

Raising awareness about vascular dementia in the African-Caribbean community in the London

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Introduction:

In 2013 the UK All Parliamentary Group on Dementia published a report on the impact of dementia in the UK's Black, Asian and minority ethnic communities that highlighted a number of issues faced by these communities that create barriers to early diagnosis in dementia and receiving appropriate care and support for both those living with dementia and their family carers. In the same year a report commissioned by the Race Equality Foundation reviewed current research on dementia in Black, Asian and minority ethnic communities in the UK and identified three key populations with higher risk factors for dementia than any others; the Irish, the South Asian Indian and the African-Caribbean. These higher risks arise partly through the age structure of these populations and partly as a result of lifetime higher levels of health risk for cardio-vascular disease in these populations. The higher risk of cardio vascular illness and its contribution to increased incidence of stroke is thought to be the main driver for the increased risk vascular dementia in these populations

It is often thought that generally migrant populations are younger on average than the host country but this assumption does not take into account the significant age structure differences between settled and new migrant populations. Settled migrant communities are established initially mainly by working age adults and patterns of migration may involve the original population of adult migrant numbers tapering after an initial surge either prompted the push of local events in the country of origin or the pull from economic opportunities in the host country.

Objective:

Risk Factors for Dementia in the African Caribbean Community

While the increased incidence of dementia has been noted for some time it is only more recently that studies have been completed at scale involving this population. Much of the dementia risk is due to the health risks associated with increased rates of cardiovascular disease within this community and the risk of vascular dementia as a consequence of the increased susceptibility to stroke. Younger onset vascular dementia is also more prevalent in the African-Caribbean community. The African-Caribbean population has a high incidence of Type II diabetes which is increasingly seen as a risk factor for development of Alzheimer's disease. The International Organization for Migration has indicated that there are life times greater risks of poor health for all migrant communities, which increases the likelihood that as members of migrant communities approach later life they will have multiple long-term health issues providing a further potential complication for those developing dementia in later life

There is considerable stigma in African-Caribbean communities regarding dementia, which plays a role in making African-Caribbean families reluctant to discuss or seek help for family members who it is feared may be developing dementia. However stigma alone is not the only reason for reluctance to access dementia services. As dementia services are located within psychiatric services discrimination and aversive treatment from mental health services within the African-Caribbean community. More broadly African-Caribbean communities anticipate a lack of influence on the provision of services. A recent issue that has been highlighted through the support work done by

Culture Dementia UK is the role that personal pride plays in refusing to seek help, particularly for men. Service professionals often have stereotyped views about African-Caribbean communities assuming community members will automatically 'look after their own' family members living with dementia and are supported in this by their community.

Initially starting out in 1998 as small local group of volunteers known as Friends of African/Caribbean Carers and Sufferers of Dementia (FACCSD) grew out of the founders experience with dementia in her own Jamaican family in the UK. The charity subsequently changed its name to Culture Dementia UK www.culturedementiauk.org and has grown to a national organisation that reaches across to many different ethnic communities and partnerships with a variety of other voluntary and public sector organisations.

Mainly through its own network contacts and partnership work it has developed a number of approaches to raising awareness about dementia in the African-Caribbean community and also a rich emotional and psychological understanding of the attitude of African-Caribbean people to dementia that adds depth to an appreciation of the obstacles to accessing information and support.

It has focused its approach to raising awareness about dementia through avenues that are familiar for the African Caribbean community and also reflect the growing use of approaches such as social media by the generation of African-Caribbean now increasingly likely to be carers for their parents who less technologically literate.

Conclusion:

There is increasing evidence that the UK African-Caribbean community at higher risk from Alzheimer's disease, vascular dementia community at higher risk from Alzheimer's disease, vascular dementia and early onset dementia than the indigenous White UK

community. This high risk is thought to be associated with lifetime health risk for this community associated with the higher prevalence of coronary heart disease and Type II diabetes. Prevention and information strategies need to be targeted at these communities to reduce health risk and encourage earlier contact with diagnostic services.

There are many barriers to engagement by members of this community with dementia services and support for carers. These include lack of information, cultural stigma, professional stereotyping of cultural caring practices, fear of discrimination from services and a cultural emphasis on personal independence. Raising awareness should include a multi-channel approach that includes traditional interpersonal information sharing and more modern social media dissemination of information since the effective audience of people living with dementia and their carers will be multi-generational and globalised. Raising awareness should take account of deeply embedded cultural forms of information transmission such as storytelling to maximise both the reach and the impact of health information messages.

Biography:

David Truswell has worked in community based mental health services in the UK for over thirty years developing services for people with complex care needs and enduring mental health problems in a career spanning the voluntary sector, local authority services, and the NHS. From 2009 - 2011 he was the Dementia Implementation Lead for Commissioning Support for London, working with commissioners across London to improve dementia services. He is the founder and Director of the Dementia Alliance for Culture and Ethnicity (www.demace.com) and an independent writer and researcher on dementia support and services for Black and minority ethnic communities, working with a number of projects and initiatives.