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Review Article

Wake Up London! - The Case for a London Regional Investment Strategy to Develop Appropriate Information and Services for Black, Asian and Minority Ethnic Dementia Living with Dementia

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Introduction

Despite commitments to develop the funding streams, resources and quality of research into the support and services for the growing number of people in the UK with dementia, there is a lack of sustained focus on the challenges this presents for UK black, Asian and minority ethnic communities [1]. Although the need for this focus has been highlighted in policy guidance [2] there continues to be very limited practical attention paid to those issues many of black, Asian and minority ethnic communities face [3,4] in living with dementia. Black and minority ethnic communities in the UK are geographically dispersed but the number of people living with dementia from the more settled migrant communities living in UK cities is likely to be higher than previous estimates, reflected in projections that by 2051 those ethnic groups with the highest proportions of people aged 50 and over will include 'Other White', Chinese, 'Other Asian', Indian and White Irish [5]. This presents a profound health equity and health economic challenge for the capital in 21st Century. London with its cosmopolitan elder population faces a huge impact from these challenges, but lacks a capital wide model for supporting living well with dementia for people from black, Asian and minority ethnic communities. In the absence of such a model the task of understanding and support will fall primarily on the shoulders of individuals, the vanishing underfunded black voluntary sector and spiritual resources such as local churches, mosques, temples, synagogues and gurdwaras.

The most recent update on the Prime Minister's Challenge on Dementia [6] drew attention to the implications of living with dementia for black, Asian and minority ethnic communities in London. It called for prioritizing the development of more appropriate diagnostic measures for people from black, Asian and minority ethnic communities living with dementia and promoted the work being done by both the Alzheimer's Society and Jewish Care to respond to the needs of the black, Asian and minority ethnic population.

London's longstanding diversity provides an opportunity to respond to the challenges presented by dementia for its substantial and diverse ethnic communities by developing a model for a dementia friendly capital that reflects its history as a city shaped by the dynamic impact of migration. The capital should be bold enough to mobilize its resources at a scale to do this beyond the traditional incremental approach to taken on health issues affecting black, Asian and minority communities. This should be a vision large enough to create a model capital city for living well with dementia for its cosmopolitan mix of black, Asian and minority ethnic communities. Its increasingly diverse population demographic should expect nothing less than this from its leaders across the politic spectrum.

A look at the Evidence

When the World Health Organization (WHO) recognized dementia as a worldwide public health priority in its 2012 report [7] it called on all governments to develop national dementia policies. The WHO report cited the UK's 2009 "Living well with dementia: A National Dementia Strategy" as one of the few instances at that time of a formalized national plan [8]. UK policy guidance has been unequivocal on the importance of responding to the particular needs of black, Asian and minority ethnic communities in the implementation of the dementia strategy [9].

However, in July 2013 when the All Party Parliamentary Group (APPG) published a report Dementia does not discriminate [10] it highlighted the continuing stigma and lack of access to appropriate services for people living with dementia in black, Asian and minority ethnic communities. 2011 census information analyzed by age and ethnicity has been publicly available since July 2013 [11] and there is a growing body of research information on the higher incidence of dementia in some black, Asian and minority populations [12-14]

Lievesley (2013) [15] in his report based on the 2011 Census data estimated that there were about 25,000 people from black, Asian and minority ethnic communities living with dementia in the UK and pointed out that 58% of the black, Asian and minority ethnic population of England live in London. This would mean that in 2011, 14,500 people in London from black, Asian and minority communities were living with dementia.

In 2009 Commissioning Support for London (CSL) produced a needs assessment based on 2001 census data to support planning of dementia services in the capital which estimated that there would be 16,846 people from black, Asian and minority ethnic communities living with late onset dementia by 2021 [16]. The more recent work of Lievesley suggests this number may well need to be revised upwards substantially. An Office of National Statistics report in 2012 states “London had the greatest changes across the majority of the ethnic groups between the 2001 and 2011 Censuses” [17].

CSL’s 2009-2011 implementation programme for the National Dementia Strategy in London examined some of the issues of concern for black, Asian and minority ethnic communities [18]. Further detailed recommendations on how living well with dementia for London’s black and minority ethnic communities could be achieved were outlined in a 2011 report by the Institute of Public Policy Research [19] who pointed out that ‘by 2031 ethnic minorities are expected to make up around a quarter of the over-80 population in London, compared to just 12 per cent in 2011’ (p7).

A report for the Race Equality Foundation [20] drawing on data from the UK national Census 2011 data identified the case for considering at least three ethnic communities, the African – Caribbean, South East Asian Indian and Irish populations for targeted information and support on living with dementia due to the age profile, health profile and migration history of these populations and the largely unrecognized scale of dementia prevalence in these communities.

A simple inspection of current published (Joint Strategic Needs Assessments) JSNAs for the capital shows no evidence of any the segmenting of dementia prevalence projections into the major ethnic groups that could be used to coordinate effectively targeted commissioning of information and support services. JSNAs are key strategic documents for London Boroughs in identifying local population level health needs for commissioning services

For London, an estimate of the prevalence of late onset dementia (over 65) in these ethnic communities is illustrated in (Figure.1) using prevalence rates for the total population identified by the Alzheimer Society (Table 1) (Alzheimer Society, undated) and population figures from the 2011 Census (Office of National Statistics, 2013).

	2011 Census Category		
	Black/African/ Caribbean/Black British: Caribbean	**White: Irish**	**Asian/Asian British: Indian**
UK Total Population	5,94,825	5,31,087	14,12,958
London Total Population	3,44,597	1,75,974	5,42,857
London as % of UK Total Population	57.93%	33.13%	38.42%
UK Dementia Prevalence Estimate	4,963	10,170	6,136
London Dementia Prevalence Estimate	2,717	2,750	2,900
London as % of UK Prevalence Estimate	54.74%	27.04%	47.27%

Figure 1

Age	% prevalence all dementias
65-69	1 in 100
70-79	1 in 25
80+	1 in 6

Table 1: Estimated prevalence for all dementias by age cohort (adapted from Alzheimer’s Society)

Major charities in the capital such as Dementia UK and the Alzheimer's Society are increasingly emphasizing the problem of late presentation to diagnostic services of people from black, Asian and minority ethnic communities living with dementia. Many of the benefits of improving the opportunity for planned support for living well with dementia, such as advanced directives and the settling of personal estate and financial affairs are lost when people do not find their way to support services until a stage in their illness when they have significantly lost many of their former capacities.

The prevalence for dementia estimated in Table1 could be even higher due to the prevalence of high rates of cardiovascular illnesses in the African-Caribbean and Indian populations and therefore the increased risk for these communities of stroke and its potential sequel, vascular dementia. Out of all the black ethnic communities identified in the UK Census categories the African - Caribbean population is the demographically oldest black population and has raised risk of dementia [21,22] and a higher incidence of early onset dementia that any other ethnic group [23].

The Irish population is frequently not considered as a culturally distinct population for targeted health information interventions, yet the numerous indicators of poor lifetime health experience for the Irish [24] and lack of attention paid to considering their cultural needs [25] would lead to anticipating that along with late presenting with dementia to support services they will usually be presenting with co-morbidities. The typical UK migrant experience of cultural displacement, discrimination and a characteristic lifelong lower income than the indigenous White population [26] is an integral element of the lives of those first-generation Irish migrants now moving into their late seventies and eighties. This must be recognized in any process for promoting engagement with dementia support and information services for this community.

Banerjee [27] has recently proposed that dementia should be understood as a routinely complex condition on the basis of the frequency that people living with dementia are usually also living with other physical co-morbidities when they are receiving health care services. When cultural factors as a result of minority ethnic and/or religious background enter in the picture for people living with dementia and their carers the stage is set for a complex and profoundly difficult experience characterizing the experience of most people from such communities when living with dementia and their supporting relatives, partners or friends. Kenisberg et al. [28] argue that faced with the uncertainty of developing a drug based treatment for dementia before 2025 current research priorities and funding investment needs to enhance the role of social and personal support and other non-pharmacological measures

A Brief History of London's Black, Asian and Minority Ethnic Communities and the Impact of Dementia

Migration into UK and the capital has a history going back many centuries [29,30]. The Irish population has for many hundreds of years been the largest single ethnic minority in the UK. A particular peak time for migration inflow from the Caribbean was the post Second World War reconstruction years and UK industrial development in the period from the mid- 1950's into the late 1960's. London saw significant inflow of migrant labour into London Transport and the NHS [31,32] during this time from the Caribbean, through recruitment drives initiated from the UK but also there were also significant economic push factors in the Caribbean. The US, another popular destination for African-Caribbean migrants, for a time imposed greater immigration restrictions [33] than the UK on Caribbean migrants. The African-Caribbean population is demographically the oldest of the Black African groups in the UK and although widely dispersed across the country the majority of people of African-Caribbean ethnicity live in London. For the Indian South Asian group, the long history of migration into the UK since the days of the British Empire and East India Company was further supplemented in the mid – 60's to early 70's by the pull of UK labor shortages due to industrial development and geopolitical events such as 'Africanisation' policies in Kenya, Tanzania and Uganda. It should be remembered that prior to 1971, many of those born in the Commonwealth would have been British passport holders. With the economic forces driving the migration movements into the UK and the rest of Europe in the period of industrial and manufacturing expansion and labour shortage from the post-war reconstruction of the early 1950s and on into the early stages of the 1970s those job-seeking young adult migrants from this period are now of an age where the age-related risks of developing dementia are increasing. For many African – Caribbean's the aspiration to retire 'back home' has not materialised or has disappointed either due to the changes in Caribbean society or because of illnesses, including dementia, in later life.

The experience of living with dementia involves significant psychological and social complexities for people from black and minority ethnic communities and their carers that contribute to delays in seeking help and support and the severity of the social isolation that they can experience. There is significant stigma attached to dementia in a number of these communities. Examples of this include those ethnic communities were the only descriptions of dementia in the community language are derogatory terms or testimony of the marginalisation experienced by both people

living with dementia and their carers within their communities. The unexamined stereotype that 'they look after their own' [34] persists as a barrier preventing professionals actively exploring support options for people beyond family carers and as a justification within such communities for excluding from community life carers struggling to comprehend how to support someone living with dementia. It also fails to acknowledge the variation in expectation of care giving both within and between black, Asian and minority ethnic communities [35].

Recent work by Das et al. [36] on family support for those living with dementia in contemporary India is a useful corrective to a simplistic 'they look after their own' narrative of patterns of kinship support in migrants' countries of origin. Their work debunks the myth that changes in historical patterns of kinship support in migrant communities occur primarily as the result of the migration experience and the influence of the migrant's host country. This work also usefully examines how patterns of kinship support are reflective of family power and economic dynamics that may leave the least powerful family members shouldering most of the support burdens.

Personal testimony from members of the African-Caribbean community at events developed by Culture Dementia UK acknowledges how personal and cultural stories of psychological independence and resilience reinforced by the experience of migration and surviving discrimination and hostility are hard sustain when faced with the need to asking for help and the loss of self-reliance that accompanies living with dementia. The fierce sense of pride and independence, important for the resilience and dignity of the Caribbean first generation migrant in a hostile environment becomes a problem at the stage when that person may need to acknowledge the need to seek help for themselves, either as someone with the early symptoms of dementia or as a career.

The Chinese National Healthy Living Centre in London has done important work in highlighting the stigma associated with any kind of mental health problem within the Chinese community and the isolation faced by people with people with mental health issues within the Chinese community. The stories of the painful struggle of individual Chinese families living with dementia find little public expression even within the Chinese community itself. (Eddie Chan, personal communication, Janet Jadavji, personal communication).

For the Census categories consolidated as 'other White' minority communities in the 2011 Census reports there is hardly any research evidence, despite the fact that consideration of the historic pattern of migration into the capital must recognize that some substantial communities, such as the Turkish and Orthodox Jewish communities in the capital have been around for some time. Little is known about the impact of dementia in these communities.

Recent Initiatives in the Capital

Recent initiatives in the capital to provide information and support to people Black, Asian and ethnic minority communities include the Alzheimer's Society's three-year project 'Connecting Communities', the first attempt to develop a large-scale programme of information and community engagement focusing on dementia within black, Asian and minority communities. It reaches across 8 London Boroughs (Croydon, Hillingdon, Enfield, Newham, Merton. Lambeth, Hounslow ad Redbridge) with an opportunity for cross-fertilisation of ideas between the sites. The Alzheimer's Society has also developed new material to raise dementia awareness in South Asian communities.

The Chinese National Healthily Living Centre recently embarked on a three-year funded pan London project on dementia awareness and support for the Chinese community which had included developing a Chinese model of dementia peer support, The Reminisce Tea House, and developing information on dementia in Chinese [37]

In the past couple of years Culture Dementia UK have developed excellent lively and creative local conferences in Brent and Luton that have provided a platform for representatives from a number of minority ethnic communities to tell their story of living with dementia in thought-provoking and engaging ways.

Irish in Britain is currently leading a consortium based approach in Brent, The Brent Dementia Alliance that has as its focus delivering dementia support and information to the population of a borough that is one of the most diverse in the UK and is notable for its significant African-Caribbean, Irish and Indian populations [38]

Commissioners in the London borough of Enfield have found that by working with local community groups to develop consortia working and a co-production approach and linking this to wider council priorities such as community cohesion they can bring a wider constituency and refreshed investment into improving dementia service planning and information provision for black, Asian and minority ethnic communities.

These initiatives are valuable along with other notable research over the past few years on working with the highly-stigmatised issue of dementia in black, Asian and minority communities. However, a regular feature of such initiatives is that they involve short term funding for local projects (usually 2 years or less) and are often are not integrated with the mainstream provision. All the examples mentioned are additionally remarkable in their attempt

to engage with mainstream services and mainstream policy at the borough level, with varying degrees of success. Where well developed services having been in place for several years such as the Pepper pot Club in Kensington and Chelsea, Tom's club in Haringey, Nubian Life in Hammersmith and Fulham, the Asian People's Disability Alliance in Brent and the Alzheimer's Society dementia café in Tower Hamlets opportunities for these services to inform the mainstream or contribute to a regional knowledge base are virtually non-existent.

New initiatives tackling the issue of dementia in black, Asian and minority communities frequently start from scratch. With predominately short term funding and the time lags in appointing staff once funding has been agreed it is not uncommon to find new initiatives will lose six months or more of their funded time 'reinventing the wheel' in the absence of any infrastructure that could inform on previous work, provide a sounding board for testing out ideas or provide access to established groups and networks in various communities.

In February 2015, the Mental Health Foundation in collaboration with the Central and North West London's Raising Dementia Awareness in Black and Minority Ethnic Communities Project facilitated an invitation only seminar for representatives from voluntary sector originations that had conducted recent work with black, Asian and minority ethnic communities in developing awareness and providing support for those living with dementia and their carers. The intention was to explore common experiences for third sector organisations who are active in this area.

The seminar group was deliberately small enough to support an honest, open and fully engaged exploration by the participants of their experience and develop a consensus view on lessons learned from this work. The seminar group also worked to identify a set of agreed recommendations for the next steps needed if the capital is to make the move from its current approach of ad-hoc isolated time limited funding for projects to embarking on developing and delivering a strategic vision of sustained improvement at scale across London to its diverse black, Asian and minority ethnic older population whose rate of increase in dementia prevalence will increase 7-fold over the next 40 years [39].

Participating organizations were:

- The Alzheimer's Society
- Nubian Life
- Dementia UK
- Chinese National Healthy Living Centre
- Community Action on Dementia, Brent
- PLIAS Resettlement
- Culture Dementia UK
- Asian People's Disability Alliance
- Race Equality Foundation
- Irish in Britain

As a summary account of the deliberations the participants identified and agreed the following:

a) Common themes-the wheel we find ourselves constantly reinventing

All the organizations around the table spoke of similar experiences for people in the communities they serve in living with dementia or being a career for someone living with dementia. These included

- People getting lost in the system,
- People experiencing stigma and exclusion from their own communities both as careers and people living with dementia stigma
- A lack of access to and engagement with culturally competent services but trying to access culturally appropriate service through the personalization, choice and control route then creates tensions when people want careers of a particular ethnicity.
- A lack of any peer mentoring arrangements
- A lack of support with appropriate housing and support packages
- Many support mechanisms do not meet the complex needs of many individuals which mean that people initially withdraw and only re-engage when things are a lot worse.
- Often people experience both discrimination from services which cannot respond to the cultural issues
- and also, the stigma of dementia in their own community.
- There are not enough culturally competent services.
- 'Dementia' translates in many languages as a very negative term
- Support from social service is often very limited dominated by the view that Black, Asian and minority ethnic communities "look after their own".
- Commissioners do not appreciate that community organizations may work for a long time with people
- living with dementia and increasingly are supporting individuals who are have much higher levels of need as result of their advancing illness.

b. Consensus recommendations-how can we build the vehicle for change

From a discussion of shared experience the seminar group

identified a number of agreed key features that needed to be in place for a more ambitious approach across the capital to take development beyond the 'reinventing the wheel' experience for community groups. These were:

- Solutions need to be joined up and "at scale"
- Health promotion programmers and ageing well strategies need to be made relevant to Black, Asian and
- minority ethnic communities including new communities (e.g. East European).
- Training for Black, Asian and minority ethnic staff should recognize how their own experience of
- discrimination will affect how they engage with clients.
- There should be some readily available resource for examples advice and expertise on good practice
- involving housing, dementia and Black, Asian and minority ethnic communities.
- Local authority housing strategies should take into account of older people and people with dementia.
- Language and terminology are a barrier - both staff training and educating communities training can help address this.
- People from Black, Asian and minority ethnic communities need encouragement to seek help earlier and be supported to do this through advocacy were necessary
- It's important to work across London and across all communities.
- The work needs to be more directly involving community groups, this means direct investment in these groups and more use of co-production in designing services
- Learning to be gained nationally as well and disseminated in London
- Important to collect evidence of need and what works for people from Black, Asian and minority ethnic communities, including peoples lived experience.
- There needs to be a London investment strategy for this that involves and builds on the knowledge of community groups and offers sustainable funding for the community groups involved. Work funded through this would be to deliver the stagey objectives rather than isolated 'standalone' initiatives. It would prioritise partnership initiatives involving community groups in sustainable delivery.
- A London-wide ' Black, Asian and minority ethnic dementia alliance' needs to be developed to support this strategy.

Envisaging a Dementia Friendly Capital for all London's Communities

Despite the worldwide reputation, the London enjoys for the diversity of its population and the value of the impact of that diversity on its cultural life, growing old and the risk of living with dementia in later life for people from black. Asian and minority ethnic communities remain a matter barely spoken of in these communities and often given little consideration in the assessment of need and planning of services. Due to the nature of migration and settlement into the capital over the past 75 years some of the highest numbers of people living with dementia in the largest long standing settled UK migrant populations (Irish, African Caribbean and Indian) are in London. The evidence is that the rate of increase in the incidence of dementia in black and Asian and minority ethnic communities will be 7-fold over the next 40 years, compared with a doubling of the incidence over the same period in the White majority. Due to the age structure of the long standing migrant communities the main effect of this overall increase will be felt in the larger settled migrant communities.

Piecemeal short term funded initiatives are unlikely to impact in any significant way on the challenge afforded by the scale of the increasing numbers of people from black, Asian and minority ethnic populations. The number with the complex co-morbidity routinely presenting in services in the moderate to late stages of dementia compounded by the complications of cultural diversity and lack of community understanding will increase considerably. Many UK migrants originate from undeveloped countries where average life span even as recently as in 2002 was less than 65 years [40]. Such communities have no historical experience of living with significant numbers of older people who lived long enough to develop dementia and significant numbers of families caring for people living with dementia.

The development of a regionally based strategy for London underpinned by sustainable investment for London focusing on a capital-wide approach to living well with dementia for black, Asian and minority ethnic communities could have many advantages across all communities [41]. In the absence of such strategy the increasingly diverse population of London will still get old and ill. Both health and social care agencies will find the cost in time, money and resources in responding by funding on an isolated case by case basis far more expensive than developing a proactive and planned approach involving integrated and proactive work that includes a properly funded role for the black, Asian and minority ethnic voluntary sector and growing independent sector.

As a result of the Mental Health Foundation/CNWL seminar participants agreed to develop an independent working alliance, the Dementia Alliance for Culture and Ethnicity (DACE). Although this initiative is currently London a based it brings together a group of participants with a considerable knowledge base present in the capital from host of organizations that already have a significant track record in the development of information, support and policy in this area. DACE created a Call to Action on the impact of dementia that was subsequently

endorsed in the 2016 Implementation Plan for the Prime Ministers Challenge on Dementia for 2020 [42]. The Alzheimer's Society in the UK is developing work to make London a more dementia friendly city and DACE is lending advice and support to this work. The Irish in Britain, one of the DACE member organizations has its own independently developed programmer of work in Brent, one of Europe's most ethnically diverse areas to develop dementia peer support for BME communities. Culture Dementia UK, another DACE member organization has worked with Health Education England and other organizations to develop 'Finding Patience' a short health information film on dementia aimed at the African-Caribbean community available on YouTube. This film has been disseminated by DACE members Facebook posts and Twitter accounts as well as presented at a national and international dementia conferences in 2016/17. DACE member organizations have also made increasing contributions to the literature on the impact of dementia in BME communities [43] and a specific guidance toolkit for a large London NHS Trust [44].

DACE's ambition is to provide:

- A reliable source of good practice and expertise for commissioning of services and local policy development
- An informed communication gateway for communication of dementia information and raising awareness and source of testimony for media campaigns across print, radio, TV and social networking
- A gateway organisation for recruiting both community researchers and research subjects from Black,
- Asian and minority ethnic communities to address the significant lack of participants from these communities in dementia research.
- A model for community cohesion in tackling one of the most significant health issues faces London' diverse population in the 21st Century.

London's diverse population has developed a number of signature cultural events in the capital, such as the Notting Hill Carnival, St Patrick's Day, Diwali, and Chinese New Year, to name just a few of the more well publicised. These events help to bring the city international recognition. Many of the children and grandchildren of these migrant communities who now have successful lives in the capital have been brought up by parents who impressed upon them the need for resilience in the face of discrimination and with the hope and promise that their hard work could bring success. Those same children as taxpayers will also be bearing the cost of additional care and support needs for parents living with dementia who will not have those care and support needs effectively served by publically funded services. A change needs to come.

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