

Early Stage Work with Raising Awareness about Vascular Dementia in the African-Caribbean Community in London

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Abstract

The impact of dementia on the UK's Black, Asian and minority ethnic communities has been identified at the highest levels of dementia policy making in the UK but this has yet to translate in to changes in how services are developed in local areas. The African-Caribbean population in the UK is demographically the oldest of the 'Black' categories in the UK census. This population has known higher risk of developing vascular dementia and early onset dementia. The raised incidence of Type II in this population also suggests it could have higher risk for Alzheimer's disease. Community organisations will need to be proactive in insisting on more attention being paid to the specific service needs of this and other minority ethnic communities. Culture Dementia UK is a community organisation showing how community groups can provide benefits in disseminating information and developing appropriate services that cannot be achieved by mainstream services alone. Building on these initiatives is an important next step that needs supporting by mainstream research.

Dementia and UK Migrant Communities

In 2013 the UK All Parliamentary Group on Dementia published a report [1] 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 [2] 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 [3-5]. 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 [6].

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.

Decisions about dementia health care provision in the UK often fail to take account of the needs of Black, Asian and minority ethnic communities because of the assumption that migrant communities generally are a younger age demographic but when the differential age structure of different communities is taken into account the African-Caribbean community is demographically the oldest of all the UK communities identified as 'Black' in the UK census (Figure 1). Dispersal of migrant communities within the host country is also very variable but historic pattern of the African Caribbean migration into the UK has been primarily around settlement in the urban areas, particularly in London [7].

The UK Census in 2011 showed London is home to 58% of the UK's African Caribbean population. Using the estimates for the proportion of people living with dementia by the Alzheimer's Society, if the incidence of dementia in the African-Caribbean population was the same as that of the white majority population that one would expect

to see over 3,000 people of Africa-Caribbean origin over 65 in London living with dementia. However there is increasing evidence that there is a higher risk of both vascular dementia and early onset dementia in the African-Caribbean community [8-10].

An issue that UK health service decision makers must address is the lack of access to appropriate services and the lack of available detail in local population data that would highlight the age structure differences between Black, Asian and minority ethnic communities to illustrate the age related risks for some communities. Public health decision makers should recognise the need for an approach to prevention that includes targeted support to African-Caribbean communities which tackles the stigma that exists within these communities in relation to dementia [11]. This information should both encourage the healthy lifestyle benefits that reduce the risk of stroke and associated risk of vascular dementia and also encourage earlier access to diagnostic services through local primary care services.

Despite recommendations [12] that have been available in the UK since the early days of the first UK National Dementia Strategy [13] in 2009 there has been little uptake in the use of third sector community organisations by the health service commissioners who are the key decision makers in deciding how financial resources are allocated in purchasing dementia services. However third sector community organisations often have substantial knowledge and active involvement with minority communities and hold a deep understanding of stigmatised health conditions, community member's fears of discrimination in health services and can provide an accessible route to sustained support networks. Mobilising the experience and resilience of community organisations is increasingly recognised as an important

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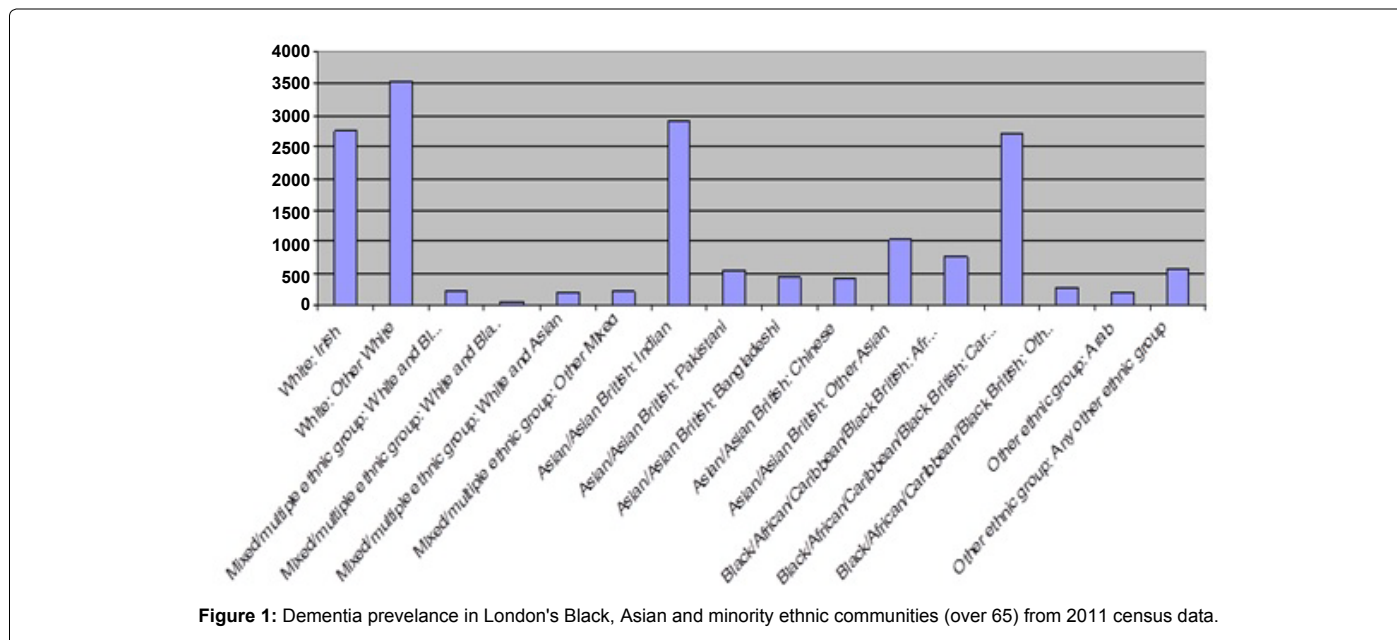


Figure 1: Dementia prevalence in London's Black, Asian and minority ethnic communities (over 65) from 2011 census data.

avenue to more general confidence building and civic participation for migrant groups [14].

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 [15]. 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 [16] which is increasingly seen as a risk factor for development of Alzheimer's disease [17]. The International Organization for Migration has indicated that there are life time 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

Culture Dementia UK - Developing a Role for a Community Group in Disseminating Information within the African Caribbean Community and Enabling Partnership Working

There is considerable stigma in African-Caribbean communities regarding dementia [18,19], 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 for older people it should be recognised there is a longstanding fear of discrimination and aversive treatment from mental health services within the African-Caribbean community [20,21]. More broadly African-Caribbean communities anticipate a lack of influence on the provision of services [22]. 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 (Ronald Amanze, stroke survivor living with mixed dementia, personal communication). 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 [23].

The work of Culture Dementia UK [24] provides some examples of how a community organisation can have an important impact on raising awareness about dementia for the African-Caribbean community and also how the dementia professional community can engage with this community through partnership work with community groups.

Initially starting out in 1998 as a 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.culture dementiauk.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 are less technologically literate.

In the last few years raising awareness initiatives it has developed have included:

- Community radio broadcasts-this has included short information slots on local radio stations as part of wider health

information inserts, e.g. Colorful Radio, BBC local radio channels

- Local conferences supported by local services. Culture Dementia UK has organised local conferences in the London Borough of Brent and in Luton supported by both community partners to reach beyond the African-Caribbean community (e.g. Irish in Britain) and include local services (e.g. GP, police)
- Culture Dementia UK has supported African-Caribbean people living with dementia or those supporting people living with dementia in speaking out to other members of the African-Caribbean community as well as to the wider local community
- Working with churches, Culture Dementia UK has worked on developing information sessions for local congregations and providing contact information in local churches
- Local churches have also provide an important contact point for fundraising events aimed at the African-Caribbean community, which also offer a platform for social gathering and celebration that can include dementia awareness raising in the community
- Through presentations to Supplementary School teachers and parents, Culture Dementia UK have reached out to an audience that is in London a very significant and influential one for the African-Caribbean community
- Through engagement with mainstream dementia conferences Culture Dementia UK seeks to raise the profile of ethnic minority issues in the dementia mainstream and challenge professionals stereotypes
- Culture Dementia UK worked with a local secondary school in raising awareness about dementia as part the schools civics class project
- Involvement with NHS Trust community engagement events, e.g. presentation at Black History Month event by Oxleas Foundation Trust
- More recently Culture Dementia UK has been focusing on video and TV as an information medium. Culture Dementia UK was interviewed about dementia in the African-Caribbean community for an hour live by AHLEBAIT TV Networks Ltd., a cable TV channel aimed at the international Muslim community. The organisation has also provided detailed script advice to Public Health England on 'Finding Patience' a public health information film on the impact of dementia on an African-Caribbean Health Education England

While recognising the value of mainstream initiatives such as the Public Health England 'Finding Patience' film clip, Culture Dementia UK favour a multi-channel approach incorporating social media, mainstream outlets and personal presentations at community events with the aim of 'stirring up the conversation about dementia in the African-Caribbean community'. As the culture of the African-Caribbean community has a strong history of oral story telling as a medium of information exchange. Culture Dementia UK feels strongly that stories about living with dementia need to be included in the everyday conversational storytelling of the African-Caribbean community.

Culture Dementia UK also provides a 24 h help and advice line that people living with dementia or their family carers can call. This

offer is an important supplement to the personal presentations and radio presentations as this allows people who may need time to reflect on the information they have received be given an opportunity to follow-up their inquiries after reflection. In the London Borough of Brent Culture Dementia works in a partnership with the local memory services providing additional advice and support if needed to African-Caribbean families during the assessment process and after a dementia diagnosis. In Brent Culture Dementia UK is also part of a multiagency partnership Brent Community Action on Dementia working to develop a dementia-friendly Brent. Brent is one of the most diverse populations of any local authority in the UK

Changing the Experience of the Care Service Process for the African-Caribbean Community

For many African-Caribbean families the process of living with dementia follows the pattern illustrated in Figure 2.

This illustrates how the person living with dementia and their carer's lives in increasing isolation from the local community until either the person living with dementia or their carer has a health crisis. Often this has been going on for so long that by the time of the crisis the carer may be on the point of ceasing to be able to continue to care or the person living with dementia may no longer be able to manage with home based support.

Culture Dementia UK promote the idea of a whole systems improvement to the dementia care pathway for the African-Caribbean community (Figure 3) and advocate that a similar approach to whole systems improvement would also benefit all other minority ethnic communities.

Conclusion

There is increasing evidence that the UK African-Caribbean 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.

Beyond the usual truism that more research needs to be done on dementia as a major and growing health for the African-Caribbean population, this research needs to be framed around much better clarity about the benefit to improving care and support and how these benefits may be delivered. The work of Culture Dementia UK indicates that community organisations can participate in a much more sophisticated way, both in design of the research parameters and carrying out the research programme. The skill, expertise and knowledge of the target

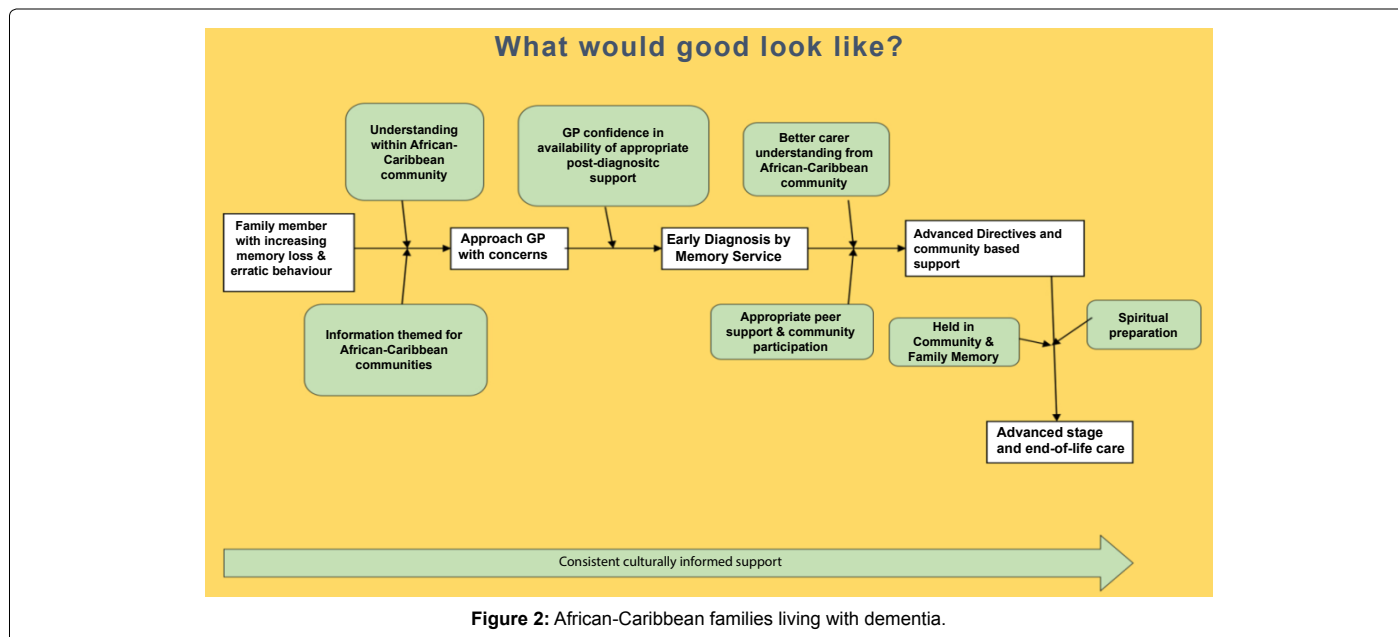


Figure 2: African-Caribbean families living with dementia.

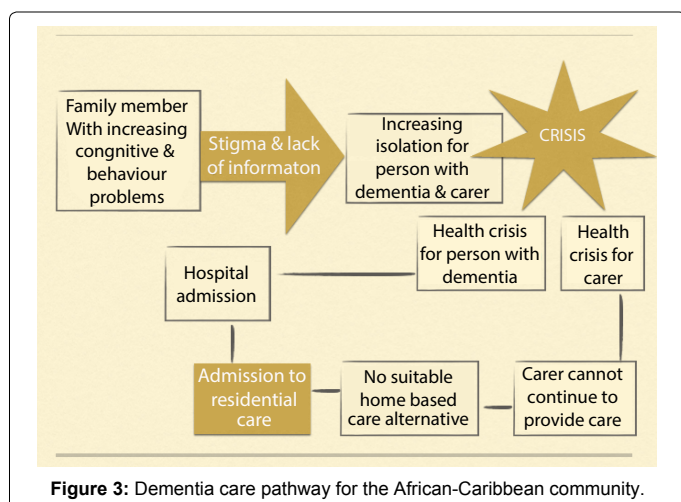


Figure 3: Dementia care pathway for the African-Caribbean community.

community that is held by community groups needs greater investment for them to be able to effectively deliver health information messages and also direct support services. There needs to be a better developed understanding and use of personal testimony as an influence for reflection and behaviour change in a culture that is highly invested in storytelling as medium for education and promoting reflection.

Through the whole of the dementia pathway for African-Caribbean people the barriers highlighted will have variable prominence at different stages. While there is a value in improving professional staff's cultural competence at all stages of the pathway a more nuanced enabling framework also needs to be found that brings into focus the potential resources of the whole community in supporting the person living with dementia and their family carers. This enabling framework could also provide a useful systemic approach for working with the experience of dementia for other migrant communities.

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