Dementia issues concerning Black and Minority Ethnic (BAME) Communities

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Hyrwyddo cydraddoldeb i bawb

Who is an 'ethnic'?

The fact that we have 'ethnic minorities' communities should make people realise that we have 'ethnic majority' communities.

Minority ethnic communities also have communities within communities eg Pakistani, Indian, Bangladeshi or Muslim, Hindu, Sikh in South Asian or Somali, Nigerian, Muslim, Christian in African

Use of the word 'ethnics' is wrong as well as an inappropriate term to describe the BAME groups.

Why do we sometimes need different approaches?

There is a difference between having an equal service provision and an equitable service provision.

Our service provision for carers of people living with dementia can be open to everyone equally, for them to access information and support. Alternatively it can be equitable by promoting the services and the support through information and publicity for those who are not using the services.

Challenge your own prejudices

All of society is conditioned to some extent about what is acceptable and what is not. Thus their 'norm' may be different to how other communities may think or behave. This difference creates an 'us' and 'them' mentality.

Welsh people are a minority ethnic population in the UK because they may speak a different language (Welsh) to most of the United Kingdom (English). Similarly, people of Irish, South Asian, African, Caribbean and Central and Eastern European heritage are also minority ethnic communities in the UK. This can bring with it a difference in how we accept and understand the different worldviews or perspectives. There are similarities and differences.

Minority ethnic communities also includes groups such as Gypsy, Traveller and Roma populations.

PERSON-CENTRED care can be achieved irrespective of language, faith, diet and culture, if we listen to carers and try to understand their position.

What is 'culture'?

All of us have a culture. The norms of our society, our language, food, faith, heritage, social class, worldview all go towards creating our culture.

Sometimes there are things that cross cultures, eg like a Pakistani, African and a Welsh man all being Christian, perhaps liking the same tastes in food.

Or they can be different, such as preferences for bathing either being the use of a shower or a bath to sit in. The way we are brought up and conditioned gives all of us our own culture - shared with some others.

Should we bother with diversity?

Should we even be asking this? The percentage of older BAME people is increasing at a faster rate that the indigenous communities. BAME people are more likely to get dementia at an earlier age. They are expected to have a 7-8 fold increase in dementia in the next few decades.

BAME populations have a higher risk of conditions such as vascular dementia because of poorer lifestyles due to increased ill-health, deprivation, lack of awareness.

Not to mention equality legislation as a legal requirement.

Suzanne Duval suzanne.duval@diverse.cymru June 2019

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Dementia and Stigma

In some cultures there is no word for dementia, whilst in others, there maybe acceptance of the symptoms of dementia. However, it may be viewed in a derogatory way, implying madness or having gone 'paagal' i.e. crazy.

Dementia is therefore stigmatised because it is seen to be a condition relating to mental ill-health or a result of spiritual possession of the person displaying the symptoms of dementia.

Targeted Interventions

In order to create a level playing field, BAME communities need access to information that is language appropriate and often through peer-led interventions such as community-based roadshows; bringing them speakers as well as presenting information via radio and satellite TV.

Intergenerational work, especially with school children, also help parents and grandparents to understand dementia.

Late presentation of dementia

Evidence suggests that BAME communities present their dementia related symptoms at a much later stage than their White British counterparts; often at the point of crisis.

Some of this is due to having a lack of awareness, whilst others fear of community stigma. A third perspective is that medical and social care practitioners do not take them seriously. Dementia it becomes secondary to other co-morbidities such as heart disease and diabetes.

Assessments and Services

Many cultures cannot relate to the questions that might be asked of them at the memory clinic. For example, many people who are from another country may not know of Churchill, but how many White British people would know of Gandhi's real name or who was the Emperor of Ethiopia in 1930?

Memory and assessment tools are being culturally adapted, but these will need to be universal.

Thinking Outside the Box

Whether it's English, Welsh, Punjabi, Urdu, Somali or Arabic, service providers need to engage with BAME communities to understand their needs, concerns and worries relating to the symptoms of dementia.

So organisations such as Diverse Cymru, Alzheimer's Society and EYST, can have an impact as they can directly reach out to people living with dementia and their carers.

Cultural Competency

Far too often, we see time limited and finance restricted projects and initiatives set up to provide 'lip service' for BAME communities. BAME people living with dementia and their carers struggle as mainstream service providers and commissioners do not understand their needs. Similarly, many services may mean well, but they do not know how to incorporate cultural competency into their commissioned services.

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