

# Understanding the barriers facing BAME communities

What are the barriers confronting ethnic minority communities attending memory services? **Jasmine Martinez** and **Naomi Wynne-Morgan** devised a research project to find out

**W**hen we audited the demographic profile of clients attending our memory service, it was immediately apparent that it did not reflect the ethnic make-up of the local population. Funding for a six-month project enabled us to investigate the barriers for black, Asian and minority ethnic (BAME) communities with the aim of identifying interventions to increase referrals and attendance from these communities.

One of the authors (Jasmine Martinez) was recruited specifically to the project, supervised by the second author (Naomi Wynne-Morgan). The project began by exploring the NHS Trust's historical relationships with BAME communities and the work it has done with them. Liaison with other organisations supporting BAME communities was invaluable in setting the scene and developing learning along the way.

To understand the barriers facing people from minority groups it was important to hear from different perspectives (Carter et al 2014); for example, GPs whose opinions on low rates of referral and attendance were sought since they are the gatekeepers to the memory service. Interpreters can be involved in GP appointments and have experience with BAME communities so they were considered to be an avenue of exploration. Finally, we wanted to hear from community leaders and the people themselves.

We decided that an online questionnaire would be the best method of getting broad feedback from time-pressured GPs and interpreters across Greenwich, one of the London boroughs covered by our trust and the focus of our project. The questionnaires were developed in consultation with clinical staff, BAME services and community organisations such as HealthWatch Greenwich, Culture Dementia UK and the Greenwich Inclusion Project (GrIP).

For GPs, the questions predominantly used a Likert scale (e.g. strongly

agree/agree/don'tknow/disagree/strongly disagree) and covered the following topics: confidence in assessing for dementia with BAME individuals, language barriers, perception of dementia in BAME communities, and cultural barriers such as stigma. Respondents were also given space for their own feedback.

A similar online questionnaire was developed for interpreters, addressing their opinions on the barriers to referral and perceptions of cultural differences preventing diagnosis and access to support services for dementia. Both questionnaires were analysed using the online polling system built into the questionnaire website.

At the same time local BAME organisations were mapped out and contact was made with over 100 groups, including charities, cultural and religious groups. A semi-structured interview method was chosen as it allowed flexibility to explore issues that may have been unknown to the researchers. The interview questions were developed from similar research (e.g. Smith 2011; Berwald et al 2016) and responses were written down as close to verbatim as possible.

We opted for convenience sampling – that is, interviewees were selected on the

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basis of their accessibility - because it is good method for initial research projects to use in generating hypotheses (Etikan et al 2015). Interviews were conducted with individuals across a range of BAME communities and subjected to thematic analysis (Boyatzis 1998).

## Results

### Participants and demographics

There was a 14% response rate from the GP questionnaire (24 respondents) while 11 respondents completed the interpreter questionnaire. Interpreter questionnaires were disseminated indirectly via the NHS interpreter service manager so it was difficult to determine exactly how many received it.

Semi-structured interviews were conducted in the community with 55 individuals from various ethnicities, including; black Asian, Caribbean and British, Asian Pakistani, Chinese, Vietnamese, Bangladeshi, Nepalese, Somali, and Irish Travellers. The age range was 36-86 years old, which gave

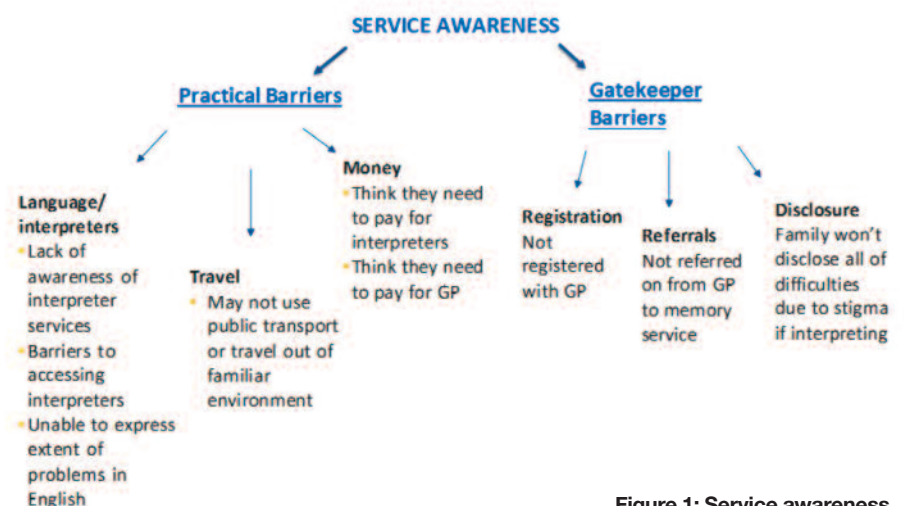


Figure 1: Service awareness

perspectives from working age to retirement age.

### GP questionnaire

Just over half of the GPs thought language barriers (58%) and written and spoken English (53%) prevented assessment of dementia in BAME communities. In spite of this fact, GPs still felt confident assessing for dementia in BAME communities (76%), a conflict between findings that warrants further investigation. They felt that stigma prevented individuals from revealing their memory problems (86%) and stopped people seeing their GP (52%). GPs also thought that BAME communities viewed dementia as normal ageing (58%) and felt that they had limited awareness of dementia and available services (82%).

### Interpreter questionnaire

The GP findings mirrored the interpreters' views. Interpreters thought that screening tools for assessing cognitive impairment changes were appropriate (73%), but just over half thought that reading and writing skills in English played a role in preventing assessment of dementia (54%). Interpreters thought it was a mix of stigma (45%) and dementia being perceived as a normal part of ageing (52%) which contributed to limited awareness of services and contact with them.

### Semi-structured interviews

Two overarching themes emerged from the interviews: service awareness and cultural differences in perception. Service awareness relates to the barriers faced by BAME communities that arise either from GPs as gatekeepers or from practical issues. Cultural differences categorise the issues specific to BAME communities.

### Service awareness

Our overarching themes of service awareness and cultural differences were further analysed into themes and sub-themes. To take service awareness first, this comprised two main themes – practical barriers and gatekeeper barriers – each with its own sub-themes (see Figure 1, left).

#### Theme 1: Practical barriers

The main practical barriers to referral were identified as language, travel and money.

##### *Sub-theme: Language and interpreters:*

One person explained how she had written down her mother's problem on a piece of paper which was then taken to the GP as she did not speak English. Many people were not aware that they could ask for an interpreter. ▶

## Implications for practice

### Engagement

From a service perspective, there were changes that could be made by clinicians to have a positive impact on engagement by creating a welcoming environment and encouraging a more curious attitude about BAME communities.

"Top tips" were written and published on the intranet for staff, highlighting barriers and issues they should be mindful of. By prompting staff to be proactive in offering interpreter services, the tips encourage them to ask how the word dementia is translated in their clients' languages.

To address language barriers a document was put together containing electronic links to information on dementia and other ICD-10 diagnoses in all languages spoken by local communities. The 10 main languages spoken in the borough, after English are: Nepalese, Polish, French, Lithuanian, Chinese, Punjabi, Somali, Turkish, Yoruba and Spanish (Office for National Statistics 2011).

This document is being shared with Alzheimer's Society and NHS England. Clinicians across the trust can now use the information with clients to help explain different conditions and mental health challenges in the person's own language.

All local BAME community group contact details have been amalgamated so that they can be given out to clients in the memory service and community mental health team. This links people to groups of which they may have been unaware and cultivates social inclusion. Additionally, it has had a knock-on effect of helping forge stronger ties between our services and these groups. Both the language document and the contact details have been added into the "Oxleas Dementia" app for people with a dementia diagnosis.

A stall promoting the memory service and research project during Mental Health Awareness Week displayed the national flags of BAME communities. The flags attracted people to the stall to talk to researchers about their countries of origin, often leading to detailed discussions about dementia within their cultures. As a result, national flags have been displayed in the memory service waiting room in the hope that minority groups will feel more welcome there.

### Pathway to memory services

The semi-structured interviews prompted interest from BAME community leaders which resulted in requests for more information on dementia and the memory service. One of the authors (Jasmine) returned to these community groups and gave culture-specific presentations, for example for the Chinese community group (in collaboration with the Chinese National Healthy Living Centre) and a Sikh community group in their Gurdwara Sahib.

We are establishing a "Trusted Leaders" network, which will comprise community leaders who will come together to work with the trust. They will be offered training on dementia – and eventually, we hope, other mental health diagnoses. The trust will also benefit from learning about their cultural differences and expertise.

The Trusted Leaders will become formal Oxleas NHS Trust volunteers, receiving training and other volunteering opportunities. The aim is that this relationship will work as a mode of liaison between community groups and trust services. Together we will be able to identify and support those living with dementia in BAME communities.

In the future, the development of drop-in clinics within BAME community groups will help to remove the barriers of travel and cost, and may begin to remove stigma as dementia support becomes more visible in the community.

### Dissemination

The project findings have been shared with GP syndicates in the locality as well as the Alzheimer's Society Equality, Diversity and Inclusivity committee. They were also presented at the Memory Services National Accreditation Programme (MSNAP) Forum.

In addition, we hope that this article will encourage contact with other NHS Trusts, health care organisations and charities who are seeking to break down barriers for BAME communities and develop a national network of learning.

► *Sub-theme: Travel* Some individuals had never travelled away from their local area. There was a concern about travelling to other parts of the borough outside the perceived safety of the cultural group.

*Sub-theme: Money* Many people thought that accessing the GP or interpreters would incur a cost which they may have been unable to afford.

## Theme 2: Gatekeeper barriers

The sub-themes under this category were related to the pathway into the memory service.

*Sub theme: Registration* Some people were not registered with a GP and would have been unable to access the memory service as referrals are only accepted from GPs.

*Sub theme: Referrals* There were examples of people who knew about the memory service but were not referred by their GP. It was not possible to establish the clinical decisions behind these situations. This may also connect to language barriers, where it may have been difficult for GPs to communicate rationales for clinical decisions.

*Sub theme: Disclosure* Some people relied on family members to interpret when seeing a GP. Stigma and privacy can influence how much individuals feel happy about sharing in these circumstances.

## Cultural differences in perception

Our second overarching theme of cultural differences in perception was analysed into two further themes about the cause of dementia and about fear and respect. A series of sub-themes around normal ageing, personal characteristics, mental

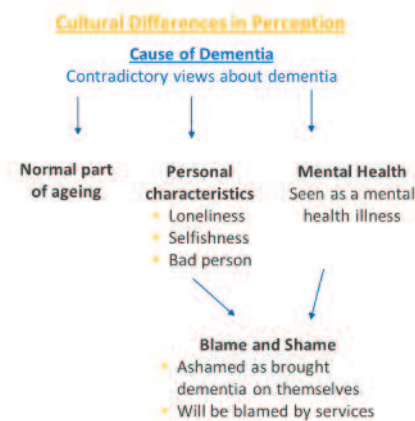


Figure 2: Cause of dementia

health, and blame and shame emerged from the cause of dementia theme (see figure 2).

## Theme 1: Cause of dementia

There was a variety of views on the cause of dementia, many of which posed challenges to referral arising from cultural beliefs.

*Sub-theme: Normal ageing* Some communities considered dementia to be a normal part of ageing and therefore there was no need to access support from services.

*Sub-theme: Personal characteristics* Some communities saw dementia symptoms as being a result of character flaws. Dementia may occur if the person was selfish or “bad”.

*Sub-theme: Mental health* Dementia was seen as a mental health difficulty rather than a neurological condition.

*Sub theme: Blame and shame* An unspoken sense of blame and shame came out of the interviews. People were either concerned about being blamed for developing dementia or spoke about blaming others who had the condition. There was a feeling of shame about receiving a diagnosis. Several individuals spoke of shying away from dementia and avoiding a diagnosis at all costs.

## Theme 2: Fear and respect

Sub-themes emerging from the fear and respect theme included feeling disrespected, lack of engagement, generational differences and stigma (see figure 3).

*Sub-theme: Disrespected and undervalued* As this research was conducted at the time of the Brexit vote, several community groups felt unwanted and fearful of how they would be perceived and treated. At a time of austerity many organisations had their funding cut and so were feeling undervalued. Many groups spoke of feeling “used” for research purposes and as though people would come in to pry and not give anything in return.

*Sub-theme: Engagement* Concern around how they would be seen and treated appeared to extend to people working for the public sector, for example the government or NHS. They spoke about avoiding services and remaining within their own cultural groups as they felt like outsiders in society. People would engage when necessary, possibly at a point of crisis.

*Sub-theme: Generational differences* Individuals from the first generation who moved to live in England spoke about the

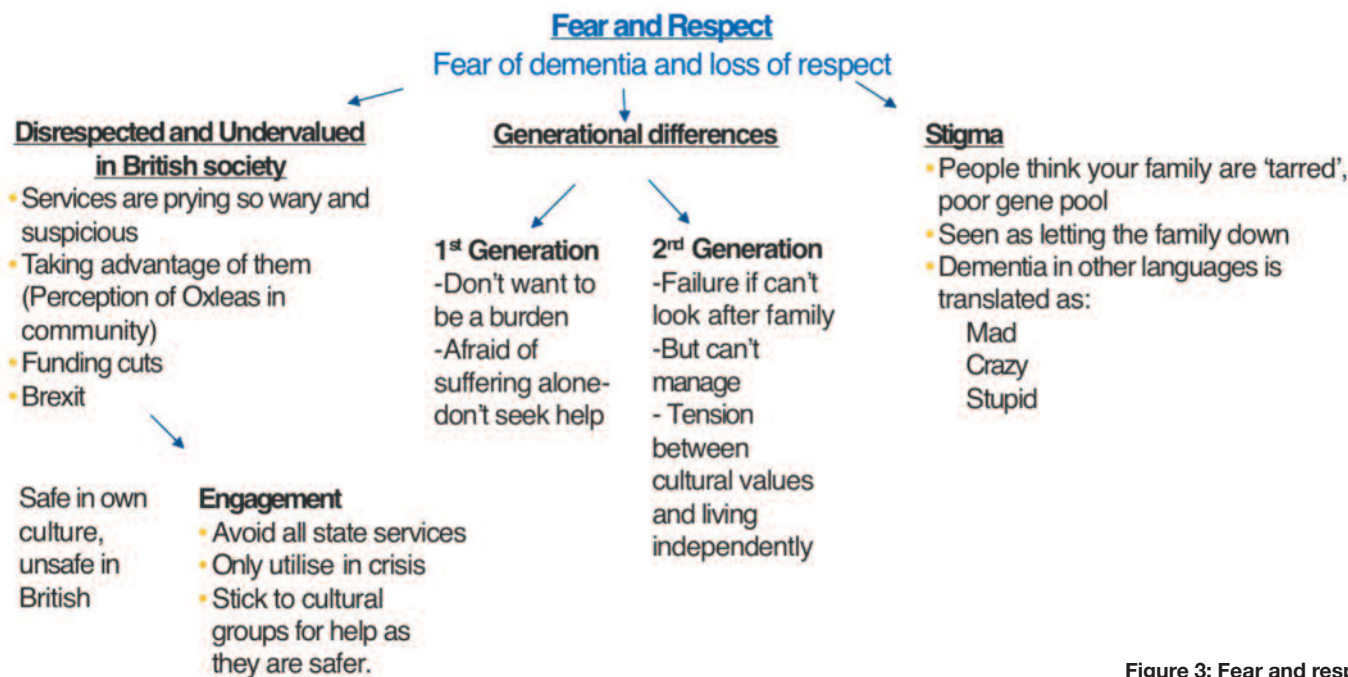


Figure 3: Fear and respect

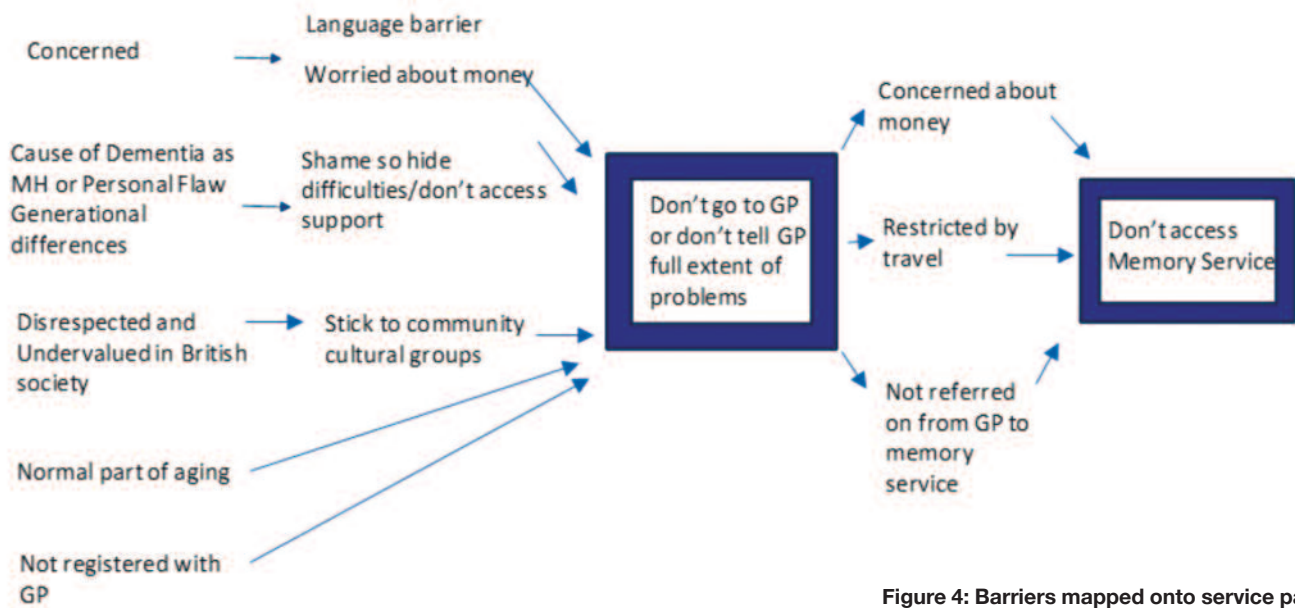


Figure 4: Barriers mapped onto service pathway

concern of being a burden to their children. They were also afraid of suffering alone, yet did not want to seek outside help or support. Second generation individuals talked about the conflict between the duty to look after their parents and yet not being able to do so. There was also a tension between the cultural values of their family and the independence they had developed growing up in an individualistic society. *Sub-theme: Stigma* Many groups also spoke of the need to hide any problems that may appear to be a “mental illness,” due to stigma and consequent perceptions of the family’s “gene pool” as making future generations less attractive for marriage. The word dementia was translated as mad, crazy and stupid in some cultures, reinforcing the stigma of this diagnosis.

## Discussion

The project identified a range of issues which prevented BAME people from accessing the memory service in proportion to their numbers in the wider population. Barriers were mapped on to the service pathway to help identify where problems could potentially be resolved (see Fig 4).

During our discussions with BAME leads in the NHS Trust and with minority communities, it was apparent that there was a level of “research fatigue”. Communities had been approached many times by various organisations about their views and consequently felt frustrated at the lack of change - they felt it was all give and no gain. Some people’s first interaction with NHS services had been at a point of crisis and had been stressful and difficult.

In combination, these factors caused a level of mistrust and reticence with

“outside” organisations and services. It was imperative that this preliminary research did not repeat these patterns, which meant it was vital that the trust developed a lasting relationship with the communities. Engagement, pathway to the memory service and dissemination of learning were highlighted as the main areas in which to focus interventions (see box p29).

## Conclusion

Our research was based on small samples and a follow-up with focus groups or interviews with GPs and interpreters would be useful. There may also be advantages in involving members of BAME communities themselves in drawing up the questionnaires and training them to carry out the interviews. This would have given ownership back to the communities and may have elicited other perspectives.

Even so, our research has significant implications for practice (see box p29). We saw that changes could be made by clinicians that would have a positive impact on engagement and by having a more proactive approach to offering the services of interpreters. Displaying the national flags of local BAME groups is one among several other initiatives to stir up interest in the memory service.

By going out to community groups and giving culture-specific presentations, the pathway to memory services has been smoothed.

A “trusted leaders network” of community leaders has come together to work with the trust, which will offer training on dementia and will learn from the network’s own cultural differences and expertise.

We believe that, by sharing and disseminating the findings of our project, we can help to break down barriers between memory services and BAME communities. In this way, we hope that our service and others like it will be used by many more people from minority groups. ■

## Acknowledgements

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