People from Black and minority ethnic communities

A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE

There is a huge diversity of Black and minority ethnic (BME) groups in the UK, as well as diversity within individual groups. Existing evidence suggests that BME groups may have more unmet end of life care needs than people from white backgrounds, and experience a number of barriers to accessing good and personalised care.[1] An analysis of data from the National Survey of Bereaved People (VOICES), which asked about care in the last three months of life in England, revealed that people from BME backgrounds (compared with white people) were:

- **more or as likely** to receive help at home
- **less likely** to rate overall care as outstanding or excellent, particularly among those who had spent time in a care home or hospice
- **more likely** to die in hospital than a care home (but no more likely to die in a hospital than at home).[2]

The findings of our review support the existing evidence and suggest that barriers include a lack of understanding, knowledge and information about end of life care, lack of religious and cultural sensitivity, language barriers, and poor communication.

Lack of knowledge

Lack of knowledge and awareness about end of life care services and support can be a barrier to people from BME communities receiving good, personalised care and making choices about where they are cared for. People told us that palliative care is not a well-understood concept for some groups, which means that they may be unaware of what palliative care aims to do, their rights and the quality of service they can expect. At one focus group, people said they did not know anything about end of life care before a family member started receiving it, and were not confident or familiar enough with the services to know what to ask for. They felt there was a lack of awareness and that information about services, including support for carers, was not available.

People's experience of accessing services was also mixed. Some people told us that they felt hospices were not accessible to them. They also thought people did not fully understand what the role of a hospice or care home was within end of life care. For example, some people felt that inpatient hospices could not meet their cultural and spiritual needs, so they would be better cared for at home. People were not always aware that a hospice could support them to be cared for at home. One focus group participant told us:

> "Not a lot of people go to the hospice – people think you go there just to die, but they offer a lot of other support."

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[1] Calanzani N, Koffman J, Higginson I, **Palliative care for Black and minority ethnic groups in the UK**, 2013

[2] Dixon J, King D, Matosevic T, Clark M and Knapp M, **Equity in Palliative Care in the UK**, PSSRU, London: London School of Economics/Marie Curie, 2015

Some of the hospices we visited were challenging these ideas by proactively engaging with different groups in their local areas. By raising awareness and increasing understanding about the role of the hospice and how they can meet the needs of different communities, the hospices were helping to change the view of some groups that hospice care 'is not for them'. This shows how hospices can take a lead in building compassionate communities for end of life care.

However, engaging with communities is not just the responsibility of hospices. Commissioners and health and care services in the community also need to talk to and involve local people, which can help to inform service development and local commissioning. Some services have produced resources aimed at developing the understanding of the end of life care needs of particular communities and how health and care services can meet them. For example, the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network has produced a film to raise awareness of the end of life care needs of BME communities.

Language barriers

Some people told us that meeting language and cultural needs is an issue. They told us about the impact of language barriers, and that health and care staff felt that talking about end of life care may be 'too culturally sensitive'.

Existing research highlights that people from BME communities are prevented from accessing end of life care services because of misunderstandings, mistrust of health and care staff and a lack of cultural sensitivity on the part of providers.[3] People gave examples of where they had discharged themselves from services, or even returned to their country of origin, because they felt isolated and fearful as their cultural and language needs were not being met.

The language barriers experienced by some people from BME communities further complicates difficult conversations. People told us about family members being used as interpreters. Although in some situations this is what people would choose, others may not feel able to communicate their true feelings and wishes through a family member. Without a professional interpreter available it is difficult to be confident that the dying person has been able to make genuine choices about their care. The case study below demonstrates how support can make a big difference.

LANGUAGE AS A BARRIER TO GOOD END OF LIFE CARE

One woman told us about losing her mother-in-law six months ago. She felt the quality of her mother in law's care was very good, but had found herself in need of support. When her mother-in-law became ill and needed end of life care, the woman cared for her, but found this so overwhelming and stressful that she began to develop anxiety and had to take sick leave. She eventually left her job and became a full-time carer. She said, "It was really hard to look after her."

While she received some care and support from local services, in reality she was providing 24/7 care. One of the reasons was the language barrier between her mother-in-law and the care workers, who could not speak Punjabi, so she had to act as an interpreter. She felt that she "had to be there all the time to explain to the staff and the managers. It was so hectic for me and my family".

When the local hospice got involved, they managed to get her mother-in-law into a respite scheme for a couple of weeks. They also provided her with training in dementia so she was better able to manage caring for her mother-in-law. She told us that she is very grateful to the hospice for their help and support, and said, "We are still in touch with the hospice and raised some money for them."

Race Equality Foundation interview

Commissioners told us that they had access to interpreter and translation services, and that patient information was available in different languages. However, in reality staff said they did not always know how to access these services, especially in a crisis, and said that they could be expensive. As in the example above, people told us that they were not always able to access an interpreter when needed.

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[3] Calanzani N, Koffman J, Higginson I, **Palliative care for Black and minority ethnic groups in the UK**, 2013

Religious and cultural needs

People told us about their experiences of chaplaincy services, some of which were mixed. In one case, the chaplaincy was unable to provide someone who was a woman to provide spiritual advice; in another the family had to find a Sikh chaplain themselves. Bereavement services were also an area where access was difficult for BME families. In one case, the service was described by a relative as a 'here are the leaflets' service. The case study below illustrates some of the issues around spiritual and cultural needs.

A LACK OF CULTURAL UNDERSTANDING

One person told us about when his aunt died from cancer in her early 80s. His aunt did not speak English and had no language support at her hospice. She was reluctant to challenge decisions and make her own choices. For example, she was on medication that was making her vomit, but did not want to challenge this. Her nephew felt this attitude came from her past experiences of healthcare in Pakistan, where one would be grateful for free healthcare, and from a cultural deference to medical professionals, "she felt doctors always knew best".

There was a chaplaincy service with an Imam available by appointment. The man's aunt wanted to talk to a woman regarding her spiritual needs and questions, as she came from a culture where women did not speak to men who they did not know. However, only a man was available and her nephew felt that a female Muslim worker available through the chaplaincy would have been better. While he felt that the health and social care practitioners were very good, he felt that the system had let her down around her spiritual and cultural needs.

Race Equality Foundation interview

Spiritual and religious beliefs are not only relevant to people from BME communities, and many people from BME backgrounds will have no spiritual or religious belief. Guidance on faith at the end of life emphasises the importance of health and care staff and services working with local communities to understand and meet spiritual and religious needs.[4]

In our local area fieldwork we found some services with a good understanding of what is important to people and respecting their individual cultural beliefs and traditions, particularly in the last days and hours of life and after death. Examples included health and care services ensuring the timely release of the deceased person's body and death certificate so that families could make funeral arrangements quickly, and enabling families to wash the bodies of their loved one as well as providing a safe viewing area so people from the Hindu community could observe cremations.

CQC ENCOURAGES:

- Commissioners and providers to engage proactively with the whole of their local community, including BME groups, to better understand and meet people's needs and to raise awareness of palliative and end of life care within different communities.
- Commissioners and providers to ensure that access to interpreters is available when needed to people who are approaching the end of life and those who are important to them.

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4 Public Health England, **Faith at end of life: A resource for professionals, providers and commissioners working in communities**, 2016

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PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers