NIHR | Policy Research Unit
Palliative and end of life care

Policy Briefing
February 2025

Facilitating and improving access to and effective use of palliative and end-of-life care services for people from minoritised ethnic backgrounds: A rapid realist review [1] [2]

What we did

- A rapid realist review drawing from 82 UK papers identified following a systematic literature search.
- An expert panel and PPI group were involved throughout the review process to guide process and interpretation.

What we found

We constructed five context-mechanism-outcome configurations (CMOc) based on our interpretation of the reviewed evidence:

- **CMOc 1: The impact of structural racism on trust and engagement in services:** Historical and institutional racism, including direct and indirect experiences of racism, can result in people from minoritised ethnic backgrounds receiving inadequate care that fails to meet their cultural needs (C). This can lead to a loss of trust (M) in services and fear (M) of poor treatment, resulting in non-engagement with palliative care and a preference for seeking support within their own communities (O). Such effects may be heightened at the end of life, a time of increased vulnerability (C).
- **CMOc 2: The cultural significance and importance of family being present and actively involved in end of life decision making:** The cultural significance of family amongst many people from minoritised ethnic backgrounds means that families often seek active involvement in end-of-life decision-making (C). This can enhance the sense of autonomy for both the patient and family, particularly when the patient trusts their family to honour their wishes (M). However, conflicts within families (M) may arise, leading to disagreement between family members about whether, for example, to withhold information from the patient about their prognosis. This can result in the patient's voice being overlooked and create feelings of ethical unease among healthcare staff (O).
- **CMOc 3: Promoting cultural sensitivity, inclusivity and awareness of palliative care:** Palliative care settings often lack cultural and religious understanding, such as having inpatient policies that fail to prioritise the need for family being present at the end of life, as well as services failing to reach and engage with people from minoritised ethnic backgrounds (C). This can lead to people from minoritised ethnic backgrounds feeling excluded (M) and creates a lack of awareness (M) about available service options, resulting in non-engagement (O) and a preference among some to die at home rather than in healthcare settings.
- **CMOc 4: The importance of services delivering culturally safe and sensitive care:** (C) Healthcare staff can deliver culturally safe, person-centred care when their practice is informed by an understanding (M) of cultures other than their own. This fosters feelings of safety (M) for people from minoritised ethnic backgrounds and their families, empowerment (M), and trust (M), in-turn improving staff-patient relationships (O) and leading to higher satisfaction for people from minoritised ethnic backgrounds and their families (O).
- **CMOc 5: Challenges of understanding concepts specific to palliative care:** The absence of suitable translation, interpretation, or understanding of the concept of palliative care and/or palliative care terminology (e.g. DNACPR) makes it difficult for people from minoritised ethnic backgrounds with limited English proficiency to understand and consent to care (C). Thus, patients from minoritised ethnic backgrounds and their families may feel the services are 'not for them' or they may lack knowledge of what available services include (M). This may lead them to self-manage or seek guidance from religious leaders instead of accessing services (O), resulting in delayed engagement with palliative care, often only as emergency hospital admissions at advanced stages of illness (O).

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

Recommendations

1. **Shift towards providing culturally safe care including:**
    - National: That the Care Quality Commission (CQC) include an appraisal of the provision of culturally safe care within their inspection standards and methodology across all settings. This goes beyond general recommendations for culturally appropriate care.
    - Regional and local: All health and social care providers implement mandatory training that focuses on the provision and delivery of culturally safe care. This should include approaches to sensitive care provision and the acknowledgement of power imbalances when addressing the care needs of those from different minoritised ethnic groups. Some reflective and experiential aspects to training may be required to apply and cement learning.
    - Local: Health and social care providers should have recruitment policies that address the equitable recruitment of staff from minoritised ethnic groups. This may include reviewing interview and recruitment practices to remove any bias, using inclusive language in advertisements, person specifications and job descriptions, and expanding recruitment approaches to reach diverse talent pools.
    - National and regional: Providers of health and social care training and education (e.g. basic and further education and training of care staff) providers including those in higher and further education settings should have admission policies that address the equitable admission and subsequent culturally sensitive education of staff from minoritised ethnic groups.
    - Local: Health providers should collaborate with local schools and colleges to deliver outreach and information events to inform people from minoritised ethnic groups about the appropriateness of a range of health and social care career options.
2. **Overcome barriers around communication and health literacy including:**
    - National: Develop a national 'glossary of terms' with people from minoritised ethnic backgrounds to standardise and ensure the cultural appropriateness of the terms used to describe palliative and end-of-life care across a range of common languages. National bodies should commission major charities in the area to lead and co-develop this glossary.
    - National, regional and local: Improve health literacy by training healthcare staff to effectively communicate complex palliative and end-of-life care concepts (e.g. advance care planning, resuscitation decisions) in more culturally and religiously appropriate ways. This may include the use of different languages but must not be limited to this given that some languages do not have literal translations of such concepts. Faith leaders need to be involved in this work; in addition, to avoid the 'postcode lottery' effect such work must be standardised at a national level.
    - Local: Ensure that all materials pertaining to palliative and end-of-life care provision are available and translated to languages commonly used within a geographical area. This includes translation of written materials as leaflets, websites, and commonly used apps. This involves going beyond existing legal frameworks that relate to improving communication and understanding i.e. Accessible Information Standard and requires input at a national level.
    - Local: In clinical areas where end-of-life care conversations are commonly held professional interpretation from those with experience of interpreting sensitive and challenging conversations is freely available.
3. **Promote inclusivity including:**
    - Local: All care providers must provide an inclusive physical estate. This may include removing religious iconography, creating multi-faith spaces, ensuring provision of estate and materials required for culturally appropriate care (e.g. bathing/showering facilities, single-sex spaces). Institutions named to reflect a particular religion may wish to consider how they brand themselves to encourage inclusive access.
    - Regional and local: Invest locally (e.g. at ICB and place levels) in ongoing 'place based' outreach initiatives in partnership with leaders from minoritised ethnic groups to proactively address information equity. Information to improve awareness and understanding of palliative and end-of-life care services should be available in appropriate languages and multi-media formats.

- Local: Individual organisations should foster partnerships with faith leaders and community organisations to build trust between community and organisation.
- Local: All relevant local care policies should be scrutinised to ensure inclusivity and cultural safety, with a shift to policies that promote individualised care respecting cultural, spiritual and religious diversity.