

Raising awareness about Vascular Dementia in the African-Caribbean community in London

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London, the UK capital is home to 58% of all those who identified themselves as African-Caribbean in the UK 2011 National Census. Demographically due to the age profile, the UK African-Caribbean population has the highest proportion of older people than any other Black populations in the Census categories as result of the history of the migration of African-Caribbean peoples into the UK. This saw a significant increase in migration of working age adults in the period from 1940 to 1960, encouraged by the UK government in World War II and the post war UK economic policy. Many of these expected to return to the Caribbean on retirement. At that time, the average life span in the Caribbean was 51.5 years . Subsequently the increasing life expectancy has risen to 74 in the Caribbean and 81 in the UK today. People have put down family roots in the UK and also the poor experience of many pensioner retirees and concerns about the limitations of older peoples services in the Caribbean have led to a high proportion of the African-Caribbean community spending their last years in the UK.

However, the UK African- Caribbean community has a proportionally higher rate of dementia than the White UK majority and a higher proportion of people under 65 developing young onset dementia. A number of researchers have speculated that this may be due to the increased risk factors of diabetes and high blood pressure in the African-Caribbean community creating a higher risk of stroke related vascular dementia , but supporting research for this hypothesis is limited and it would be more accurate to say the causal factors are unknown.

There are strong cultural factors within the African-Caribbean community, combined with the social historical experience of racism that can create a complex dynamic of resistance to seeking diagnosis and treatment for dementia, particularly for men. Denial of problems and a refusal to seek help or diagnosis can often lead to a major crisis before there is any engagement with professional support services and frustrate efforts to develop ongoing support links with services. This can be further complicated by clinicians who assume that in minority ethnic communities ‘ families look after their own’ when family carriers may be overwhelmed by other competing caring obligations, have no understanding of the complexity of the care needs of the person living with dementia and little appreciation of how long they may be living with the illness . Culture Dementia UK and the Dementia Alliance for Culture and Ethnicity, both voluntary organizations, have been working on dementia awareness raising and providing support for the African-Caribbean community in London for several years. Some of the consistent themes that we find emerging from the community awareness work are:

- The view that nothing can be done because dementia is an inevitable part of getting old
- The common belief that African-Caribbean people do not get dementia or if they do, they must be in some way at fault

- The fear that services are like to be racially discriminating and don't understand Caribbean culture
- The recognition that people have been fiercely independent all their lives and don't want others ‘fussing over them’ because they need help
- The concern about being ‘left out’ of community life

We have developed information and resources for working with these communities available at <https://www.culture dementiauk.org/> and <https://www.demace.com/>We feel it is important to have a sensitivity to the African-Caribbean cultural narrative of independence and resilience when encouraging help-seeking in dementia and encouraging people to look for support’ Is also important to recognize that while stigma plays an significant role in reducing help-seeking behavior it is only a component of a more complex dynamic interplay of factors that includes cultural stereotyping by professional staff.

The approach we have taken to raising awareness has involved a variety of methods intended to create a wider community dialogue about dementia, ensuring the community is more informed about dementia where conversations about the illness are normalized rather than treated as a taboo subject. In doing this we feel it important to talk to the whole community, not only older people and carriers, as dementia has an impact on the whole family and its social circle.

This approach has included:

- Interviews and information slots on community and local radio, community TV, BBC regional TV, BBC's Victoria Derbyshire Show and Channel 4 News
- Contributing to the design and script development of a dementia information film Finding Patience on dementia in the African-Caribbean community commissioned by Health Education England
- Developing the websites of Culture Dementia UK and the Dementia Alliance for Culture and Ethnicity and distributing information via their social media feeds
- Organizing local dementia conferences for diverse communities that bring together people living with dementia and their careers into a shared social learning space with dementia professionals
- Presentations to schools and colleges on dementia – in 2012 over 80% of inner London pupils were from a minority ethnic background
- Presentations to church community groups

We have encouraged from an African-Caribbean community people living with dementia and their family carriers to find their own voice and speak from their own experience in these events. All those working with Culture Dementia UK are of African-Caribbean heritage with family

experience of living with dementia. We have also encouraged people from the community living with dementia and their carers to find the confidence to speak of their experience as contributors or co-authors of newspaper articles, dementia journal articles and books on dementia.

References:

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