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An ageing BME population in the UK

- Estimated that there are currently 25k people with dementia from BME communities (E&W)
- Projected to increase to 50k by 2026...
- ...and 172k by 2051 (All Party Parliamentary Group, 2013)
BME communities and dementia

- APPG on dementia (2013) identified dementia as the biggest health and social care challenge facing UK society...and
- ...people from BME backgrounds are being ‘failed’ by the system
- National Dementia Strategy emphasised that health and social care staff should take account of BME dementia needs...but
- Service providers report challenges in including BME people (Williamson, 2012)
BME communities and dementia (cont)

- Lower levels of awareness about dementia …and
- High levels of stigma among BME communities (Moriarty et al., 2011)
- BME people underrepresented in dementia services…
- And present to services later (APPG, 2011)
- But, no reliable figures and evidence base is limited
- Also lack of research
Health outcomes and the Somali population

- Largest BME community in Camden
- Long established BME community in the UK
- Poor health outcomes
- Barriers to accessing services (structural)
- Ability to navigate systems (agency)
Aims of the study

• First, to fill gaps in knowledge about the Somali community’s experiences of dementia;
• Second to gather information about service needs and issues relating to access;
• Third, to gain an understanding of the levels of awareness of the needs of Somalis among service providers;
• Fourth to make recommendations for policy and practice and to raise awareness of dementia among Camden’s Somali community.
Methodology

• Qualitative
• Interviews with care-givers (9)
• Interview with person with dementia
• Workshops/focus groups with community members (8)
• Interviews with service providers (8)
Theoretical background

- positionality – social ontologies with reference to nationality/ethnicity and religion/culture – can inter-relate or ‘translocate’ in shaping experiences of dementia and care
- Cultural and religious beliefs/experiences of dementia
Findings: caregivers

• Issues in identifying symptoms of dementia
• Experiences of caring for a loved one with dementia – cultural expectations
• Experiences of accessing services/navigating systems – ascription and difficulties in diagnosis
• Support needs and gaps
• Impacts on family
Findings: stakeholder perspectives

• Lack of awareness of the needs of the Somali community in Camden
• Issues around identification of dementia
• Barriers to services
Conclusions

- Gaps identified at first stages of Dementia Care Pathway (Awareness and Identification)
- As a first step – there is a need for awareness raising among Somali community
- Need for training/support for GP
Recommendations

- There is a need to recruit Somali outreach workers in order to engage the community.
- Information and education about dementia needs to be culturally appropriate both in terms of content and the way it is disseminated.
- Specific resources are needed to successfully implement the Dementia Care Pathway.
Recommendations (cont)

- There needs to be a long term commitment to building trust among the Somali community in Camden
- Health and social care organisations need to be present in community spaces to successfully engage
- It is necessary to further engage about the service needs of people from Somalis backgrounds
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