**Dementia in Black and Minority Ethnic Communities in Hampshire: Development of a Time to Change Campaign**

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It is predicted that by 2051 Black and Ethnic Minority (BME) groups will make up more than a third of the population of England and Wales and there will be 3.8 million older adults from BME groups (Lievesley, 2010). At present there are as many as ten thousand older adults from a BME background with dementia in England and Wales (Shah, 2008), and as the number of older adults from BME backgrounds is set to rise this will also increase rapidly. Given this it is important to note that that those from a BME background appear to be at a greater at risk of dementia. In the U.S., African Americans have been found to have nearly twice the prevalence of dementia as their white counterparts (Demirovic et al., 2003). Similarly research in the U.K. has shown a higher prevalence of dementia in those from African-Caribbean backgrounds (Adelman, 2009; Richards et al., 2000). Richards et al (2000) found that 22% of an older African Caribbean sample in London met the criteria for dementia, compared to 4% for white British, after accounting for differences in education and occupation. There is also evidence that those with dementia from this ethnic group are younger, and have higher levels of vascular dementia, possibly due to higher rates of hypertension (Adelman, 2009). Other research suggests that the prevalence of dementia is only higher in those from BME background who have poor English (McCracken et al., 1997). However, those from a BME background with dementia also appear to be more cognitively impaired (Cooper, Tandy, Balamurali, & Livingston, 2010).

Despite possibly being at a greater risk of dementia, there is considerable evidence for a lack of awareness in BME communities in the U.K. (Azam, 2007; Seabrooke & Milne, 2004). Many BME carers report having not heard about dementia before the person they care for was diagnosed, and many still not know the appropriate diagnostic term (Adamson et al., 2001). Indeed there is no word for dementia in Asian languages (Azam, 2007; Seabrooke & Milne, 2004), and many Asian service users with dementia do not see terms such as dementia or Alzheimer’s as applying to them (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011). Those from Asian backgrounds often see dementia as a part of normal ageing (Seabrooke & Milne, 2004; Turner, Christie, & Haworth, 2005), and few see it as an organic disease (Seabrooke & Milne, 2004). There is a lack of knowledge about symptoms, with less awareness that personality and speech can be affected (Purandare, Luthra, Swarbrick, & Burns, 2007), and those from BME background are less likely to see dementia as treatable (Seabrooke & Milne, 2004; Turner, et al., 2005). In addition there are high levels of social stigma around the illness in Asian communities (Azam, 2007; Seabrooke & Milne, 2004), with some seeing dementia as due to a lack of family care (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007) or related to religion (MacKenzie & Coates, 2003). Similarly eastern European carers feel stigmatised and see dementia as ‘insanity’ and often attribute memory problems to physical health incidents such as falls (MacKenzie & Coates, 2003). Other research suggests those from BME communities sometimes blame the patient for their symptoms (Adamson, 2001; La Fontaine, et al., 2007), and those from Asian communities may fear dementia in the family damaging their prospects of arranged marriage (Mackenzie, 2006).

Perhaps as a result of this lack of awareness and stigma, research suggests that those from BME backgrounds do not know where to get help (Bowes & Wilkinson, 2003; La Fontaine, et al., 2007). In addition language problems, stigma and concerns about confidentiality are seen as barriers to accessing services (Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009; Seabrooke & Milne, 2004). A systematic review of evidence mainly from the U.S. suggests that those from BME backgrounds access services later when their dementia is more severe (Cooper et al., 2010). In the UK research suggests that many from Asian communities often try to hide problems (MacKenzie & Coates, 2003), and only come to the attention of services when symptoms are severe (Seabrooke & Milne, 2004), or when people comment or carers can no longer cope (Mukadam, Cooper, Basit, & Livingston, 2011). This means that it is harder for preventive interventions to be employed (Seabrooke & Milne, 2004).

Thus there is of a lack of awareness about dementia in BME communities, and such a lack of awareness appears to prevent help seeking and may account for the under representation of BME groups in dementia services (Moriarty, Sharif, & Robinson, 2011; Seabrooke & Milne, 2004). There is evidence that increasing knowledge about dementia in these communities and helping them see it as an illness helps facilitate access to services (Mukadam, Cooper, & Livingston, 2011; Seabrooke & Milne, 2009). Providing information and education for BME communities is therefore indicated (Moriarty, et al., 2011; Seabrooke & Milne, 2003).

The Time to Change campaign (www.time-to-change.org.uk/) is a national campaign launched in October 2007 which aims to reduce stigma against mental health problems. This has tried to tackle discrimination in a number of different ways such as high profile media campaign with the help of celebrities such as Stephen Fry, community events, training for health professionals, and resources for employers. This campaign has reached 34 million people in England so far, and has been shown to improve public attitudes and reduce discrimination. An overview of campaign is provided by Henderson and Thornicroft (2009). Recently Time to Change has tried to target attitudes towards mental health problems in the South Asian community, after research showed specific problems in this community, such as causes being misunderstood, shame and secrecy, and fear of marriage prospects being damaged. Leaflets have been made available in Tamil and Gujarati, and a campaign was launched this summer in Harrrow for the South Asian community. A local Time to Change Campaign has also been running in Hampshire with various events to improve awareness including a stand at an Asian festival.

In Older Peoples Mental Health services in Hampshire, psychologists are currently working with the local Time to Change Campaign Manager and other staff to extend this anti-stigma campaign to target older adults. This will focus predominantly on attitudes towards dementia. We will link this with a campaign shortly to be launched with the South Asian community (this is the largest BME population in Hampshire, Hampshire County Council, 2009). Given the research described above, we believe it is especially important to tackle stigma and attitudes towards dementia in order to increase the number of ethnic minority older adults seeking help for memory difficulties.

We hope to achieve this in a number of ways using similar methods to previous local and national campaigns. Current ideas are:

1. Develop a leaflet on dementia for South Asian elders specifically. This will take a similar format to leaflets used on the national campaign and translations will be available. This will include a quote from a community elder about stigma in the Asian community, as well as information about dementia and available services.

2. Display a billboard at the local acute hospital. This is a work in progress, but is likely to contain a myth fact statement as has been done in the national campaign: Myth: Dementia is a normal part of ageing. Fact: Dementia is a disease of the brain. A focus group with a community mental health team for older adults has been conducted to develop additional ideas for anti-stigma for posters.

3. Liaise with local community elders, organisations such as the Asian elders’ network, and religious leaders to help distribute leaflets and information.

4. Measure attitudes before and after the campaign in a sample from the BME community.

5. Work with shopkeepers to tackle stigma: service users and carers reported finding it frustrating as some do not understand dementia and sometimes ban service users from shops. It was suggested at a local user carer meeting to develop stickers for shops to put in their window to show that they are ‘dementia friendly’.

6. Combine this work with a DVD which has been developed for the trust for those with early stages of dementia attending a ‘Memory Matters’ course. This includes a section by an Asian community elder on stigma.

7. Put descriptions of these activities on the trust website, and discuss at trust events.

This project in the early stages of development at present, and how many of these aims will be achieved is unclear. However we believe that this campaign is important given that BME communities appear to be especially stigmatised towards dementia. Given the increasing number of older adults from a BME background, tackling attitudes towards dementia is essential so that help is accessed as early as possible.

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