Traveller end of life care experiences and needs: thematic analysis

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Introduction

- Travelling communities are Europe's largest minority ethnic group who experience worse health outcomes than non-travelling communities.[1]

- Barriers to accessing palliative care include lack of awareness of available services and conflict with staff, exacerbated by cultural misunderstandings.[2]

- Little is known about end of life care needs of travelling communities, nor of potential solutions to current problems.[2]

Methods

- Secondary thematic analysis of audio recordings, originally collected for non-research purposes.[3,4]

- Two focus groups: One with ten Travellers, one with ten Travellers and three non-community members. Sixteen short interviews with staff working in a hospice setting. Interviews and focus groups were facilitated by a member of the travelling community.

- Qualitative rigour through double coding, researcher triangulation, peer debriefing, reflexive journal.[5]

Results

Theme 1: Central role for family at the end of life

"It must be very daunting for them [staff]... I do understand that, but then they got to understand it's our sort of family... because we are large families."
[Community member 15, focus group 2 (Mixed)]

Theme 2: Specific community rituals around death

- Home and hospice were preferred above hospital as locations for care in the last days of life. Community traditions included the ritual to "sit up" all night after a death and share memories of the person's life.

Theme 3: Traveller identity vital yet hidden

"...I'm not going to tell them. Because... if I start saying I'm a Gypsy... I know it's not going to be the same. So, it's almost like a self-preservation."
[Community member 5, focus group 1 (Travellers)]

Theme 4: Travellers' suggestions to improve end of life care

- Good communication from healthcare professionals, provision of space for visiting family, cultural awareness training, and same-gendered nursing care.

Multi-level tensions permeated the Traveller end of life healthcare experience (demonstrated in figure 1 below):
- Personal tensions between a strong sense of identity and perceived need to hide this identity in the healthcare setting.
- Social tensions between Travellers and healthcare professionals, in relation to specific ways to improve their experiences.

Discussion

Implications for practice, policy and research

- Implementation of suggestions to improve end of life care may be problematic e.g. hospices may not have a room for family to gather in.

- Updating NHS ethnicity monitoring to include travelling communities would help to encourage identity disclosure, allowing increased focus on their needs and enable national monitoring of health outcomes.[6]

- Supporting healthcare professionals to adopt a personalised care approach is likely to be more effective than a single cultural awareness training session.[7]

- Collaboration is key: Service co-creation, in the research context, would enable transition from suggestions to active change.

Strengths and Limitations

- Focus groups and interviews were facilitated by a travelling community member which may have led to more open discussions.

- Findings were discussed with the community member who led the discussions and interviews to ensure they resonated with a Traveller.

- Reduced depth of insight due to the nature of secondary analysis and reduced transferability as participants' sociodemographic details were not available.

Conclusions

- Concealment of identity adds to the challenge of effectively tailoring end of life care to meet an individual's and their family's needs.

- At a systems level, co-creation of end of life care services is vital to meet cultural needs. Mixed focus groups may have value.

- At an individual level, personalised care should be provided to all patients.

- End of life care is a universal healthcare need. Changes in this area of healthcare could impact access and engagement in other areas, paving the way for resolution of health inequalities in these communities.

Figure 1: Personal and social tensions experienced by Travellers

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Full article in BMJ SPC (2023)