



Thousands of people from BAME communities could be living with dementia in secret, says leading expert

- One of the UK's leading dementia consultants among the black, Asian and minority ethnic community, Mohammed Rauf MBE, is supporting Music for Dementia in helping families affected by the disease
- Cultural shame associated with the condition means some communities do not even have a word for 'dementia'
- It means BAME people with dementia are often hidden away and not getting the care they need - while carers are missing out on vital support including music therapy
- The Music for Dementia campaign is calling for a more culturally inclusive approach to dementia care to cater for BAME communities, saying that one size does not fit all

XX July, 2020. UK. Thousands of people in the UK could be living with dementia in secret because of shame surrounding the disease, a leading expert has revealed.

Official figures on how many people from the black, Asian and minority ethnic communities have dementia in the UK could be vastly underestimated, according to Mohammed Rauf MBE, a leading voice in the BAME dementia space.

While around 25,000 people from BAME backgrounds are accepted to have the disease in the UK¹, the stigma attached across a number of cultures means there are growing numbers who are having to cope with dementia in silence and undiagnosed, though this is perhaps likely to be in the thousands.

Mohammed Rauf MBE, a leading voice in the BAME dementia space, says even many of those who have been diagnosed are missing out on vital care which could significantly alleviate symptoms of dementia, including music therapy.

Mr Rauf is joining charity Music for Dementia in calling for more awareness and a more culturally inclusive approach to care to cater for the BAME communities, so the health and social care system is more understanding of the cultural impact on the condition.

Mr Rauf – who has written about the issue in a blog post for Music for Dementia - said: "Ethnicity has only very recently started to be captured in dementia healthcare provision. As a result, the BAME dementia communities are underrepresented in data and there is a lot of guesswork involved. As the number of BAME older people increases in the UK, there is to be an expected 7 to 8 fold increase in dementia amongst these communities in the next few decades, meaning we could reach numbers in the region of 150,000 very quickly.

"There is a stigma around dementia in some cultures leading to the BAME dementia communities not actively seeking support, and cultural shame associated with the condition means that many communities don't have a word for 'dementia'. Not having a word for dementia in the five main South

¹ <https://www.alzheimers.org.uk/for-researchers/black-asian-and-minority-ethnic-communities-and-dementia-research>

Asian languages (Urdu, Punjabi, Hindi, Gujarati and Bangla) creates a difficulty when you attempt to have conversations about a subject that has no identifiable term in those communities.

“The stigma around dementia is due to a lack of understanding. Dementia is thought about in a derogatory way by many people in the BAME communities. Some think it is madness, possession by jinns or witchcraft, others think it may be a punishment from God. So, the family carers and the person with dementia hide it and do not easily seek help or assessment. This means they miss out on vital support, such as music therapy, until they reach the point of crisis and more intensive support is needed.

“It’s a vicious cycle. When intensive support is needed, there is then stigma on top of that. Some BAME families won’t ask for additional help due to fear of prejudice from services and are reluctant to move relatives to a care home due to concerns about how that will be perceived in their community. Many families quietly try to get on with caring at home which leads to service providers thinking the BAME communities are happy to look after their own because their numbers are very low at the point of seeking help and support.”

He added: “Whilst BAME communities are seen to have English as a barrier to accessing services or support, it is important to recognise other social and economic barriers that exist which hinder access to the right support. Existing services are often not equipped to provide cultural competency in their support as they don’t always think there’s a need for diversity in their provision.

“BAME carers are more likely to be isolated from mainstream services and often people from BAME communities are not sure where or how to find information about dementia. There must be more education and training for family carers and staff working in dementia services on how to give culturally acceptable care and support people with dementia.”

Music for Dementia has republished its COVID-19 Musical Guide to include a cultural differences and music statement - providing guidance to carers within the BAME communities on how to effectively use music, rhythm or recitation to help people living with dementia find comfort and respite from symptoms.

Grace Meadows, Programme Director of Music for Dementia, said: “We want to make sure everyone living with dementia – no matter what their background is – has access to the care that is right for them and takes the whole person into account. This is why personalised care is so important.

“Having access to personalised music, in the right way and at the right time, has been shown to be more impactful and meaningful in helping to counter the symptoms of dementia, such as anxiety and agitation. In addition, it facilitates communication, creativity and importantly enables you to see the person for who they are, through the music that matters to them. We want to ensure everyone has equal access to music as part of their dementia care.”

Senior BME Dementia worker, **Ripaljeet Kaur**, is part of the Touchtone BME Dementia service based in Leeds. Ripaljeet has been trialling music therapy sessions for people living with dementia in the BAME communities as part of Touchstone’s South Asian Dementia Café Hamari Yaadain.

She said: “It’s important that music is culturally sensitive. We try a lot of different music in the music therapy sessions and ask those attending what music they actually enjoy and want to listen to, as opposed to just assuming.

“A moment that stood out for me was when a Sikh lady who is normally very quiet in our regular sessions came alive during a music session. She got really involved and started singing a song that she knew from her younger years - it was extremely heart-warming.”

Music for Dementia's [blog series](#) from leading experts in the dementia space gives personal perceptions and reflections designed to inspire and support communities to continue to help and prioritise people with dementia.

-ENDS-

NOTES FOR EDITORS

About Music for Dementia

Music for Dementia campaigns for people with dementia to have the right to music as part of their care and access music free of charge, wherever they are. We are calling on the music industry, philanthropists, and the health and social care sectors to help make it free and easy for people with dementia to access music.

Music for Dementia has partnered with Live Music Now to launch a new Musical Care Taskforce, which brings together more than 60 leading representatives from across health, social care, dementia and music with the aim to make music an essential element of dementia care. We are also working closely with DCAN which is a newly formed initiative from the Alzheimer's Society, NHS England and Improvement and the Coalition for Collaborative Care.

In September 2019, we launched our Musical Map – an online interactive map which will become the largest and most comprehensive database of dementia-friendly music services in the UK.

Music for Dementia - <https://musicfordementia.org.uk/>

Musical Map for Dementia - www.musicalmap.co.uk

About The Utley Foundation

The Utley Foundation was founded in 2014 by Neil and Nicky Utley. The Foundation exists to advance social causes and to act as a catalyst for greater funding and wider action for the causes it supports. Music is a personal passion of the founders and trustees and underpins many of the key funding areas of interest to the foundation. The trust has other charitable objectives including Armed Forces Veterans, Children and Overseas Aid.

About Touchstone

Touchstone was born out of an identified need for friendship and community in South Leeds in 1982. A Social Worker, Sylvia Landells, and CPN, John Clare, saw that large numbers of vulnerable people were left isolated and distressed out of hours and at weekends, so they set up a "weekend club" which was to grow into Touchstone.

Touchstone's BME (Black and Minority Ethnic) Dementia Service provides specialist support to people living with memory problems or a diagnosis of dementia and their carers from ethnic minorities. Their aim is to raise awareness of dementia within BME communities by breaking down the barriers that exist about dementia and bring it out into the open so that people can access the support they need while meeting their language, cultural and religious needs.

Touchstone - <https://touchstonesupport.org.uk/community-services/bme-dementia-service/>

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