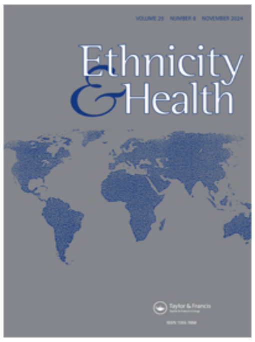

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'COVID impacted my life in so many ways': a qualitative study of the lived experiences of the COVID-19 pandemic among people of Black ethnicities living with HIV in England

Zoe Ottaway[a,b], Denis Onyango[c], Vladimir Kolodin[b], Abi Carter[d], Rob Horne[e], Lucy Campbell[b], Lisa Hamzah[f], Frank A. Post[a,b], Shema Tariq[g,h] and Emily Jay Nicholls[g]

[a]King's College Hospital NHS Foundation Trust, London, UK; [b]King's College London, London, UK; [c]Africa Advocacy Foundation, London, UK; [d]Chiva, London, UK; [e]Centre for Behavioural Medicine, School of Pharmacy, University College London, London, UK; [f]St George's University Hospital NHS Foundation Trust, London, UK; [g]Institute for Global Health, University College London, London, UK; [h]Central and North West London Foundation Trust, London, UK

ABSTRACT

Objectives: COVID-19 disproportionately affected people of Black ethnicities whilst also negatively affecting the health, wellbeing and livelihoods of people living with HIV. This may have been amplified by pre-existing socioeconomic marginalisation, poorer health, and structural racism. Despite being disproportionately affected by the pandemic, little is known about lived experiences of the COVID-19 pandemic within these communities. Given these disparities, this paper explores the lived experiences of the COVID-19 pandemic among people living with HIV and of Black ethnicities in England.

Design: This qualitative study, comprising five focus group discussions (FGDs) with people of self-reported Black ethnicity, living with HIV in the UK ($n = 30$). FGDs were conducted between June and August 2022. Topics covered included beliefs and attitudes about COVID-19 (including prevention), COVID-19 information sources and lived experiences. Data were analysed using a reflexive thematic approach.

Results: Analysis of the data generated several main themes: the collective trauma experienced by Black communities; racial bias influenced by inequitable research; conflicting COVID-19 health messages and medical mistrust; socioeconomic marginalisation including financial hardship; intersecting oppressions such as sexism and ageism; and the overall impact of living with a stigmatising condition such as HIV. Participants additionally found navigating the infodemic, being labelled 'clinically vulnerable,' and balancing multiple non-medical needs alongside their cultural, spiritual, and religious beliefs, challenging.

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CONTACT Zoe Ottaway zoe.ottaway@kcl.ac.uk Department of Infectious Diseases, School of Immunology & Microbial Sciences Faculty of Life Sciences & Medicine, Kings College London, Denmark Hill, SE5 9RJ

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Conclusion: The COVID-19 pandemic has had profound and enduring multidimensional impacts on the lives of people of Black ethnicities living with HIV. This study reveals how socioeconomic, cultural, behavioural, and biological factors intersected to shape experiences of the pandemic within these communities in the UK. Our data illustrate the lived realities of worsening health and social inequalities due to COVID-19, while at the same time highlighting the central importance of trusted community organisations in mitigating some of these negative impacts.

Trial Registration: Ethical approval was obtained from the University College London Research Ethics Committee (Project ID/Title: 6698/004).

Introduction

Globally, the COVID-19 pandemic disproportionally affected people of Black ethnicities (Irizar et al. 2023), in both low- and high-income settings (Sze et al. 2020). Overall people from Black ethnic backgrounds were at greater risk of COVID-19 acquisition (Sze et al. 2020) and severe morbidity (Irizar et al. 2023), with mortality rates 30 per cent higher in Black versus white people (Apea et al. 2021). Black people with HIV also had lower initial rates of SARS-CoV-2 vaccination uptake, with institutional trust and message perception shaping vaccination decision-making amongst the community (Campbell et al. 2022; Crawshaw et al. 2024).

Those with comorbid medical conditions, such as HIV, were particularly affected by disruption to healthcare services (Ottaway et al. 2024); individuals with pre-existing cardiovascular disease, hypertension, obesity, diabetes, kidney disease and those living with HIV with poor immunovirological control were all at increased risk of adverse COVID-19 outcomes (Ottaway et al. 2024; Williamson et al. 2020). It is important to note that many of these conditions are highly prevalent in Black communities in the United Kingdom (UK) (Bhaskaran et al. 2021; Geretti et al. 2021; Ottaway et al. 2024).

COVID-19 negatively affected the health, wellbeing and livelihoods of communities living with HIV with one in five people living with HIV reporting a loss of employment or income, over a quarter of people reporting worsening mental health and 40 per cent reporting a lack of social contact and loss of essential peer support networks during the pandemic ('Positive Voices 2022: Survey Report - GOV.UK' 2024). These communities are also likely to experience other vulnerabilities such as financial and food insecurity, immigration insecurities, stigma (structural/institutional, public/community, internal/self), mental health issues, low literacy levels and language barriers (National AIDS Trust 2014).

There were inconsistencies in the global response to COVID-19, with non-pharmaceutical interventions and policies varying by country (Haug, Geyrhofer, and Londei 2024). These differing responses, along with variable mental health support, particularly for people of Black ethnicities (Gupta et al. 2024) and a lack of structured practical help (employment, financial) (Lenoir and Wong 2023) compounded confusion and distress amongst diasporic communities (Mahmood et al. 2021). Additionally, historical and contemporary mistrust, and a lack of culturally appropriate messaging, meant pandemic-related conspiratorial messaging thrived (Vandrevala et al. 2023), which served to alienate and stigmatise Black communities further (Vandrevala et al. 2022).

By using qualitative methods, we provide a deeper and more nuanced understanding of the lived experiences underpinning patterns observed in quantitative literature. To date, no qualitative studies have focused on the impact and lived experiences of COVID-19 amongst people of Black ethnicities living with HIV in the UK. In this paper, we present findings from the first qualitative study in England to explore, in detail, the lived experiences of the COVID-19 pandemic among people of Black ethnicities living with HIV. Informed by intersectionality theory (Crenshaw 2013) we explore the impact of both HIV status and ethnicity and how they intersect, along with other marginalised identities, to shape the experiences of our participants.

Materials and methods

This was a qualitative study comprising focus group discussions (FGDs) ($n = 5$) with people of Black ethnicities living with HIV in England, conducted between June and August 2022, with sample size determined by data saturation (Fusch and Ness 2015). Recruitment took place after the omicron variant wave of SARS-CoV-2 had subsided, when the mandatory use of face masks and social distancing measurements were no longer in place and towards the end of the pandemic. This FGD study was part of the wider COVID-AFRICA study; a large, multisite, mixed-methods observational study investigating the impact of COVID-19 on people of Black ethnicities living with HIV in England (Ottaway et al. 2024). This present study received ethical approval from the University College London Research Ethics Committee (Project ID/Title: 6698/004).

Focus group discussions

FGD methods were chosen due to their potential to engage research participants within their social contexts; to destabilise power dynamics between ‘researcher and ‘researched’; and to facilitate the co-construction of meaning (Wilkinson 1998), all of which were felt to be of particular value when discussing the lived experiences of people likely to experience multiple axes of oppression (Weldon 2008). Thirty participants were approached and recruited by staff through our community partners: Africa Advocacy Foundation (AAF), a south London community-based charity that promotes access to services for disadvantaged Black communities, including those living with HIV, and Chiva, a charity which supports children growing up with HIV and their families, across the UK and Ireland. Individuals were eligible if they were aged ≥18 years, English speaking and of self-reported Black ethnicity. Sampling was purposive to maximise diversity of ethnicities, age and gender.

FGDs were conducted online ($n = 3$) using Microsoft Teams, or in person at AAF premises ($n = 2$) and co-led by AAF staff member and one other research team member. FGDs were audio-recorded with consent, and contemporaneous notes taken by facilitators, lasting between 90 and 120 min. Participants were asked to provide written informed consent and were informed that they were free to withdraw from the study at any point up to the end of the FGD. All participants received £20 in recognition of their time and expertise. Due to the informal method of recruitment, the number of potential participants who declined to take part in the study was not recorded.

The FGD topic guide was informed by a review of existing literature and the experiential knowledge of the study team. This was further refined through discussion with

Table 1. FGD participant characteristics.

Characteristic	Number of participants (total $n = 30$)
Female gender	17
Age (years)	Median 41 (range 21–72)
SARS-CoV-2 vaccinated	21
Black African ethnicity: region of birth[a]	
East Africa	5
West Africa	1
Southern Africa	9
Central Africa	1
Non-Black African ethnicity (Black British, Black Caribbean)	2
Duration of residence in UK (years)	
5–14	3
15–29	9
>30	5
Highest level of educational attainment[b]	
Secondary	9
Higher	15
Employment status	
Employed	8
Unemployed/retired/ other	14
Student	2

[a] As defined by the African Union (African Union 2024).

[b] Secondary education was defined as up to secondary school. Higher education was defined as college or university education (including higher professional qualifications).

AAF staff and members. The topic guide covered beliefs about, and attitudes towards, COVID-19 and its prevention, community COVID-19 perspectives, COVID-19 information sources, and lived experiences of the pandemic (see Appendix 1). Participants also provided socio-demographic information (see Table 1).

Data analysis

FGD audio recordings were transcribed verbatim by a professional transcription agency, and transcripts double checked for accuracy by three different team members. Data were analysed thematically, using a reflexive, inductive analysis (Joy, Braun, and Clarke 2023) by the first author using NVivo software version 14 (Jackson and Bazeley 2017). Reflexive thematic analysis is an iterative approach to qualitative data that allows researchers to explore and understand underlying themes, with specific attention to researcher subjectivity. First, all transcripts were read and discussed by the study team to identify themes. Informed by these discussions, the first author coded the transcripts and developed a codebook by grouping identified sub-themes into broader thematic categories. This was an iterative process in which several key themes were identified, including collective trauma, conflicting messages/(mis)trust, health vulnerability, socioeconomic marginalisation. Consensus was reached through discussion with all study group members regarding themes. The codebook was applied to all transcripts and two experienced qualitative researchers on the study team reviewed preliminary findings.

Intersectionality theory

Our study is informed by intersectionality theory, a framework and approach acknowledging and foregrounding how various social identities (such as ethnicity, gender, age, and HIV status) intersect and interact, leading to unique experiences of oppression for individuals who hold multiple marginalised identities (Crenshaw 2013). These identities are not unidimensional and 'additive' but rather intersecting and co-constitutive (Bowleg 2012). We sampled participants purposively according to ethnicity, gender and age to allow us to explore how these multiple, and often intersecting identities, shape individual experience. In our analysis we specifically foreground these identities and their intersections to provide richer understanding of their role in shaping experience.

Reflexivity statement

We are an ethnically and gender-diverse team with substantial experience of either research or delivery of healthcare and/or psychosocial support to people living with HIV. We are therefore particularly interested in the intersections between ethnicity, migration history and HIV status. FGDs were co-conducted by DO a Black African cisgender man, and a member of AAF staff with well-established relationships with group members and previous experiences in facilitating focus groups (Kolodin et al. 2024). Other co-facilitators included VK, a White European cisgender male social scientist and Clinical Psychologist (PhD) and ST, a British Pakistani cisgender woman, HIV Consultant, Principal Research Fellow, and social scientist (PhD, MSc in Medical Anthropology and Epidemiology). Analyses were undertaken by EJN, a White, UK cisgender woman, Senior Research Fellow and qualitative medical sociologist (PhD) and ZO, a White UK cisgender woman, and HIV clinician who is currently undertaking her MD (Res) exploring the impact of the COVID-19 pandemic on people living with HIV, with input from DO and ST. Together the study team have extensive academic and clinical experience of working in the field of HIV medicine and strong links to and experiences of working with communities.

Results

We present findings from our five FGDs comprising 30 participants (range 2–11 per FGD). Some focus groups had a small number of participants due to pandemic restrictions and mitigation measures (new COVID-19 diagnosis requiring self-isolating for example).

The age range of participants was 21–72 years with two FGDs specifically recruiting younger participants (in collaboration with Chiva); 57% of participants were women. The majority of participants were of self-reported Black African ethnicity; with one FGD specifically recruiting non-Black African participants (Black Caribbean); 90% were born outside of the UK (Table 1).

In what follows we describe the experiences of our participants as people of Black ethnicities who are also living with HIV. In doing so we organise our findings according to the intersections of various axes of marginalisation, highlighting the impact of both ethnicity and HIV on experiences of the COVID-19 pandemic.

Collective trauma among Black communities

The COVID-19 pandemic resulted in significant levels of illness, suffering and death amongst global Black communities who shouldered the burden of COVID-19 morbidity and mortality. This collective trauma emerged in all of our focus groups, with several participants sharing their personal experiences of loss. Restrictions on international travel, and other legally enforced pandemic restrictions, prevented diasporic communities from travelling to be with dying relatives. This led to resentment at restriction measures with participants lamenting 'lost' opportunities to grieve:

> I lost so many friends and relatives and when they were sick you couldn't visit them, when they died you couldn't bury them, [because] my country [Zimbabwe] was on the red list.
>
> (Female, Black African, FGD 2)

Furthermore, the pandemic directly contributed to daily lived experiences of discrimination through the naming of SARS-CoV-2 variants after countries/regions in which they were first detected, and the familiar trope of migrants importing infections (including HIV):

> When the South African variant came out, I was heavily stigmatised in my friendship groups and, I got really like jokey remarks at work from people going, 'See you South Africans you are coming over, bringing your variant of COVID over here.'
>
> (Young female, Black African, FGD 4)

Several of our participants felt that their heightened vulnerabilities as people of Black ethnicities were ignored by the Government, systems, and policies, by policy makers while at the same time, they were exposed to media representations of their communities being disproportionately impacted by COVID-19:

> When you watch TV and you see people dying and there was also something, it was mostly Black people.
>
> (Female, Black African, FGD 2)

The impact of race on experiences of COVID-19 amongst people living with HIV

The impact of race on the lived experiences of COVID-19 in people with HIV were partly informed by experiences and legacies of racial discrimination and exploitation within healthcare systems. Most participants felt that research into COVID-19 was insufficient, and that existing scientific evidence was not applicable to Black communities. They reported widespread mistrust of research processes, citing historical examples of medical racism and a fear of being subjected to further unethical practices where they may be treated as 'guinea pigs.' These concerns were often heightened by living with HIV:

> When it comes to medication and [Black, HIV positive] people, I almost feel like I am some kind of guinea pig for something.
>
> (Female, Black African, FGD 4)

Some suggested that western governments were inflating risk and creating fear to detract from other current political issues, whereas in Africa COVID-19 was just one of several other concerns and not given the same weight. Others discussed the possibility of 'Black immunity' to COVID-19, their beliefs fuelled by apparent low COVID-19 mortality rates reported by African nations. Regardless of these COVID-19 beliefs, there was consensus as to disparities in the global pandemic response. This included perceived lack of inclusivity in policymaking, resulting in approaches that did not consider their communities' specific needs:

> I do want answers on as well because I feel like it was just put out so extreme the way we had go into lockdown, stay in our houses, not be able to go out and I feel like we should be asking questions you know.
>
> (Female, Black African, FGD 4)

With the belief that biomedicine and policies were failing to attend to their needs, participants reported turning to culturally bound responses to the pandemic, such as traditional medicine and religious practices:

> Western medicine was not the right way to go about treating COVID, so our culture had to get its own way of treating COVID, and the cultural way is the better way.
>
> (Young female, Black African, FGD 4)

Lots of participants referred to COVIDex, a herbal remedy developed and licenced in Uganda in 2021, as a 'proven cure' for COVID-19. Participants felt strongly that western governments had deliberately refused to collaborate with African nations to upscale COVIDex manufacturing globally, thus denying people within the African diaspora a potentially beneficial treatment.

The perception that their needs were not being addressed by policy makers and researchers resulted in participants turning to their religious beliefs as a source of protection:

> So, at one point my youngest sibling actually got COVID and I told my parents that she should stay at home and quarantine and do all sorts of stuff, and then my mum just turned around and she was like, 'No, there's nothing wrong with her' and my parents are like religious, and they were like, 'She's covered in the blood of Jesus, you know, she's fine.'
>
> (Young female, Black African, FGD 4)

Lack of trusted information and a sense that their communities were being overlooked in the pandemic response, meant that mis/disinformation rapidly propagated within community information ecosystems, especially via WhatsApp. This led participants to identify a specific need to engage with their communities through awareness campaigns to counter these messages:

> When COVID hit lots of my work then became about getting out clear accurate and reliable information about COVID and HIV to my community in an accessible way.
>
> (Female, Black Caribbean, FGD 6)

Many participants felt overwhelmed by the volume and nature of information being shared on WhatsApp but found it challenging to counter misinformation as they did not want to dismiss, or disrespect, other people's firmly held beliefs. The lack of clear and consistent messaging from the UK Government and healthcare professionals caused widespread confusion, negatively impacting mental health because of the 'doom and gloom of the news cycle.' Participants attributed varying levels of credibility to different sources of information, which coupled with community beliefs, the fluidity of Government guidance and intersecting with the communities heightened vulnerability to

COVID-19, meant our cohort, unsurprisingly, reported frequent difficulties navigating pandemic mitigation measures.

The impact of socioeconomic marginalisation on experiences of COVID-19

Some FGD participants spoke of their heightened risk of SARS-CoV-2 acquisition, which included other risk factors such as their occupation, forcing them to make difficult trade-offs. For instance, those who were key workers had to balance the knowledge that they were at increased risk of acquisition and poorer clinical outcomes because of their occupation, ethnicity and comorbid medical conditions, with a sense of moral duty as a front-line worker, with no possibility of mitigating risk through homeworking, and a need to maintain an income:

> As a person that works in a school, when I read about the statistic of COVID affecting people of African descent more than White people I was like, how does that affect me? I remember we had a little questionnaire about whether we want to come into work, and I didn't know how to fill that in, because one: I had my responsibility to my job, but also, I had the responsibility to myself to keep myself safe.
>
> (Young female, Black African, FGD 4)

The impact of gender on experiences of COVID-19

Participants in our FGDs described how pre-existing health disparities, stigmas and gender discrimination were amplified for Black women during the pandemic. Those in low-income roles (often key workers) with large multigenerational households to support, strained to balance various competing needs such as performing the bulk of domestic and emotional labour, including childcare, home-schooling, and organising food provisions, while also being in paid employment:

> Yes, and then you get home, and the kids are like [needing help], the washing needs doing, the cooking needs doing, everything else still needs to be done, but somehow I have got to sleep, and it was nuts.
>
> (Female, Black Caribbean, FGD 6)

Unsurprisingly this physical and emotional burden had negative impacts on mental health, especially as some felt that it was hard to ask for or access support due to cultural stereotyping:

> I think it needs to change. That it shouldn't be instantly thought of that you need to be a strong Black woman. We need support too. Who is going to support us? Who do we have to turn to? Who is going to put their arms around me? It is … it is why we ended up, well why I ended up, burning out.
>
> (Female, Black Caribbean,, FGD 6)

The impact of age and HIV status on experiences of COVID-19

The pandemic had a profound impact on the mental health and wellbeing of young people in our FGDs. Several participants perceived COVID-19 advice and policies as ageist and believed that lockdowns had disproportionately interrupted their lives.

Disrupted education and prolonged enforced social isolation had significant negative psychosocial outcomes:

> I feel like it's taken away social experiences from a lot of [young] people and its increased anxiety in general. We don't really socialise, and we spend a lot of time excluded in our rooms. Because that has gone on for so long, it's now become a norm to us. Even being able to just go back into uni and do a face-to-face [class] is kind of very different because all I have known is to be online.
>
> (Younger female, Black African, FGD 4)

These negative consequences were felt deeply by parents, who struggled to know how best to support their children while meeting other responsibilities:

> My daughter, going through puberty, spent most of the time just in her room. She would barely come out and I think that she was speaking to a lot of her friends online, but it felt like I was losing my relationship with her. And then I just had to work all the time.
>
> (Female, Black Caribbean, FGD 6)

Considerations about risk extended beyond the individual; participants who lived in multigenerational households were sensitive to the risk they may present to other family members, sometimes resulting in them or their families implementing measures to reduce this:

> My first day coming back from school, during the lockdown and I remember my mum saying when I got in, she was like, 'You need to go and have a shower, and give me all of your clothes.' So, I was like, 'Okay, fine.' So, I gave her all my clothes and she burnt them in the back garden. We were burning my clothes in the back garden.
>
> (Young female, Black African, FGD 4)

Older participants were particularly anxious about their heightened risk of acquiring SARS-CoV-2 or adverse clinical outcomes due to the intersecting influences of older age, race, poor housing conditions (including overcrowding), and their HIV status. However, despite the increased risk presented by living in multigenerational households, several participants reflected on the emotional comfort of being in a social bubble with loved ones:

> So, for those three months [in lockdown] I was with my family. The children made me feel like nothing is going on. The little children would play with me 'grandma come on, do this, do that.' So, at the end of the day, we go to bed [and] by the time we woke up we continue our play. It was really hard before.
>
> (Older female, Black African, FGD 2)

The impact of HIV status on experiences of pandemic restrictions and healthcare access

The pandemic caused anxiety among many participants, particularly in relation to living with HIV. They had been initially categorised as *extremely clinically vulnerable* and advised by post to shield by the UK Government (UK Government 2021). Many had been living well with HIV prior to this, with well-controlled HIV on antiretroviral medication and normal immune function, often being informed by their HIV clinics that HIV was a manageable long-term condition. Consequently, being labelled as extremely clinical vulnerable came as a surprise and prompted fear and confusion about what this meant for their health, their work, and their families:

> The worst thing that made me fearful was the letter that I got from the Government because I'm one of those with comorbidities and it was a lot of stuff that was there and then I got a phone call to protect myself, shouldn't go out, I shouldn't do this.
>
> (Female, Black African, FGD 1)

Furthermore, most participants were unsure about the origins of the letter notifying them about their clinically vulnerable status as it was unclear who had sent it and whether it meant their confidentiality had been compromised, a particular concern given the stigma around HIV:

> It wasn't very clear to say like it was from NHS. It was literally just a letter pushed through the door and I was like I'm confused, has it come from the council? And if it is from the council, how do they know [I have HIV]? I don't know. I don't really know how I felt about it. I was just rather confused.
>
> (Young female, Black African, FGD 4)

People living with HIV need to have consistent access to HIV medication to maintain virological suppression and stay well, as well as regular clinical monitoring. Often participants experienced significant disruptions to their usual HIV clinic services. Some clinics were cancelled altogether (for example those with well controlled HIV were moved from six monthly to annual monitoring); some clinics were conducted remotely, often by telephone. The majority had been living with HIV for a long time and had built trusted relationships with healthcare professionals, with the importance of engagement in care reiterated to them on a regular basis. Due to the long-term and trusted relationships that people living with HIV have with their providers, disruptions in services and the inability to secure appointments made some participants less willing to follow and trust other medical and government advice about COVID-19, especially if that wasn't discussed with their HIV doctor. As a result, the disruption to services, and changes to their longstanding routine care appointments, sometimes impacted their ability to stay well with HIV, contributing further to anxieties:

> I was running out of meds, and I didn't have, I hadn't had an appointment in I'd say a year from that time. So yes, I was a bit worried, like just a little bit worried.
>
> (Young female, Black African, FGD 4)

Many participants had relied upon community organisations (including peer support) for emotional and social support, a vital resource when living with a stigmatising condition. Lots of those support systems were disrupted or transformed (into remote services) by the pandemic, with loss of social connection and negative consequences on mental and physical health:

> COVID has had an impact on me, someone dealing with HIV, by not being able to go to like certain youth groups during that time, because that is my support system, you know. That is where I go and, you know, confide in these people and it helps me take my [HIV] meds.
>
> (Female, Black African, FGD 4)

However, in the absence of their usual support networks, frequently participants developed new ways of coping including spirituality and religion and enjoying the natural world. Older participants living with HIV saw parallels between the HIV and COVID-19 pandemics, drawing upon resources they had previously used to cope with their HIV diagnosis and now applying them to COVID-19, giving hope and strength to younger participants:

> I liked watching like the old timers be like ‘this is our second pandemic, we are good.’
>
> (Young female, Black Caribbean, FGD 6)

Discussion

This is the first paper to describe the lived experiences of the COVID-19 pandemic among people of Black ethnicities living with HIV in the UK. This has included a discussion of the impact of contemporary and historical collective trauma within Black communities and how this shaped individual pandemic experiences. By taking an intersectional approach, we have also highlighted the importance of understanding multiple intersecting axes of oppression, exploring how race, socioeconomic marginalisation, age, gender, and HIV status intersected to amplify existing social and health inequities.

The disproportionate levels of COVID-19 morbidity and mortality in Black people had a traumatic impact on the lived experiences of these communities during the pandemic. This collective (re)traumatisation, a key topic discussed in all our focus groups, intersected with the effects of structural racism, inconsistent global policies, inequitable access and provision of testing, treatment and vaccines which all served to compound death rates through mistrust, alienation, and stigmatisation (Public Health England 2020).

People of Black ethnicities were more likely to work in higher-risk, lower paid jobs which were considered essential during the pandemic, such as health and social care work (The Health Foundation 2020). Concerns around vulnerability, especially in terms of occupational exposure, was reinforced by witnessing the deaths of colleagues and patients while working on the frontline, which had a profoundly negative impact on their mental health. Indeed, our findings are in line with other studies showing that UK healthcare professionals from Black and other racially minoritised backgrounds were more likely to report feeling worried and anxious, disempowered, disadvantaged and discriminated against, and that as a result they were less likely to raise concerns with their line manager (Ali et al. 2021; Gogoi et al. 2024).

Our participants highlighted how conditions of diaspora and restrictions on international travel exacerbated mental health challenges by preventing them visiting loved ones and therefore being unable to access vital kinship networks. We trace how experiences of collective trauma were shaped by both the interaction between the multiple social categories in which they belong (diaspora, frontline workers) and by the inequitable systems in which they occur.

The geographical naming of SARS-CoV-2 variants (such as the ‘South African variant’) was seen as a further attempt to burden the community and assign blame. Through the narrative of migrant communities importing infections, stigma amplified racist and negative stereotypes that predate the COVID-19 pandemic (see Aliens Act, 1905 (Wray 2006)).

In addition, participants felt that potentially beneficial COVID-19 treatments (such as COVIDex) were being deliberately withheld from them, reigniting medical mistrust rooted in painful histories of unethical medical practices involving Black communities (The Commonwealth Fund 2024). Racial inequalities coupled with social marginalisation facilitated the development of a flourishing (mis)information ecosystem amongst these communities. Moreover, the overwhelming volume of information caused confusion, misunderstanding, contributing to mistrust amongst our participants, who reported difficulties navigating the pandemic as a result of conflicting information. In line with our findings, other studies have documented the need for access to trusted, clear, and accurate educational materials targeted to Black communities to encourage prevention behaviours in relation to COVID-19 (Brand Bateman et al. 2021; Kemei et al. 2022).

We specifically sought the views and experiences of younger Black people, a group who are often neglected in research. We found many experienced disrupted education and prolonged enforced social isolation which significantly impacted on their lived experiences and perceptions during the pandemic. Our results correspond with other studies looking at young people's mental health during the pandemic amongst the general population (Panchal et al. 2023) and specifically focusing on young people of minoritised ethnic backgrounds (Burgess et al. 2022; Lenoir and Wong 2023), where it was shown that young people were more likely to be adversely affected in terms of mental wellbeing, social isolation and reduced levels of academic support (Goldstone and Zhang 2022). Our study complements these findings by exploring these intersecting discriminations alongside living with a stigmatising condition such as HIV. Despite these multiple inequalities leading to significant negative psychosocial outcomes, and a lack of essential peer support services, the young people in our study, and other studies involving young people of minoritised ethnicities, reported encouraging patterns of resilience, drawn from their own life experiences to self-manage the fear and uncertainty associated with the pandemic (Burgess et al. 2022).

Further support, particularly for our older participants, came from living in multigenerational households. While this support led to concerns of increased vulnerability due to domestic exposure and exacerbated socioeconomic challenges, older adults valued the comfort and inter- and intragenerational support they received during the pandemic. Modes of drawing upon support might have changed during the pandemic, but the significance of social connectedness and support within the family remained constant, as reported by others in the UK and elsewhere (Derrer-Merk et al. 2000). On the other hand, those who relied on community organisations for support described experiencing loneliness due to service closures as a result of social distancing measures, resulting in lost social connections, a finding that is in line with other studies (Mahmood et al. 2021). The *COVID-19 Social Connectivity Paradox* has been used to describe the need for social connectedness during the pandemic while maintaining social distance (M. L. Smith, Steinman, and Ea 2020). Older adults in our study often felt their autonomy was challenged by guidelines that legitimised ageism, and that the decision to classify all people over 70 as clinically vulnerable amounted to age discrimination (Scott 2020). Despite this, the majority adhered to government-enforced mitigation measures to protect themselves and their families. The stoicism amongst older UK adults, despite inequitable pandemic policies, has previously been reported (Derrer-Merk et al. 2022).

The balancing of such competing needs, for example supporting older family members in multigenerational households, was felt disproportionately by Black women in our focus groups. They described the challenges of needing to mitigate their own COVID-19 risk, due to HIV status for example, while maintaining an income (often as frontline workers) to support family overseas. Not only this, but women were providing the bulk of childcare, undertaking much of the housework and were largely responsible for homeschooling during the pandemic (Xue and McMunn 2021). The mental and physical burden of daily life as a 'strong Black woman' left them feeling overwhelmed and often burnt-out. As a result of needing to support extended networks and members, both practically and emotionally, while themselves living at the intersection of racial and gender inequalities, UK Black and ethnically minoritised women faced some of the heaviest burdens of the pandemic (Abdelshahid and Habane 2021). The detrimental effect of these intersecting oppressions on the pandemic lived experiences of Black women, combined with the social determinants of poor health they face has also been explored in other studies (Abdelshahid and Habane 2021). By specifically teasing out the effects of gender, we respond to calls to explore COVID-19 experiences through a gender-responsive, intersectional lens (Ryan and El Ayadi 2020) and demonstrate that Black women's pandemic experiences were based on multiple intersecting structural inequalities such as race, class, and gender.

By approaching our data intersectionally, we have been able to explore the impact of the converging HIV and COVID-19 pandemics on the lived experiences of the Black people living with HIV in our study. Previous quantitative research has highlighted the impact of the COVID-19 pandemic on access to healthcare services amongst people of Black ethnicities and resulting disengagement from HIV care (Ottaway et al. 2024); as well as a significant association between social isolation, food and migration insecurity and severe COVID-19 outcomes in Black people living with HIV (Dominguez-Dominguez et al. 2024). The nationally representative survey of patients living with HIV in the United Kingdom 'Positive Voices' ('Positive Voices 2022: Survey Report - GOV.UK' 2024) highlighted the lives, experiences and healthcare needs of people living with HIV during the pandemic. In this qualitative paper, we go further by exploring and describing in depth several themes which speak to persistent inequalities which were exacerbated by COVID-19, such as a lack of culturally appropriate information, the confusion and distressed caused by shielding recommendations, and bias in healthcare access and delivery, drawing a direct line between structural and institutional racism and the disproportionate adverse effects of COVID-19 on Black communities living with HIV. The compounded social stigma experienced by our participants, due to living with HIV, led to worsening mental health, which was subject to further stigmatisation, during the pandemic and a further widening of previously reported and existing health inequalities. These inequalities necessitated many to draw strength from skills and attitudes they had developed as a result of living with HIV. This *pandemic expertise* has been shown in other global qualitative work evaluating the experiences of living with HIV during the COVID-19 pandemic (Mars et al. 2024) with others also highlighting this complex interplay of stressors at individual, interpersonal, community and systemic levels on the pandemic lived experiences of people living with HIV (Smith et al. 2024).

Overall, the pandemic had a profoundly negative impact on our participants' psychological, social, and economic wellbeing resulting from multidimensional challenges across all aspects of their lives. This minoritised group of Black people living with HIV reported worsening mental health (especially anxiety and social isolation), financial hardship, challenges balancing competing demands, and confusion regarding public health advice. Additional challenges included disruption to clinical services which compromised their ability to manage their HIV diagnosis, heightened anxiety because of being categorised as extremely clinically vulnerable, and the loss of vital community support networks. Our study demonstrates that lived experiences of Black people with HIV during the pandemic were influenced by wider oppressive systems and discrimination that were structural and interpersonal, systemic, and individual, personal, and impersonal. Despite these profound inequities, participants showed incredible strength and resourcefulness during the pandemic. What is clear from our data is that there is an urgent need to address the specific psychological, social, and practical support available to people from racially and ethnically minoritised backgrounds, particularly those living with stigmatising conditions such as HIV, to safeguard the health and wellbeing in future pandemics.

Strengths and limitations

The strengths of our study include the diversity of study participants in terms of age and gender. Our recruitment of a predominantly female cohort helps to address the underrepresentation of women in HIV research and reflects the epidemiology of HIV in Black communities in the UK. By recruiting participants through partner organisations, we were able to gain the communities perspectives and include participants who may not be engaged with healthcare services and who would otherwise not have been included (Bateman et al. 2021). Being able to recruit this often-underrepresented group, led to a rich dataset and meaningful insights into the lived experiences of people of Black ethnicity living with HIV during the COVID-19 pandemic. This was further strengthened by focus group methodology which enabled contributions from all participants, enriching discussions and allowing in depth exploration of emergent issues, including group divergence, and challenging of apparent consensus. Through co-creation and co-analysis with Africa Advocacy Foundation we were also best placed to gather rich data, as participants are likely to have been more comfortable sharing their experiences having been recruited through a trusted community organisation. Taking an intersectional approach to analysis, we were able to interrogate these inequalities, taking each of these social identities separately, and together, to more comprehensively understand the experiences and perceptions of the COVID-19 pandemic in this group.

However, our study is not without limitations. Given the predominantly London-based sample, findings may not be transferable beyond London. Furthermore, our study was conducted in 2022, and we may not have captured the longer-term impact of the pandemic. Participants were English speaking and those with a language barrier may have been further marginalised. It is also important to note that overall, our cohort had high levels educational attainment.

Recommendations for policy and practice

Policies should acknowledge the wide-ranging and corrosive effects of structural racism and co-create (with affected communities) responses that are fit for purpose so that health and social inequalities are not further amplified in future pandemics. Public health messaging and pandemic responses should specifically consider and align with the lived experiences of racialised and stigmatised people such as Black communities living with HIV. This study documents the impact of COVID-19 in these communities and as such our recommendation that policies need to consider intersecting factors is evidence-based. A participatory approach, involving community organisations as key stakeholders in the development, delivery and dissemination of targeted research and evidence-based policies, will ensure that outputs are tailored and culturally appropriate to help mitigate the impact of disinformation ahead of future pandemics. Policies need to explicitly address how to minimise disruptions to health, social care, and community services as part of preparedness plans, and in doing so, consider how we more effectively communicate health information to marginalised communities. Future studies should continue to draw upon multisector collaborations to increase the representation of marginalised groups in research. Better facilitating the meaningful and ethical involvement of marginalised groups within research serves to improve health and research literacy and build trust with communities who have experienced historical medical and research-related abuse.

Conclusion

This study is the first of its kind, tracing the significant multidimensional impact of the COVID-19 pandemic on people living with HIV who are of Black ethnicities in the UK. We explore our participants lived experiences, rooted in intersecting disadvantage, and underpinned by structural racism and conditions of diaspora such as collective trauma, socioeconomic marginalisation, and stigma. Our intersectional approach has highlighted the importance of exploring how these multiple axes of oppression intersect and shape pandemic experiences. Despite this, we should acknowledge and celebrate the strength and resourcefulness of these communities, recognising that solutions to many of these issues must be co-created in partnership with them.

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Authors’ contributions

The study was designed by VK, DO and ST. VK, DO, AC coordinated recruitment and along with ST conducted the FGDs. ZO performed the analyses with input from EJN and

ST. ZO, EJN and ST interpreted the findings. ZO wrote the first draft of the manuscript with input from EJN and ST. All authors reviewed and approved the final version of the manuscript.

Ethics approval and consent to participate

Ethical approval was obtained from UCL Research Ethics Committee (Project ID/Title: 6698/004).

Availability of data and materials

The database contains personal and sensitive information and is therefore not publicly available. Access to the study data and/or samples is governed by the National Health Service data access policy and those of King's College Hospital NHS Foundation Trust, the study sponsor. The Gen-AFRICA and COVID-AFRICA studies are open to collaborations, and all requests from researchers who meet the criteria for access to fully anonymised patient-level data will be considered. Concepts can be submitted for review to the principal investigator (Prof. Frank Post; email: frank.post@kcl.ac.uk).

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