



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

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Executive Summary

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The study

COVID-19 had a disproportionate impact on people of African and Caribbean descent, with high levels of illness and death. People from these ethnic minority backgrounds experience some of the highest levels of material disadvantage in the UK, and historically have had worse access to palliative care services, compared to the majority white community. This study sought patients (by proxy), bereaved relatives and health and social care professionals' views on experiences of palliative and end-of-life care during the pandemic. Public recruitment from more than 150 organisations and social media resulted in the conduct of 39 semi-structured Interviews. This report summarises the views of 26 bereaved relatives and 13 professionals.

Main messages

Three major themes were identified in the interview data:

Representation

- Families described a mistrust of the healthcare system and anticipated inequitable care based on their previous experiences.
- Some professionals felt that racism was entrenched in the NHS, and exacerbated by the strain of the pandemic.
- Relatives did not see themselves reflected in the services and as a result, felt that palliative and end-of-life care services were not for them. They did not expect service providers to understand their needs and experiences

Personalisation

- Relatives and professionals perceived a lack of cultural and religious sensitivity in palliative and end-of-life care services.
- Families felt that they missed out on services because assumptions were made about what they wanted and needed, based on ethnicity.
- Professionals described services being stripped back to the minimum during the pandemic, with person-centredness suffering as a consequence.
- All participants agreed that restrictions on visiting had an important impact on all aspects of palliative and end-of-life care provision.

Awareness and education

- Relatives and professionals felt that people of African and Caribbean descent were often not aware of the palliative and end-of-life care services available, and not enough was done to overcome this.
- A lack of knowledge of how to provide care to diverse communities, a reluctance to ask, and a fear of making mistakes were all cited by professionals as barriers to equitable care.

Participants' recommendations for change:

- 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 and end-of-life 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.

Summary

Person-centred, culturally competent care at end-of-life was not the norm for our participants during COVID-19. Expectations of poor and inequitable care appeared to be widespread amongst people of African and Caribbean descent. Sustained action on multiple fronts is likely to be needed to address them. This study also identified deficiencies that are well known and impact on all, irrespective of ethnic background. This reinforces the need to provide equitable access to personalised palliative and end-of-life care for all citizens, and to make specific steps towards ensuring equity for people from ethnic minority backgrounds.

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Email: pru-manager@manchester.ac.uk

Telephone: 0161 306 7797