

Report highlights growing need to improve end of life care for minority ethnic groups

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With Black, Asian and Minority Ethnic (BAME) groups aged 65 and over set to treble in the next 25 years, there is a growing need to rethink how accessible and appropriate end of life care is to people from diverse communities and their families, say palliative care experts.

A report: Palliative and End of Life Care for Black, Asian and Minority Ethnic Communities in the UK commissioned by Marie Curie Cancer Care and Public Health England from the Cicely Saunders Institute at King's College London, published today, highlights that the end of life care needs of BAME communities are varied, growing, and despite examples of good practice, overall not adequately met.

In England and Wales it is predicted that by 2026 there will be over 1.3 million people from BAME groups aged 65 and over, compared to just



over half a million in 2001. By 2026 almost half a million will be aged 70 and over.

With this <u>ageing population</u>, there is an urgent need to address reasons for low levels of use of palliative and end of life care services by BAME communities.

A systematic review found that lack of knowledge about services, misunderstandings and mistrust (due to previous experiences of discrimination), and a lack of cultural sensitivity on the part of service providers are identified as some of the reasons for low uptake of end of life care by BAME communities. The report authors say these issues can in part be addressed by improving communication with the patient and their family.

The report recommends that service providers and commissioners recognise the growing need for improved end of life care for BAME communities and that they learn from examples of best practice, some of which are highlighted in the report.

While the report acknowledges that better training is needed for health and social care professionals to enable them to provide appropriate care to BAME groups, it also notes the importance of avoiding assumptions and stereotypes and listening to patients and their families about their needs and preferences at the end of life.

Dr Jonathan Koffman, report author from King's College London, said: 'Our study highlights some of the issues people from BAME groups and their families face during advanced disease and the end of life that prevent them from accessing vital services which can significantly improve the quality of their lives.

'Issues such as lack of knowledge about what is on offer and mistrust of



services due to previous experiences may contribute to low uptake of specialist <u>palliative care</u>. These issues need to be examined locally and changed where relevant.

'Service providers should take into account the issues raised by this report and review how well their palliative care services are meeting the needs of the community.'

Professor Julia Verne, Clinical Lead for Public Health England's National End of Life Care Intelligence Network said: 'This report shows that there are examples of excellent practice both in the UK and internationally. We need to learn from these to ensure that end of life care is both equitable and accessible to all.

This can mean addressing practical issues, such as providing adequate translation services where these are needed, and understanding how quality of care varies from one area to another. For example, the report shows that examples of best practice are localised in areas with more ethnic diversity. We need to ensure that learning from these areas is shared across the UK.

'Above all, we need to listen to what BAME communities need and remember that every individual is different.'

Dr Ian Gittens, Diversity Project Manager, Marie Curie Cancer Care said: 'With progress now being made in ensuring access to care is not influenced only by a person's clinical diagnosis, our attention now needs to recognise that ethnic, cultural and other differences can impact on all aspects of health and the uptake of healthcare.'

'The challenge for us all now is how we ensure that end of life care is appropriate and accessible for all.'



The report, 'Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK: Demographic profile and the current state of palliative and end of life care provision' is published by Marie Curie Cancer Care and Public Health England.

More information: www.mariecurie.org.uk/en-GB/wh ... and-inclusion/?Tab=2

Provided by King's College London

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