



## **Palliative and End-of-life care experiences of people of African and Caribbean dEscent (PEACE)**

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**Full Report**

**May 2022**

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# 1. Context

## 1.1 Policy Issue

Palliative care is an essential service, now identified as a basic human right (1). Despite this, one in four UK families are believed to miss out on crucial support at the end-of-life (2). Experiences during the coronavirus pandemic have highlighted the need to address inequities in experiences of, or access to, palliative and end-of-life care (3,4). COVID-19 had a disproportionate impact on some sections of the UK population, with high mortality rates in different age, ethnic minority, socioeconomic and occupational groups (5). This project addresses this critical topic, with an exploration of the experiences of palliative and end-of-life care amongst people of African and Caribbean descent.

Throughout this report, when we refer to palliative and end-of-life care, we are describing the care received by the majority of decedents, delivered by community and hospital staff who were not palliative care specialists. Our interviewees had experience of deaths in hospital and community settings. Box 1 defines terms that are used in this report.

## 1.2 Scoping of the evidence

Ethnic minority groups comprise one fifth of England's population (5), and the proportion of older people in minority ethnic communities is rising. This has important implications for providers of palliative care, who must be sensitive to diversity in religious practices, cultures and languages (6). Yet, most research into how to provide culturally competent palliative care for ethnic minority groups is out-dated, out-with the UK, or from London, where ethnic minorities groups make up over 40% of the population (6–9). We know little of experiences across England, where such populations are more disparate (6,10,11).

This study focuses on people of African and Caribbean descent. They experienced some of the highest rates of COVID-19 death, and many experience significant material disadvantage (6,10–12). Death rates from COVID-19 have been twice as high as in white populations of similar socioeconomic status (5). People of African and Caribbean descent are also less likely to access specialist palliative care (10,13–16), despite the crucial role such services can play in improving experiences for people with COVID-19 (17). A better understanding of the reasons behind inequities, and the impact of the coronavirus pandemic.

### 1.3 Box 1 Definitions

#### **Palliative Care**

The active, holistic care of patients with life limiting illness and their families. The control of physical and psychological symptoms and social and spiritual problems are paramount. The aim is to achieve the best possible quality of life for patients and their families by focussing on their goals. Care provided is therefore personalised. Palliative care includes but is not limited to end of life care. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (18–20).

#### **Generalist palliative care**

The majority of palliative care is delivered by multi-professional teams who are not specialists in the field. Generalist palliative care should provide holistic assessment of patients' needs including basic symptom control and psychological, social, spiritual, and practical support. They should also coordinate care, signpost to services and conduct open and sensitive communication with the person, their family, and professional staff. Specialist advice should be sought and referral to specialist teams should occur when necessary (18–20).

#### **Specialist palliative care**

Specialist palliative care services may be statutory or voluntary. They manage complex palliative care problems that cannot be dealt with by generalist services. They include multidisciplinary specialist palliative care teams who provide assessment, advice, and care in community, hospice and hospital settings. Specialist in-patient facilities (for example hospice beds) provide care for people with complex problems that cannot be managed adequately in other settings. Bereavement support services may also be provided. (18–20).

**People of African and Caribbean descent:** This report focusses on people who self-identify as being from the ethnic groups described by the Office for National Statistics as Black Caribbean; Black African; Black Other (5). The term “People of African and Caribbean descent” was suggested by the project’s patient and public involvement and engagement group (PPIE) in preference to the term “Black”.

**Racism:** A system (consisting of structures, policies, practices, and norms) that structures opportunity and assigns value based on phenotype, or the way people look (21). Racism can manifest as individual or group acts and attitudes or institutional processes that lead to disparities (22).

**Institutionalised racism:** Differential access to the goods, services, and opportunities of society by race. Institutionalised racism is normative, sometimes legalised, and often manifests as inherited disadvantage. It is structural, having been codified in our institutions of custom, practice, and law, so there need not be an identifiable perpetrator (21).

**Personally mediated racism:** Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race. This is what most people think of when they hear the word “racism.” Personally mediated racism can be intentional as well as unintentional, and it includes acts of commission as well as acts of omission. (21)

## 1.4 Research aims and objectives

### Aims

This study aimed to explore the views and experiences of families and professionals on palliative and end-of-life care for people of African and Caribbean descent during and after the COVID-19 pandemic.

### Objectives

To explore patient (by proxy), family, health and social care professionals' and community workers' views on:

1. Experiences of end-of-life care (EOLC)
2. Barriers to accessing EOLC
3. How EOLC could better meet the needs of people of African and Caribbean descent.

## 2. Approach

### 2.1 Study design

This research project used an exploratory approach and qualitative methods. Semi-structured interviews were undertaken with bereaved relatives and a range of health, social and community care professionals.

### 2.2 Inclusion and Exclusions Criteria

#### 2.2.1 Inclusion Criteria

Inclusion criteria for bereaved relatives/carers:

- Adult over 18 years of age.
- Bereaved relative / carer of a person of African and Caribbean descent who died in the UK during the COVID-19 pandemic - April 2020 to March 2022.
- Participant had a caring role and/or sufficiently close relationship/contact to have insight into the experiences and perceptions of the decedent.

Inclusion criteria for health, social care and community-based professionals and voluntary community workers:

- Working as a professional providing care and or support to people of African and Caribbean descent in the last year of life during the pandemic.

#### 2.2.2 Exclusion Criteria:

- < 18 years of age.
- Lack of capacity.
- Unrelated or insufficient knowledge to report EOLC received.

### 2.3 Recruitment

We used a combination of purposive and snowball sampling to maximise recruitment. We approached over 150 local and national health, social care, voluntary, charitable and educational organisations via email. These included: religious foundations; bereavement charities, such as Cruse; providers of end-of-life care support such as Marie Curie; refugee

services; hospices; older people's organisations; organisations supporting African and or Caribbean communities, such as lunch clubs; regional health organisations such as Healthwatch; University networks; and national trade unions such as Unison. We also approached contacts in relevant health and social care organisations, through networks such as CHAIN (NHS online mutual support network for people working in health and social care). We advertised participation in the study via social media, including Twitter (NIHR account), Facebook and radio promotion via Spice FM (South Asian and Diverse Radio for Tyneside). We also used 'word of mouth' recruitment, building on existing networks with people of African and Caribbean descent, and disseminated information about the research via text message, email, phone calls and WhatsApp.

Initially we planned to interview only bereaved relatives. As recruitment was slow in the first few months of the project, a decision was made in September 2021 to broaden the inclusion criteria to include health, social care and community-based professionals and voluntary community workers. Recruitment for this group was conducted via public adverts and existing networks.

### 2.3.1 Inauthentic interviews

As interviews progressed, the researchers became concerned that some of the people coming forward for interview had not been bereaved in the UK. It appeared that people were posing as relatives in order to take part in the research. The wider team, study sponsor and funder were notified and recruitment was suspended whilst the matter was investigated. The team's response to this is detailed in the Appendix 1. For the purposes of this report, it is important to note that none of the interview data judged to be inauthentic has been included in the analysis.

## 2.4 Data collection

Interviews were conducted via videoconferencing platforms (Zoom or Teams) or telephone and lasted between 30 minutes and 2 hours. A topic guide was developed in collaboration with the patient and public involvement and engagement group (PPIE). Interviews explored which services were and which were not used in the last months of life, and the reasons for this (e.g. access or awareness). We also explored participants' views on the care received, and what they would change, specifically, how future services can be sensitive and respond appropriately to the needs of people of African and Caribbean descent. Participants taking part in interviews were offered a £25 voucher, on the recommendation of the PPIE partners.

## 2.5 Analysis

Data were analysed using thematic analysis. This approach provided flexibility to enable us to apply a range of theoretical frameworks to the data to interpret and situate our findings in a policy and practice context (23).

A coding frame was developed, adapted and applied to the data. The research team met regularly to discuss, develop and refine themes. PPIE partners were involved in analysis, providing their insights and reflections on suggested themes and anonymised data extracts. NVIVO software was used to manage the data.

## 2.6 Ethics

**Ethics** : This project was approved by Newcastle University Research Ethics Committee (2077/10053/2020 (including amendments 2077\_1, 2077\_2, 2077\_3))

## 2.7 Patient and public involvement and engagement (PPIE)

PPIE was integral to this project from inception to completion. We worked with a dedicated group of PPIE partners comprised of eight people of African and Caribbean descent. They were diverse in self-reported ethnicity, gender, geographical location and occupation. Some of the group had experience of bereavement, some were healthcare professionals who have provided palliative care, and others were drawn from Voluntary, Community and Social Enterprise (VSCE) organisations who have supported people of African and Caribbean descent during the pandemic.

The group met online using a secure video conferencing software. To reduce the potential for digital exclusion, we drew on NIHR guidance on holding a PPI meeting using online tools ((24)). This ensured the reliability of the meetings, given COVID-19 social restrictions at the time. Three meetings were held, each of two hours duration.

PPIE partners influenced the research in a number of key areas:

- **Terminology:** Concerns were raised about use of the acronym BAME and the use of 'black people'. A consensus reached by PPIE partners was that the preferred term was 'people of African and Caribbean descent.'
- **The scope of the research question:** Partners felt that the voices of bereaved relatives from ethnic minority groups should be heard, as they are often overlooked and their needs poorly understood.
- **The importance of a qualitative approach:** Semi-structured interviews were perceived as an effective way of exploring individual narratives and providing a good understanding of lived experience.
- **Recruitment:** PPIE partners and stakeholders stressed that recruiting marginalised population groups often requires word-of-mouth information sharing. This is based on trust.
- **Ethical concerns about interviewing bereaved people:** Partners supported the view in the literature, that discussion may be therapeutic, but stressed the importance of sensitive/appropriate questioning and offering bereavement support.
- **Developing recruitment materials and interview topic guide:** We were advised to draft a callout document that was flexible for use in different formats and could be used to recruit participants. The group co-designed the interview topic guides and public and participant facing material, to ensure they were sensitive, comprehensive and culturally appropriate.

## 3. Findings

We completed 39 interviews in total. Twenty-six interviews were with bereaved relatives, 18 of which yielded authentic data. Participants ranged in age from 21 to 68 years, 11 females and seven males. Sixteen participants were of African and Caribbean descent themselves, one self-identified as British Asian and one as Turkish Cypriot. Decedents ranged in age from 25 to 88 years. More detailed demographic data on the bereaved and the decedents are included in the Appendices 2 and 3.



Thirteen interviews were completed with health, social care and community-based professionals and voluntary community and social enterprise (VCSE) workers. Participants ranged in age from 27-69 years, eight were female, five male. Seven were of African and Caribbean descent. Four were White British or Irish, one self-identified as Chinese and one as British Pakistani. Eight were medical or nursing staff, four were community workers and one was a voluntary community worker. More detailed demographic data is included in the Appendix 4.

### 3.1 Key Themes

The findings are organised around three key themes:

- Representation, which encompasses ideas of discrimination and racism.
- Personalisation, including culture and the impact of COVID-19.
- Awareness and Access, within which support before and after death and communication and involvement in decision-making are important.

### 3.2 Theme 1: Representation

Relatives and professionals reflected on the lack of representation of people of African and Caribbean heritage in healthcare. They noted that people depicted as the COVID-19 response and frontline workers were predominantly white.

*'If you're trying to encourage the Black community to go to the hospital, well, then actually at the early stages there wasn't any evidence that the media were speaking to black nurses and doctors at that time ... there are lots of people who have come over from the Caribbean who have worked in the National Health, and clapped for them, but on television, you didn't see that ... there was lots of missed opportunities to speak to, erm, niche communities in a way that was, that- and then the government said, "Oh, you know, but people are not taking up," well, why would people take it up, because you're not talking to us.'* Relative 9

*'When they started doing all the clapping thing for the NHS, at first all the images that they would show, they would all be white staff ... now, black staff, as in black doctors, black female doctors started doing their own on TikTok, you know, er, you know, to show that, "Look, we're here as well, what about us?'"* Professional 12, VCSE

Both relatives and professionals perceived this lack of visibility as being discriminatory. Some professionals felt that it may represent institutionalised racism. All felt that a diverse healthcare workforce was important, one that reflected the communities served. The provision of information in different languages, using images of staff of different ethnic backgrounds, was proposed as a way of enabling people to feel they belong.

*'So, when people do come to the hospice, do they feel represented? You know, if- if they feel like they don't belong, erm, because they don't see themselves in the workforce... in the staff and the volunteers, then they're not- you know, they're less likely to share their experience in a positive way, with others in their community.'* Professional 6, Clinical

*'We don't see ourself there. That's why it's happening. As soon as we start and, "We're here to help you," even if it's your food, your language, something to, like, they really do care, they're really listening, I think that... because if a white person just comes to talk to you about palliative care and you don't see yourself, I'm like, "Well, it's only them."'* Relative 5

### 3.2.1 Racism and discrimination

Both relatives and professionals spoke about what they perceived to be racism in healthcare. Race-based assumptions about people of African and Caribbean descent were felt to cause differential decision-making about treatment, care and support.

*'I think that's also their knowledge, that, "Oh well, that community of people, they like to look after their own, so just leave them to get on with it." When I say 'they', I mean, people I like from the NHS system, you know; so, it could be ... the district nurses, it could be your GP, you know.'* Professional 12, VCSE

Some relatives commented that people of African and Caribbean heritage may delay in presenting to services when ill, anticipating a different level of care, because of their ethnic background.

*'If it's COVID-19, you know it's serious, just go to the hospital, don't be afraid that maybe you might be overlooked. Yeah, you know, sometimes there's that fear, there's that fear, somehow. (...) Actually it somehow deters people from getting that, enough help somehow.'* Relative 8

*'They feel like they are not given the same care. To me, I think medication is not just the medicine. It's also the - the emotional part whereby you talk to someone nicely, tell them, "You'll feel better, don't worry". But you see, sometimes, because of some people who are racist, they won't talk nice to the person. And maybe that will discourage the person; maybe even, and say, "Let me go home." Yeah, you see?'* Relative 6

Differences in relatives' and professionals' understanding of discrimination in healthcare emerged in the interviews. Relatives felt that racism was difficult to articulate and prove. They described concerns about being treated fairly. Some told of how they were left with a feeling that they had received differential treatment on the grounds of race:

*'You pick up a tone, you pick up a, a vibe. I can't explain it. You see how somebody talks to white people and then you ask something, you know, like, you know, you might be in a queue waiting ... you know, healthcare professionals or whatever talking in one way, and then you, you might ask something similar whatever, and you get a different response, and a lot of white people, you might not notice it if you're the white person... But as black people we do. It's very difficult, because ... you can't prove it always. Most of the time you can't ... you are made to feel that, you know, you've got a chip on your shoulder, you are imagining it, you know, it's not, yeah. But it is. It's very real. Yeah. Definitely. Like I said, I've got a lot of experience of this unfortunately.'* Relative 3

Six relatives cited population health data about ethnic health inequalities in COVID-19 deaths and childbirth to support narratives of their experiences of discrimination, or fear of racism in healthcare:

*'With childbirth, I know the, the mortality rate is highest in black, black women. I know that as well, erm, and I do worry because of my race and because I'm a woman I'm always worried that I'm gonna receive, erm, poor quality of care, that's my main worry as well.'* Relative 4

Relatives reflected on racism in wider society, and discrimination on the basis of other characteristics, such as gender, age and migration status.

*'So, if you're, if you've experienced racism within society, why would you then think in, in health that you're, you know, that you're going to be treated fairly? And it wouldn't be obvious, it wouldn't be things like, "I'm going to go and try and kill someone-" ... but it would be about someone waiting for attention and being overpassed; it would be that subtle. I don't think it is that kind of someone's deliberately doing something to harm, but it's that kind of, erm, er, maybe at the end of the line where someone rings in and says, "I'm not well." So, my friend who died of COVID, she had rung in and said that she was having difficulty breathing but was encouraged to stay at home.'* Relative 9

*'Yeah, they say we're supposed to be just used to pain and ..... women are just supposed to deal with pain.'* Relative 4

In contrast, the professionals were more direct, providing examples of what they perceived to be institutionalised or personally mediated racism:

*'I think it's also difficult with nurses as well because, you know, they live... A lot of them will ... they'll live in [Town 3] and they'll be from [Town 3] and they've grown up in [Town 3]. And they're amazing and like so dedicated to the community that they serve but they're also quite... A lot of them are quite narrow in their outlook. And they might, you know, they will have had pretty kind of closed, working-class upbringings where it's fairly common to have, erm, views that I would certainly consider to be overtly racist. And they probably wouldn't consider to be overtly racist but, you know, may, might not even acknowledge them to be discriminatory, but I would certainly be like, "That's racist." So there's a lot of kind of work to be done to try and... I, I think it's really difficult to have those conversations in the workplace without kind of making people feel like they're being judged but they have to happen.'* Professional 13, Clinical

Two professionals commented on the historical and current lack of representation in senior posts and roles in the NHS, and how this is related to power. However, others reported on a shift within their workplaces, with the appointment of new black chief executives. Professionals did, however, acknowledge the difficulties of tackling interpersonal and institutional racism.

*'There are certainly in existence, my experience of the snowy white peaks of the NHS. Erm, you know, the higher you go up, the more white and male it becomes, erm, and that, that is seen, you know, all of the time. Erm, I, I think that there is an intersection as well with class here.'* Professional 11, Clinical

### **3.3 Theme 2: Personalisation**

The importance of a personalised or person-centred approach to palliative care emerged consistently across our interviews. Relatives and professionals highlighted that there may be particular cultural and religious norms and practices around end-of-life care for people of African and Caribbean descent. But in such a large, diverse population, generalisations about culture, religion and history are seldom helpful. Instead, they stressed the need to ask about people's priorities. Families that included healthcare professionals also commented that they needed information on care provision and accessing support. Other relatives talked about their sense of duty to fulfil caring roles for older members of the family. Both groups were wary of healthcare providers making assumptions about what they knew or needed.

*'I don't think we should have a blanket approach to everybody. And I think we do need to be mindful, and just be brave and ask people, you know, "Is there anything in your culture that is important to you, and that can help me deliver care better?"*

Professional 6, Clinical

*'I just think that there's too many assumptions made, that we do kind of cope within our communities and, and that's it.'* Relative 7

This sentiment was also reflected in the professional interviewees, who suggested that people need to be encouraged to share information on their needs and expectations. It should not be assumed others will know.

*'With the African and Caribbean, I think the conversation that I would have with them, I would ask, "What would you like us to do at this stage?" Because you wouldn't know, you wouldn't know, because some people are Christians, some people are Muslims, some people believe in traditional ancestral beliefs, so you have to respect all those. So if you ask the relatives or ask the patient, if the patient can communicate with you, they should be the one giving you the lead and telling you what they expect and what they want you to do.'* Professional 2, Clinical

Almost all the professional interviewees remarked on the role of religion in decision-making at end-of-life, both positive and negative. Relatives emphasised the role of faith leaders and religious rituals in end-of-life care. Spiritual wellbeing was also mentioned. Prayer could be a source of comfort and a uniting force, but professional recognition of religious sensitivities was also needed (as relative 5 notes, below). A minority (four) of relatives recalled being asked about their religious beliefs by health care providers, and in these cases, appropriate provision was made. Conversely, neglect of religious practices was a potent cause of distress. One relative reported that Muslim after-death rituals were not followed, leaving them feeling that *'they just dumped him anywhere.'* (Relative 13)

*'We come from that community that you don't, er, you just keep quiet. You're like, "You know what, let's go and pray about it." With us, it's, "Let's go and pray about it." I'm like... I know we need to pray, but sometimes you need professionals to do their bit as well.'* Relative 5

Many components of care that were identified were relevant to people of all ethnicities. Food and music preferences, for example, may or may not be culturally specific. What our interviewees described, was an inability of services to meet these needs for people of African and Caribbean descent.

*'The care service is not set up for ... cultural differences, let alone my dad, certainly not. So whether it's in terms of food, whether it's in terms of the family ... I remember we talked about food. But just having familiar things, ... whether it's familiar music.'* Relative 3

### 3.3.1 Impact of COVID-19

The coronavirus pandemic and associated social restrictions had a significant impact on the provision of care. All participants reflected on how people of African and Caribbean descent were disproportionately affected by COVID-19, which heightened fear in the community.

*'the amount of people of African and Caribbean descent and Asian people that died in the pandemic- [...] is completely disproportionate to the number of white people who died. [...] And so they, I did see that fear, I definitely saw that fear in, in those patients and their relatives.'* Professional 9, Clinical

They mentioned the increased risk of infection, greater likelihood of poor health outcomes and disruption to social life and customs. A sense of isolation was a particular concern in bereavement, when families were obliged to be self-reliant.

*'But I can tell you it was a very, very, hard situation. It was very hard to face the way that things went. Because you know, when someone passed away, if you have people around it's different but I was alone, no one was there so. No one came to visit me because of COVID lockdown, many restrictions. You cannot meet people, you cannot do that. It was in the first, first lockdown so a very, very, difficult situation.'*  
Relative 10

### 3.3.1.1 The significance of restrictions on visiting

Both relatives and professionals described the significant impact that restrictions on visiting had on the experience of palliative care. Many relatives were not able to see their loved one before they died and spoke of the distress this caused. A number felt that they were not involved in decision-making and received insufficient information about their relatives' status and care. Whether this was directly related to COVID-19 restrictions or reflective of communication between families and healthcare more generally, is difficult to ascertain.

*'the one that I struggled with ... the most really was just dealing with not knowing you know, like just waiting for that phone call and not knowing so it's kinda like you wake up but your day does not really start until you get that phone call to say, 'Th-This is where we're at,' and even if you do but it's only for a short period of time but three hours later you can't just then phone in and say, 'Oh how is he now?' Or you can't – you know, so yeah, the communication is the one that I really struggled with the most. N- not getting the information and obviously not knowing'* Relative 1

Healthcare professionals understood the importance of facilitating visits, but were also acutely aware of the need for restrictions. They described difficulties in navigating the social restrictions at different points in the pandemic and the impact on patients and families. Beyond health services, the social restrictions meant that many bereaved families had limited support after the death.

*'Yeah, I think as time went on, we were just realising that's not humane and that nobody wants to die alone, so you know, allowing some people in with, you know, relative precautions, erm- [...] was important.'* Professional 9, Clinical

*'And having to say no to people coming in, I think that was also really, erm, er, very challenging.'* Professional 11, Clinical

Remote means of communication (FaceTime, What'sApp, mobile phone and text messaging) were used to help relatives stay in touch with the patient and this is covered in Section 3.4.1 below.

### 3.3.1.2 The demand on the health service, and impact on care

The demands placed on the health service by COVID-19 were part of every narrative, but families and professionals had different interpretations of the impact. Staff described the challenges faced in providing care, with high workloads, complicated cases, and staff illness. Relatives focussed more on the experiences of individual relatives, with care and services subject to delay or failing to meet expectations.

*'But I think the main thing is probably the volume. Like I said at the beginning, it's like the sheer numbers of people and the fact that not a lot of people get better'*

Professional 13, Clinical

*'Yeah, I think it was really difficult. I do get that the nurses, doctors were quite busy but I feel, erm, more attention should have been put on my uncle. And the appointments and the transplant should have been scheduled on time because as I said it was an ongoing condition, it was a year. And I feel like if he had that proper care, he would still be here today'* Relative 2

### **3.4 Theme 3: Awareness and Access**

Professionals and relatives felt that palliative care may not be offered, understood or accepted by patients of African and Caribbean descent.

*'I don't think we're as proactive in offering palliative care services to people from the Black community as we are to other people. [...] I think... I don't know if people feel like the, they, they're not, they wouldn't be accepted, the services wouldn't be accepted, or they're not needed or... like that kind of perception of strength certainly in, you know, black men, certainly from the Caribbean community in [City 2], like not accepting help, but I also just don't think it's been, you know, offered.'* Relative 13

Participants identified the influence of culture on the social acceptability of talking about death, suffering, and grieving.

*'There is a, erm, a belief, an understanding, a, a silent consensus that you don't talk, you don't talk about your hurts, you don't talk about your upsets, you don't talk about your, your fears or your concerns in that way ... this also goes back to the event of enslavement, because there was a huge lack of distrust amongst ourselves, because we never knew who was going to go back and tell master and so that would equal a whipping or you could even lose your life'* Professional 5, Self-employed

*'In the Black community, there's still that taboo of going for support and talking things out ... especially with the older ... that stigma and that taboo is still very much there ... some of them are probably not aware that these services are available, but some of them are aware and just wouldn't use them just because of the stigma.'* Relative 26

*'I've known friends that died of cancer, my friends that didn't want to tell anybody ... I tried to signpost ... to a support group. [but they said] "I don't know what they do in support group. They just drink tea ... all these white people'.* Relative 5

Professionals who were born (or had relatives) overseas described how the absence of healthcare systems in other countries may influence how people access care in the UK. This, along with cultural beliefs, could lead to some people choosing to self-manage or seek advice from religious leaders instead of accessing NHS services. Professionals readily acknowledged healthcare providers lack awareness of specific cultural practices and needs and diversity within cultures.

*'if you ask the healthcare professionals ... there is still a lack of understanding about different cultural beliefs. In Africa they think Africa is, er, or Afro-Caribbeans are just one community, they're not. Africa is a continent. There so many diverse communities in Africa, so I recognise that this study is concentrating only on Africa, but Africa is such a big continent, and you have different cultures and different backgrounds. [...] And, and you know, you can't just turn around and say, "Oh well, if I go to Grenada it's going to be the same as St Lucia or Barbados, or, or Antigua.'*

*They're all different, they have all different practices, they have different communities, different cultures, different, you know, it might as well be Asia and Europe, you know, it can be as diverse as that.'* Professional 4, VCSE

A general mistrust of authority, born out of experiences of discrimination, was also noted as a factor that influenced decisions to access services.

*'...in terms of my uncle's case, the elder generation, I think have been through more in terms of systemic, erm, obstacles and systemic kind of biases, erm, so they are gonna be more reluctant to take up any form of intervention or care-erm because the trust just isn't there. Relative 7*

Our participants' narratives encompassed a general need to increase professional skills and raise public awareness about death, dying and the services available. They also talked of a particular understanding of religion and cultures that would enhance care for people of African and Caribbean descent. Many relatives and professionals identified greater visibility within communities and strong relationships between care providers and faith/community leaders as potential strategies. One relative championed the potential contribution of older generations from diverse communities and the NHS workforce, as rich resources for learning about cultural diversity in healthcare. There was a general feeling that responsibility to find out about what support is available should not lie with families who may be disadvantaged at a difficult time in their lives.

*'So I think on the whole, improving education amongst both the public and the healthcare professionals about what end-of-life care is available, er, what palliative- [...] care is available and what support, erm, is available.'* Professional 7, Clinical

*'Yeah, so, I think- erm, I think reaching out to the community actually is- is really important. Linking with faith leaders, erm, and community groups'* Professional 6, Clinical

Improvements that would have wider benefits across the population were also identified by professionals and relatives. One professional commented that greater awareness of end-of-life care amongst healthcare professionals may reduce demands on palliative care specialists. Care homes and home care were specific settings highlighted by families as requiring better trained staff for end-of-life care.

### 3.4.1 Communication and decision making

The COVID-19 pandemic had a profound effect on communication between professionals, relatives and patients, and within families. Remote modalities were often the only way that people could stay in contact, and some of these were new and unfamiliar to patients. Relatives described telephone calls from healthcare providers as infrequent, unclear or poor quality. Videocalls and use of video conferencing platforms with hospital patients were seen on the media coverage of the pandemic, but not uniformly available to our interviewees.

*'...We were able to FaceTime them, which was really lovely. The staff members, the carers, allowed us to call them on their private phones because there was no facilities ... there were no, they didn't have mobile phones for staff, erm, because I guess it wasn't a thing that they were expecting would go on for, and then to try and get, you know, smartphones for every resident to have their own connection. So, we were really appreciative of the, the staff who allowed that to happen.'* Relative 14

Changes in the mode of communication had a knock-on effect on the content of conversations. Open and honest communication was the aspiration for all interviewees. Relatives wanted information that was correct, timely, and sufficient to allow them to take part in decision-making and prepare for what was to come. They also felt that it was important for services to initiate contact with families not vice versa. Healthcare professionals talked of the importance of building trust with families and devoting time to end-of-life conversations, including advance care plans. They stressed that good relationships with families made it easier to understand what they were going through, and provide better support.

*'It feels really inadequate, me trying to support people over the phone when you've not even really met them before'* Professional 10, Clinical

In practice, changes associated with COVID-19 served to restrict the involvement of families in decision-making at end-of-life. They stressed the benefits of being able to see their relative, to understand their decline, but this was often not possible. Only one relative reported a positive experience of involvement in treatment decisions. Others were informed of treatment plans but felt they were unable, or had insufficient information, to make informed decisions. Decisions were made without their knowledge or consent. Only one relative reported that they had been able to challenge this status quo.

*'So I was going to ask them not to do it up 'til Christmas. Maybe just give it two days so that you know, the kids at least can have.....Christmas, so I don't know if they could have asked me whether they should do it but I don't if that – I don't know whether that was an option or not because all they said is um, 'This is what we're going to do now,' so It- I don't know if there was an option for me to say, 'No, can we see, is there anything that can...? Because I didn't know how bad it was the brain haemorrhage. I didn't know if there was anything that can be done, like I don't know anything about brain haemorrhages, I don't know if they could drain it, I don't know if they could operate like, I- I didn't know – I didn't have any more information all they said was like, 'This is what's gonna happen because he's had a brain haemorrhage and we don't think he's gonna survive.'* Relative 1

Professionals' capacity to spend time building relationships with relatives was limited during the pandemic, and they had few opportunities for early identification of end-of-life to support planning. They reported their discomfort in conducting conversations about resuscitation and palliative care over the phone and the negative impact this had on relationships with families.

Access to support before and after death was hindered by service closures and reduced provision during the pandemic. COVID-19 restrictions prevented families and friends providing unpaid (informal) care. Families felt that they were left to care for dying relatives without the necessary support, equipment or knowledge. Many described experiences that were overwhelming and incurring a lasting psychological cost. Support was more likely to be perceived as adequate if families were familiar with the healthcare system or able to advocate for their rights. Relatives who had access to specialist palliative care teams felt that this provided continuity of care for the family unit.

*'Erm, the fear that was within us all was, are they safe? Are they being looked after? Is anybody speaking to them? What is their, who's looking after them whilst they're in the hospital? Are people just in beds and being walked by? And that is pretty much*



*what was happening. So, they would do the medication, erm, as it got busier there was less interaction...So, in mum's case, she was a bed number; we would call, "Oh, bed number 25," erm, "there's a call for bed number 25, if somebody could-" And my sister said, "Can you please stop calling our mother as bed number 25..."* Relative14

All interviewees highlighted that improvements in end-of-life care are needed across the board, not just for African and Caribbean communities. Bereavement support was singled out as an area where services needed particular development.

## 4. Discussion

### 4.1 Summary of findings

Our findings are important to three key areas.

- First, care provided at the end-of-life for people from Black African and Caribbean backgrounds fell short in cultural competence and personalisation. Access to services was influenced by a mistrust of a healthcare system that did not reflect their communities, and assumptions that were made about what they wanted and needed, based on ethnicity. Some professionals also raised the possibility that racism may be entrenched in the NHS, and exacerbated by the strain of the pandemic.
- Second, COVID-19 had an adverse impact on the experience of care for all, irrespective of ethnicity. Visiting, virtual communication, and the absence of bereavement support were areas of particular concern.
- Third, longstanding deficiencies in end-of-life and palliative care were evident during, and exacerbated by, the pandemic. Communication, shared decision-making and bereavement care were singled out. Priorities suggested by participants included - challenging assumptions and building professional confidence and competence to provide culturally sensitive care. Work may also be needed to raise awareness of palliative care services amongst some African and Caribbean communities.

### 4.2 Inequity of palliative care provision on the basis of ethnicity

Research over a number of decades has reinforced the need to improve end-of-life experiences and ensure equitable access to palliative care (25). Certain populations miss out, but the underlying reasons for this and solutions to resolve this, remain obscure (6,11,26–28). It has been suggested that the way palliative care is provided should be diversified (9). Care should be personalised to patients and family requirements (29). This includes the need to provide culturally competent care (15). Our study reiterates that requirement, whilst also providing suggestions from those with lived experience to how this can and should be done.

Improving representation (including in advertisements and staffing) was proposed as a way of encouraging people of African and Caribbean descent to access services, and in turn improve end end-of-life care outcomes. Previous studies support the importance of this, particularly amongst healthcare leaders and providers in order to mitigate mistrust in healthcare systems (30). Recent research has highlighted the presence of, and the need for action against racism in specialist palliative care provision (25,31,32). Our findings emphasised the importance of avoiding cultural presumptions and acknowledging our discrepancies as a catalyst for change. Participants proposed joint education initiatives

between local communities and palliative care providers to improve access, although there is no specific evidence of effectiveness to support this approach.

### **4.3 Inadequacy of care resulting from of Covid 19**

Many of the deficiencies in care highlighted in this study may have arisen from the demands inflicted on services by COVID-19. These were relevant to all, irrespective of ethnicity (3,4,33,34). There is a growing body of evidence for the negative impact of hospital, hospice and care home visiting restrictions (35). Communication and lack of access to appropriate technology exacerbated this issue, further isolating people from their social support networks (36). There is speculation that a secondary bereavement pandemic will result (37). Recent literature suggests that policies introduced to reduce the spread of COVID-19 disproportionately affected those from ethnic minority backgrounds (32). Our study was not designed to evaluate the comparative impact of the pandemic on people of Black African or Caribbean descent. However, we did gain an in-depth understanding of the importance of community support rather than formal health and social care structures. The pandemic damaged these networks and left people isolated, and in many cases unable to appropriately mourn and attend religious ceremonies.

### **4.4 Longstanding inadequacy of palliative care which transcends ethnicity and the pandemic**

COVID-19 had an adverse impact on access to support before and after death and involvement of patients and families in decision-making (3,4,33,34). However, many of the findings are not specific to the pandemic. Research and evaluation of practice has consistently called for action to improve communication and decision-making at the end-of-life (38,39)(40). Guidance has been developed by the National Institute for Health and Care Excellence (NICE) that stresses the importance of holistic care and support, particularly communication and involvement in decision making (20,41). Our participants' accounts suggest that there is still work to be done. The few participants who had access to specialist palliative care services highlighted the benefits. Expansion of these services may contribute to a general improvement in end-of-life experiences.

### **4.5 Strengths and limitations**

Proxy interviews can never capture the detail of lived experiences, but the views of relatives are important and have implications for bereavement. Proxy interviews also allow exploration of the entire end-of-life care period, including care prior to and after the death and in bereavement. A retrospective approach supports evaluation of care provided to people who deteriorated suddenly, or in whom the dying phase had not been recognised. Recruitment to this study was challenging, despite use of the research team's existing networks and contact with more than 150 diverse organisations. The decision was therefore taken to interview health and social care professionals. This added a range of complementary perspectives. Professional insights into barriers to access, service cultural competence and acceptability were useful in the way they diverged from those of families.

A small number of the relative interviews were judged to be inauthentic, which reduced the size of our dataset. Remote interviewing has become an established approach in qualitative research during the pandemic. Reflections on our experience, from initial suspicion to drafting this final report, are being shared with other research teams.

### **4.6 Participants' recommendations for change:**

Throughout their narratives, the participants made suggestions for improving services. These were grounded in experience and not necessarily supported by research evidence. The following were proposed by more than one participant:

- Acknowledging that racial and cultural stereotypes are barriers to provision and uptake of services may be an important first step to enhance services. Recognition of cultural and religious needs and diversity within African and Caribbean cultures is critical.
- Building professional confidence and competence to provide culturally sensitive end-of-life and palliative care was felt to be a priority, whether through training, education or other routes.
- Better representation of people of African and Caribbean descent in public facing materials and within services may help to facilitate access to care.
- Awareness could be raised amongst African and Caribbean communities on the presence and value of palliative care services.
- Enabling remote engagement to allow the inclusion of families who live at a distance or are unable to visit was often overlooked during COVID-19, but would benefit all.

## 4.7 Implications

This study was conducted during the coronavirus pandemic, but the findings have implications for care provided beyond COVID-19. The delivery of culturally competent, personalised end-of-life care for people of African and Caribbean descent appears to be the exception, rather than the norm. Participants proposed ways of addressing this issue, that have implications for recruitment policies, workforce development and training and how the NHS relates to local communities. Improvements in end-of-life care that would benefit all, could be focussed on communication, shared decision-making and bereavement care. However, implementing change in all of these areas is known to be challenging and resource intensive.

Where end-of-life and palliative care provided to people of African and Caribbean descent was poor, this may not have been directly related to ethnicity. Applying an ethnicity lens to existing evidence on interventions to enhance equity and quality in end-of-life care may be a useful precursor to further empirical research. Comprehensive and accurate data on ethnicity are essential building blocks for evaluation and research. Promotion of their collection within routine and research datasets may also be helpful.

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## 6. Appendices

### Appendix 1: Inauthentic Interviews, detection and management

Most people who volunteer to take part in a research interview have a story to tell. Participants are often motivated to share their experiences by a desire to help others through education; preventing harm; and thanking people for things that went well. Participants might also benefit from the interview. Taking part in research may be their only opportunity to talk about their experience at length – no one has ever asked them before, or no-one wanted to listen.

The problem of inauthentic interviews has been previously reported (42,43). Literature highlights the resources wasted and potential erroneous conclusions that might result (42,43). However, the literature is far from comprehensive. To our knowledge, no previous reports have described individuals posing as bereaved relatives. This adds an extra complexity because usual safety netting procedures may have been relaxed to reduce barriers to recruitment, incorrectly calling out someone who is bereaved as being inauthentic could be extremely damaging and individuals may have genuine reasons for not wanting to discuss certain situations. Equally ethnic minority groups may have a valid reluctance to share details linked to citizenship status or health/financial state benefits. Covid-19 further exacerbated the likelihood of having inauthentic interviews by necessitating the use of remote interviews and normalising relatives lack of knowledge about the end of the decedent's life due to social restriction and lack of visitation. Remote research methods are now becoming the norm and as such formalising the identification and reporting of inauthentic research participants should be done in order to empower researchers and help guarantee the validity of conclusions drawn.

#### Risk factors for inauthentic interviews in this study

- Open recruitment
- Remote interviews
- Monetary time compensation
- Patient narratives were omnipresent in the global media.

#### Red flags about authenticity, noted by researchers

- A lack of detail and narrative in the accounts:
  - Participants provided 'yes' 'no', persistently closed responses.
  - Uncertainty about basic details of the decedent
- Concerns about the interview setting:
  - Whispered prompts
  - Physical environments which looked unusual for the UK.
- Irregularities with the how demographic details were provided.
  - Email addresses appeared to be spam-like, with random combinations of letters and numbers.
  - Postcodes provided were identical across several of the inauthentic participants.

#### Actions that were taken

- Researchers examined their own positionality and biases.
- Discussion with the wider research team (with demographic and professional status diversity) to explore alternative explanations.
- Re-visit the recordings and transcripts and coordinate a blind analysis of authentic and suspicious transcripts amongst the wider research group.

- Notification of the sponsor and funder
- Removal of suspected inauthentic data from the dataset
- Heightened awareness for future interviews
- Dissemination of experiences to research colleagues

## Appendix 2: Relative characteristics (authentic interviews)

Age	21 – 68 years (mean 39)
Gender	F = 11, M = 7
Self-defined ethnicity	<i>People of African and Caribbean descent:</i> African = 10 British African = 1 British = 2 British African Caribbean = 2 Caribbean = 1 Turkish Cypriot = 1 Asian British = 1
Self-reported first language	English 16 Kiswahili 1 Turkish 1
Area of residence	North West = 2 North East = 2 Midlands = 4 South East = 3 London = 7
Relationship to relative*	Daughter/Son = 6 Spouse/partner = 4 Niece/Nephew = 5 Granddaughter/Grandson = 3 Sibling = 1

\*Note total sums to 19, as someone was niece to one decedent, and granddaughter to another.



### Appendix 3: Decedent characteristics

(Nb This relates to 20 decedents, and there may be more than one decedent per interviewee)

Age	25 – 88 years
Gender	F = 8, M = 12
Interviewee-defined ethnicity	African = 12 Nigerian = 1 Jamaican = 4 Caribbean = 1 African Caribbean = 1 Turkish Cypriot = 1
Interviewee- reported first language	Nigerian = 1 (as reported by participant) Yoruba = 3 Turkish = 1 Punjabi = 1 English = 14
Area	North West = 1 South West = 1 Midlands = 4 South East = 4 London = 8 Nigeria = 2
Occupation (or previous)	Health/Social care = 1 Hospitality = 1 Office/IT = 2 Unknown = 1 Self-employed = 1 Surveyor = 1 Retired = 13
Timing of death	March – August 2020 = 6 Sept 2020 – Feb 2021 = 5 March – August 2021 = 9 September 2021 onwards = 0
Cause of death	COVID-19 = 10 Long term condition = 9 Long-term condition COVID-19 = 1

#### Appendix 4: Professionals' characteristics

Age	Range 27 – 69, mean 41
Gender	F=8 M=5
Self defined ethnicity	People of African and Caribbean descent African (British= 5 Indian African = 1 Caribbean =1 British Pakistani = 1 Chinese = 1 White British or Irish = 4
First language	Ndebele/Zulu = 1 Igpo = 1 French = 1 English = 10
Area	North West = 8 North East = 2 London = 2 South East = 1
Employing organisation	NHS = 8 Community services= 3 Self-employed = 1 Charitably funded hospice = 1
Role	Doctor/Nurse = 8 Community healthcare = 4 Voluntary sector = 1
Time in role	1 – 25 years

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