

## Practitioner's Blog

# Dementia has no boundaries

Mary Dawood RN, BSc (Hons) MSc

Consultant Nurse, Emergency Directorate, Imperial College NHS Trust, London, UK

An older lady of south Asian origin was brought to the emergency department as she was confused and unwell. Her family, with whom she lived, were not too sure of her age but thought she was about 80 years old. She had been living with her son and daughter in law for many years and spoke only her own native language. The family gave a history of her having Type 2 Diabetes but no other medical problems. She was usually well, self caring and often did the cooking. However, they also reported that she had become increasingly forgetful and sometimes confused over the past year but they had not taken her to the doctor as they considered this a normal part of aging. They brought her to the emergency department because she had become very confused, was wandering and agitated and intermittently did not recognize them. They were very worried for her and did not understand what was happening.

Obtaining a clear history was difficult not just because of her confusion but also because of language and cultural barriers. This lady, originally from Pakistan, had come to the UK to join her family who were well settled here. She was reliant on them and had little contact with anyone else. She was registered with a GP but had not been to see him recently. The lady was examined and, following blood tests and X-rays, a decision was made to admit her as she had significant cognitive impairment suggestive of undiagnosed dementia. There was also concern that she might be delirious. The family were understandably very upset and anxious at the prospect of her being separated from them and admitted into what would be, for her, a very strange environment where nobody would be able to understand her or speak her language. Great effort was made to reassure the family and to advise them that one of them could stay with her to comfort her and to try and minimize the unfamiliar and distressing impact of admission to hospital. However, all the family members had work commitments and so they had to leave her for a few hours while they went home to sort out how they could arrange to stay with her over the following few days.

The lady was visibly bewildered and seemed very frightened despite staff making every effort to reassure and comfort her. Although clearly confused she was mobile and tried, desperately, to leave. It was an upsetting and challenging situation for the staff whose priority at this point was to ensure her safety. Ultimately this lady needed one to one nursing while her family was not with her.

This case is not unusual and sadly scenes such as this will become increasingly common with an aging population and a continuous and consistent rise in the incidence of dementia. One of the defining features of some dementias is the progressive loss of short term memory and sense of place whilst long term memory remains intact. What makes this case different is the likelihood of dementia and short term memory loss with the added complications of language and culture. It is estimated that there are approximately 800,000 people living with dementia in the UK and of these a significant number, thought to be

about 25,000 belong to Black and Minority Ethnic (BAME) communities. (APPG 2013)

In the UK, the BAME population is defined as all ethnic groups with the exception of White British. Greater London, the West Midlands and the North West have the largest BAME populations. The majority of the older BAME population belong to Indian, Pakistani, Chinese, White Irish and Black Caribbean communities. Many of them migrated to the UK in the late 1950s – early 1960s and usually lived and worked within their own communities; they had little contact with the host population. In these communities self-contained communities it was easy to use their own languages; it helped them feel more comfortable initially and perhaps lessened the melancholy and sense of alienation that is so often synonymous with being an immigrant. It is also well recognized that immigrants everywhere have a fundamental need to maintain their sense of identity and close links to their homelands. However, as a consequence, many of these first generation immigrants, particularly those from India Pakistan and Bangladesh and especially women, either never learnt to speak English at all or developed only a smattering of the language. Many also lived with the dream of returning to the country of their birth when they retired and the reality of growing old in their adopted country was perhaps not something they considered or planned for.

Dementia is the biggest public health and social care issue facing society today. Considerable efforts have been made to raise awareness and promote understanding of this dementia, improve the care and support individuals and families living with this condition (DH 2009, DH 2012). There have been national initiatives on screening for cognitive impairment in older adults and ensuring early and timely referral to memory services but there is evidence that these initiatives have not always reached BAME communities (Daker-White *et al.* 2002, Seabrooke 2003, Moriarty *et al.* 2011)

This case all too clearly demonstrates there may be less awareness, perhaps greater stigma and different cultural understandings of dementia among members of BAME communities. Dementia is no discriminator of gender, ethnicity or socioeconomic status but different communities will perceive dementia through a different lens and face their own unique challenges.

Language and cultural differences may partially explain why BAME people tend to present later than their white counterparts, to memory clinics and dementia services. The lack of culturally-sensitive dementia services may be an additional factor. When they do access dementia services, BAME people may find the information provided has little bearing or relevance to their own culture. Reminiscence therapy, for example, may feature life in post war UK. This may not necessarily hold fond memories for people who, at that time, were newly arrived immigrants grappling with a sense of loss, dislocation, and alienation. Indeed it is important to bear in mind that many BAME people who have dementia may have distressing memories of having

had to flee their homelands because of war or other political strife. For them, reminiscence therapy may be not only counter-productive but crass and ill advised. Other possible barriers to equity in care may be outdated but still prevalent stereotypical perceptions that some communities prefer to look after their own. Such beliefs may result in BAME individuals with cognitive impairment being overlooked when they desperately need assessment and care (Social Services Inspectorate 1998).

In 2013 the All Party Parliamentary Group (APPG) called for Public Health England to raise awareness amongst minority ethnic groups by funding a pilot awareness campaign to inform communities about dementia. They found evidence of social isolation and stigmatizing attitudes among some communities but they also found examples of good care and recognition of the need for earlier intervention for people with memory problems (APPG 2012).

In order to deliver the best possible care to all people with dementia we need to engage our BAME communities to help design appropriate services that recognize and address the added complexities of language, faith and culture. A culturally competent approach would establish ways of communicating with patients of diverse backgrounds many of whom have limited English, limited health literacy, alternative health beliefs, and other needs (Bettancourt 2006). Perhaps then this sad predicament of the Asian lady and her family and the distress it caused will become a rare event.

## REFERENCES

All Party Parliamentary Group on Dementia (2013). *Dementia does not discriminate. The experiences of Black Asian and Ethnic communities*. July London, Alzheimer's Society.

[www.alzheimers.org.uk/site/scripts/download.php?fileID=1857](http://www.alzheimers.org.uk/site/scripts/download.php?fileID=1857)

Bettancourt JR (2006) Cultural competence and medical education: many names, many perspectives, one goal. *Academic Medicine* 81: 499-501.

Daker-Whit G, Beattie AM, Gilliard J, Means R (2002) Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. *Aging & Mental Health*, 6 (2): 101-108.

Department of Health (2009). *The clinical and health economic care for early diagnosis and intervention services in dementia*. London, Department of Health.

Department of Health (2012). *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015. A report on progress*. London, Department of Health.

Moriarty J, Sharif N, Robinson J (2011) *Black and minority ethnic people with dementia and their access to support and services. Research briefing*. London, Social Care Institute for Excellence.

Seabrooke V, Milne A (2003) Developing dementia services for an Asian Community. *Nursing and Residential Care* 5 (5): 240-242.

Social Services Inspectorate (1998) *They look after their own,*

*don't they? Inspection of community care services for black and ethnic minority older people*. London, Social Services Inspectorate.

## ADDRESS FOR CORRESPONDENCE

Mary Dawood, Consultant Nurse, Emergency Directorate, Imperial College NHS Trust, London, UK, email: [mary.dawood@imperial.nhs.uk](mailto:mary.dawood@imperial.nhs.uk)