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# Black and minority ethnic people with dementia and their access to support and services

By Jo Moriarty, Nadira Sharif and Julie Robinson

## Key messages

- An increase in the number of older black and minority ethnic (BME) people in the UK is likely to lead to an increased need for dementia services.
- Lower levels of awareness about dementia and the existence of stigma within BME communities help explain why BME people are currently under-represented in dementia services.
- However, staff can adopt several approaches to improving the uptake of services, such as developing different information resources and appointing workers with responsibility for outreach.
- Staff working in dementia services would like more training on how to give culturally acceptable care and support to BME people with dementia.
- Carers of BME people with dementia may feel reluctant to ask for help, although support in the form of carers' groups and respite services may be appreciated. Different communities may have differing views about whether they wish these services to be culturally specific or mixed.
- The current UK evidence base on supporting BME people with dementia and their carers is very limited and reliant upon a small number of local studies.

## Introduction

Black and minority ethnic (BME) people are generally under-represented in dementia services and the development of appropriate health and social care services to meet their needs has been a longstanding policy priority.<sup>1-5</sup> The government wants to identify new indicators for local health and social care services, based upon the outcomes that people with dementia and their carers want.<sup>6</sup> The number of BME people with dementia in the UK is increasing as people who moved here during the period from the 1950s to the 1970s are reaching their seventies and eighties, so it is important that these new indicators pay attention to the wishes of this group of people and their carers.

This briefing discusses the barriers currently faced by BME people in accessing dementia care services and some of the ways in which services can become better at responding to the needs of BME people in their locality.

## What is the issue?

Dementia currently costs the UK economy about £23 billion per year.<sup>7</sup> This is twice the cost of cancer, three times the cost of heart disease and

four times the cost of stroke.<sup>7</sup> Estimates of the number of people currently living with dementia in the UK range from around 684,000<sup>8</sup> to 822,000.<sup>7</sup> Among these, it is thought that approximately 15,000 are from a minority ethnic group.<sup>9</sup> Although population ageing means that the number of people with dementia overall will increase, the number of BME people with dementia will grow even more sharply.<sup>9</sup> This is because the frequency of dementia rises with age and the number of BME people in their seventies and eighties is growing steadily.<sup>10,11</sup>

In the past, organisations responsible for planning and delivering services have reported that they know very little about the numbers of BME people with dementia in their area,<sup>4,12</sup> and have shown variable progress in strategic approaches to developing services for BME people living in their locality.<sup>13</sup> We now have better information on this subject. The majority of BME people live in London, the Midlands and the North West of England. Most BME people with dementia have Black Caribbean and Asian Indian backgrounds because these are the BME communities with the highest proportion of older people.<sup>14</sup> Currently, just nine per cent of Black Caribbean and six per cent of Asian Indian people are aged 65 and over compared with 16 per cent of White British people.<sup>14</sup> However, by 2051, 30 per cent of Black Caribbean and 29 per cent of White Irish people will be aged 65 and over compared with 27 per cent of White British people. Twenty-one per cent of Asian Indians and 20 per cent of Chinese people will be aged 65 and over.<sup>11</sup> Overall, BME older people will be more ethnically diverse and will be more evenly spread across the UK, as people move from inner cities to suburban and rural localities.<sup>11</sup>

Within this broad picture, some commentators have begun to emphasise the immense variety to be found among the BME populations in the UK, coining the term 'super diversity' to

illustrate increasing diversity in aspects such as country of origin, socioeconomic status, religious and cultural traditions and legal status.<sup>15</sup> All these changes have important implications for the likely demand for dementia services in the future.

Overall, the proportion of BME people affected by dementia is broadly the same as that found among white people<sup>16</sup> although, as yet, there have been no large-scale UK prevalence (frequency) studies in which there have been sufficient numbers of BME people in the sample to compare the frequency of different types of dementia across different ethnic groups. However, vascular dementia (caused by problems with the supply of blood to the brain) is thought to be more common among Asian<sup>17</sup> and Black Caribbean<sup>18-20</sup> people because they are more prone to important risk factors for vascular dementia such as cardiovascular disease,<sup>21</sup> hypertension,<sup>22,23</sup> and diabetes.<sup>24,25</sup> Overall, vascular dementia is thought to affect around 22 per cent of people with dementia<sup>26</sup> but we do not know how many people with vascular dementia are from a BME group. Even among people with Alzheimer's disease, signs of damage to the blood supply in the brain can sometimes be observed alongside the other changes caused by the disease.<sup>27</sup> This is sometimes known as 'mixed dementia'.

Early onset dementia (a rare type affecting people under 65) is more frequent among BME people. While just two per cent of people with dementia in the UK have the early onset form, the equivalent rate for BME people with dementia is six per cent.<sup>8</sup>

Although women are generally at greater risk of dementia, mainly because they tend to live longer than men,<sup>8</sup> it has been suggested that there are currently more BME men than women with dementia in the UK.<sup>28</sup> This conjecture is

based on the greater numbers of BME men who moved to the UK for employment reasons between the 1950s and 1970s, but it has not been tested in epidemiological studies.

## Why is it important?

Dementia affects everyone in society, irrespective of gender, ethnicity and socioeconomic status.<sup>9</sup> However, there is evidence that BME people with dementia present later to dementia services than their White British counterparts, when their dementia has become more severe.<sup>29</sup> The consequences of this are discussed in the section on 'Findings' (see page 4).

A number of policy documents suggest ways in which local services need to develop so that they are more responsive to the needs of BME people in their locality. The dementia guidelines produced by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE),<sup>30</sup> along with the National Dementia Strategy<sup>9</sup> emphasise that health and social care staff should identify the specific needs of people with dementia and their carers arising from aspects of diversity, such as gender, ethnicity, age (younger or older), religion and preferences about the delivery of personal care. The revised implementation plan for the National Dementia Strategy<sup>6</sup> and the *Dementia quality standard*,<sup>31</sup> based on the priority areas identified in the NICE/SCIE guidelines, emphasise the need to develop services that support people with dementia at all stages, from diagnosis to palliative care. The most recent Carers' Strategy guidance<sup>32</sup> identifies a need for services to reach out to carers from BME communities and to develop information and advice services that are accessible to all carers. The White Paper, *Healthy lives, healthy people*<sup>33</sup> envisages a new role for local government in health promotion, so it is important that

attention is paid to services for BME people with dementia as part of wider strategies designed to reduce health inequalities.

## About this briefing

The aim of this briefing is to give people who provide and use social care services an overview of research evidence by:

- gathering, appraising and summarising key national evidence about BME people and their carers within the context of dementia
- describing what evidence is available on social care-led interventions to address the needs of BME people with dementia and their carers
- illustrating the impact of social care-led interventions on health and wellbeing
- identifying gaps in research
- identifying the implications for social care practice development.

The methods used to identify and organise material in this briefing were developed by SCIE. They include undertaking systematic and reproducible searches of the literature. The searches include looking for specific material on all the main UK ethnic groups, including gypsy/traveller communities and Irish people. However, it was striking that the references gathered contained more material on some ethnic groups or very little, if nothing, on other ethnic groups. The searches of the literature are not exhaustive and the quality of the research is subject to minimal appraisal. The briefing aims to provide a signpost for further reading, rather than a definitive account of 'what works'.<sup>34</sup>

The challenge of tailoring dementia care services to ethnically diverse populations is not unique to the UK and similar work has been undertaken

elsewhere, notably in the USA.<sup>12</sup> However, this briefing only considers research carried out in the UK, with the exception of four journal articles on vascular dementia.<sup>22,24,25,27</sup> This is because variations in factors such as migration history, politics, and systems for funding and delivering health and social care services make cross-country comparison very complex and some issues may not be relevant to a UK readership.

Having found very little material specifically looking at social care-led interventions – none of which involved systematic ‘before and after’ comparisons – we decided to concentrate on some of the barriers to using dementia care services faced by BME people with dementia and their carers, and some of the ways in which they can be overcome.

## Findings

### Prevention, early intervention and diagnosis

Although it is not currently possible to prevent dementia, there is potential for certain BME communities to reduce the risk of developing vascular disease and possible vascular dementia by adapting their lifestyles in terms of diet, exercise and smoking cessation. BME people seem to be at greater risk of developing vascular dementia,<sup>19,28,35</sup> so resources providing relevant and useful advice to BME people on this topic are needed.

Statement 2 of the *Dementia quality standard*<sup>31</sup> refers to the need for ‘people with suspected dementia to be referred to a memory assessment service specialising in the diagnosis and the initial management of people with dementia’. But research suggests that BME people with dementia are less likely to receive a diagnosis or receive it at a later stage than their White British counterparts.<sup>19,36–38</sup> It is important that BME

people with dementia have access to memory assessment services because:

- Having a diagnosis allows people to access dementia-specific services, including the possibility of being prescribed drug treatments for different types of dementia.<sup>28</sup>
- Potential causes for symptoms that may be mistakenly attributed to dementia (such as depression or adverse reactions to medication) can be investigated and treated.
- People with dementia who receive an early diagnosis can make plans for how they would like to be cared for in the future, such as arranging lasting power of attorney or setting up an advance directive.<sup>39</sup> This is emphasised in Statement 5 of the *Dementia quality standard*.<sup>31</sup>
- Late diagnosis may also have a negative impact on family carers, who may become more stressed if they have been caring for some time without any support.<sup>37</sup>

Advances in the early diagnosis of dementia have highlighted the differences between those people who receive an early diagnosis compared with those who do not receive a formal diagnosis or who are only diagnosed once their dementia has become severe. While there are some risks to acquiring the ‘label’ of being a person with dementia, such as the impact on self-esteem or the likelihood of experiencing discrimination,<sup>40–42</sup> it is not clear how far lack of access to early intervention services contributes to negative attitudes about dementia among BME communities (see sections on ‘Awareness’ and ‘Stigma’, on page 5).

### Understanding life history and dementia

The benefits of biographical and life-story approaches for people with dementia are increasingly recognised.<sup>43,44</sup> As research into the

experiences of BME people with dementia has developed, some researchers<sup>45,46</sup> have emphasised that an important starting point in achieving personalised approaches to services is the need to pay greater attention to the diversity and complexity that exists within the life stories of people with dementia. This is because the way people have structured their lives and identities over the life course will influence their experiences of dementia.<sup>47,48</sup>

For example, in one study where White British, Black Caribbean and Asian people with dementia were interviewed about the impact of dementia on their lives and asked to respond to a fictionalised example of a man with dementia, it emerged that while there were some similarities in participants' responses, there were also differences. While White British participants set greater value on remaining independent, Black Caribbean respondents were conscious of becoming a burden to their families, and Asian respondents took pride in the presence of family support.<sup>48</sup> The authors referred to these feelings as 'valued elements of life' and concluded that services need to respond in ways that reinforce rather than challenge these attitudes. This involves practitioners taking account of people's sense of individual identity, and the factors that contribute to it, and considering how these may be influenced by their ethnic and cultural identity.

Our identities are also affected by the sociopolitical context of our lives. Few of the current generation of BME older people will have been born in the UK and aspects of their life histories that may need specific consideration include:

- country of origin
- migration route and reasons for migration
- age at migration

- the cultural experiences of individuals and their communities in the UK and their country of birth.<sup>46</sup>

This approach also helps to avoid stereotyping (see section on 'Training', on page 8), as workers are more likely to get to know people with dementia according to these individuals' own perceptions of their identity, rather than making assumptions about what individuals want, based on generalisations about different ethnic or cultural groups.<sup>47</sup>

### Awareness

Raising awareness within BME communities about dementia is an important first step in improving their access to services<sup>28</sup> and there is considerable evidence suggesting lower levels of awareness among BME groups of the causes of dementia and the way that it affects people's lives.<sup>2,4,20,29,35,37,38,48-51</sup> An added complication is that there is no word for 'dementia' in most South Asian languages.<sup>2,41,51</sup> Studies have also reported lower levels of awareness among Black Caribbean,<sup>4,20,35</sup> and Irish<sup>4</sup> communities.

As a result, many BME people and their families are more likely to see the symptoms of dementia as 'normal ageing'.<sup>28,29,38,50,51</sup> This may lead to the assumption that nothing can be done to assist them, and result in people only seeking help from services once the symptoms of dementia have become very severe,<sup>37,38,52</sup> by which time the person with dementia may no longer have capacity to set out preferences for future care. In some circumstances, families and professionals may disagree about the way they conceptualise and talk about their experiences of dementia.<sup>53,54</sup>

### Stigma

Stigma is found in all cultures, but the way it is expressed varies between them.<sup>54,55</sup> On the

whole, public understanding of dementia has improved considerably in recent years, although it would be wrong to assume that stigma about dementia no longer exists.<sup>36</sup> However, levels of stigma may be higher among Asian,<sup>17,49,51,55,56</sup> Irish,<sup>4</sup> Black Caribbean<sup>4</sup> and Eastern European<sup>55,56</sup> older people and carers. Religious beliefs may account for some stigma among Asian people. For instance, among those who believe in reincarnation, dementia may be seen as a punishment for behaviour in a past life.<sup>56</sup> Research with Black Caribbean and Irish people<sup>4</sup> suggests they are more inclined to see dementia as a 'mental illness', rather than the result of physiological changes in the brain. Among Eastern Europeans, stigma may relate to experiences of persecution<sup>56</sup> and the need to 'keep face'.

Stigma may lead to reluctance to use services in case this results in a person's dementia becoming public. In communities where there are arranged marriages, the knowledge that a family includes a person with dementia is thought to jeopardise children's marriage prospects.<sup>4,55,56</sup> Carers may also find that they experience stigma because of their association with the person with dementia.<sup>54</sup>

### Improving information about dementia and the services that are available

Statement 3 of the *Dementia quality standard*<sup>31</sup> proposes that people newly diagnosed with dementia and/or their carers receive written and verbal information about support options in their local area. However, almost without exception, studies report high levels of uncertainty among BME people about how to access dementia services and how these services could help.<sup>4,17,49,51,56</sup> For example, carers in one study likened the process of accessing services to 'a battle in which they were constantly fighting to receive information, advice and practical assistance'.<sup>57</sup> This picture is consistent with reports given by BME older people as a whole.<sup>58</sup> However, it is also possible to find

examples of ways in which services or researchers have been successful in publicising information about dementia and improving awareness among BME communities, particularly where attempts have been made to do this in conjunction with local communities.<sup>28,51,55</sup> Examples include:

- Using neutral language in leaflets, such as 'memory problems' for dementia and 'looking after' instead of being a 'carer'.<sup>41,54</sup> This avoids making assumptions that people understand what is meant by these terms.
- Developing a multi-purpose leaflet<sup>28</sup> instead of individual leaflets from each separate service. Such a leaflet would include information about memory problems and about what sort of help is available.
- Holding 'roadshows' at religious establishments and community centres.<sup>51</sup>
- Providing DVDs and videos about dementia.<sup>52</sup> This approach is particularly useful where members of a community are neither literate in English nor their mother tongue.
- Publicising information on local radio stations.<sup>4,51,56</sup>
- Creating links with local communities – for instance, at places of worship.<sup>52,55,59</sup>
- Appointing outreach workers who can work with local communities.<sup>12,28</sup>

Different approaches may work better with different communities in different places. For example, the Croydon Memory Clinic spent time developing links at local places of worship and later found that referral rates for BME people reflected their distribution in the population as a whole.<sup>59</sup> By contrast, in Kent a meeting attended by more than 400 people at a local *gurdwara* (Sikh place of worship) resulted in just one referral to a specialist dementia service. Better results were obtained after general practitioners (GPs) invited their patients to come for a

consultation about memory problems and then offered to make a referral to the service.<sup>28</sup>

Clearly, it is important to recognise that all these approaches take time to be effective.<sup>60</sup>

## Carers

There is a small but growing number of research projects<sup>20,35,37,56</sup> and reviews of research<sup>61</sup> that have looked specifically at the experiences of BME carers of people with dementia. It has been shown that such carers tend to have strong expectations about the role of women and adult children in care-giving.<sup>35,37,56</sup> Carers may be reluctant to ask for help and this may be the result of one or more of the following:

- They may not be familiar with, or identify themselves with, terms such as 'carer', 'care-giver' or 'respite'.<sup>61,62</sup> This is not simply about terminology – BME carers may find it difficult to distinguish between tasks deriving from an illness or disability and kinship obligations.<sup>62</sup>
- They may feel that family care is preferable and that services will not meet the standards they want.<sup>4,49</sup>
- They may fear that others in their community will criticise them for using services.<sup>20</sup>

However, there is evidence of some convergence between the issues faced by BME carers and their White British counterparts.<sup>62</sup> More BME carers, particularly adult daughters or daughters-in-law, are now combining caring responsibilities with paid employment.<sup>2,4,52</sup> BME populations are becoming more geographically dispersed<sup>10,11</sup> so that adult children are less likely to live near their parents than in the past<sup>51</sup> and 'distance care-giving' is likely to become more common.

There is also evidence of some convergence between BME and White British carers in terms

of expectations about care-giving. A study of Black Caribbean, Asian and White British carers of people with dementia<sup>57</sup> divided participants according to whether they held a 'traditional' or 'non-traditional' care-giver ideology on the basis of their responses to an in-depth qualitative interview. Traditional carers conceptualised care-giving as 'natural, expected and virtuous' while non-traditional carers were more likely to talk about how care-giving conflicted with other aspects of their lives or their sense of self-identity.

While Asian and Black Caribbean carers were more inclined to hold 'traditional' ideas about care-giving (often associated with religious beliefs) than their White British counterparts, some Asian and Black Caribbean carers held non-traditional beliefs.

Overall, the study highlighted the diversity among BME carers. Most importantly, it concluded that holding a traditional ideology about services does not mean that these carers will not need support from services. For example, approaches that emphasised the need for carers to have time off from caring and focused on the benefits that the person with dementia would gain from using a particular service worked better with traditional carers. By contrast, non-traditional carers wanted help in maintaining their roles outside care-giving (such as paid employment). They also wanted support that took account of their relationship with the person with dementia – for instance, in helping them deal with feelings that they were a 'bad person' because they found caring difficult.<sup>57</sup>

In terms of specific services for carers, two studies have reported on the effects of support groups specifically for BME carers of people with dementia.<sup>51,56,63</sup> In the first, carers and people with dementia were offered the opportunity to attend a support group as part of a wider

specialist service for Asian people with dementia and their families.<sup>51</sup> In the second, Eastern European<sup>56</sup> and Asian carers<sup>56,63</sup> took part in a 10-week carer support programme.

These studies offered clear lessons in terms of the need to:

- ensure that such groups are led by speakers of community languages so that those attending can speak in their first language
- take care to select venues that are suitable
- take account of cultural and religious needs in terms of providing refreshments and transport (for instance, making sure that women needing transport to attend the group were not offered a male driver if they did not want to be driven by a man who was not a member of their family).

Despite these efforts, not all the carers invited to the groups felt that they were able to attend. In some instances they explained that this was because they might be criticised within their community.<sup>63</sup> This emphasises the challenges in reaching out to carers who may feel under a strong sense of obligation to avoid asking for outside help.

Those who attended the groups valued the chance to socialise and find out more about dementia. Some participants reported that they developed friendships at the group and continued to meet up afterwards.<sup>51,56,63</sup>

BME carers have also highlighted the need for respite<sup>4,52</sup> and advocacy services.<sup>51</sup> Day care may be more acceptable than other types of respite, such as home-based respite or short stays in care homes.<sup>4,52</sup> This is in keeping with the findings from the study of BME carers<sup>57</sup> which suggested that emphasising the benefits of a particular service for the person with dementia may be a more effective way of encouraging BME carers to use respite services.

Statements 6 and 10 of the *Dementia quality standard*<sup>31</sup> call for carers of people with dementia to be offered an assessment of their emotional, psychological and social needs, and if accepted, receive a tailored intervention to address these needs, including access to a comprehensive range of respite services.

### Training and workforce development

In addition to the barriers to accessing services caused by lack of awareness about dementia, stigma and expectations about seeking outside help, BME people with dementia and their carers may be discouraged from using services if they feel that practitioners lack the confidence and competence to cope with language and cultural differences.<sup>45</sup>

Research has suggested that if organisations and practitioners hold stereotyped ideas about BME people with dementia, and in particular the extent of family support or preferences for certain types of care, then this can be an important factor discouraging BME people with dementia and their families from using services.<sup>4</sup> For example, in an article entitled 'Hidden shame', St John points out that: 'Comments such as "Everyone is equally welcome here" assume that all people have the same needs regardless of cultural experience. Providing the same service for everyone when needs are different is not equitable as the outcomes will vary for users from different groups in the community'.<sup>52</sup>

While many practitioners feel they need more training to enable them to support BME people with dementia, both in terms of improving their knowledge about dementia and in helping them to be better informed about the cultural and religious practices of BME people with dementia,<sup>53,64</sup> access to this sort of training is variable.<sup>12</sup> Priorities for improving training generally consist of developing practitioners' language and communication skills. For example,

knowing basic words in community languages such as greetings, 'drink' or 'lavatory'<sup>36,45</sup> is both courteous and an indication of acceptance and commitment. It is also important that practitioners recognise different cultural conventions in terms of how to address people (for instance, whether it is acceptable to use first names) and aspects of non-verbal communication, such as eye contact, gestures and touch.<sup>65</sup>

The lack of suitable assessment instruments has also been noted.<sup>17,45</sup> Some instruments may be culturally biased and overestimate the severity of dementia in people with lower levels of education or among people who are not proficient in English. For BME people with dementia who have learned English as a second or additional language, their ability to speak English may be lost as their dementia progresses.<sup>65</sup> While there is an expanding literature discussing the cross-cultural validity of tests and interviews used in medical assessments,<sup>66-74</sup> little attention has been paid to whether social care assessments and reviews of BME people with dementia and their carers are culturally biased. Reinforcing the point about the importance of good communication,<sup>65</sup> conducting an assessment or review in a culturally sensitive way may be as important as the content of the paperwork itself.<sup>75</sup>

Where interpreters are being used, they should ideally be briefed beforehand, including a discussion about the importance of confidentiality.<sup>65</sup>

### Specialist and generic services

There is a longstanding debate about the role played by specialist culturally-specific services for BME people with dementia. Being the only BME person with dementia in a dementia service in which the rest of the service users and the workforce are White British, especially if there

are few attempts to provide culturally sensitive care, can lead to BME people deciding not to continue with that service.<sup>36</sup> This is why some BME people with dementia and their carers may prefer to use generic care services designed for their ethnic group even when staff do not have the skills and resources to provide dementia care.<sup>2</sup> The isolation experienced by BME people in services in which there is little ethnic diversity and high rates of refusal to use services are among the reasons for the development of specialist culturally-specific housing and care homes for BME older people with<sup>64</sup> and without dementia.

It has been suggested that different ethnic groups have different preferences for 'mixed' or culturally-specific dementia services. In Haringey, a study suggested that Black Caribbean and Irish people with dementia and their carers preferred 'mixed' services, although participants from both communities emphasised the importance of providing culturally acceptable care in the form of suitable food, social activities and creating an atmosphere in which people felt at home.<sup>4</sup> However, Gujarati Asians interviewed in the same study set more importance on having services in which care was provided by Asian staff. This was also the finding of a project in Bradford where being able to talk in their first language and having the right sort of food and attention to religious needs were seen as important by the participants.<sup>51</sup> Examples of specialist dementia services for BME people include:

- housing<sup>64</sup>
- day care<sup>52</sup>
- home care<sup>76</sup>
- care homes<sup>12</sup>
- advocacy.<sup>60,77</sup>

However, concerns have been expressed about the impact of short-term funding on the

sustainability of services such as these and their limited ability to spread good practice.<sup>53</sup> There can also be tensions between the pressures on funders to show that they are not wasting public expenditure and the time needed to build up relationships and establish trust with local communities.<sup>60,77</sup>

In services which are not aimed at a specific ethnic group, recruiting an ethnically diverse group of staff – especially those who are bilingual<sup>28,52</sup> – or appointing link workers who can engage with local communities,<sup>45</sup> has been seen as important in improving service uptake among BME people with dementia. Specialist advocacy services can also make links between services and BME communities.<sup>60,77</sup>

### Limitations of existing research

Although the research evidence base on BME people with dementia has expanded, it is still very limited.<sup>61</sup> The majority is based on local studies in areas where there are greater concentrations of BME people with dementia such as London,<sup>4,77</sup> Bradford,<sup>51,55,56</sup> Manchester<sup>38</sup> or Birmingham.<sup>49</sup> Some accounts are written by those directly responsible for providing the service, which may influence what is researched or reported. In terms of written outputs, three independent evaluations – one in Kent,<sup>2,17,28,52</sup> one in the West Country,<sup>1,5,12,36</sup> and one in Bradford<sup>47,55,56,63,78</sup> – account for the majority of UK-based literature.

While understandable in terms of the current demographic profile, most studies have looked at Asian and Black Caribbean people with dementia, with only one study looking at Eastern European<sup>47,55,56,78</sup> or Irish carers.<sup>4</sup> As the UK population becomes more diverse, this highlights the lack of information on

other groups, such as Chinese people with dementia.

It is also striking how few studies directly report the perspectives of people with dementia. Only one<sup>48</sup> reported the views of people with dementia, and another<sup>51</sup> interspersed comments from people with dementia with those of others, rarely making clear the capacity in which different participants were speaking. Forbat<sup>54</sup> suggests that because BME people with dementia access services at a later stage than their White British counterparts, they may lack capacity to take part in research, making it more complicated to involve them in research studies. No material discussing BME people with dementia living in care homes was identified, possibly because such people are unlikely to have received a formal diagnosis of dementia. Despite the emphasis on personalisation, the material retrieved suggested a similar lack of published research on BME people with dementia at the time of writing. Given the government's commitment to expanding personalisation,<sup>79</sup> it will be important to identify whether this situation reflects differential access to personal budgets among BME older people.

### Conclusions

Despite the limited nature of the evidence base, a number of recurring themes emerge in research looking at BME people with dementia and their carers. The first is the difficulties they face in accessing services and being able to choose care and support in the forms that they would like. These difficulties arise from what seem to be lower levels of awareness about dementia and greater levels of stigma among some communities. These factors influence the ways in which families seek support and there is evidence that BME people with dementia access services at a later stage than their White British

counterparts, when they may find it harder to set out their preferences for their current and future care needs.

While carers of BME people with dementia face similar issues to their White British counterparts, factors such as differing expectations about care within their family and the wider community, and services that are not culturally acceptable, can mean that they face additional pressures.

While examples can be found of ways of increasing awareness of services and service uptake among BME people, these seem to work best where local communities have been involved in the process. At the same time, the workforce needs help in adapting to providing more individualised approaches to care that recognise people's ethnicity, along with other aspects of their identity that are important to them.

Nevertheless, the sparse nature of the material identified in this briefing suggests that the increase in the number of BME people with dementia in the UK does not seem to have been accompanied by an increase in research looking at their needs and preferences and evaluating how well services are attempting to meet them.

In terms of how the research that does exist is disseminated, although reviews<sup>5,61</sup> and commentaries<sup>69</sup> on services for BME people with dementia in the UK do exist, they are few in number. Accounts of service developments are often written up as reports, of which only a limited number of copies are printed, or which are placed on websites that no longer exist, or which are produced as articles for trade and professional journals. This means that it can prove difficult for those involved in dementia services to access information about the topic. In this context, this briefing represents one of the few attempts to draw together research findings for managers and practitioners.

## Implications from the research

### Implications for the policy community

- It is important for policy-makers to find ways of involving BME people with dementia and their carers in developing services,<sup>2</sup> and examples of successful ways of improving awareness and uptake of services do exist.<sup>28,45,51,76</sup>
- The timescales for evaluating the success of services and uncertainties about funding can affect the long-term sustainability of services for BME people with dementia.<sup>53,60</sup>
- More information on the pathways that BME people have taken to access dementia services is needed.<sup>29</sup> More information is also needed on services which have ensured that BME people with dementia are not under-represented.<sup>59</sup>

### Implications for commissioners

- Commissioners need to be aware of the increase in the number of BME people likely to need dementia services<sup>10</sup> and the increasingly dispersed nature of the BME population,<sup>11</sup> which means that all localities will see an increase in the number of BME people needing care and support.
- Local research<sup>4,17</sup> and consultation<sup>51</sup> with communities are important first steps in developing services.
- Differing strategies may be needed to reach different BME communities.<sup>4,55</sup> Different communities may have different preferences for services,<sup>4</sup> so it is important to commission a range of ways of supporting BME people and their carers.

### Implications for practitioners

- Practitioners need to recognise the impact of stigma and cultural expectations that can

influence the willingness of BME people and their carers to access services.<sup>35,37,56</sup>

- Leaflets, DVDs and other resources exist that can assist practitioners in sharing information about dementia and the support available.<sup>51,52</sup> Some of these are not specific to a particular service or part of the country, while others could be adapted comparatively easily for local services.
- It is important to find ways of supporting BME people with dementia and their carers that affirm and enhance their sense of self-identity<sup>48,57</sup> and are not based on stereotypical assumptions.<sup>45</sup>

### Implications for people who use services and their carers

- BME people with dementia and their carers need support aimed at improving access to screening and diagnostic services. This will help them make greater use of early intervention dementia services and support them in planning their future care.<sup>28</sup>
- As the population of BME people with dementia and their carers becomes more diverse, it will become increasingly essential to ensure that they have access to support tailored to their own individual circumstances.

### Implications for researchers

- While recognising the practical and methodological difficulties of involving BME people with dementia in research,<sup>54</sup>

researchers need to find ways of documenting the experiences of BME people with dementia themselves. This will give additional insights into the way that dementia impacts on people's quality of life.<sup>48</sup>

- Research looking at the way BME people with dementia and their carers experience the process of assessment and review<sup>54</sup> could potentially yield insights into a number of topics, ranging from how BME people and their carers conceptualise dementia, to service preferences, and whether there are ways in which training for those undertaking assessments might be enhanced. This information should be linked to outcomes.
- Researchers need to collect more specific information about services which makes it easier to identify what sort of care and support people want and why.<sup>4,56</sup> It seems that information about 'services' is analysed in a very general way, which makes it harder to identify which types of support are best able to meet which needs and preferences and in what circumstances.
- Despite the relatively higher representation of some ethnic groups in research on the experience of dementia and access to services, overall the research is limited. Some communities, such as gypsies and travellers, do not feature in any of the material searched. Therefore, consideration needs to be given to distributing future research efforts more equally to include such seldom-heard groups.

## Useful links

Free downloadable leaflets about dementia in community languages from Alzheimer Scotland: [www.alzscot.org/pages/info/otherlanguages.htm](http://www.alzscot.org/pages/info/otherlanguages.htm)

Article in the June 2010 issue of the Alzheimer's Society *Living with dementia* magazine about a scheme in Hackney developing peer support networks for BME people with dementia as part of the National Dementia Strategy:<sup>6,9</sup>

[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1375&pageNumber=3](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1375&pageNumber=3)

Facebook page on dementia and BME and refugee communities in London:

<http://en-gb.facebook.com/posted.php?id=122493921131184>

Information and resources from the award-winning 'Meri Yaadain' (My Memories) project: [www.merियाadain.co.uk/index.html](http://www.merियाadain.co.uk/index.html)

Publications, news and resources from Policy Research Institute on Ageing and Ethnicity (PRIAE): [www.priae.org/](http://www.priae.org/)

## Related SCIE publications

**Dementia Gateway:**

[www.scie.org.uk/publications/dementia/index.asp](http://www.scie.org.uk/publications/dementia/index.asp)

**Open Dementia e-Learning Programme:**

[www.scie.org.uk/publications/elearning/dementia/index.asp](http://www.scie.org.uk/publications/elearning/dementia/index.asp)

**Social Care TV dementia resources:**

[www.scie.org.uk/socialcaretv/topic.asp?guid=6ddc31cf-a355-46cf-9fce-2685b51272d3](http://www.scie.org.uk/socialcaretv/topic.asp?guid=6ddc31cf-a355-46cf-9fce-2685b51272d3)

**Race equality discussion papers:**

[www.scie.org.uk/publications/raceequalitydiscussionpapers/index.asp](http://www.scie.org.uk/publications/raceequalitydiscussionpapers/index.asp)

**Report on the mental health and well-being of BME older people:**

[www.scie.org.uk/adults/prevention/bmeolderpeople.asp](http://www.scie.org.uk/adults/prevention/bmeolderpeople.asp)

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## About the development of this product

### Scoping and searching

Scoping and searching was carried out in April 2010 with further searching in May and June 2010.

### Peer review and testing

Lead author is a topic expert. The briefing was peer reviewed internally for methodology, and externally by an independent topic expert.

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- 29 Black and minority ethnic parents with mental health problems and their children
- 30 The relationship between dual diagnosis: substance misuse and dealing with mental health issues
- 31 Co-production: an emerging evidence base for adult social care transformation
- 32 Access to social care and support for adults with autistic spectrum conditions (ASC)
- 33 The contribution of social work and social care to the reduction of health inequalities: four case studies
- 34 Communication training for care home workers: outcomes for older people, staff, families and friends
- 35 Black and minority ethnic people with dementia and their access to support and services

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### Social Care Institute for Excellence

Goldings House  
2 Hay's Lane  
London  
SE1 2HB

tel: 020 7089 6840  
fax: 020 7089 6841  
textphone: 020 7089 6893  
[www.scie.org.uk](http://www.scie.org.uk)