Dementia and Black, Asian and Minority Ethnic Communities

Report of a Health and Wellbeing Alliance project

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Acknowledgements

Key Messages

- The number of black and minority ethnic people with dementia is increasing, and increasing faster than for the White British community.
- Inequalities between and within communities are having a significant impact on black and minority ethnic people living with dementia and their families. There continue to be challenges at all stages of the dementia pathway, from prevention through diagnosis, care and end of life.
- Knowledge of dementia is still quite poor across communities, and even among professionals. This has a significant impact on issues such as prevention.
- Black and minority ethnic carers are still poorly supported in most of England and continue to face barriers to participation.
- Services in some areas are working to address these issues, and voluntary sector organisations have often led the way in developing services that meet the needs of their communities.
- Where services have been most effective is where local partnerships have been able to coordinate activities and use limited resources to their best effect. However, some areas are further ahead than others. Similarly, some areas have few, if any, local voluntary sector organisations with the capacity to undertake such work unsupported.
- Where services and support are well-coordinated and resourced, it can have a transformational effect on individuals and families.

Introduction

The project came out of the October 2016 roundtable on dementia and BAME communities. Participants in the roundtable came together at the end of the event and in the following weeks to develop an action plan to be taken forward by partners. Resources for delivery of parts of the action plan were identified through the additional funding stream available to Health and Wellbeing Alliance members. The Race Equality Foundation, in partnership with Faith Action and Friends, Families and Travellers, successfully bid for the funding through this process.

The project set out five key areas of work to progress over the following six months: partnership, resources, professional events, community events, and research engagement. This report will set out the key activities and outputs from these areas of work before going on to discuss the themes that emerged from the events.

Partnership

Delivery of the action plan requires a partnership approach in order to secure the resources, reach into communities, and access into services, to secure the necessary scale and pace of change. The Foundation sought to build on the network developed by the Dementia Alliance for Culture and Ethnicity (DACE), as well as developing local networks and practitioner networks through our events, and enabling these groups to engage with each other.

We were able to engage national organisations, both large organisations such as the Dementia Action Alliance, the Housing Learning and Improvement Network (LIN), and smaller organisations such as Dementia Adventure. Several of these connections have led to further work, for example the Foundation is now working with Housing LIN and Dr Nigel de Noronha on an analysis on the experience of housing deprivation for black and minority ethnic older people, and with the New Policy Institute on low income black and minority ethnic older people. We were also able to connect with Diverse Cymru at the Bristol event and establish a link with their three year work plan on dementia and black and minority ethnic communities. We engaged with the Skills for Care Dementia Meaningful Care workforce Group around how their new framework could support better care for black and minority ethnic people with dementia.

At a local level, the events offered a good opportunity to develop relationships and partnership with local organisations. We engaged with a range of organisations including Bristol Black carers, Dhek Bhal, Culture Dementia UK and local faith organisations.

There were also opportunities to re-engage with people who had been working in this area. For example, a black and minority ethnic carers support group in Tameside being organised by someone who had been involved with the now defunct national black carer's network.

In terms of further influencing the health and care system beyond the original partners, the project has led to discussions with the Care Quality Commission on creating a resource for use by inspection staff. Similarly, NICE have expressed an interest in the work to feed into their guidance on *Dementia: assessment, management and support for people living with dementia and their carers*.

Since the formal end of the project, we have continued discussions with DACE on how they can develop as an organisation to become a representative national voice on the issue of dementia and black and minority ethnic issues. DACE has formalised its legal structure and is currently working through its governance to enable it to take on funding and delivery of projects in partnership.

Resources

Through both desk-based searches and engagement with partners at all levels, we were able to identify a significant number of resources developed specifically in response to dementia in black and minority ethnic communities. We developed an online list of these resources during the course of the project, and it is currently being updated to include the presentations from the events, relevant publications, vid, pamphlets, and research papers.

For example, the Dementia Wellbeing Service in Bristol had produced a number of videos in community languages, with members of the community, running through basic questions about dementia. These were available in Cantonese, English, Polish, Punjabi, Somali and Urdu.

The Chinese National Healthy Living Centre developed and popularised a new word for dementia. This helped to reduce stigma as the most commonly used words in Cantonese to describe dementia were associated with being mentally ill or having a learning disability.

We also commissioned a number of pieces of work to bring together evidence on specific topics and for specific communities. These included: dementia and end of life care, dementia and carers, and a series of pieces on the experiences and issues for specific communities: South Asian, Chinese, Caribbean, Irish and Jewish. David Truswell also produced an updated version of his 2013 briefing on dementia and black and minority ethnic communities, looking at developments over the past five years. These are currently being quality assured, before being designed and published.

Dementia and black and minority ethnic community briefings:

Dementia and black and minority ethnic communities – where are we now? (updated) David Truswell – Dementia Alliance for Culture and Ethnicity (DACE)

End of life care - Dr Jonathan Koffman, King's College London

Access to services - Jo Moriarty (forthcoming), King's College London

Carers – Dr Sahdia Parveen and Professor Jan Oyebode, University of Bradford

Specific communities' pieces:

- South Asian - Akhlak Rauf, Meri Yadaain
- Chinese - Eddie Chan, Chinese National Healthy Living Centre
- Caribbean - David Truswell, DACE
- Irish - Mary Tilki, Irish in Britain
- Jewish - Padraic Garrett, Jewish Care

Community events

Six community events were organised in London, Leeds, Rochdale, Birmingham, Peterborough, and Bristol. These were intended to primarily reach community organisations and members of the public. The programmes included service provider and service user presentations, as well as some amount of basic information about dementia and black and minority ethnic communities. This then led to whole group discussion.

The London event was chaired by Jabeer Butt. It heard from David Truswell, Tom Lam from the Chinese National Healthy Living Centre, and Ade - a service user from Friends, Families and Travellers.

Tom Lam explained how the Chinese National Healthy Living Centre had developed an awareness and support service for Chinese people and their carers over three years. This involved working with their member organisations, particularly Chinese community centres, to put together an offer that included workshops, starting reminiscence tea houses, training, multi-lingual support, befriending, referrals, and a carer's support group. They also worked to develop and popularise a new word for dementia, as the existing vocabulary for dementia was derogatory and stigmatising.

Ade took us through his journey from diagnosis, where the initial effect and impact was to steer him into a deep depression and alcohol abuse. However, he managed to bring together family and friends with support services in a way that now means he is able to do the things he wants to do, irrespective of his condition.

The Leeds event was chaired by Heather Nelson from the Black Health Initiative. It heard from Akhlak Rauf and Ripaljeet Kaur. We had secured two service users and one carer but unfortunately none of them were able to make the event on the day, underlining the continued difficulties to participation faced by carers and service users.

The Birmingham event was chaired by Clenton Farquharson – the chair of Think Local Act Personal, David Truswell, and Dr Jay Chauhan – a former housing association chief executive who is now working on care in the West Midlands. Ronald Ferguson, a service user, also presented to the session.

Ronald explained his struggle to find and put together the services and support he needs. In particularly, he was concerned about financial management and his independence.

The Peterborough event was chaired by Jabeer Butt. It heard from David Truswell and Samir Jeraj from the Race Equality Foundation.

The Bristol event was chaired by Jabeer Butt. We worked with the Dementia Wellbeing Service and Subitha Baghirathan from UWE. Two carers supported by the Dementia Wellbeing Service presented at the event, Min and Khadra.

Subitha outlined the nine month research project undertaken by UWE together with the local council, CCG, and voluntary sector organisations. The research was informed by eight focus groups and 48 interviews and revealed differences between and within black and minority ethnic communities, as well as commonalities such as lack of knowledge about risk factors & prevention; and growing dementia awareness among leaders of BME-led VCSOs. The report had 18 recommendations, which were taken on by a city-wide working group. This model of city-wide collaboration and cooperation could be applied to other parts of the country.

We also commissioned Shahid Mohammed and BME Health and wellbeing to organise two events in Rochdale. One was at a women's group (Bengali, Ugandan and Pakistani) and the other was at the BACP men's group (Pakistani, Kashmiri and Bengali). All the sessions were delivered in English/Punjabi/Urdu and Bangla.

Attendees at one of the Rochdale events organised by BME Health and Wellbeing

Professional Events

Three events were organised in Leeds, London and Bristol with the aim of reaching professionals within health and social care. David Truswell designed a programme to take participants through the pathway, exploring the issues for black and minority ethnic people at each stage while also examining what works to address these issues. Each event also heard from an experienced local practitioner working with black and minority ethnic people with dementia.

In Leeds this was Akhlak Rauf from Meri Yadaain. Akhlak outlined some of the common issues facing black and minority ethnic communities, such as late and inaccurate diagnosis, access to services, and the impact on family carers. He

explained how an approach that learns good practice, tailors its approach, invests resources, engages carers and involves commissioners, can help overcome the inequalities between and within groups.

In London Jazz Browne from Nubian Life presented on the development of their service from a social and luncheon club to a day care organisation. Many of the original members had never planned to grow old in the UK. Opening a day centre allowed their needs to be met. Now 75% of members have dementia, and the service has developed to meet those needs using the 5F Service Framework.

In Bristol, Trish Caverley from the Dementia Wellbeing service took the group through how the service employed three community development workers to work with people and communities that were under represented. This informed development of a BAME organisational plan, along with some local research by UWE. Consultation events pointed to the need for a simple video resource to act as a starting point for conversations at community events. Films in six community languages were produced, reinforced by leaflets, and used in combination with Q&A sessions at community and faith venues. The service also worked with local BAME radio stations, and with medical professionals within communities to disseminate information. The Service is part of the BME Dementia Working Group, a city-wide initiative to bring together statutory, academic and voluntary sector partners.

We also had the support of Shahid Mohammed at the Bristol event, who gave a presentation about the development of BME Health and Wellbeing in Rochdale.

Research engagement

Part of the project was to influence the research agenda in both being better at involving and recording black and minority ethnic people within large-scale studies, and making the case for specific research on dementia and black and minority ethnic communities.

The Foundation had specific meetings with Joint Dementia Research, the National Institute of Health Research, and Alzheimer's Research UK, as well as the British Heart Foundation. There was also engagement with the Stroke Association.

The meeting with Joint Dementia Research led to further discussions about how they could best improve the ethnic representation within their research cohorts, which was then progressed through the NIHR in their work with local research centres. We

are currently in discussion with Prof Richard Cheston at UWE about further developing the evidence base on ethnicity and talking forward a more significant piece of work.

The work with Alzheimer's Research allowed us to test out one of their products, a translated leaflet explaining the basics of dementia. These were brought to the events and distributed, and we were also able to provide feedback on the font and design of the leaflet to make it more useful.

We were also able to engage with a number of researchers from various institutions working in this area. This helped in development of briefings as well as identifying resources. Discussions with many of them has also led to the suggestion that a virtual network could be developed. Possible participants are listed in the box below.

Possible participants in research network on Dementia and BAME Communities

Prof. Jyoti Choudrie, Professor of Information Systems, University of Hertfordshire
Moïse Roche, Division of Psychiatry, University College London
Dr Sahdia Parveen, Centre for Applied Dementia Studies, Bradford
Eleanor van den Heuvel, Ageing Studies, Brunel University
Dr Richard Cheston, Health and Social Sciences, UWE
Dr Karan Jutlla, School of Nursing and Midwifery, De Montfort University
Dr Jonathan Koffman, Reader in Palliative Care, King's College London
Prof. Jan Oyebode, University of Bradford
Dr Jo Moriarty, King's College London
Dr David Hewson, Professor of Health and Ageing, University of Bedford
Subitha Baghirathan, UWE
Dr Mary Tilki

Themes from the events

Throughout the events a number of common themes emerged from the conversations we had. These were not necessarily the same in each area, but do reflect the general issues being surfaced and some of the ways in which these are being addressed.

Carers

We managed to secure the involvement of carers in several of the community events. However, carers are still largely invisible, with few specific services to support black and minority ethnic carers. Where these do exist, they are largely part of a more inclusive local service or part of a specific black and minority ethnic-focused organisation or project. Similarly, Tide is an organisation for carers of people with dementia, and has done work with black and minority ethnic carers. Carers still face barriers to participating, with three carer speakers having to drop out of one of the events due to a range of issues. In Bristol we heard how carers experience isolation within the family and within the community.

Gender

The gendered nature of caring was something that came up quite often in discussions. Women provide the overwhelming amount of unpaid care within families, often in their role as wives or eldest daughters. Similarly, one person explained how their mother developed dementia and its effect on her behaviour, which became more aggressive and in itself became a barrier to services and a source of isolation.

Stigma

Stigma was discussed at all the events. It was felt that while it was important not to overstate it as a factor in inequalities compared to the newness of dementia for many black and minority ethnic communities, it is still a factor in people and families seeking help and support at an early stage. During one discussion with a local radio producer in Peterborough they said they struggled to find black and minority ethnic people with dementia who are able to talk on radio because they have often been diagnosed late and were already too ill to participate. There was also a wariness of diagnosis as reinforcing stigma and becoming a barrier to social inclusion or not

actually resulting in any help being given. The work being done by the Chinese National Health Living Centre in changing the language and vocabulary used in the community to a more positive and supportive

New technologies

The presentation from Alex Jadevji in Birmingham outlined how technology could be deployed to support black and minority ethnic people with dementia. These were ideas he and his wife developed as a result of one of their parents living with dementia. They included, for example, remote communication and monitoring so that family members can check in and check on people – even if they live in another country. The use of 'smart' technologies also means information can be shared with the relevant family and services.

Inequality

Inequalities between and within communities were noted at all events. Poorer and more isolated communities particularly struggled. For example, in presenting her research on Bristol, Subitha Baghirathan noted the differences between the more middle-class Sikh Asian communities, who were keen to get more information and to access services, and more working class Pakistani Muslim communities who were less likely to have information about dementia and had worse access to services. Smaller and newer communities, such as the Chinese and Somali communities, were less likely to be provided for. For example this could be because their numbers were not sufficient to have services commissioned in the case of Chinese communities, or because the relatively young Somali population meant demand for dementia services is currently quite low and easily lumped in with other communities rather than specifically commissioned.

There were clear differences between areas of England. While places such as Leeds and Bristol had several organisations working on dementia and black and minority ethnic communities, in other parts such as Peterborough there was just one worker employed by the local Alzheimer's Society and no specific black-led VCSE organisations we could find.

Workforce

People across the board, general public and professionals know very little about Dementia, this applies even to people who may have a relatively key role for example in teams providing services to people living with Dementia. People feeling they also knew very little about cultural issues impacting on dementia care, especially people from BAME communities feeling professionals lacked cultural understanding. Knowledge of dementia policy or NICE guidance was particularly poor. The events

attracted few commissioners, doctors and nurses. This is important as undiagnosed people from BAME communities living with Dementia will be seeing clinical staff on a regular basis as their other health co-morbidities spin out of control as a result of their dementia.

Commissioning

Local services and partnerships are at different stages. However, this does not necessarily reflect the level of need in those localities. Bristol's city-wide work is bringing together a range of partnerships from the statutory and voluntary and community sector, and is supporting by an evidence base developed by local researchers from the University of West England. Leeds had a strong set of community organisations working together and able to influence local services. By contrast, Peterborough was at a relatively earlier stage. Some areas had commissioners who were engaged and responsive to local needs and others had a much poorer relationship. One of the suggestions to come out of the Leeds event, where a commissioner attended, was to develop a co-commissioning guide for NHS and Local Authority commissioners along a staged path to better services for black and minority ethnic people with dementia.

Diagnosis

There were a number of issues relating to diagnosis raised throughout the events. It is clear there are still severe barriers to diagnosis, and particularly timely diagnosis. These range from misdiagnosis through lack of information and understanding, to inappropriate diagnostic tests, and inaccessible memory clinics.

The importance of access to timely and appropriate support following diagnosis was also highlighted. Attendees at the London heard from Ade, who received a diagnosis several years earlier and fell into a period of depression and alcohol abuse. However, he had a supportive network and accessed services that could help him do the things he wants to do – maintaining an active social life, holidays to France, and trips out. This contrasted with the experience of another service user, Ronald Ferguson, who continues to struggle to bring together the people and services he needs to support him. This has created conflict and stress in his life, whereas he would rather be focused on the things that he enjoys. However, both Ronald and Ade could have benefited from better post-diagnosis support.

Prevention

In several of the events we prompted discussion of prevention and risk-reduction. It was clear there was a poor understanding of risk-reduction and dementia, with many people still believing that it was an inevitable part of ageing, or an unpreventable

disease. There was a fatalism, 'they are working on all these cures, but it's too late for my mum' often linked to feeling nothing could be done other than wait for a pharmacological cure.

Specialist Housing

The role of housing is something that is being recognised. One of the Birmingham presenters, Dr Chauhan, is developing a proposal for an 'extra care village' that can provide specific support for black and minority ethnic people living with dementia. There were also workers present from housing associations and their support services who attended the Leeds professional event. Previous work from Age UK and the National Housing Federation has also highlighted the ways in which housing associations, both black-led and mainstream, are supporting black and minority ethnic people with dementia.

VCSE role

The value of services provided by the voluntary sector was recognised across the events. At a local level, the VCSE is often meeting unmet or under-met needs within black and minority ethnic communities. Organisations such as BME Health and Wellbeing and Yecco have emerged because of the experiences of their founders, and the solutions they have developed. Shahid Mohammed, founder of BME Health and Wellbeing, started as a carer for his mother – who had vascular dementia, but was misdiagnosed and had poor experiences of services. Alex and Janet Jadavji used their experience of caring to develop some technological solutions to the challenges faced by people living with dementia. Nubian Life changed and adapted from a luncheon club to a care organisation for Caribbean elders. The challenge is in ensuring good quality in statutory services, and supporting the development of voluntary sector services in areas beyond those already mentioned.

Similarly, larger and/or organisations that a serving a more general section of the community, such as Touchstone Support and Tide, have developed and supported projects and services at a local level to address the needs of black and minority ethnic people.

At a national level, the voluntary sector plays an important role in supporting and amplifying the voice of black and minority ethic people with dementia and their families and carers. The project itself reflects the growing recognition of race equality and dementia among policy-makers as a result of lobbying, events, and briefings.

However, it is important to recognise that many of these organisations are increasingly fragile and overstretched due to funding pressures and increasing demand. Where funding is available, it is still often short-term and unable to support the development of a sustainable service.

What next

The project was intended to take forward a significant part of the action plan developed following the October 2016 Roundtable. It has succeeded in doing both that and laying the foundations for further work agreed as part of the plan. In order to take forward the rest of the plan, resources need to be found within the health and care system.

Various potential future work streams were also identified or emerged as part of this work. The need to improve commissioning, potentially through the development of a co-commissioning guide for local government and health services, was underlined by commissioners who wanted to see clear guidance on how they can steadily improve services for black and minority ethnic people. Similarly, the development of regional and national networks to support black and minority ethnic carers would make a significant difference to unpaid, mostly female, family carers who can easily become isolated.

Developing the appropriate health, care and support infrastructure is crucial. Housing, for example, has had relatively little attention, but will be vital for ensuring people living with dementia can continue to live in familiar and supportive environments.

While the focus of the project was on people with dementia, prevention was identified as increasingly important. Further work to improve understanding of how dementia risk can be reduced and how that can reduce inequalities between and within groups should be a priority.

The Bristol model of bringing together local services and partners, commissioning research, and then using that partnership to support change, could provide a useful blueprint for the development of other areas in responding to the needs of black and minority ethnic people with dementia. Supported at a national level through delivery of the action plan, such local partnerships could deliver real change in access and quality of services.

Recommendations

The fragility of small and local black and minority ethnic voluntary sector organisations needs to be addressed. At least two of the organisations we worked with were on the brink of collapse. System partners need to examine how they can support existing organisations and encourage their development in areas where there is a clear need.

System partners should support the continued development of a coordinating voice for black and minority ethnic people living with dementia.

Voluntary sector organisations are well-placed to deliver awareness-raising sessions, and system partners need to consider how that can be supported with the aim to reduce rates of late diagnosis.

Professionals need better awareness of dementia. System partners and workers in other public services need a clearer understanding of what dementia is, and what their role is in prevention, diagnosis, and care.

System partners should look to develop co-commissioning guidance in collaboration with local government and the voluntary sector. This could set out manageable steps to improve services and build success over a period of time.

System partners need to continue to encourage the research community to pay greater attention to race and ethnicity in research on dementia. The apparent lack of even inclusion of race and ethnicity as a category of data in several significant studies is concerning.

System partners need to help address the lack of support for carers, particularly the lack of a coordinating voice for black and minority ethnic carers that could hold services to account, support the development of local groups and influence policy and practice.

Appendix – Resources

Support and Care for People Living with Dementia from Minority Communities'

http://www.ncl.ac.uk/media/wwwnclacuk/instituteforageing/files/dementia-in-minority-communities-support.pdf

Diversity and inclusiveness in dementia : listening event report, Salford, Salford Institute for Dementia

http://usir.salford.ac.uk/35270/1/Diversity-and-Inclusiveness-in-Dementia-report.pdf

Wake Up London! – The case for a London regional investment strategy to develop appropriate information and services for black, Asian and minority ethnic people living with dementia

https://www.mentalhealth.org.uk/sites/default/files/wake-up-london.pdf

What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings

http://journals.sagepub.com/doi/abs/10.1177/1471301214534424

Black & minority ethnic older people - health and social care

https://www.kingsfund.org.uk/sites/default/files/field/field_pdf/Library-reading-list-BME-older-people-Nov2014.pdf

Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise

https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12363

Gearing up Housing Associations' responses to tenants with dementia from black and minority ethnic groups

https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/safe-at-home/rb_oct15_diversity_dementia_gearing_up.pdf

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Projects

Pavee Point and the Alzheimer's Society of Ireland, Republic of Ireland https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Traveller-Education-Training-Pavee-Point.aspx

Outcomes:

- An information poster about the signs and symptoms of dementia was produced for use by primary health care workers for the Traveller Community
- As a result of the training from The Society perspective we understood more about the resources that are needed to improve awareness about dementia in the Traveller Community but also a deeper understanding of the needs of Travellers and the issues they are faced with

Accommodation

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Dementia: the untold story of our BME population

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Cultural barriers to dementia care

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