM, Hansen B, et al. Confronting COVID-19 in under-resourced, African American neighborhoods: a qualitative study examining community member and stakeholders’ perceptions. *Ethn Health* 2021; 19: 1–9.
22. Obinna DN. Essential and undervalued: health disparities of African American women in the COVID-19 era. *Ethn Health* 2021; 26: 68–79.
23. Chandler R, Guillaume D, Parker AG, et al. The impact of COVID-19 among black women: evaluating perspectives and sources of information. *Ethn Health* 2021; 26: 80–93.
24. Björk Brämberg E and Nyström M. To be an immigrant and a patient in Sweden: a study with an individualised perspective. *Int J Qual Stud Health Well-being* 2010; 5: 5106.
25. Garcia DS. Evaluation of 3 behavioral theories for application in health promotion strategies for Hispanic women. *ANS Adv Nurs Sci* 2016; 39: 165–180.