



Thinking Ahead: the perspectives of ethnic minority communities on resuscitation decisions

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Background

Improving Advance Care Planning and increasing its equitable access is a key government strategy. People from black and minority ethnic (BAME) communities access palliative care services less, and are less likely to undertake formal Advance Care Planning. As a result, they are more likely to continue to receive aggressive interventions and are less likely to die in their preferred place.

As Leicester has such a diverse population, it is an ideal location to explore a rich range of opinions, especially of South Asian communities.

Aims

Identify barriers and enablers

Define

outcomes

 Identify barriers and enablers to healthcare professionals (HCPs) discussing deterioration and decisions about resuscitation with patients and families from BAME communities

 Define person-centered outcomes in decision making about resuscitation in advanced disease

Improve training

 Identify HCP training needs to support them in caring for patients and families from BAME communities

Increase knowledge Add to evidence base regarding public opinion about resuscitation decisions and Advance Care Planning

- 1) Health, Department of. 2008. "End of Life Care Strategy- promoting high quality care for all adults at the end of life." In.:
- 2) Evans, N., A. Menaca, E. V. Andrew, J. Koffman, R. Harding, I. J. Higginson, R. Pool, M. Gysels, and Prisma. 2011. 'Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy', *BMC Health Sev Nes*, 11: 141.
- 3) Detering, K. M., A. D. Hancock, M. C. Reade, and W. Silvester. 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *British Medical Journal*, 340
- 4) Wright, A. A., B. H. Zhang, A. Ray, J. W. Mack, E. Trice, T. Balboni, S. L. Mitchell, V. A. Jackson, S. D. Block, P. K. Maciejewski, and H. G. Prigerson. 2008. 'Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment', Jama-Journal of the American Medical Association, 300: 1665-73
- 5. Calanzani N, Koffman J and Higginson I. 2013. "Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK " In.: Kings College London: Cecily Saunders Institute.
- Kai, J., J. Beavan, C. Faull, L. Dodson, P. Gill, and A. Beighton. 2007. 'Professional uncertainty and disempowerment responding to ethnic diversity in health care: a qualitative study'. PLoS Med. 4: e323.

Literature Review

I conducted searches on Medline, Embase, Psychlnfo, ASSIA and Web of Science. The key findings include:

The Western model of candour and patient autonomy is not a universal value. The beliefs, values and needs of ethnic minority populations in the UK have not been explored to see if the Advance Care Planning model 'fits' for them.⁵

Patients from some minority ethnic groups are more likely to desire aggressive medical interventions regardless of prognosis and impact on quality of life. The reasons for this are complex and not yet established.²

Healthcare professionals do not feel confident in providing culturally appropriate care for BAME patients and families.^{2,6}

What is Advance Care Planning?

Formally discussing, documenting, and reviewing patients' preferences for future care:

Cardiopulmonary resuscitation

Place of death

Mechanical ventilation

Lasting Power of Attorney

Artificial hydration/ nutrition

Methods

A mixed methods, largely qualitative study guided by a Patient and Public Involvement (PPI) group.

Semi structured interviews with up to 15 doctors and senior nurses.

They will discuss their

experience of advance care planning and making decisions about resuscitation with patients and families from BAME backgrounds.

4 workshops, each with up to 8 public volunteers using **Q** methodology.

Participants will then be asked to summarize their views, commenting on the reasoning for their order in a short **interview**.

A quantitative framework, which facilitates the ranking and analysis of statements to study subjectivity and shared viewpoints.

Participants sort ~50 statements reflecting the diversity of possible views about resuscitation by their feelings towards them and their order of importance. The Q set statements will be informed by the literature, interviews, PPI group and refined by an expert panel.

Impact

Education and Research

- Develop evidence base about Advance Care Planning with BAME patients
- Develop teaching resource
- Integrate knowledge into existing teaching programmes

Policy

- Provide evidence and recommendations for interventions to develop healthcare practise and empower patients
- Inform national policy through the team's links to professional bodies

Healthcare Professionals

 Identify methods HCPs can utilise to facilitate culturally congruent Advance Care Planning

Patients

- Improve access for BAME patients and families by raising awareness of findings in local communities
- Improve experience of end of life care for BAME patients and families