UNDERSTANDING THE MEANING OF END-OF-LIFE DISCUSSIONS AND RELATED DECISIONS AMONG OLDER SOUTH ASIANS LIVING IN EAST LONDON: A QUALITATIVE INQUIRY

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Background South Asians constitute the single largest ethnic minority group in the United Kingdom, yet little is known about their perspectives and experiences on end of life and its related care.
Aim This paper examines attitudes and expectations that older South Asians expressed towards the discussion of death and dying and decision making.

Methods Five focus groups and 29 in-depth, semi-structured interviews were conducted with a total of 55 older adults aged between 52 and 78 years. Participants from six South Asian ethnic groups were recruited from 11 local community organisations. Constructive grounded theory was used as data analysis approach.

Findings Trust is a category that captured views and experiences of participants that consists two key themes. The theme ‘avoidance of discussion’ relates to the relative absence of discussions around death and dying among participants. Participants neither expected to have discussions about their own death and dying within their family, nor to assume any involvement in related issues of decision making. The second theme ‘locus of authority’ relates to beliefs and experiences about the delegation of decision making to family members.

Conclusion Older South Asians living in East London make efforts to adhere to important social and cultural values relating to death and dying, and rebuild and adapt those values during the challenges of living in an emigrant society. Future research should explore the perspectives of second-generation adult children towards end of life care decisions.