

Worksheet 19:

The needs of people with dementia from diverse communities

Currently people from BAME (Black and Minority Ethnic) communities are under-represented in services and they are often diagnosed at a later stage of their journey or not at all.

There is also a lack of awareness of availability of services, how they might help or how to access them. Also, the stigma that surrounds dementia in some BAME communities deters people from using services that are associated with the condition.

Generally, there is felt to be a lack of culturally sensitive dementia services.

Often people feel that the support available is not appropriate and does not address needs relating to faith or culture. There may be assumptions in some areas that there would be no demand for culturally sensitive dementia services.

Research suggests that there are a number of myths circulating about dementia among some BAME communities.

This is largely to do with the association of dementia with mental illness. Some Black Caribbean people believe that the mental illness was a result of a person being possessed by evil spirits. Some Black Caribbean and Asian people view dementia as a 'white person's disease', because they have not come across the condition in their country of origin. They believe that people in their community got this disease as a result of coming to the UK. Most BAME groups seem to associate dementia with 'getting old' or mental illness. Some Chinese people have a strong belief in retribution for bad behaviour. Serious health problems are assumed to be retribution for past bad deeds.

It is important to avoid assumptions that families from BAME communities do not require any outside help.

As well as the stigma and taboos surrounding dementia, assumptions that BAME families always 'look after their own' can increase the likelihood of social isolation. Becoming isolated from the community removes potential sources of practical and emotional support for families living with dementia. It also compounds the lack of awareness of dementia among that community.

In some BAME communities people accept certain behaviours as part of the ageing process. It is only when somebody becomes a danger to themselves or to somebody else that people actually take action. When families do approach the GP with concerns about the person, the lack of a concept of cognitive impairment or dementia can make it difficult to provide a coherent account of symptoms. This creates another barrier to diagnosis.

Worryingly, some people from BAME communities report that some GPs stereotype people from certain groups. Irish are seen as 'drinkers', Asians as 'whingers'. Such stereotypes result in some people not seeing their GPs, while the symptoms of those that do are often not taken seriously.

There is no consensus on what constitutes an ethnic group, and membership is something that is self-defined and subjectively meaningful to the person concerned.

The terminology used to describe ethnic groups has changed markedly over time and, however defined or measured, tends to evolve in the context of social and political attitudes or developments.

Ethnic group is also a very diverse term, encompassing common ancestry and elements of culture, identity, religion, language and physical appearance.

Below is the Government-recommended country specific ethnic group question for use in England.

‘What is your ethnic group?’

White

1. English / Welsh / Scottish / Northern Irish / British
2. Irish
3. Gypsy or Irish Traveller
4. Any other white background, please describe

Mixed / Multiple ethnic groups

5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed / Multiple ethnic background, please describe

Asian / Asian British

9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background, please describe

Black / African / Caribbean / Black British

14. African
15. Caribbean
16. Any other Black / African / Caribbean background, please describe

Other ethnic group

17. Arab
18. Any other ethnic group, please describe

Ref: <https://www.ethnicity-facts-figures.service.gov.uk/style-guide/ethnic-groups>

Think about a person with dementia from ONE of the ethnic groups listed above; write down what you think their needs and preferences might be.

How would you find out what their needs and preferences might be?

Why is it so important to adopt a more inclusive response and provide culturally appropriate services for people from BAME communities?