



Research Article

Exploratory study from an end-of-life research partnership network to improve access for ethnically diverse communities in one region

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Plain language summary

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This study developed a research partnership which brought together key partners, including commissioners, healthcare providers, faith leaders, representatives of community organisations, academics and the wider public, including informal carers who represent the diverse and multifaith communities of Bedfordshire, Luton and Milton Keynes. Interviews ($n = 11$) with service providers and a series of face-to-face roundtable workshops with community stakeholders, service providers, informal carers and faith leaders were conducted to both enable all people's voices to be heard and develop a shared understanding of the challenges that minority ethnic groups face in accessing palliative and end-of-life care.

While medicalised services (e.g. hospices) are available, minority ethnic groups often depend upon informal carers, faith and community support, that is, 'non-institutionalised' routes that focus on providing love and care but have limited medical expertise. Stakeholders felt that there was a lack of integration between these routes, and while they both acknowledge they need to engage with each other more, they remain uncertain of the best way to achieve this. Families revealed they want more help and support to look after their loved ones. However, they want medical institutions to be more personable and compassionate, giving more weight to non-medical needs. This was particularly important to families from multifaith communities whose beliefs about death are far from Western medical practices.

The study led to a new understanding of the importance of patient and public voice and how this can be facilitated among ethnically diverse communities. Through being flexible, agile and inclusive, we, through this partnership, were able to build trust and stimulate research activity that will have increased relevance and impact in addressing inequity. Healthcare providers and community stakeholders need to find new ways of working together to increase access to palliative and end-of-life care and better meet the needs of ethnically diverse patients and their families.