



Key messages

- Different communities have different dementia-related needs.
- The number of people affected by dementia from BAME communities will rise more rapidly than the number from white communities.
- Different understandings of dementia, ageing and care-giving may prevent people coming forward to seek help.
- Psychological services need to be culturally appropriate.

Evidence briefing: Dementia, accessibility and minority groups

The aim of this document is to provide an overview of the needs of people who are affected by dementia, their families and carers from black, asian and minority ethnic groups. This briefing paper aims to summarise research and clinical evidence in this area and to aid commissioners and other stakeholders to shape the service landscape. It is not intended to be read as a set of recommendations for practitioners.

Key messages

- **Different communities have different dementia-related needs, and should not be treated as a single homogenous grouping.** This briefing paper will use the term 'black, asian and minority ethnic' (BAME) people and communities to refer to both white and non-white groups who differ from indigenous white people and communities in terms of their race, culture, religion, traditions and upbringing⁽²⁾. However, we acknowledge that this can be a somewhat misleading term for at least two reasons: firstly because it may suggest that different communities can be seen as a single, collective whole, thereby not acknowledging the unique needs of individuals; and secondly, because there is enormous variety among BAME populations in the UK, with immense diversity in many aspects such as religion, country of origin and culture⁽¹⁾. In addition, the needs of white minority groups are often discounted.
- **The numbers of people from BAME communities who are affected by dementia will increase more rapidly than those of the white community.** The number of people affected by dementia from BAME communities is expected to rise significantly. The All-Party Parliamentary Group on Dementia suggested that the current estimate of nearly 25,000 people with dementia from BAME communities in England and Wales will grow to nearly 50,000 by 2026 and

over 172,000 people by 2051. This is nearly a seven-fold increase in 40 years⁽²⁾. It compares to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period. By 2051, there will be six times as many Black Caribbean cases, 12 times as many Indian cases, 22 times as many Bangladeshi cases and 45 times as many Black African cases of dementia compared to 2001⁽³⁾. This differential increase in the numbers of people affected by dementia is largely due to two factors:

- Dementia is more common amongst Asian and Black Caribbean communities, at least in part because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common. In addition, social factors, such as fewer years spent in education, lower levels of income and lower socio-economic status (all of which have been associated with dementia risk) may accentuate the risks for some BAME communities⁽⁴⁾.
- People who settled in the UK as young adults in the 1960s, 70s and 80s are only now reaching an age where there is a significantly higher risk of dementia.

■ **Within some BAME communities, different understandings of dementia, ageing and care-giving may act as barriers that prevent people coming forward to seek help.** Thus in most South and East Asian languages, there is no equivalent word for ‘dementia’, and symptoms such as memory loss or the misrecognition of faces and places may be understood either as normal ageing or as the consequences of physical ill-health or of a mental illness. Furthermore, the words that do exist to describe the changes associated with dementia tend to be derogatory, with a greater likelihood that dementia will be experienced in terms of shame⁽⁵⁾. The role of family members who act as carers may also be at risk of being more invisible within some BAME communities. Similarly, carers may themselves be less able to access existing structures and mechanisms for support within the statutory and voluntary sectors⁽¹⁾. Families may also feel under greater pressure within their community to care for a family member without seeking outside support⁽³⁾. These factors have typically been associated in the research literature with the apparent tendency for people from BAME communities who have dementia to seek help at a later stage in their illness than their white British counterparts^(6, 7).

■ **Psychological services need to be culturally appropriate.** The process of assessment and diagnosis of dementia can be affected by language difficulties^(8,9). For instance, although some assessment and screening measures have been validated in a variety of languages including Gujarati, Bengali, Punjabi, Hindi and Urdu, they still require either a bilingual clinician to administer them or the presence of a skilled interpreter. Similar problems can affect participation in psychological interventions. The forms of dementia-related problems that people may present to their GP, nurse or psychologist may be different in older people affected by dementia from BAME communities. For instance, challenging behaviour may differ in nature in older people originating from the Indian subcontinent compared to their indigenous white British counterparts, with one study finding that people with dementia from India were less likely to be anxious or phobic⁽¹⁰⁾. The research literature also suggests that previous experiences of hostility and racism among some communities may also deter people from seeking help⁽³⁾. These cultural and religious differences may need to be reflected in a wide range of care options up to and including palliative care. This may include being more flexible in providing services in locations where people from BAME communities are present, including spiritual centres (such as Gurdwaras, temples and churches) and secular venues such as community centres, restaurants, hairdressers and barber shops.

Calls to action

A number of challenges prevent people from black, asian and minority ethnic communities accessing dementia services in general, and more specifically psychology services.

■ **The policy context for service developments** – the 2010 Equality Act requires that all health and social care services in England, Scotland and Wales must provide their services without discrimination. Yet, while research in the UK is limited, it has highlighted the ethnocentrism, lack of culturally tailored provision and negative evaluation of mainstream services by people who have used them⁽¹¹⁾. For instance, there is evidence to suggest that people from many BAME communities are more likely to enter dementia services at a later stage in the illness, and to receive services that do not take account of their needs⁽¹²⁾.

Calls to action

- Secure equality of access to treatment for patients from different ethnic groups
- Work closely with BAME communities to raise awareness of dementia
- Overcome stigma by ensuring that dementia awareness campaigns are specifically directed at BAME communities
- Ensure all services are delivered in ways that are culturally appropriate

It is important, therefore, that developments in dementia services adequately identify those local needs that exist, and take steps to ensure that they are met. Both commissioners and clinicians should also be mindful of the need to secure equality of access to treatment for patients from different ethnic groups, in particular those from different cultural backgrounds⁽²⁾.

Example of good practice

Slough's Punjabi Cognitive Stimulation Therapy (PCST) was established in response to requests from service users for evidence-based interventions that were suitable for the local community. CST is an evidence-based intervention for individuals with mild to moderate dementia that aims to stimulate and engage people with dementia within the context of an enjoyable social environment that facilitates learning. CST is delivered in 14 weekly sessions, each lasting for one and a half hours. Each week is centred around different themes, including food, sounds and word associations. In keeping with the ethos of Slough Memory Clinic, the PCST adaptation was based on the needs of the members of the group. Following the development of PCST, the Punjabi Dementia Information Group was established in Slough. This was a wider, multi-agency initiative and has been instrumental both in delivering a programme of dementia awareness sessions (which includes a range of dementia related information that has been translated into Punjabi) and in carrying out a survey of attitudes towards dementia within the community.

- **Working closely with BAME communities to raise awareness of dementia.** Evidence shows that knowledge and understanding about dementia in some BAME communities is often low, with BAME communities having varying levels of knowledge and awareness of the condition. For instance, compared to comparable Caucasian communities, Chinese people may be more likely to believe that Alzheimer's disease is a normal part of ageing⁽¹³⁾, less likely to correctly recognise dementia symptoms⁽¹⁴⁾ and have less knowledge about Alzheimer's disease⁽¹⁵⁾.
- **Overcoming stigma.** Although stigma is attached to dementia in all communities, it is likely that levels of stigma are higher in BAME communities and that this acts as a barrier to seeking help^(16, 2). As a number of modifiable risk factors for dementia, such as high blood pressure, diabetes and heart disease, are higher within a number of BAME communities^(4, 17, 18), preventative work is vital to significantly reduce the risk of dementia. Given that the prevalence of dementia will increase at a much higher rate within BAME communities, it is especially important to ensure that dementia awareness campaigns are specifically directed at BAME communities. Working closely with

religious and cultural centres, in addition to primary care, may help to raise awareness, challenge stigma and improve access to specialist services. Given the stigma surrounding dementia within some BAME communities, it may be that other health services can play an important role in advising about dementia and facilitating referrals to memory clinics. Thus the commissioning of emergency services as well as diabetes and rheumatology clinics, should all address the dementia needs of BAME communities.

- **All services need to be delivered in ways that are culturally appropriate.** It is important for commissioners to ensure that all services are delivered in ways that support the psychological wellbeing within all communities that they serve. Thus, assessments need to take into account language barriers, and different cultural expectations and beliefs, with, for instance, adequate translation services available. Similarly, leaflets and DVDs about dementia and dementia services need to be made available in a number of different languages, as for instance, the Alzheimer's Society and Alzheimer's Scotland have done. Peer support workers who are local people who have an understanding of their communities have the capacity to play an important role to engage, help inform, educate and facilitate understanding around dementia, as well as helping to challenge assumptions about dementia. This might, for instance, take the role of black, asian and minority ethnic community dementia navigators⁽¹⁹⁾. More generally, psychologists should be aware of the reluctance of people within some BAME communities to engage in 'talking therapy'⁽²⁾, and to consider other ways of providing support, for instance by empowering existing structures within BAME communities.

Example of good practice

An Electronic Resources Handbook for Central and North West London Memory Services – Dementia information for Black, Asian and minority ethnic (BAME) communities. This handbook is an information resource to help clinicians and support memory clinic staff in Central and North West London Memory Clinics and to help them to signpost people with dementia from BAME communities more effectively. It also contains information on local demographics and working with interpreters in dementia care.

- **The need for more research.** In the UK, most of the studies about people with dementia from BAME groups tend to be quite small-scale and are mainly undertaken in large urban areas where these populations are most concentrated⁽¹⁾. More research is needed in a number of areas: to help us to understand the barriers within services that may prevent people from BAME communities from accessing adequate services; to validate assessment scales and questionnaires; and to adapt existing interventions so that they are suited to the needs of different BAME communities. More generally, people from BAME communities are all too often invisible within dementia research, either because they are not participants, or because their ethnicity is discounted. There is an important need then, for those publically funded structures that support dementia research, such as Join Dementia Research, to focus on making research opportunities available to people affected by dementia from BAME communities.

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