



A personalised approach isn't always enough - response of specialist palliative care and hospice services to people from ethnic minority groups diagnosed with COVID

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What we knew:



What we did:

- Survey of palliative care services & hospices

“Have you encountered patient or families with COVID-19 who are from black and minority ethnic groups?”

“Are there any differences in how you are supporting or reaching them?”

“Are there any groups (different religions, cultures) where you have found supporting the individual needs of people affected by COVID-19 particularly challenging?”

What we found:

- 93/277 (37%) responding UK services supported ethnic minority groups

- YES:

- 1) London 39/93 (42%)
- 2) North West 10/93 (11%)
- 3) Midlands 10/93 (11%)

- NO:

- 1) South East 31/161 (19%)
- 2) North East & Yorkshire 29/161 (18%)
- 3) North West 26/161 (16%)

- Services who supported those from ethnic minority groups were more likely to have hospital palliative care teams (64%) and less likely to be hospices (38%)

Theme 1 disproportionate adverse impact of restricted visiting

We had a lot of distress from Muslim families about the strict visitation policy, as high numbers of people at the time of death is associated with a better afterlife

Hospice Service, North West England

Theme 2 compounded communication challenges

There was an issue with language barriers among those who don't speak English and no longer have their family members to translate for them ... In addition, translators were not available in [the] Trust

hospital palliative care team, London

Theme 3 unmet religious and faith needs

changes to care of the body after the death and funeral arrangements is impacting some families more than others. Some of these differences are likely to be influenced by religious beliefs and culture.

hospital palliative care team, London

Theme 4 mistrust of services

Some of the areas we work in have always been difficult to really access, some families now closing the doors to us, still trying the same way, haven't changed approach

Hospice Service, West Midlands

a lot of people [from ethnic minorities] are so frightened that they are not allowing the help and support they need until it is a crisis

Hospice Service, East England

Some lack of self-reflection.....

“[they have] different expectations”

Hospital palliative care team, London

“[they are] misunderstanding about the role of pall care.”

Hospice service, East England

The Muslim community have struggled with aftercare practices and needed greater guidance

Hospice service, East Midlands

Examples of good practice

We had Quran cubes brought in for dying patients

Hospice service, North West England

End of life situations are dealt with differently with all families - some people will always see things differently - it is our role to adapt to provide the support that they specifically require and will accept

Hospital service, North East England

Key Points

- Is the gap between who gets the “best and most” and “worst and least” widening?
- “one size all” policies may have caused disproportionate harm during the first wave of the pandemic



What next?

1. What are your thoughts on how Covid-19 has affected people from ethnic minority groups at the end of life?
2. Did the presentation resonate with your experiences or sense of what has happened locally?
3. How can palliative care meet the needs of ethnic minority patients and families better?

CovPall Team, Study Partners and Funders

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Thank you

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