Meri Yaadain

Giving voice to BAME dementia matters

'Intercultural care' at Alzheimer Europe Conference 2019

The Founder and Director of Meri Yaadain CiC, Mohammed Akhlak Rauf MBE, was invited to present a keynote speech at this year's prestigious 'Alzheimer Europe Conference 2019'.

This was an excellent opportunity to showcase the similarities between all the different communities and the cultural variances that require a nuanced approach when working with BAME communities. This presentation highlighted the changing attitudes towards dementia as well as the transitions in communities themselves in relation to their views on accessing information, using services and issues such as factors influencing decision-making in families.

Faith, gender and prejudice were presented as key aspects connected to the dignity and stigma associated with dementia and dementia care for BAME people living with care and their family carers. Above all, it was the need to understand people's lived experiences so that 'person-centred care' could incorporate 'family power-dynamics' and 'relationship-centred care' when supporting dementia needs in BAME communities.

More information on intercultural care can be accessed by downloading the report from Alzheimer Europe: www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice

Meri Yaadain CiC

Meri Yaadain (meaning my memories), was set up in January 2006 and became registered as a Community Interest Company (not for profit organisation) in 2019.

As a community organisation our aims are to:

1. Raise awareness of dementia and its symptoms and behaviours amongst the Black Asian Minority Ethnic (BAME) communities

2. Work with service providers to challenge inequalities regarding availability of information and culturally appropriate dementia support services

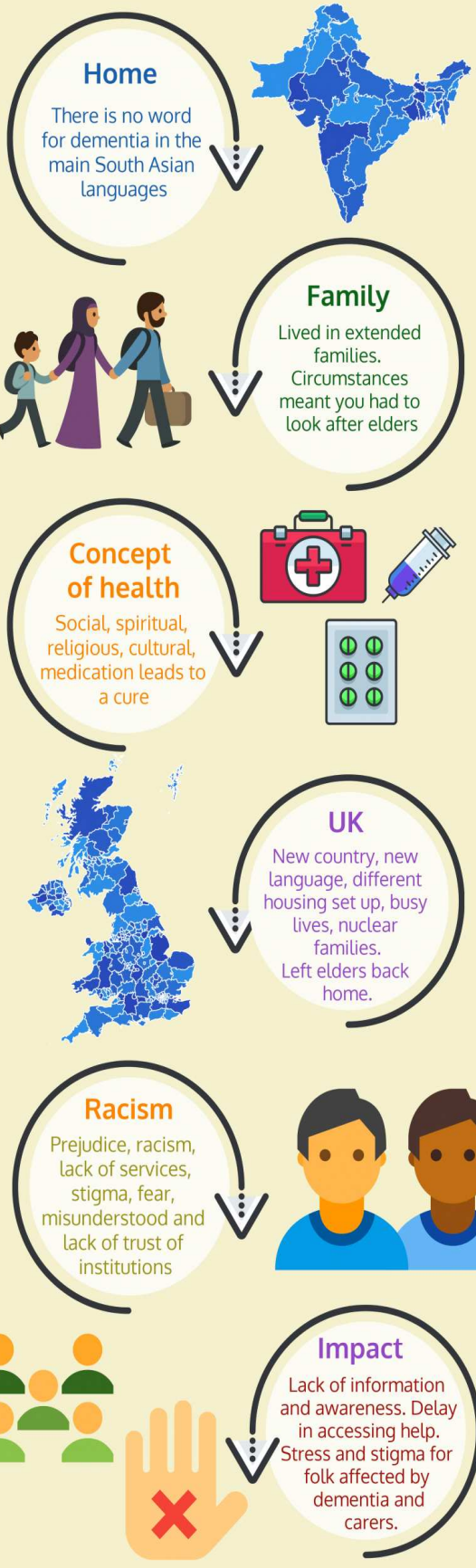
3. Work in co-production with BAME people living with dementia (PLwD) and their family carers to design and deliver culturally competent training for organisations and individuals

4. Raise awareness of the challenges for BAME PLwD and their family carers at a local, regional, national and international level.

Impact of migration on the BAME dementia experience in the UK

Meri Yaadain

The journey from 'home' to life in the UK



This infographic demonstrates the impact that migratory experience has on migrant communities, their social construct of dementia and accessing dementia care.

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Dementia and migrant communities

Although many (if not most) of the Black Asian Minority Ethnic people who migrated to the United Kingdom in the 1950's onwards through to the 1970's, did so with a view to return home, they were not able to do so. The main reason for this was the changes in the immigration laws of the 1960's and 70's. They forced the migrant labour to choose between staying in the UK (and inviting their families to join them) or to return home knowing they may not be able to return.

But how does migration affect people with dementia? Well the answer is not as simple as it may seem. There are people who may revert back to their first language 'mother tongue' as many people call it. There is also the issue of migrant communities holding on to their values, beliefs and customs relating to what is dementia, how it is to be cared for and how the family is affected by the stigma from other family members, relatives, friends and society in general.

Migrating to another country can also have result in issues such as experiencing prejudice and racism. This in turn can lead to a mistrust of institutions that are public or state organisations and services designed to help folk when there is a need. Social Services and the take up of residential, nursing or respite care is limited mainly due to anxiety of language, faith and appropriate care from a cultural perspective.

BAME communities in the UK

Black Asian and Minority Ethnic (BAME) refers to communities other than indigenous English, Welsh, Scottish or Northern Irish people living in the UK.

This usually implies people who are of Asian, Arab, African, Far Eastern, Caribbean, Central and Eastern European origin of heritage.

Minority ethnic communities have an increasing ageing population which points to a seven to eight fold increase in dementia (and dementia care) in the next few decades. Whilst BAME communities are seen to have English as a barrier to accessing services (or support), it is important to recognise the barriers that exist. Social and economic deprivation, social constructs of dementia and care as well as prejudice and discriminatory practices (directly or through well-meaning but ignorant practices) can all hinder access to the right support.

The importance of research

One of the biggest challenges of the current times is dementia. It is estimated that every 3.2 minutes, one person in the UK falls victim to dementia. In order to help combat the challenges posed by dementia, investment in research to find a cure as well as better understanding of care needs is necessary.

Whilst lots of money is being poured into understanding the issues relating to dementia, there is a vital need for people living with dementia as well as people caring for a relative or a friend living with dementia to get involved with research.

Our Founder & Director (Mohammed Akhlak Rauf) is a registered Champion with Join Dementia Research because we believe we need more BAME folk to sign up and get involved in dementia research.

Some people do not know how to get involved in research, whilst others are not sure if hey should do so. Researchers make sure participant details are confidential and anonymised. Ethically approved research should put your mind at rest.

For more information, visit Join Dementia Research at: https://www.joindementiaresearch.nihr.ac.uk/

20-25,000

BAME people in the UK live with dementia

7 to 8 fold dementia

increase in dementia expected amongst BAME communities

Q: What is dementia?

Dementia is a collective term used for a number of conditions that affect the brain.

Depending on which part of the brain is affected, results in respective symptoms and behaviours.

Some types of dementia are better known than others, such as Alzheimer's Disease or Vascular Dementia.

Q: Does it affect all communities?

Dementia does not discriminate between different communities. However there are some differences that may be more or less prevalent in some communities than others.

Lifestyle can impact on some communities such as the South Asian and African Caribbean, where Vascular Dementia may be more likely due to stroke.

Q: Why is there a need to raise awareness?

Not everyone is aware of dementia, others have misinformation about it. Some people even think it might be normal as we get older or that it is a may be a punishment from God.

Better information and services might mean we can delay or prevent certain types of dementia.

Being informed can lead to accessing support and better care.

Q: Is there a cure for dementia?

There is no known cure for dementia, although some medication can help delay progression.

Millions of pounds are being invested into trying to find a cure.

However, it is also important to think about the care concerns whilst we wait for a cure.

Lots of research and services are working on supporting people with dementia and their family carers to 'live well' with dementia.

Q: What can I do if I want to know more?

Lots of help and information is available, locally and nationally.

You can search the internet for 'information on dementia', types of dementia and on help or tips regarding caring for someone with dementia.

Or contact us at info@meriyaadain.co.uk if you would like to talk to someone about where to get help and information.

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Researcher Spotlight...

Oladayo Bifarin

What you are researching:
My doctoral study is aimed at understanding the influence of the mainland Chinese culture on caring for older people. I am particularly interested in the lived experiences of older peoples' carers in the Chinese workforce. I am looking to understand the potential future needs of families affected by the one child policy as the ageing population is rapidly and irreversibly increasing.

Why do you think BAME people should get involved in research?
Subcultures exist within cultures and assuming that researchers are aware of this, is arguably doing communities, such as the BAME, a disservice. Although researchers may have high educational attainments, they may not always be able to reach out to subcultures within communities; which then makes the involvement of the BAME members very important. Getting involved in research, BAME participants will be able to add to knowledge and also widen the researchers' perspectives on the wider BAME communities (subcultures). A good example of this will be the opportunity to play an active role in research, such as co-producing research questions and helping researchers to have a better understanding of their data at the stage of analysis.

How can researchers ensure BAME communities can trust them?
In a recently conference in Doncaster, a researcher stated that more or less the same research questions have been explored by researchers with regards to the facilitators and barriers for statutory services. This was especially true when it comes to the BAME groups. They then went on to ask a prominent question: where is the research on how to make services adaptable and accessible?

BAME people can be said to be getting despondent to having to answer the same questions over and over again with nothing to show for it as underrepresentation within statutory service for older people services for instance, continues to be a problem. This is despite the investment directed at understanding the needs of this group of people. Researchers must do something differently to appeal to the BAME individuals as there must be a shift from these simplistic target driven measures to making genuine engagement with the BAME people. Methodologies must differ and researchers should endeavour to build relationships with BAME communities by creating a conducive environment for these people to take ownership of projects.

Hints and tips

Wandering

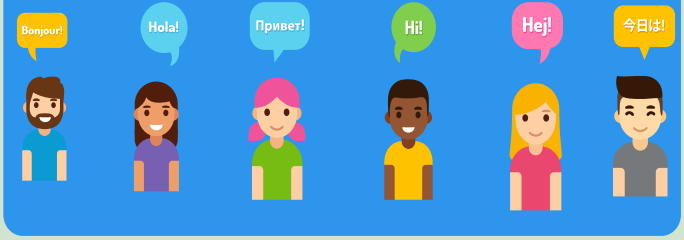
Some carers tell us that they do not know what to do if their relative with dementia is prone to wandering. For some people this may be within the home, but for others, the person with dementia may actually leave their home.

Please do not lock them in the house like a prisoner, but try to understand why they want to walk off and where they are wanting to go. Perhaps let local shops know that s/he has dementia, leave a contact number on a card in their pocket and perhaps also let the police know incase the relative gets lost and is reported to the police.

Communication

Communicating with a relative living with dementia is often difficult as dementia progresses. Depending on the type of dementia, it may be that your relative may quickly lose their ability to talk, to find the right word to express them self or even able to communicate in English if they have an earlier community language.

- Use smaller, clearer, simple words and sentences
- Be engaged - look towards the person you are talking to
- Use caring and loving expressions to give reassurance
- Keep calm and use diversion if repetition or difficult questions are asked



Meri Yaadain CiC support BAME people living with dementia and their family carers to access information and support so that dementia care can be less difficult to manage. Carers vary in how they cope with dementia, whilst some people with dementia become really worried about what is happening to them. We work to help alleviate these worries and difficulties by supporting families and working with service providers to better understand how they can provide culturally appropriate information and services.

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