The experiences of dementia of people from three BME communities: balancing the need for support against fears of being diminished.

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What is the issue?

- An estimated 25,000 people of Black, Asian and other Minority Ethnic (BME) origins live with dementia in UK - a number which is expected to increase seven-fold by 2051 (APPG on dementia, 2013).
- Diagnosis is more likely to occur at an advanced stage of the illness (Mukadam, Cooper and Livingston, 2011; Tuerk and Sauer, 2015).
- People from BME communities remain under-represented in specialist dementia services and are more likely to draw on those services with which they are more familiar, such as religious institutions (Parveen, Peltier and Oyebode, 2017).
- Over 90 different languages are spoken in Bristol, with Bristolians being born in at least 50 different countries and following more than 45 religions (Bristol City Council, 2011, 2015)
- Numbers of BME people in Bristol likely to have dementia are higher than those using Dementia Wellbeing Service
- People from BME communities are not visible in general dementia support groups and services
Research Questions

• What experiences do people from three different BME communities have, who provide care for people who are living with dementia in Bristol, of dementia-specific care?

• What do they believe are the reasons why people might be reluctant to access care?
Methodology

- A grounded theory approach to data analysis was used (Strauss and Corbin, 1990)
- This research study focused on people of Caribbean, South Asian and Chinese origins who had experience of dementia and were living in Bristol.
- Central to the research were collaborative partnerships developed between researchers and Voluntary and Community Sector Organisations (VCSOs) led by older people of BME origins.
- Participants where recruited through BME led VCSOs
- 48 participants were recruited for one-to-one interviews and 8 Focus Groups were carried out
• Choice of either being part of a focus group, or being interviewed individually.
• A semi-structured interview (SSI) schedule was created
• Data collection took place between March and September 2016.
• All interviews and focus groups were audio recorded and then transcribed
• Trained interpreters were present during interviews and focus groups when required
• All Focus Groups were carried out at the premises of BME-led VCSOs, while interviews were either carried out at participants’ homes or in the premises of the VCSOs, depending on the wishes of the participants.
Challenges in recruitment

• Men were declining to be involved
  – Researcher proactively attend local barber shops and social clubs, the men did not want these conversations to be recorded, instead they were used to shape the context of the report
What was found

• Ethnicity and inequalities intertwine with stigma around dementia and affect the take-up of mainstream services – while people from BME communities recognise a need to be adequately supported, they do not wish to be diminished by this process.
Caribbean community

“When people do have dementia, the family member really has to put their foot down, to let someone in [to provide care]. The person in dementia gets paranoid about letting someone in ... It’s an invasion.”
• Concerns about “being locked up”
• Standing out – being the only visible person from a BME community in a service populated by white people
• Cultural needs such as language and food
South Asian Community

“I don't think it is talked about. People are just getting their head around mental health. I don't think it has even occurred to people to think this is an issue that we have got to deal with. They are still coming to terms with the taboo around mental health. Dementia will be the next thing to tackle ... From my experience, people think it is just mental health or forgetfulness or they put it down to old age. They don't realise it's dementia.”
• For some South Asian participants, dementia was framed within a context of superstition.
  – the word *pagal* might be used to describe behaviours were similar to dementia. This word is used in a number of Indian languages and can denote a madness caused by evil spirits or previous bad actions.

• There was a lack of knowledge about dementia as a distinct health condition
  – an emerging awareness of the need for more information.

• Making dementia visible was more acceptable if this was done in settings they were familiar in, run by their own community members.
A Chinese woman, described how her sons preferred that she should not talk about her husband’s diagnosis of dementia outside the family

“because it was not appropriate and [...] people might look down on them”.
• Different linguistic terms are used to describe dementia-like symptoms in Cantonese and Mandarin - all had negative overtones.
  – The Mandarin word ‘Chī-dāi’ (癡呆), the character “chi” translates into English as “idiotic” or “silly”, while the character “dai” means dull-witted.
• Participants described how the social act of talking about dementia was an act of diminishment as it exposed a part of oneself - of one’s family - to outside judgement.
Into practice

• **Raising awareness**: clearer messages need to be communicated in a range of ways about risk factors and prevention amongst BME communities.

• **Increasing awareness of GPs**: further work is needed to raise the awareness of GPs about the dementia risk and needs of people from BME communities.
• **Improving access to qualified, dementia-trained interpreters:** access to interpreting services across different communities needs to be improved.

• **Training for VCSO staff:** as part of partnership working that needs to be developed locally, training on dementia specific activities should be provided to BME led VCSOs
For more information...

Please go and watch the video:
https://www.youtube.com/watch?v=FWuRjrdlxAI

Or, read the full report:
References


Bristol City Council (2011), *Census data*, Bristol City Council: Bristol.


