Promoting mental wellbeing for older people from diverse ethnic backgrounds suffering from dementia

Professor Rachel Tribe & Dr Pauline Lane

Professor Rachel Tribe School of Psychology, University of East London

Dr Pauline Lane Faculty of Health, Social Care and Education, Anglia Ruskin University and South Essex Partnership University NHS Foundation Trust

Introduction-Facts and figures

We live in a diverse and multicultural society and increasingly, residential care services will be working with elders from a wide variety of cultural backgrounds. 8.2% of all Black and Minority Ethnic (BME) people are classified as elderly, this translates to approximately 500,000 BME elders resident in the UK based on the 2001 census data (PRIAE, 2009).   While many elders will enjoy their later life in good health, Shah (2008) notes that depression and dementia are common disorders in older age. Indeed it has been estimated that some 29 million people are living with dementia and global population ageing will inevitably result in huge increases in the number of cases of dementia (World Health Organisation 2010).   Research now suggests that Eastern and Southern Asia will see dementia growth rates more than double in the next twenty years and Latin America, North Africa and the Middle East can expect to see a rise of over one hundred percent (Alzheimer disease International cited in WHO Bulletin 2011). The term dementia is used to describe a group of disorders in which memory and thought processes (cognition) are affected. The condition can be caused by a number of underlying disorders, including Alzheimer's disease, and vascular disease. While the early onset of dementia is known, the prevalence generally increases with age. It has been estimated that there are currently about 11,000 people from Black and minority ethnic(BME) groups living with dementia in the UK and that 6.1% of these people have experienced an early onset of the condition (Alzheimer's Society website,2011). There is also evidence to suggest that people from some ethnic groups are experiencing higher rates of vascular dementia, for example people with African- Caribbean and Asian heritage (Adelman 2010; Livingston 2001).

Shah (2008) also raises concerns about the lack of appropriate services for BME elders and their relative lack of referral to older-adult psychiatry and specialist services. He suggests possible barriers to pathways into care for BME elders suffering from dementia may be one of the reasons for this. It may be useful to know that the term 'dementia' does not exist in every language (Bowes & Wilkinson, 2002) and not all cultures will view dementia as a disease (Downs 2000). In some cultures, cognitive impairment may be regarded as a natural and inevitable consequence of ageing (Lindesay, 1998) and therefore it may take families some time to seek help. Additionally, many cultures have a stigma attached to 'mental health issues' and family members may feel embarrassed to talk about the loss of mental capacity (Moriarty et al 2011). However, care professionals can help by providing information and talking openly about the dementia and engaging the elder and their family in helping to plan care. A Royal College of Psychiatrists report (2009) states that the Department of Heath should be funding research into screening and diagnostic instruments for dementia in the BME community to ensure that these are readily available. If BME elders with dementia are not finding the services they require this is a serious issue of concern which needs addressing.

Cultural Diversity

As care professionals, it is useful to extend our knowledge of other cultures, as well as reflecting on how our own culture might impact on the care that we give. While it is true to say that we all come from different cultural backgrounds, we often perceive our own cultural background as the norm and assume that this is generalisable, when it is not . Therefore, it is useful to understand what is 'normal' for the residents in your care, as this may well diverge from your own ideas and experiences. When we are working from elders from backgrounds different to our own it is important to recognise not only diversity within different groups but also to recognise the difference between individuals from the same ethnic group. For example, people may originate from the same country but they may have different cultural backgrounds, different religions, speak very different dialects and will often have had very different familial and educational experiences and consequently they will have very different needs. No country has a unitary culture.

Acknowledging cultural needs during admission.

Obviously, one of the best times to develop an understanding of the cultural needs of an elder is during the admissions procedure. This will offer an opportunity to talk to the elder and their family and to find out about their cultural/ personal beliefs and needs. For many people from Black and minority ethnic (BME) communities, areas such as

personal cleanliness (and rituals or taboos attached to this), as well as diet may be particularly important. It is also helpful to ask the elder and their family about their spiritual beliefs and practices, as some people will feel that their religion plays an important role in maintaining health as well as in their healing.

When developing a care plan it is useful to know that in some cultures it may not be deemed appropriate to talk to 'a stranger' about personal issues. So it is useful to allow plenty of time for the process and to explain what a care plan is all about. It is also useful to be aware that different families may have different expectations of their elders. For example, most care homes will encourage their residents to be as independent as possible, but independence itself is a very Western concept, and in some cultures, elders would be expected to be cared-for their old age. In addition different cultures may take different positions around gender, and women from some cultures may be offended by male carers . A notion of what constitutes good mental health also varies across cultures (MacLachlan, 2008).

Culture and Language

Clearly one of the biggest external markers of culture is language and understandably, life can be very isolated if no-one in the care home speaks your language. The authors heard of a Chinese elderly man living in a residential home where everyone thought he was deaf. Over a period of time he became increasingly withdrawn. Eventually the gentleman would not leave his room. Fortunately, the care home manager called in an interpreter and it turned out that the man was not deaf but he did not speak English. While his daughter spoke English, she forgot to mention that her father did not.   Ideally, in residential homes, all of the staff would speak the same languages as the elders in their care. However, often this is not possible, so it is good to employ at least some staff that speak the same languages as the residents.

However, when addressing significant issues (such as an elder being taken ill, a change to their medication, a change in the room/ routine etc) it is very important to employ a professional interpreter. It is also helpful if all of the staff can learn a few words of the different languages spoken by residents, as this will help to make the residents feel

more at home. Communication for simple things like 'come and have your medication' or 'it is time for a meal' can be improved by having phrases in ethnic languages written phonetically in English for staff to use.   Whilst, research suggests that the ability to maintain fluency in more than one language often decreases with advancing age (Paradis, 2008) and bilingual elders with Alzheimer's may have problems selecting the appropriate language. They may also find it difficult to switch between languages and they may use the wrong language in the wrong setting (Friedland & Miller, 1999). Therefore language and communication in residential care can be seen as one of the foundations stones to help you provide cultural sensitive care to elders.

Supporting BME elders living with Dementia

The term dementia is used to describe a group of disorders in which memory and thought processes (cognition) are affected. The condition can be caused by a number of underlying disorders, including Alzheimer's disease, and vascular disease. Over time, an individual may forget their name, the identity of family members.   They may also develop apraxia (a disorder of the brain and nervous system in which a person is unable to perform tasks or movements when asked) and agnosia (a loss of ability to recognize objects, persons, sounds, shapes, or smells) can also occur. Symptoms can develop in different stages depending on the type of dementia involved, although it inevitably leads to a worsening of memory as it progresses over time and while the early onset of dementia is known, the prevalence generally increases with age. There is also evidence to suggest that people from some ethnic groups are experiencing higher rates of vascular dementia, for example people with African- Caribbean and Asian heritage (Adelman 2010).

Diagnostic and screening instruments for dementia

An assessment for dementia should take place if an individual has been displaying symptoms for six months or more.   Cognitive tests (which measure a person's ability to think , understand and remember) at the time of the testing are widely used in diagnosing dementia by clinicians. Cognitive tests will form one part of a consultation with a psychiatrist, psychologist or neurologist specially trained in working with older adults. The most commonly used assessment tools are the Mini Mental State

Examination (MMSE), the cognitive abilities screening instrument and the clock test. Any resulting scores would need to be considered by the clinician with due regard to an individual's current health status, background, language and education. Sometimes a close family member is also asked to either complete a questionnaire or to discuss matters with the elder's clinician. An MRI or CT scan may also take place to look for any organic changes.   Screening may take place at a GPs surgery in older age services or in a memory clinic.

There are a number of difficulties with the screening instruments used for the diagnosis of dementia with BME elders.   Those developed and standardised in one ethnic group may not be appropriate for use with another ethnic group (Shah, 2004; Patel & Mizra, 2000).   This means that dementia can be difficult to diagnose in BME elders and it has been suggested could lead to an under estimate of its prevalence. The reasons for this include issues of language within tests. Also the fact that tests are developed within one culture and are therefore inevitably influenced by it, also plays a role.   In addition, levels of formal education and subsequent skills in literacy and numeracy may effect results. It is interesting to note that The National Institute for Health and Clinical Excellence (NICE) guidelines relating to medication (Cholinestrerase inhibitors) for dementia were found at judicial review in 2007 to potentially discriminate against people whose first language was not English, as the assessment tool commonly used for diagnosis is not always valid across cultures or in people who are not English speakers. Instruments for BME elders are being developed in various languages, whilst this is to be commended, some have not been through a comprehensive evaluation process.

Making the environment more inclusive

While this article has focused on some of the challenges in working with BME elders, working with a multicultural community can also offer enriching and interesting opportunities. Every elder will bring with them their own life experiences as well as cultural assets. There are a number of ways to build on the cultural diversity within a care home. Suggestions might include
- Running focused activities that celebrate cultural diversity- for example, residents could choose a year, and map out what every resident was doing that year to create a collective memory board.
- Ensuring that notices, newspapers, magazines/ DVDs/ films or cable TV are available in different languages.
- Using a world map, residents , family members or staff could identify where people where born
- Signage in the home can be written in the more common ethnic languages spoken there.

- Running a resident-lead cookery classes so that people can share their favorite family food.
- Offering music, gardening and art classes as they are all activities where a shared language is not always required.
- A religious festival chart is useful in the home and it offers an opportunity to celebrate different festivals together.
- Inviting different community groups into the home to share singing, dancing etc.
- Have culturally relevant artifacts in the home
- Taking elders out to visit lunch clubs and community events so that they can meet and talk in their own language.

Bibliography

Adelman, S. (2010) Prevalence and recognition of dementia in primary care: a comparison of older African-Caribbean and white British residents of Haringey. Doctoral thesis, UCL (University College London).

Alzheimer's Research Trust (2010) Dementia 2010: The prevalence economic cost and research funding of dementia compared to other major diseases. Alzheimer's Research Trust Web site accessed 28th November 2010 http://www.dementia2010.org/reports/Dementia2010Full.pdf

Friedland & Miller (1999) D. Friedland and N. Miller, Language mixing in bilingual speakers with Alzheimer's dementia: A conversation analysis approach. *Aphasiology*, 13 . 427–444.

Lindesay, J. (1998) Diagnosis of mental illness in elderly people from ethnic minorities. *Advances in Psychiatric Treatment*, 4, 219-226

Livingston, G. & Sembhi, S. (2003) Mental health of the ageing immigrant population: *Advances in Psychiatric Treatment 9, 31-37*

MacLachlan.M. (2006) *Culture & Health* Chichester:Wiley

Moriarty, J., Sharif,N., & Robinson, J. (2011) Black and Minority ethic people with dementia and their access to support and services.
www.scie.org.uk/publications/briefing/files/briefing35.pdf

NICE (2007) *Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease*. NICE technological appraisal guidance 2 (amended). London: National Institute of Health and Clinical Excellence.

Paradis. M (2008). Bilingualism and neuropsychiatric disorders Journal of Neurolinguistics, 21,3,199-230

Patel, N. and Mirza, N. (2000) 'Care for ethnic minorities – the professionals' view', *Journal of Dementia Care*, 8, 1, 26–2.

PRIAE (2009)

Royal College of Psychiatrists report (2009) no Cr156
http://www.rcpsych.ac.uk/publications/collegereports/cr/cr156.aspx

Shah, A. (2008) Estimating the absolute numbers of cases of dementia and depression in the Black and minority ethnic elderly population in the UK*. International Journal of Migration, Health and Social Care 4,2,4-15*

Shah, A. (2004) accessible at
www.publications.parliament.uk/pa/ld200506/ldselect/ldsctech/20/20we18.htm -

Shah, A. Oommen, G. & Wuntical, B. cross-Cultural Aspects of Dementia*. Psychiatry, 7,2, 94-97*

World Health Organisation (2011) Looming dementia epidemic in Asia. *Bulletin of the World Health Organization* 89: 166–167. WHO publications

World Health Organisation (2010) The World Health Report : Health systems financing: The path to universal coverage. WHO publications

Useful websites

A link to national mapping of projects for BME elders to support their mental well-being.
www.nmhdu.org.uk/silo/files/bme-mapping-doc.pdf

NHS; Dementia
Provides Information on Introduction ; Symptoms ; Causes ; Diagnosis ; Treatment and Prevention
in Urdu, Turkish and Portuguese. http://www.nhsdirect.nhs.uk/articles/article.aspx?articleid=124

Nice guideline no 42 on dementia available at www.nice.org.uk

National dementia strategy. NHS Evidence
www.library.nhs.uk/HealthManagement/ViewResource.aspx?resID=291187&tabID=290
&catID=4031

Dementia Catalogue - Alzheimer's Society's Dementia Knowledge Centre database
http://liberty3.alzheimers.org.uk/Liberty3/gateway/gateway.exe?application=Liberty3&
displayform=frame&login=false