

BACKGROUND:

Black or Black British ethnicity experiencing the highest number of child deaths, followed closely by Asian or Asian British ethnicity in the UK. Terminally ill minority ethnic children is inequitable and parental experience of child death and bereavement support for minority is a “neglected area of research” (Ainscough & Fraser et al., 2022).

RESEARCH QUESTION:

What are the experiences and support needs of minority ethnic parents whose child has died?

AIM:

The aim of this evidence synthesis is to integrate and bring together findings from extant qualitative research, so a comprehensive understanding of the experience and support priorities for bereaved minority ethnic parents emerges.

METHODS:

Epistemologically this qualitative synthesis is a configurative review (Thomas et al., 2017), more a realist on the idealist-realist continuum, not problematising available literature, but interested in understanding complex emergent themes including divergent data from the included studies (Booth et al., 2018). Thematic analysis (Thomas and Harding, 2008) has been used to synthesise heterogenous data from diverse epistemological positions. Themes were developed deductively.

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used as a tool to define key elements of the review question, and to inform the search strategy accordingly. All searches were conducted from the year 2000 until present day. 7 studies were identified for inclusion. The content and utility of findings were quality appraised using the Critical Appraisal Skills Programme (CASP), as well as modified CASP (Long et al., 2020).

RESULTS:

Theme 1: The Centrality of Religious and Cultural Frameworks

Grounded in history, mythology and social mores of their native lands, ethno-cultural frameworks provide practical, emotional and spiritual support. Death rituals are a communal acknowledgement and celebration of the life of the deceased child. Faith leadership and practical support like keeping vigil with the parents, help with making immediate post-death decisions and funeral arrangements, subsidising the costs of food and ceremonies are examples of community-led psycho-social support.

The death of a child however carries considerable intra-cultural stigma, met with male stolidity and deemed a “curse” upon the family in certain communities, penalised by social ostracization and feelings of guilt and social isolation.

Theme 2: Communication from the healthcare professional

A toxic trio of language barriers, medical authority diffidence and low levels of health literacy in immigrant minority ethnic parents poses a significant challenge. A lack of interpreters and the poor quality of professional information sharing means that parents do not understand their child’s condition, symptoms or prognosis, and are left feeling mistrustful of healthcare professionals. Inconsistent, incomplete and non-transparent communication facilitate conflict with healthcare professionals and leaves parents feeling ignored.

Parents find healthcare professionals respecting their religious and cultural beliefs re-assuring.

Theme 3: Death of a child: An Existential Loss, and Continuing Bonds.

Intra and inter-personal grief from the death of a child is set in the ecology of the family, the community, the geography, the culture and the religious frameworks that parents were raised in. “Untimely” deaths are viewed negatively in certain cultures penalising the parents and the extended family with stigma and isolation. However, continuing bonds in the form of ritual practice for a theistic sanctification of the deceased child can facilitate post traumatic growth, build parental resilience and meaning making, providing a mechanism for including the deceased child in everyday life.

Legal requirements for autopsy are a major stressor for parents.

CONCLUSION:

This qualitative synthesis is the first study to explore the bereavement experiences and support needs of minority ethnic parents. The findings speak to a complex and dynamic interplay of religious and culture driven frameworks, in the context of socio-economic disadvantage, poor health literacy, immigrant status and systemic, pervasive and chronic racism and internalised ethno-cultural invisibility. This synthesis corroborates the importance of clear, consistent and culturally respectful professional communication and further research on lived experience of bereaved minority ethnic parents.

RECOMMENDATIONS:

1. Attentive, demonstrably non-directive communication, that facilitate a sense of psychological safety allowing for repeated clarifications and for expressing concerns.
2. Aligned with Public Health framework, Building community-based networks of support around bereaved minority ethnic parents through community-based awareness building on palliative care. Awareness building in community centres led by community centres, hospice community engagement teams.
3. Community-based grief awareness education led by local community centres, faith groups and grief charities.
- 4.. Grief education for professionals in caring roles to acknowledge and include frameworks for disenfranchised grief in resource poor minority ethnic parent, by virtue of their immigrant status.

‘So, if a child is died today, we will be spending maybe a week, going to their family gathering in the evening. Ladies will be cooking food and people share. Men may help in the cooking food as well. But each member of the family will be bringing a dish and shared in the evening’. (Keith, Rwanda, CL) Pearson et al., 2023

“A Chinese mother was angry when a physician did not consider the cultural importance of family involvement. An intern “impolitely” asked the family to leave the room so that he could talk to the patient alone. This mother described the intern as “mean,” stating, “He never considered our feelings.” Davies et al., 2010

“Moreover, one private practice midwife, Kaitlin, expressed the view that some HSPs did not acknowledge cultural differences within their service approach, saying some health professionals: ‘really don’t see culture as something important’. Pearson et al., 2023

“The night before she died, the nurse kicked me out of the room and told me I was doing more damage to her —because I was holding her and touching her. She said I shouldn’t stimulate her and she took her away from me —she took my last night that I had with my daughter away.” Brooten et al. 2013

“Her care leading up to her death was awesome—They were very understanding to our needs—They were in tune with what we wanted and they let us do what we wanted—They gave us our privacy. but they checked on us to see that we were ok—The doctor actually came to our daughter’s funeral” Brooten et al., 2013

Maria felt devastating grief at the loss of Jaime, and she continued to feel that no one could understand the depth of her pain. “They say that time heals but it doesn’t heal. The death of my son never rests.”— Maria Garcia Doran, 2006

