NIHR Policy Research Unit Palliative and end of life care

Awareness, knowledge, and trust about palliative and end-of-life care among different ethnic groups in the UK ^{1 2}

What we did

- An online survey with a nationally representative sample of people aged 18 and over was conducted. This survey was completed by 2,164 adults living in the UK on January 22-23, 2024. 13.6% (n=294) of respondents were from minoritised ethnic groups.
- We held a workshop with five public collaborators from minoritised ethnic groups in September 2024 to help us interpret the survey results.

What we found

- Awareness: Overall, 74% said that they had heard of palliative care and knew a lot / a bit about it.
- Knowledge: Overall, 78% correctly understood that palliative care does not involve giving medicines to people to shorten their lives.
- Trust: Overall, 74% reported a great deal or a fair amount of trust in healthcare professionals to provide high-quality care towards the end of life.
- Irrespective of age, gender, and socioeconomic position, people of Asian ethnicity, and people of Black, Caribbean or African ethnicity, had lower levels of awareness and knowledge of palliative care, and lower levels of trust in high-quality care provision towards the end of life, compared to White British people. People with non-British White background had lower levels of knowledge of palliative care, compared to White British people.
- Lower socioeconomic position was significantly associated with less awareness and knowledge of palliative care, and to a lesser extent with trust in healthcare professionals to provide high-quality care towards the end of life.

Recommendations

- Responsibility for increasing awareness, knowledge, and trust in palliative and end-of-life care rests with policymakers, service leads, and commissioners. There is growing evidence of inequality and inequity in access to and use of palliative and end-of-life care services by minoritised ethnic groups in the UK. Health and care professionals and researchers should proactively establish links with community groups, and use languages and networks of minoritised ethnic groups, to gain their trust, learn about their needs, and promote knowledge and awareness of palliative and end-of-life care.
- Deliver culturally congruent palliative and end-of-life care services. The delivery of culturally congruent palliative care services to enhance equitable care requires consideration of training and recruitment of an ethnically diverse workforce into the UK healthcare system, and providing religious and cultural competency training for all health and care professionals.
- Research to understand the needs and views of people from minoritised ethnic groups. Research to
 inform whole system policy solutions to improve palliative care for minoritised ethnic groups is needed.
 Having diverse research teams, recruiting community researchers, and providing adequate remuneration
 can build trust and reduce barriers to conducting research.

² Note: Information presented in this policy briefing is currently undergoing peer review.











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