



University of
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MANCHESTER

A Fragmented Pathway

Experiences of the South Asian Community and the
Dementia Care Pathway: A Care Giver's Journey

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Dedication

I dedicate this book to my mother Hajra Bibi, whose prayers are always with me.

Foreword

I wanted to write this account because of my personal experiences as a care giver for my mother. My mother lived with us and was eventually diagnosed with vascular dementia. I emphasise eventually, because getting the diagnosis was not as straight forward as it should have been or as we expected. There were many barriers and obstacles that we as a family had to encounter throughout the journey and the delay in getting the diagnosis had many consequences.

I suppose the first time I publicly talked about my experience as care giver was in 2013. It was during my volunteering work with the Alzheimer's Society I was asked by the local Carer's Resource Service to speak at a full Adult Social Care team's training day. After I had spoken one of the participants approached me and said that it must have been really hard for me to talk about my mum. It was, because it was so personal and it wasn't anybody else's story – it was simply our life that we were living on a day to day basis. I also wanted to leave our experience as a lasting legacy for my mum.

I believe some people from the south Asian community may not be able to talk about dementia and their loved one who is living with it, but I think it is really important for me to share my experiences because mental health conditions and dementia are still sadly a taboo subject with stigma attached, particularly in my own local community.

Until 2012 I had worked in the public sector for over 23 years, and in 2012 my mother's mental and physical health began to deteriorate which led me to take early retirement and I gave up employment to become a full-time care giver. After a period of time and whilst I was still sharing my caring responsibilities with my wife – who was my rock throughout - I felt it important to set about on a campaign to engage with the south Asian community and healthcare professionals to start a process of raising awareness of dementia, carer givers and End of Life Care. This was to ensure that other families would be better informed and aware of the challenges they faced and the support available.

I also wanted to ensure that the Dementia Support Services, the Police, Health Commissioners and health care professionals were aware of the nuances that affect the south Asian and BME communities – i.e. one size does not fit all and the south Asian, BME community shouldn't be treated as a homogeneous group and they are definitely not 'hard to reach', perhaps just easier to ignore.

Shahid Mohammed, April 2017

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Background and Context

Dementia is a growing, global challenge. As the population ages, it has become one of the most important health and care issues facing the world. The number of people living with dementia worldwide today is estimated at 44 million people, set to almost double by 2030¹. With an ageing population, dementia is soon to become the biggest burden on healthcare systems around the world. In 2010, the global cost of dementia was around £400 billion and this figure will continue to rise as more people are diagnosed each year. It is estimated the costs of dementia are higher than cancer, stroke or heart disease². According to The Race Equality Foundation (2013), around 35.6m people are currently living with dementia worldwide; a figure that is expected to double by 2030 and triple by 2050.

In England, it is estimated that around 676,000 people have dementia³. Dementia has, and will continue to have, a huge impact on people living with the condition, their carer givers, families and society more generally because:

- Dementia is now one of the top five underlying causes of death and one in three people who die after the age of 65 have dementia⁴
- In November 2016, BBC News reported that Dementia, including Alzheimer's disease, had overtaken heart disease as the leading cause of death in England and Wales (BBC Health, 2016).
- As the population grows and ages, the economic burden of dementia is expected to rise significantly (Department of Health, 2013).
- According to The King's Fund⁵, the total annual spending on dementia is projected to reach £35 billion in 2026

In 2013, the UK used its presidency of the G8 Dementia Summit⁶ to spearhead a global effort to tackle dementia through research⁷.

Again in 2015, UK Prime Minister David Cameron in his 'Challenge on Dementia 2020' (February 2015) stated in the foreword of the report that *'dementia takes a huge toll on our health and care services...with the numbers of people with dementia expected to double in the next 30 years and predicted costs likely to treble to over £50 billion'*.⁸

¹ World Alzheimer's report 2014

² Dementia in Black and Minority Ethnic Communities: Meeting the Challenge - Nov 2013

³ Alzheimer's Society, 2013

⁴ Dementia UK, 2014

⁵ Brayne, Gao, Dewey, Matthews, 2006

⁶ Department of Health, 2013 - Dementia: State of the Nation, p 11

⁷ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf

⁸ G8 Dementia Summit: Global Action Against Dementia, report published 10th April 2014

⁷ Alzheimer's Society, 2013

⁸ 'Challenge on Dementia 2020' February 2015, p 3

Defining dementia

The term 'dementia' describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's disease, a series of small strokes or other neurological conditions. Around 60 per cent of people with dementia have Alzheimer's disease and around 20 per cent have vascular dementia, which results from problems with blood supply to the brain. There are other less common forms of dementia for example dementia with Lewy Bodies and Frontotemporal Dementia. Currently, dementia is not curable. However, medicines and other interventions can lessen symptoms for a period of time and people may live with the condition for many years after diagnosis. There is also evidence that more can be done to delay the onset of dementia by reducing risk factors and living a healthier lifestyle⁹.

The most common types of dementia stated above are all progressive. This means that the structure and chemistry of the brain become increasingly damaged over time. The person's ability to remember, understand, reason and communicate will gradually decline. As dementia worsens, the person will need more and more support with daily living. Their behaviour and mood will also change. Eventually, the changes in the brain will begin to cause mild symptoms, but which are initially not bad enough to count as dementia. Subtle problems in areas such as memory, reasoning, planning or judgement may cause difficulties with more demanding tasks.

Looking at dementia as a series of three stages - early, middle and late - can be a helpful way of understanding the changes that occur over time. Alzheimer's disease usually begins with very minor changes in the person's abilities or behaviour. Such signs can often be mistakenly attributed to the normal process of ageing. As Alzheimer's disease progresses, the changes become more marked. The person will need more support to help manage their day-to-day life. They may need frequent reminders or help to eat, wash, dress and use the toilet. They are likely to become increasingly forgetful - particularly of names - and may sometimes repeat the same question or sentence over and over. At the most late or severe stage, the person with Alzheimer's will need even more help and will gradually become totally dependent on others for nursing care.

The use of terms

The terms 'Black and Minority Ethnic' (BME) and 'Black, Asian and Minority Ethnic' (BAME) are both terms commonly found in research and general literature. I use the term 'Black, Asian and Minority Ethnic' abbreviated as BAME because the focus here is on the South Asian community. I also use the term 'minority ethnic' in preference to 'ethnic minority' because it stresses the fact that everyone belongs to an ethnic group, rather than an ethnic group's minority status. The blanket term 'South Asian' may be used to refer to studies of Pakistani, Sikh, Gujarati or other 'South Asian' 'sub'-groups.

An ageing diverse population in the UK

According to the 2011 Census, 14 per cent of the UK's population is BAME¹⁰. This total is nearly 8 million people, which is roughly the same as Scotland and Wales combined.

⁹ Prime Minister's 'Challenge on Dementia 2020' - February 2015

¹⁰ ONS 2012

The BAME population is not only growing, but it is more diverse than in the past. Until the 1990s migration was predominately from the 'Old' or 'New' Commonwealth, in the latter case primarily the Caribbean and South Asia. The rise in the number of minority groups in the UK has been driven by population growth and immigration. In the 2001 Census there were 230,000 BAME people over the age of 65, but this is expected to increase significantly in the coming decades, to around 2.7 million by 2051 (Botsford et al; 2015). The majority of these older people who migrated in the 1950s, 60s and 70s may have come with short-term plans and with the intention of returning to their country of birth. However, with a better quality of life, better income and more opportunities, the majority chose to stay within the UK permanently.

The 2011 census has demonstrated that a growing proportion of the black and minority ethnic population in the UK is now aged over 65, with particular growth taking place in the 75+ age group (NOMIS, 2011). This presents challenges for providers of dementia services if they have not worked with these groups previously or if their commissioning processes do not take into account the major shifts in demographics currently taking place. Such diversity of race, language, religion and culture within and between people of different ethnic groups can produce inequalities in health and uptake of health services. It is important to try to understand these differences and to reduce inequalities if health services are to be improved across the whole population.

The Myth of Returning home

People from the Indian sub-continent have been travelling to Britain from as early as the 17th century. Pakistanis are now the third largest minority ethnic group in Britain, however, very few details are known about their socio-economic position.

It is relevant to point out that migration of Pakistanis into Britain was to fill unskilled textile jobs in Yorkshire and Lancashire textile mills - post World War 2.

At the time of the partition in 1947, a large-scale movement of population took place between India and Pakistan. Various surveys have shown that many of these displaced people came to Britain, thus becoming migrants twice.

It was estimated in 1951 that there were 5000 Pakistanis (including Bangladeshis) in Britain. In 1961, the estimated number of Pakistanis reached 24,900 and by 1966 it had grown to 119,700. However, there was a drastic decline in the number of immigrants coming as workers.

In the 1960s and 1970s the myth of returning home was quite common. However, more recently this myth among Pakistanis has diminished because of economic circumstances and the future of their children, which most of them see as being in Britain.

BBC Website 'Our untold stories' 2014

My family's migration story

Like many first generation Pakistanis, my father arrived in the UK in the early 1960s; having experienced the 1947 partition, which came about after India and Pakistan gained independence from Britain, resulting in over fourteen million people being displaced. Many of our forefathers, including my parents actually experienced two migrations – the first one was in 1947 when the Punjab was split into two to allow for independence to take place, and the second after the second world war when people from the commonwealth were invited to come and fill the labour shortages in the UK.

My father was in his twenties when he arrived to the UK, he was the first of my family to arrive, leaving my mother and sisters in Pakistan who arrived much later. His journey to the UK wasn't without its challenges, he travelled through many countries by road with a group of other men – his passport is witness to all the border crossings and visas he needed to progress onwards to the next border. My father first worked in Edinburgh, Scotland and eventually moving to Northwest England working in foundries, and finally settling to work as a 'spinner' in several textile mills.

After many years, my mother and elder sisters joined my father in the UK. My mother would tell me that she had to give up her role as a housewife raising the family in order to seek employment because my father had a very bad accident at work where he was crushed behind a truck and was bed-ridden for a long time. As there was no other source of income coming into the family, no benefits, and my older siblings were still at school and babysitting me in between mum's shifts. I recall my mother telling me that she would walk in the snow for miles going from one textile mill to another looking and asking for work. Despite all the adversities i.e. language barrier and racism was rife; she eventually found work, and spent a considerable amount of time working shifts and returning home to look after the family. When my father's health improved, he resumed his role in the textile mills; and as he was a skilled tradesman in Pakistan and India he re-trained as a Plumber, Joiner and Builder. As a result of his technical knowledge and natural ability to fix things, he was quickly promoted as a technician in the mill. He also became a very well established and respected member of the local community. Interestingly my parents actually spent more years living in the UK than they did in Pakistan; because Pakistan as a sovereign nation was only created in 1947.

As a family, we established roots in Rochdale, where I was born and have spent all my life in the area in which I grew up in. Our family's story and many others reinforced the 'myth of returning home' was in fact true – just a myth!

BME communities and dementia

'If you are 65 today you were born in 1948. Obviously Windrush, which is the first period of post-war large-scale migration to the UK from minority ethnic populations, happened in 1948... So, most of the people who are presently over 65 are overseas-born, and I think that raises a distinctive set of issues for the current older minority ethnic population.'

Omar Khan (APPG during oral evidence 2013)

For many communities, life expectancy in the UK may now significantly exceed life expectancy in their country of origin. This may mean a greater likelihood of them developing dementia than would be the case in the country they originate from. For example, the current life expectancy for Pakistani women living in Pakistan is 67.5 whereas for Pakistani women living in the UK it is 77.3 (Civitas, 2011). The All-Party Parliamentary Group (APPG) report on Dementia 'Dementia Does Not Discriminate' July 2013, reported that the number of people with Dementia from Black, Asian and Minority Ethnic (BAME) groups is expected to rise significantly as the BAME population ages. The Centre for Policy on Ageing and the Runnymede Trust applied well established Dementia prevalence rates to census data, giving a current estimate of nearly 25,000 people with Dementia from BAME communities in England and Wales. This number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051.

The report further states that currently, people from BAME communities are under-represented in services and they are often diagnosed at a later stage of the illness, or not at all. Indeed, there are no reliable figures available it is likely that dementia is more common among BAME communities as the risk factors, high blood pressure, diabetes, hypertension and high cholesterol are more common (APPG 2013). Vascular dementia is also believed to be more prevalent among BAME groups as they are more prone to such risk factors (Moriarty et al; 2011).

The prevalence of dementia in South Asians is set to increase (Department of Health, 2002), and the rise in cases of dementia in South Asian communities (Lawrence et al., 2011) will greatly impact on the lives of older people and their families in this minority population, however little is known about how South Asians understand dementia in the UK.

Emerging research suggests that the prevalence of dementia is higher in the Black African Caribbean and South Asian UK populations, and also that the age of onset is lower for Black African-Caribbean groups (Truswell, 2013).

'The treatment of dementia in South Asian communities poses particular challenges, one the one hand we know that dementia is no respecter of race or ethnicity; in fact, we have reason to think that people from south Asian communities may suffer from dementia even more than people from other communities. That is probably because people in south Asian communities have very high rates of high blood pressure, heart disease and diabetes.'

Dr Shanu Datta, Consultant Psychiatrist for Older People, Birch Hill Hospital, Rochdale.
Purani Yaadein (Old Memories film 2014) Interview

This may be a factor why BAME communities have a low diagnostic/referral rate (APPG report 2013); as the assessment could be considered to be too euro-centric to enable an effective, culturally appropriate diagnosis and I revisit this later. In some communities' dementia is assumed as part of the natural aging process resulting often in acceptance and non-action; this is exacerbated by the fact there is no word for 'Dementia' in many Asian languages.

So, there is a particular need in the South Asian Community for accessible information on Dementia both to raise awareness, so encouraging diagnosis and to enable people with Dementia to live successfully at home.

The significance of religion

The religious expectation of duty to care cut across Islam, Hinduism and Sikhism. Care-givers from all three religions say that their faith placed a responsibility on them to care for the person with dementia. Islam, for instance, emphasises respect for all older people, with children having a special responsibility towards their parents; and it is considered a communal obligation and a virtue to care for the elderly, even for extended family members.

Our family's experience

I experienced problems in seeking a diagnosis from our GP for my mum, who was eventually diagnosed with vascular dementia, and also having to deal with the challenges of becoming a carer. Over a period of two years' mum's condition deteriorated, both mentally and physically and it became extremely difficult for us to continue to care for her needs and maintain a normal family life as I was working full-time. The strain of caring became untenable, so we consulted the local Mufti (senior Muslim scholar) to seek an Islamic ruling on whether we could consider respite or even consider placing mum into a specialist dementia nursing home. As the main carer for mum it was a decision I had tormented over for a long time; and whilst caring for mum was a rewarding but hugely challenging experience, we found that as her health worsened it was taking its toll on me and family's health and wellbeing. Even considering a dementia nursing home for mum was not easy given religious and cultural norms, and ultimately placing mum in one was a decision I did not take easily. The Imam advised that if it was in mum's best interest then it was permitted.

We felt compelled to seek guidance from the Mufti because of the pressure and expectations from our extended family to continue to care for mum – irrespective of her needs or the stress being placed on me and my family. The perception was, that by not continuing to care for mum, meant perhaps I was not fulfilling my duty as a son; and it was only after getting the 'authority' from the Mufti I was able to arrange a best interest meeting with the extended family, mum's Consultant Psychiatrist and her community nurse at the memory clinic where it was decided that the best interest for mum was to be admitted into a specialist high dependency nursing home.

It is also worth noting that, from my experience, there is confusion within some BAME communities on the difference between residential/sheltered accommodation and high dependency nursing homes – and that's where I believe some of the issues around stigma and abandonment may arise. I often found myself explaining to people in my community that mum was in a **high dependency dementia nursing home** where she had 24/7 nursing/clinical presence and NOT in sheltered accommodation.

Stigma and mental illness in BME communities

'Stigma is an attribute, behaviour or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.'

World Alzheimer's Report 2012 (p12) – Overcoming the stigma of dementia

Stigma exists in all cultures, but the way in which it is expressed in different cultures varies. The phenomena of stigma can be a factor in delaying seeking support because families want to conceal or ignore the early signs.

In the Muslim community in particular¹¹, there is social and cultural stigma associated with accessing services that provided care outside the family. This stigma tended to be fuelled by negative stereotypes that usually emerged from extended family members rather than the immediate family who were in need of those services. This is exacerbated further when and if a need arises to tackle any kind of mental health problem, including dementia.

There are other influencing factors such as discrimination, higher rates of poverty and employment or poorer health, so developing a stigmatising illness could be amplifying those disadvantages. The shame associated with a stigmatised condition could also deter people from the south Asian community in accessing help – which often leads to family's further experiencing isolation. Furthermore, in communities where the culture of arranged marriages is still prevalent, families may not wish to disclose that a relative in the household has dementia because it could be perceived that mental health 'runs in the family' thereby reducing the chance of marriage or it could lead to a breakdown in the marriage – especially if there is an unmarried daughter in the family.

It was reported by dementia care workers at the *'Dementia in black and minority ethnic communities: Meeting the challenge'* learning event that some Black and Minority Ethnic communities are very close knit and most people are related or know each other. This may lead to fear or embarrassment about being the subject of gossip or damaged pride at having to ask for help with caring for a family member with dementia.

There is often misunderstanding about the causes of mental health problems including dementia, these include:

- Black Magic
- The will of God
- Genetic

Family relationships have a strong and integral role. Yet in seeking to protect relatives with mental health problems from gossip and stigma – and also to protect the wider family's reputation; there is a tendency for the close family to reduce the amount of contact the person might have with the extended family or wider community. Party and wedding invitations, for instance, may be declined. In some BAME communities it is common for the families of the bride and groom to look into each other's backgrounds to ensure their child is marrying into a 'good' family. Along with other genetic illnesses, evidence of mental health would impact on the status of the family and its desirability. Any marriage prospects may also be damaged because of the perception that perhaps dementia or other mental health condition is incurable and can be passed on through the generations via genes. This can be seen as a serious threat to marriage proposals where arranged marriages are common. Amongst the south Asian community, the Izzat (Honour) and Sharam (Shame) reflects on the actions of family, affecting their social standing in their community but also within family in their native country. For instance, the family 'izzat' could be lost through attracting 'sharam' for example disclosing that a family member has mental health issues.

¹¹ Bradford, 2008; Oldham, 2008

Black Magic

The reason why some south Asian communities believe in demonic possessions and spirits stems from a number of factors. Firstly, in south Asian communities and associated languages there is no terminology for mental health conditions such as dementia, schizophrenia, bipolar disorder, and the symptoms and behaviour is seen as similar to demonic possession. Secondly BAME elders from the Indian sub-continent may have witnessed exorcisms or heard of such incidents within circles of friends and extended family members or heard village folklore which has been passed down from generation to generation, which over time becomes embedded in cultural beliefs.

During a 'Culture and Dementia' awareness training session to Greater Manchester Police officers, I was approached by a senior Police Officer who wanted to share an experience of 'black magic'. The officer recalled an incident when he was responding to a domestic disturbance; when he arrived at the house he found that an elderly Asian (Muslim) lady was acting oddly and was very agitated. The officer further explained that the elderly husband was constantly repeating the word 'Jinn' in Punjabi; the officer thought the husband meant that the lady had been drinking gin (the drink), hence her agitated behaviour. However, it was only when the son spoke to the officer and explained (in English) that his mother had actually been diagnosed with dementia but sadly his father was still in denial and was insisting that his wife was possessed by a *Jinn*.

In Islam, *Jinn* (or djinn), are supernatural creatures made of smokeless fire. They are frequently found in Islamic folklore and are mentioned in the Qur'an. Historically, they are portrayed as menacing creatures that can harm humans, or drive them mad. People in Muslim societies have traditionally seen jinn as the cause of mental illness and neurological diseases. Since western health professionals tend to be unfamiliar with this belief premise, diagnosis may prove quite challenging; especially when any patient-doctor interaction is already impeded by language problems and cultural differences¹².

The Dementia Pathway and the BAME population

The National Institute for Health and Care Excellence¹³ (NICE) has established a 'Dementia Care Pathway', which outlines how a Person with Dementia (PwD) should experience services and how different services should connect. The Dementia Care Pathway can be summarised as having broadly six stages:

| | | | | | |
|-------------------|-----------------------|---------------------------------|---|----------------------------------|-------------------------|
| Prevention | Identification | Assessment and Diagnosis | Early Intervention and Treatment | Living well with dementia | End of life care |
|-------------------|-----------------------|---------------------------------|---|----------------------------------|-------------------------|

'The quality of dementia care across providers is variable, and transitions between services need to be improved. People with dementia are likely to experience poor care at some point along their care pathway, but they have the right to expect good care and it is unacceptable that they should receive a variable quality of care.'

Care Quality Commission 'Cracks in The Pathway' p.9 (Oct 2014)

¹² Lim et al; 2014

¹³ An executive [non-departmental public body](#) of the [Department of Health](#) in the [United Kingdom](#)

GP access and referrals

Dementia: GPs say patchy services fail patients

Doctors have raised fresh concerns about the level of support people with dementia and their carers get from the NHS and social services in the UK. The Royal College of GPs says until the situation improves, doctors will have to weigh up whether there is any advantage in early diagnosis.

GPs have a key role in co-ordinating care for people with dementia, but the Royal College of GPs says in some places services are collapsing under the pressure of more diagnoses.

A quarter of doctors warned they would be less likely to refer a person with suspected dementia to specialists to make a firm diagnosis.

BBC (July 2015)

General Practitioners essentially act as gatekeepers to accessing other primary care services and secondary care services. Older people from several different BAME groups are well aware of services provided by GPs (Barker 1984; Bhalia and Blakemore 1981; McCallum 1990), and have high general practice consultation rates (Adamson et al. 2003; Balarajan, Yuen and Raleigh 1989; Donaldson 1986; Gillam et al. 1989; Lindsay et al. 1997a; Livingston et al. 2002).

However, despite the prevalence of dementia in different BAME groups being comparable to or higher than in the indigenous white British group, the prevalence of BAME older people in contact with Old Age Psychiatry Dementia Services (OAPDS) is generally low (Beattie et al. 2005; Blakemore and Boneham 2004; Bowes and Wilkinson 2003; Daker-White et al. 2002; Jagger 1998; Lindsay et al. 1997a; Rait and Bains 1997; Seabrooke and Milne 2003; Shah and Dighe Deo 1998). Moreover, BAME people with dementia present to services at a more severe stage of dementia than their white British counterparts (Mukadam et al. 2011a, 2011b).

'Often when you go to A&E they refer us back to our GP; but the reason people go to A&E is because they cannot get an appointment when they need it. So, if you're ill today what would be the point of a GP appointment in a week or two weeks' time...?'

Comment from participant
(BME Health & Wellbeing focus group for HMR CCG - Jan 2015)

In December 2014 BME Health & Wellbeing were commissioned by the Heywood, Middleton and Rochdale Clinical Commissioning Group to facilitate focus groups amongst the south Asian community in Rochdale; the theme of these sessions was 'NHS Winter Pressures'. Throughout the focus groups we heard many stories and instances where people shared their personal health experiences. We were provided with graphs by the CCG, one of the tables which showed the top four wards that were accessing/self-referring to A&E the most were wards with high numbers of BAME groups residing there. We wanted to establish why BAME people were attending A&E rather than self-medicating, utilising the Minor Ailments Service or visiting their GP. Difficulties in getting through to and making GP Appointments was a common factor

Our experience of accessing GP services

As my mother had a long history of mental health issues she always had the support of the local MERIT team (community mental health); and the support we had from the Mental Health Care Coordinator/Nurse was fantastic. When we started to notice a change in mum's health and cognitive abilities, it was also noticed by my mum's mental health nurse. Under 'normal' circumstances you would expect that the first port of call for us would be to contact our GP (which we did) to seek some understanding and hopefully to get a diagnosis, advice or referral to a specialist – sadly this didn't happen. I was well aware of the known difficulties with getting doctors' appointments, however given mums frailty, comorbidities and age we expected she would be on a health priority pathway and response list. However, we often struggled to get beyond the health centre telephonist, let alone convince our GP to visit mum at home because of her limited mobility and the difficulty in travelling to the clinic. This was the first real barrier to seeking help and accessing any support – this was actually a cry for help, which wasn't heard until much later.

A home visit was eventually made after much persistence; however, upon a quick assessment the GP simply dismissed mum's deterioration in cognitive abilities, agitation, forgetfulness and change in 'normal' behaviour as simply old age; and 'nothing to worry about' rather than suggesting carrying out further tests or referring accordingly.

Knowing my mum when she was well and also when she would have relapses in her mental health. I knew something wasn't right. We sought a second opinion for another GP; he was the first person who mentioned the word 'dementia' to us – we genuinely had no concept of what this word meant. I discussed it further with the mental health community nurse and she also concurred that given mum's change in behaviour and other signs, it was likely that mum had the onset of dementia. The nurse attempted to carry out the Mini Mental State Assessment but she was unable to continue beyond the first few questions.

Essentially the diagnosis was made via the Community Mental Health Team rather than by our GP; furthermore, there were never any referrals to the memory clinic at any point. In fact, we encountered a 'revolving door' of services where mum would be admitted to various mental health wards because of her associated mental health issues – usually triggered by a call to an out of hours GP who would only assess mum's symptoms on how she would present at that time.

During the course of one to two years after diagnosis we had relatively good experiences of dealing with very competent, sympathetic clinicians and health care professionals including doctors, consultants and community mental health teams; but sadly, there was a huge level of inconsistency in quality of care.

We had to circumvent the system just to get mum referred to a specialist and had it not been for the MERIT team I honestly don't think we would have got all the help and support. We feel that they were our one stop shop; not our GP!

In my view the diagnosis of my mum's vascular dementia was made by default; it really seemed like a fragmented process to us!

The pathway to reach secondary Old Age Psychiatry Dementia Services (OAPDS) encompasses several sequential stages. First, recognition of a problem by the patient and/or the family; consultation with the GP; recognition of the illness by the GP; referral to secondary care specialist services by the GP; and recognition of the illness in secondary care (Goldberg and Huxley 1991).

Potential difficulties in this pathway may be due to factors related to patients and their families, general practice and secondary care (Shah et al. 2005a). When families do approach the GP with concerns about the person, the lack of a concept of cognitive impairment or dementia can make it difficult to provide a coherent account of symptoms. This creates another barrier to diagnosis; further exacerbated by the experiences of many families of long waiting times for a GP appointment. This was identified during focus group work by BME Health and Wellbeing for Oldham and HMR Clinical Commissioning Group (Jan/Feb 2015) as by far the biggest issue for participants. They were concerned about not being able to get an appointment on the day required and having to wait for days or sometimes weeks for an appointment. Interestingly there was an expressed view that most of the issues exist with south Asian GP surgeries (i.e. where the GP is south Asian); and that White GP surgeries are much better in terms of being able to get an appointment, being referred to a specialist promptly (when needed) and the ability to see a doctor in the evening.

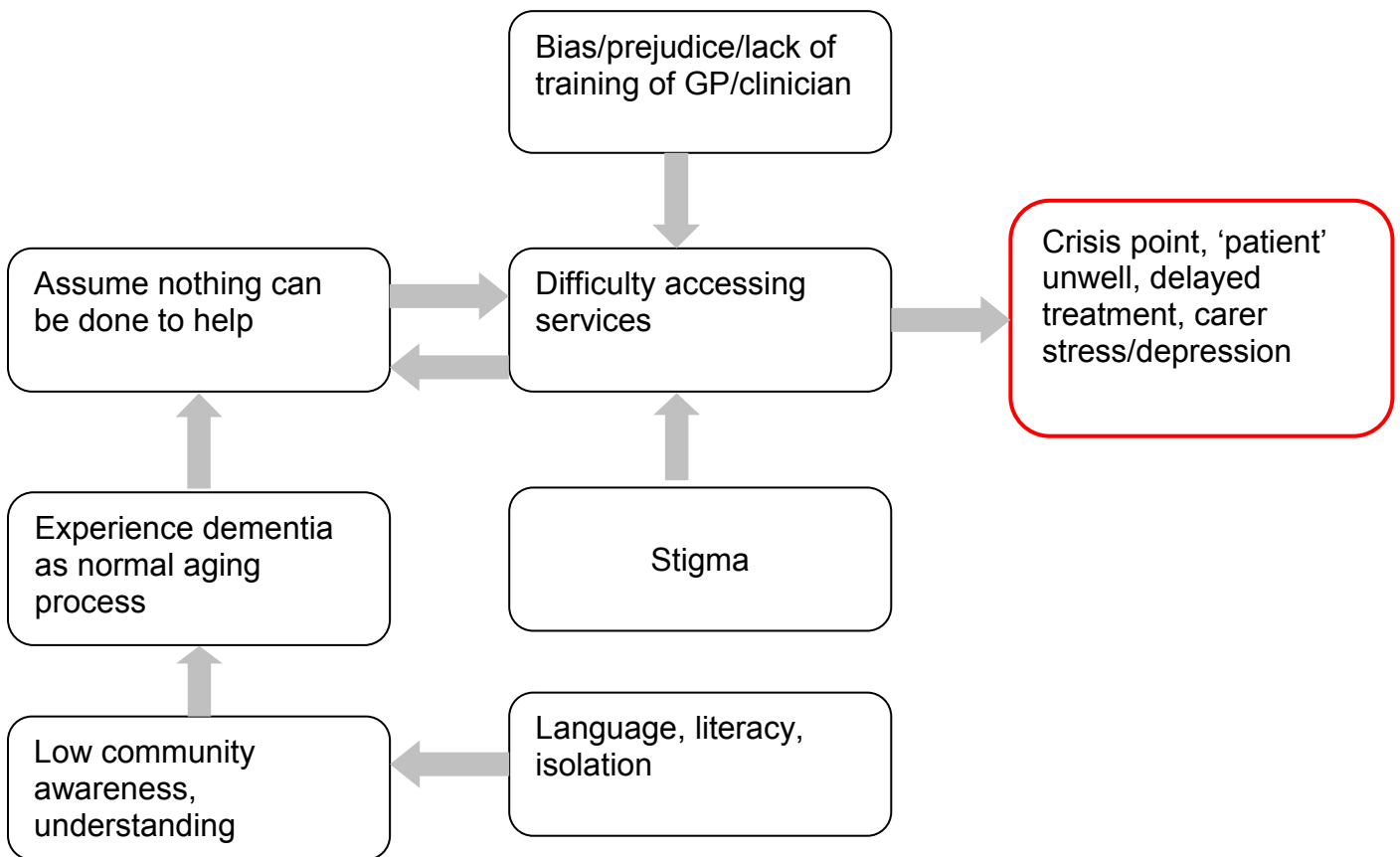
Older people and their family members may be unfamiliar with the symptoms of dementia and dismiss them as old age (Adamson 2001; Bowes and Wilkinson 2003; Marwaha and Livingston 2002; Purandare et al. 2007; Shah et al. 2005a). These reasons may be amplified if the older person is unable to communicate potential symptoms to family members and/or the GP either due to lack of appropriate vocabulary or fluency of English (Shah 1997a; Thomas, Thornton and Shah 2009; Thornton, Shah and Thomas 2009). Family members may not be able to communicate their concerns to the GP for the same reasons.

Older people and their families may believe that nothing can be done to help them, there could be a lack of awareness of available services, or of how to access them. They may believe that available services are inadequate, inaccessible and culturally insensitive. They may have had previous poor experience of services and may fear stigma attached to dementia (Age Concern and Help the Aged Housing Trust 1984; Barker 1984; Bhalia and Blakemore 1981; Bowes and Wilkinson 2003; Hopkins and Bahl 1993; Manthorpe and Hettiaratchy 1993; McCullum 1990; Lawrence et al. 2006; Lindsay et al. 1997a; Livingston et al. 2002; Mukadam et al. 2011a, 2011b).

In other words, for people to recognise dementia within the community there needs to be an understanding of dementia as being a health care problem, a view not always present in older South Asians (Mukadam et al, 2011).

In some BAME communities there is also the fear that once the disclosure of mental health has been made to the *family* doctor it may not remain confidential; or they choose to consult traditional healers than GPs (Bhatnagar 1997). Some older BAME people may feel that they are a burden on their families (Lawrence et al. 2011). Family members may also feel that it is their duty to continue to look after older people (whether or not it is in best interest of the person with dementia); fear that other may criticise them for seeking help, delay seeking help until they cannot cope or others comment on the problems, and believe that diagnosis alone maybe purposeless (Adamson 1999; Lawrence et al. 2008; Mukadam et al. 2011a, 2011b).

Barriers to BAME groups accessing dementia services



Source: D'Agostino, A. (2012): Improving Dementia Services for BME Communities in Croydon, Croydon BME Forum

If dementia is identified by the GP, it may or may not be treated, and this is due to several factors. The GP may believe that nothing can be done that ethnically sensitive care services are not available, and may have had previous poor experience of secondary care referrals (Shah et al. 2005a). If the dementia presenting to the GP is less severe or lack troublesome behavioural and psychological signs and symptoms of dementia, then onward referral to secondary care may be considered unnecessary (Shah et al. 2005a). As discussed above, there are many well-known barriers which can inhibit south Asian people from recognising dementia and approaching their GP, including: reduced awareness of dementia; stigma; considering symptoms as normal ageing; believing that GPs only deal with physical symptoms, and believing that nothing can be done for memory problems if they are God-given.

Screening instruments have been developed for some BAME groups (Botsford et al; 2015); such as the Mini Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975) has been developed in Gujarati, Bengali, Punjabi, Hindi and Urdu (Lindesay et al 1997b); Rait et al 2000a), and in English.

Memory clinic access and diagnostic tools

As stated earlier, there are some screening tools for dementia for use with BAME groups. However, there are no diagnosis instruments for use with older people from BAME groups (Botsford et al; 2015). Traditionally, there tends to be the reliance on gathering history from family and carers and mental state examination to form diagnostic conclusions (Botsford et al; 2015).

For those individuals living with dementia or their carers who already cannot speak English fluently enough to interact with health professionals, dementia poses obvious challenges, from proper diagnosis and knowing about the services available at the memory clinic to adequate and appropriate support (Botsford, J., Denning, K.H. (2015): Dementia, Culture and Ethnicity – Issues for All).

'Getting a diagnosis can be difficult for people from BAME communities as the Mini Mental State Examination isn't culturally appropriate. The majority of the older population who originate from India/Pakistan have either not been educated or are illiterate, so asking them to write or draw shapes can be very unsettling and intimidating for them. Also, GP's in the past have not put much emphasis on encouraging people who are concerned about their memory to get a diagnosis.'

Prior et al, 2013

Additionally, a significant proportion of older people from BAME communities are illiterate in their mother tongue (Barker, 1984; Manthorpe & Hettiarachy, 1993; Lindsay et al., 1997b). This has important implications not only for any assessments but also for communication of information about treatment and available services. Communication difficulties can be minimised if the clinician is fluent in the patient's language (Ong, 1991).

There are several other types of diagnostic instruments; however, the main difficulty with all the screening tools for dementia is that only bi-lingual clinicians can use them because the questions are in the BAME older person's language (Botsford et al, 2015; Oommen, Bashford and Shah, 2009). There are no instruments that can be administered by English-speaking clinicians in English, with the interpreter translating the question to the patient and then the answer to the clinician, and with the clinician scoring (Oommen et al; 2009).

A number of BAME people articulated that they wanted to see interpreters who are of their age and background (Ali et al; NIMHE Oldham Report 2008). Importantly though, good interpreting is about more than language proficiency and the literal exchange of words; it is about the interpreter putting forward the user's view of their situation. Guidance from the NCPIC (2013) suggests that the use of sensitive and appropriately translated materials and interpreters who have the correct *language* and *dialect* of the person with dementia is essential to avoid relying on family members to act as interpreters, which is not considered to be good practice.

'Our mother tongue is Gujarati so they should send someone who is Gujarati; it would be better and helpful. If they speak Hindi or Urdu then there would be difficulty with some of the words. Sometimes they send Punjabi people. It would be better if they sent a Gujarati person.'

(Raj Mistry, a Gujarati man)

'I think most people who do interpreting speak Dhaka dialect. This can cause problems for a Sylheti-speaking person. I think Sylheti-speaking interpreters should be provided for Sylheti people. Another example, say a person is from the Chittagong area. If you have a Sylheti-speaking interpreter then this person won't understand the Sylheti dialect. For them, there should be someone from Chittagong doing the interpreting.'

(Maroof Khan, a Bangladeshi man)

JRF, Access to Services with Interpreters (2004)

Hospital admissions

Admission to hospital can be stressful and unsettling for people living with dementia; especially if they are unable to speak English and from a different cultural and religious background. Furthermore, if the staff at Accident and Emergency/Hospital wards are unfamiliar with dementia or indeed the language and cultural needs of the patient can often make the experience, needlessly, more stressful.

However, some A&E departments had considered how confusing, noisy and disorientating the emergency department could be for patients living with dementia. One department had identified quieter, less busy areas away from the main activity of the emergency department (Care Quality Commission 2014).

Emergency admissions to general hospitals involving people with dementia have increased over recent years. Around 14% more admissions occurred in 2012/13 compared with the previous year and around 48% more than in 2008/09. Public Health England (March 2015) reported on the *'Reasons why people with dementia are admitted to a general hospital in an emergency'*; the report stated that people with dementia, along with the general population, are prone to developing physical conditions as part of living and the aging process.

However, people with dementia can have more complex needs than those of the general population because of the condition, which can potentially result in difficulty with assessment or treatment prolonging the individual's recovery period. If the complex needs of such individuals remain unaddressed, then a likely outcome is that emergency hospital care is required.

Data on the impact of ethnicity on risk of emergency admission is fairly limited, but being from a minority ethnic group is associated with a higher risk of emergency admission (Bottle et al; 2006).

Our experience of hospital admissions

As a family, we've had a lot of mixed experiences of hospital admissions with mum; some good and bad but mostly average.

Prior to mum being diagnosed with vascular dementia, mum had been admitted into several psychiatric wards because of her deteriorating mental health. Some wards and staff would provide wonderful care and support to mum and to us, ensuring we were fully informed of every step of mum's treatment and recovery – however I also had many issues with some staff and wards on how mum would be treated. For instance, on one of our regular visits to an out of town (as no beds were available in our home town) psychiatric ward where mum was being looked after, we found that the staff had put her in a room on her own, dishevelled and without her head scarf on, at the very far end of the ward. Establishing who was in charge in this particular hospital ward was a challenge in itself as none of the ward staff were in uniform or identifiable in terms of hierarchy; we certainly got the impression that we were being ignored.

Once the staff nurse was located and identified, I asked why mum had been isolated and left on her own; the response astounded and angered me equally – apparently mum was shouting something in '*her own language*' and the staff didn't know what she was saying. It turned out that mum just wanted some company and was looking for her scarf!

When we first experienced that mum's health was deteriorating was after an incident at home, mum was complaining that she couldn't move her right leg but was insistent that she did not want to go to hospital. From past experiences, we could understand why. Anyway, mum then tried to climb the stairs but was physically unable to do, my eldest son and I ended up carrying mum to her bed – again on her insistence. I called the ambulance much to mum's displeasure, and after some assessment the paramedics suspected a stroke but were uncertain so they wisely decided to take mum to hospital. After spending some time in the A&E cubicle mum was moved to a ward; during which time several tests were attempted, including an MRI but mum would repeatedly sound the panic alarm as she felt claustrophobic. Mum was eventually shifted to the Acute Medical Unit and then discharged without us ever actually getting an official diagnosis of what caused the problem with the leg – we suspected a possible mini stroke i.e. TIA?

We found on one occasion that mum had been left on her own waiting to be discharged, with a bag of her belongings beside her wheelchair at AMU waiting to be picked up by ambulance crew – there was no chaperone with her and we weren't informed that she had been discharged.

Mum's health quickly deteriorated after that incident, and her movement in the leg became increasingly limited and we saw that it was becoming more and more rigid. Mum eventually resorted to having to use a zimmer frame to walk around. This sense of losing 'control' led to mum having increased episodes of depression, anxiety and agitation. But no clinician ever made the connection that mum's mental health could have been linked to, and as a consequence of the mini- stroke. Which is why more work needs to be done to inform and educate people that someone living with dementia may also develop mental health issues.

Mum would suffer from regular bouts of UTIs during the course of her ailing health; and because she would often refuse to take anti-biotics, or any medication for that matter, she would be taken to hospital.

On one of these many admissions I received a call from the ward Sister at 2am because mum was shouting (in Punjabi), but they couldn't understand what she was saying, I could actually hear mum shouting while I was on the phone. When I arrived in the ward I noticed that mum was in a dishevelled state, half naked, left on her own with the curtains fully drawn – I was in tears! When I managed to calm mum down, it transpired that the nurses were trying to force mum to take pills even though her notes explained she is on covert medication because she was deemed 'non-compliant'. It would seem that mum's notes were either not read properly by the ward staff or discussed at the hand over? All mum was asking for was bed sheets to be changed; once I managed to persuade mum to take her medication and had her sheets changed she settled.

Mum then started to suffer from sudden 'blackouts', and whilst these episodes would normally last a few minutes, mum would be taken to A&E and then transferred to a ward – this happened on several occasions. However, it was later thought that mum could have been having TIA's, which as know from research can be a contributory factor to developing vascular dementia – brought on by co-morbidities. We found that the hospital staff and doctors would seem bemused with mum's health and why she was having the 'funny turns'; so much so she was once even prescribed Epilim, an epilepsy drug!

A positive experience of one of the many occasions mum was admitted to hospital was when she was take to the geriatrics ward of A&E; the consultant showed compassion as mum was clearly distressed and waited for me to arrive before undertaking any tests. Mum would only agree to provide mum samples whilst I was with her otherwise the nurse or doctor would know about her displeasure in being treated like a pin-cushion.

Living well with dementia: Life Stories and reminiscence

As the symptoms of dementia develop and individuals begin to lose their short-term memories, longer-term memories may come more to the fore. This may be distressing for people who migrated to the UK during the mid-twentieth century and experienced hostility and racism. It will also make reminiscence work, which can be therapeutic for many people with dementia, very difficult as it may stir up memories of a difficult period in people's lives.

A focus on life stories has been a strong theme in developing person-centred care in services for people with dementia. Crucial to the life story work of many BAME people is the role and meaning of culture, religion, family life, routines, community norms, diet and dress (Botsford et al; 2015).

In Bradford, 'Meri Yaadain' use activities such as cooking or craft which can cut across cultures as there is no need for language. There is also a need to speak to older people about the activities that they are interested in. For example, a group of Irish elders said they were "fed up of being packed off to bingo" and wanted reminiscence projects focused around talking; listening projects; befriending, with particular focus on getting out into the community by going to a café or library, for example; or singing activities.

Understanding the histories and life courses of BAME people with dementia helps care staff to support them to live well. Being aware, for instance, and having an understanding of the origins of people who migrated to the UK from rural Punjab in the 1950's – what that looked like, its smells, sense of community and situation – can help make sense of what the older

people may be saying or experiencing. Having appreciation of migration experiences often includes recognition of the role and influence of racism, hostility, marginalisation and discrimination (Mackenzie 2007).

However, *'talking therapies'* are not part of many cultures. Also, the taboos associated with Dementia mean people are reluctant to admit publicly that someone in their family has the condition. As mentioned earlier, because there is no term for Dementia in south Asian languages it is often referred to in terms such as 'not being able to remember things', 'being forgetful', 'losing memory', 'going crazy' or being possessed by 'Jinns' i.e. supernatural creatures in Islam (see section on Black Magic).

Care givers and care

Carers UK reported that England's half a million Black Asian Minority Ethnic (BAME) carers save the state £7.9 billion a year amounting to 41% of local authority total spend on social care – in stark contrast to the investment that is there to support them. The research further shows that BAME carers provide more care proportionately than White British carers, putting them at greater risk of ill-health, loss of paid employment and social exclusion. Certain groups also experience greater levels of isolation, namely Pakistani and Bangladeshi carers. BAME carers face the same challenges as all carers, but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion (Carers UK, 2011).

It is ingrained in the south Asian community to take care of family members for longer than in the general population, which is usually what most people with dementia want – to stay at home for as long as possible. But there comes a stage in the disease where behaviour and caring responsibilities may put too much of a strain on the family carer(s). It is then that people with dementia are usually admitted to a care home. But most south Asian people feel that care homes are not suitable for their requirements.

Although some husbands and sons are classed as the registered carer (the carer known to services), they frequently defer to their wives, daughters and sisters for practical help. Consequently, the majority of hidden carers (carers unknown to services) are often daughter-in-law whose husbands are officially classed as the registered carer (Dwyer and Coward 1992; Gliberman 1996; Juttla 2011; Yeo and Gallagher-Thompson 1996). Providing care to a person with dementia is a long-term commitment with a potential long term health impact on the caregiver. The daughter-in-law, who have never worked in the UK post-migration, experience the feeling of being 'trapped' and 'powerless' in family (Blakemore and Boneham 1994; Juttla 2011) even more, creating tensions and often finding themselves in powerless positions (Bhachu 1988; Lamb 2000).

Our experiences of care giving

While my mum eventually started to receive the care and interventions that she needed from healthcare professionals, which in itself was often overbearing for my mum and us, there was very little (if any) support for us as family and care givers. The experience of 24/7 caring often led to high levels of stress, depressive symptoms, poor physical health, and disturbance in our family relations and dynamics – we encountered social isolation and periods of financial instability.

It is also worth emphasising that as a family we had to deal with balancing mum's health

care needs in the household whilst maintaining a family life, with children. Undoubtedly it became a strain for everyone in the family and extremely stressful for my wife and me, even though the whole family including my children provided caring duties – our children were in fact ‘Young Carers’.

My wife was my absolute rock; she cared for my mum like her own. She provided all mum’s personal care, which included changing (incontinence pads etc.), cleaning and bathing mum. She also supported me and our children throughout; whilst maintaining our caring roles.

Without the right support in place, carers often find their own health and wellbeing suffering as a result of the care they provide. By putting their loved one first, carers can put their own needs last, struggling to find time to exercise, eat healthy meals, see friends and family, or even see the doctor. A survey by Carers UK found that this is having a knock-on impact on carers’ physical health, mental health, and relationships with others.

This has consequences for carers’ mental health, with 84% saying they feel more stressed, 78% saying they feel more anxious, and 55% reporting that they have suffered from depression as a result of their caring role – significantly more than in 2014 (State of caring report 2015).

The role of gender within the South Asian community amongst older people tends to be traditional and remains quite static in correlation with views and traditions from their country of origin. Whilst older Muslim households generally allow the men to make their own decisions and health and social care, women still rely on their social networks, even though this ‘tradition’ is beginning to be challenged by the younger generation (Hamlett et al.; 2008).

‘Never in residential care... Not done in our community... How can you think about doing this when their children are still alive...?’

A Pakistani carer
(as quoted in APPG Dementia does not discriminate Report 2013)

Against the stereotype of communal responsibility/care, we know of individuals from the south Asian communities who have taken on the sole caring responsibility for relatives with dementia. A number of reasons were given for this, including a reluctance to seek help due to shame surrounding older relative’s behaviour or perceived ‘madness’; community traditions or expectations about caring responsibilities, such as religious duties to care, the role of women in the family, only allowing close relatives to provide support; or because the family themselves are isolated in the community.

The decision to place a person with dementia into a care home is never easy, with a number of factors leading up to the decision. Davies et al. (2012). Most south Asian and Muslim carers perceive home care as being superior to that provided by care homes, as they could provide adequate access to religious and other social factors. Whilst the high costs of nursing homes are often prohibitive, cultural factors dictate that care would be provided in the home, almost certainly by a female caregiver (Wezel et al., 2014).

Older people with dementia from BAME communities residing in a care home are one of the most marginalised and invisible groups of service users in the UK. They experience multiple disadvantages arising from a having a stigmatised condition, living in a setting that may not

meet their needs effectively, and is away from their family, community and social and cultural norms (Botsford et al; 2015). However, the number of older people with dementia from minority populations who may need to be admitted to a care home is rapidly growing.

Our experience of nursing care

I believe we were one of very few (if any) Asian families locally who had decided to place a parent in a specialist, high dependency Dementia Nursing home. As the main carer for mum it was a decision I had agonised over for a long time; and while caring for my mum was a rewarding but hugely challenging experience we found that as her health worsened it was taking its toll on me, my wife and children. Even considering a dementia care home for mum was not easy given religious and cultural norms, and ultimately placing mum in one was a decision I did not take easily or lightly.

The nursing home staff were great; but I had to worked with them during my mum's stay on issues relating to her diet (i.e. halal) and advising them on mum's language, cultural and religious needs. They were very accommodating and understanding, mum was comfortable and content there. But mum's naive social workers and other professionals would often point out during discussions that there aren't many (if any) Asian/Muslim residents in care homes because *'it isn't what they do...'* and that *'you normally look after your own...don't you'* I felt I had to constantly explain my circumstances, and that would depress me.

I still believe there is much confusion within some communities regarding the difference between, residential home and care/nursing homes – that's where I believe some of the issues around stigma arise from. I often explained to people, including relative that mum was actually placed in a high dependency dementia nursing home with 24/7 nursing/clinical presence and intervention because of her increasing needs.

We still had to face negative and ignorant comments form extended family members and individuals in the community – I would often say to them *'live in my shoes as a carer'*; to which there would be no reply.

In summary then, whilst there is limited evidence on BAME communities with dementia and their carers; the following themes appear to recur (Moriarty et al; 2011):

- BAME people living with dementia and their carers face difficulty in accessing services and often access services later
- An inability to exercise choice in care and support services because of lower levels of awareness of dementia and higher levels of stigma among some communities
- Different communities have different expectations about care and service providers have stereotyped BAME groups in terms of *'they look after their own'*

Last years of life care: Palliative Care

The World Health Organisation has defined palliative care as the physical, emotional, social and spiritual care provided to people with advanced and progressive illnesses. Although palliative care is often associated with care for dying people, it is increasingly being recognised that palliative care can be given throughout the course of an illness There has been growing concern in recent years about the accessibility and the responsiveness of

palliative care to the needs of people most commonly referred to in the UK as being 'minority ethnic' (Hill and Penso, 1995; Firth, 2001). Hospices and palliative care services have also been criticised for not engaging fully with race equality.

Robust evidence of ethnicity related disparities in access to palliative care is patchy and is hampered by the poor recording of ethnicity in key data sets and in service provision. Evidence from small-scale and qualitative research suggests that there is a lack of understanding amongst palliative care providers of the specific and varying needs of minority ethnic service users. Wider evidence suggests that specific resources and opportunities need to be established to enable the full participation of minority ethnic patients and carers in user involvement initiatives (Begum, 2006).

People who do not speak the dominant language can face particular obstacles in accessing and using palliative care services (Firth, 2001; Randhawa et al 2003, Gunaratnam 2006b).

The challenge for health and social care in a multicultural society is for practitioners to have a greater awareness of faith and cultural practices to enable better care to the dying person (Johnson et al, 2005; al-Shahri and al-Khenaizan 2005; Mootoo 2005; Prosser, Korman and Feinstein 2012).

Hospices in the UK must meet the challenge of an ageing Muslim population by overcoming barriers that deter Britain's largest faith minority from using their services, ensuring that language, cultural and religious needs are met.

My experience of receiving End of Life support and care for mum

Sadly, my mother became very ill around Christmas time 2015, with her dementia, COPD and pneumonia. After spending around a week in hospital the hospital staff explained that the prognosis of a recovery was not good. So, I decided to make palliative care arrangements at home after having a very frank discussion with the ward manager. He explained that from his experience at the hospital, not many south Asian/Muslim families either want to talk about **end of life** or even consider **palliative care**.

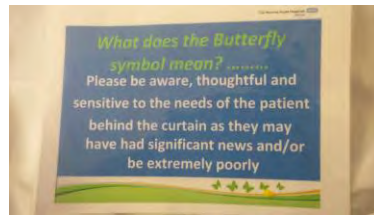
The ward staff, Occupational Therapist and the Transfer Nurse were absolutely fantastic; particularly given that the transfer home arrangements were to take place a few days before Christmas, we all managed to have mum home on Christmas eve.

When mum came home we had amazing support and care for her from district nurses, Spring Hill Hospice (Hospice at Home) nurses, carers and doctors – they were all exceptional.

I made it clear to everyone that I wanted mum at home with me and my immediate family; the response from the nurse who I spoke to was amazing. She said that now that I had decided that we wanted mum home she could start the process of transfer almost immediately.

I informed my family and relatives about the news and said that the staff were happy for mum to have as many visitors at the hospital as she wanted. During one of my visits I noticed that there was a butterfly symbol attached to the cubicle curtain and the curtains were closed. When I entered the cubicle my family members told me that the ward manager had said that it was okay to keep the curtain closed if that's what family and mum wanted;

on entering the cubicle I noticed another laminated A4 sign (picture attached) on the table, it essentially informed people that the person in the cubicle has received significant news and/or is very poorly and to be respectful.



I thought that was such a beautiful and delicately explained message. I also think it would be useful to have the written sign attached on the outside of the curtain or some text on the butterfly sign to make the other patients and visitors aware of the butterfly symbol and its significance.

The ward nurse had passed over the transfer to the NHS Transfer nurse who was very supportive and explained everything that would happen; to be honest I was surprised to learn that some of the paperwork still has to be faxed to other NHS departments and colleagues. At one point, I recall the transfer nurse saying that she was struggling to get hold of a person but was persevering! She was extremely professional throughout.

Whilst everything was going on in the background and the transfer was being arranged, I was able to spend some time with mum in her cubicle and I feel blessed that I was the last person mum spoke to. I then headed home in order to make the necessary arrangements to receive mum and move furniture etc.

During the course of the day I received calls from many people including the OT who wanted to know if we had a carbon monoxide detector - I didn't but we got one, if the room was big enough to allow access on all sides - it was, the bed company phoned about delivery time, the oxygen delivery man called me to arrange the drop off, the carers contacted me as did the transfer nurse - as you can imagine it was all a bit hectic and quite overwhelming. I was in Bradford for a meeting in the morning on the day mum was arriving home and I was on tenterhooks and wouldn't lose sight of my phone.

Had my son and I not been able to move/re-arrange the furniture to accommodate the bed and equipment I think we would have been stuck? I think there ought to be a service that is made available to assist families with the practicalities when someone is being transferred home who is end of life. I'd hate to think if an older people or someone with a disability is unable to move furniture, or what if the person coming home didn't have anyone at all?

The morning of mum arriving home I went to the GP surgery to have mum transferred back to mum's old 'family' doctor - the practice manager and the GP were brilliant, very supportive. The paperwork was ready for me to sign when I arrived at the surgery.

The bed and the oxygen arrived in time - although the bed's air mattress what somewhat temperamental, as the alarm would go off and we couldn't work out how to turn it off or why it was bleeping - even the nurses said they couldn't work out the problem with it.

Mum was home for around 3pm, and all we had were the notes from the ambulance crew - but there was no 'hand-over' and there was no one (nurse/doctor) who either came with

mum or was waiting for her with us at home to ensure she was okay and to support us.

We felt a little isolated at the time and we didn't have any 'intervention' until early evening when the Hospice at Home nurses from Springhill Hospice arrived. They were very professional and took charge straightaway; and quite by chance our GP also arrived home to check on mum while the Hospice nurses were with us. When the hospice nurses checked the medical notes, they noticed that mum's prescriptions had not been signed by the hospital discharge doctor; luckily the GP had only just left and I was able to call him back and he signed the paperwork.

At this stage mum was comfortable but was only able to respond with eye movements - whenever I introduced my children to her, she acknowledged them.

When the district nurses arrived they hadn't brought the syringe driver (for the pain relief medication) with them, but they did bring it the following day.

I think the rotation system between the hospice nurses and district nurses does work, but I'm still not sure what and how their respective roles differ - other than the hospice nurses only work until a certain time and the district nurses are on call 24/7.

Sadly, mum passed away with the whole family around her on Christmas Day.

I had to remain calm and composed in order to make all the arrangements, thankfully I was previously informed by the hospice nurses that I had to call 101 to report the 'expected death'. I had reminded our GP to ensure that he had to upload the 'expected death' status for mum on the NHS system otherwise it would have caused unnecessary delays.

In Islam, we have to try our best to arrange the funeral as soon as possible after death - and in order for me to make the necessary arrangements I had to contact the district nurses to visit and remove the catheter and syringe driver from mum. This again meant I had to leave a voicemail message during a very upsetting time with everyone around me crying and distressed - trust me it was very difficult for me to remain composed (I collapsed later!).

When the district nurses arrived, I assumed they had done everything they had to, however the following morning when my wife and other female members of my family were bathing mum they found that the nurses had left a needle in mum's leg. Thankfully no one was hurt but it was not a nice thing to see.

Soon after mum passed away, and even before the funeral, we started to receive visitors who came to pay their respects. As Muslims, we open our doors to anyone and this 'official' period of mourning lasts for 3 days after which we are meant to regain some normality and re-instate the furniture etc. Although this rarely happens, as we had people visit us for weeks afterwards.

The other issue (probably because it was Christmas) was that we were stuck with the bed and the oxygen tanks in the room in which people were sitting; they were not collected until the new year.

I also think providing some cultural and religious awareness training for EOL staff would be extremely beneficial; particularly so that they understand why we have to bury our dead as soon as possible, and the reason we have the three-day mourning period.

Conclusions

From my own experience, I can conclude that people from BAME communities are still encountering difficulties in navigating the dementia care pathway.

In the progress review of the National Dementia Strategy from a race equality perspective, Truswell (2013) suggested that the policy guidance relating to BAME communities was overlooked and that a more targeted approach was essential.

We know that the current 'dementia care pathway' does not address the unique issues faced by BAME people with dementia; for instance, the 'triple discrimination' covering language, ethnicity as well as dementia.

In the APPG Dementia does not Discriminate 2013 report, it was highlighted that local areas need to understand properly the needs of their local community in order to get the right support in place. There may be assumptions in some areas that there would be no demand for culturally sensitive dementia services. However, the growing numbers of people with dementia from ethnic minorities and the increasing dispersal of older people from BAME groups mean all areas need to be aware of local need. Omar Khan (Runnymede Trust) pointed out that:

'There are now only two local authorities in all of England that have fewer than 800 ethnic minority people living in them, whereas before there were many local authorities that had fewer than 100 ethnic minority people living in them, as recently as 2001.'

However, I find that whilst the APPG report did highlight the good work that is happening in certain areas of the country, I feel it did not go far enough in terms of pushing for changes to legislation or indeed policy reforms. Sadly, I think that was a missed opportunity to make a real difference on influencing national, regional and local dementia strategies.

The reason could be that despite best endeavours to embed equality and diversity in services; the policies and cultures of commissioning organisations may not support this.

The 'protected characteristics' of the Equality Act 2010 can potentially apply to people with dementia, and more so to BAME people with dementia. Essentially, all public sector (e.g. Councils, CCGs and NHS trusts) and third sector organisations have to comply with the law. Furthermore, from April 2013 the new legal duties set out in the Health and Social Care Act requires NHS England and CCGs to reduce inequalities, both in terms of access and around health outcomes of patients.

We also know that the care needs and lifestyles of BAME older communities are changing; which is why it is important to rethink how we can communicate information and raise awareness in communities at grassroots in a more inclusive manner, in other words one size does not and should not fill all. Every community is different and commissioners need to understand that, and further accept that the 'micro' communities that often do not reach out for help are the one that most often need a helping, sympathetic hand.

We need to be mindful that there are differences in how people with dementia want to receive and access support; some may prefer to have carers in their own house; whereas other BAME people may want better access to day and respite services to give carers a deserved break. There is still little known about the prevalence of dementia in amongst

BAME groups, but we know enough to accept that some of these communities are at higher levels of risk than the indigenous white population.

Notwithstanding the challenges, we need to better understand and tackle the issue of social isolation amongst BAME elders; and we need to improve the method of communication and links with potential service-users and the 'silent' carers.

Truswell suggested that improvements in cultural training in the care pathway are linked to the reduction of late diagnosis among BAME communities; therefore, there is still the very real need for cultural competency training and awareness among care professionals so that health care staff are better supported.

Stigma and taboo within the BAME and wider communities are still major barriers to finding solutions for the problems related to Alzheimer's disease and other dementias such as vascular, including low rates of diagnosis and service uptake. Therefore, it is essential to take action to dispel lingering myths about dementia to reduce stigma.

Key Recommendations (see Appendix 1 for the full list)

1. The Government, Commissioners, the NHS and Local Authorities need to focus more on Dementia as part of any wider strategy for older South Asian and BAME people – 'shine a light' on data. Identify current BAME dementia diagnosis rates and set targets for improvement.
2. Strategic organisations (i.e. CCG's) should pledge longer term funding commitments within the voluntary sector in terms of funding and resources to ensure the continuation of work ensuring sustainable outcomes can be achieved. Small third sector groups find it increasingly difficult to gain funding for their work beyond a 'pilot' period - particularly those that work on single identity health issues e.g. BAME Dementia. There shouldn't be the need for reliance on year of year funding, rather it should be integrated into mainstream commissioning.
3. People from BAME communities still have problems navigating the dementia care pathway; commissioners need to identify and support those individuals who deliver awareness workshops in the community to raise awareness of dementia and provide sign-posting.
4. Health care providers need to have an understanding of, and appreciation for the beliefs and religious preferences of their BAME patients and carers in order to provide optimal care for them. A lack of cultural understanding or sensitivity amongst health and care professionals often leads to a lack of flexibility in their responses to people with dementia. Appropriate cultural awareness training should be given, to include experiences of migration, to health and social care staff.
5. Health and social care staff should be employed to do outreach work in the community. Delivering health talks in community languages and distributing information is an effective and well appreciated method of disseminating information. There should be regular visits from district nurses or health visitors trained in dementia to assess carers' need for help. The assessment process should be quick and user friendly.

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Appendix 1: Recommendations (FULL LIST)

Stigma and taboo within the BAME and wider communities are still major barriers to finding solutions for the problems related to Alzheimer's disease and other dementias such as vascular, including low rates of diagnosis and service uptake. Therefore, it is essential to take action to dispel lingering myths about dementia to reduce stigma.

1. Services need to 'reach out' to families and ensure the cared for person is supported to live well with dementia at home.
2. Develop an Asian/BME link nurse role specifically for Punjabi/Urdu/Bengali and other Asian speaking people of Asian origin; ideally someone who is a qualified community psychiatric nurse, who speaks Punjabi, related languages and English and understands the cultural, religious and linguistic issues
3. Instigate and promote community based health and dementia champions; these individuals who work and are trusted within a community. These people can also help 'open the door' to more sensitive issues such as mental health and sexual health – including for older people.
4. Assumptions must not be made by service providers that member of the south Asian community necessarily 'look after their own' – undertake listening events to learn about the issues affecting disparate communities, and then formulate tangible outcomes to address the inequities.
5. Share 'real-time' good practice with service providers and healthcare professionals; as it was suggested at a 'listening event' in Bradford that useful information tended to end up in research journals, rather than with health practitioners or commissioners.
6. More 'grass-roots' awareness of dementia needs to take place, as it is important that awareness campaigns do not just target people who are already using services. There needs to 'out of the box' thinking in how to reach communities that need to be reached; there has to be community based workshops, roadshows with other agencies, partnership working between the third and statutory sector, word of mouth, engaging with key figures in community such as BME elected members and utilising local media – print and radio. By educating community members on dementia and the support available would help overcome the stigma and help people with dementia to live more independently.
7. Leaflets should be produced in community languages ensuring that information for the Asian community should target the entire family to help communicate key facts between generations. The contents should be written clearly, simply, with images for easy reading – however literature should be complementary to an overall marketing campaign.
8. Printed information should be displayed in GP surgeries, community/faith groups, libraries and publicised on local radios, free newspapers and via other BME media sources. Watching DVDs and listening to the radio are more effective ways of reaching older carers
9. There should be one person contact throughout diagnosis and a specialist dementia nurse (maybe the Asian Link Nurse?) should be based in GP surgeries to be involved in relevant dementia care and signpost to secondary care services.

10. Local commissioners should develop an understanding of the dynamics of their local communities. Engaging with some communities may require more outreach work or support, but this does not mean that they are 'hard to reach', just that different strategies might be needed.
11. GPs to undergo dementia training as proposed in the Dilnot review in order to promote timely diagnosis to reduce the number of south Asian communities reaching out to services at crisis point.
12. There should be a better working relationship between GPs, community health teams, chiropodists and district nurses and other clinical personnel.
13. Mainstream research into dementia needs to include ethnicity data, which should lead to developing evidence based strategies in partnership with BAME communities, dementia 'activists', carers and service providers to remove barriers.
14. Develop, in partnership with third sector groups, effective community based strategies i.e. Dementia luncheon cafes/Memory garden. For example, Tower Hamlets as part of their 'Faith in Health' project have established a bespoke Dementia café for Muslim people within a mosque
15. More life-story work ought to be instigated, in a sensitive way to capture the rich history of the early generations that arrived in the UK
16. Empower local religious leaders and work with faith groups who can share information to the respective communities. The 'Faith in Health' project is one such initiative in Tower Hamlets which trained 120 imams to raise awareness of dementia; the imams subsequently delivered sermons on dementia.
17. Undertake accurate statistical analysis of the number and profile of BAME older people in care home settings.
18. Different religious, cultural or ethnic groups are not homogenous; there is a need to speak to service users as well as community workers and recognise that there are 'communities within communities' (i.e. micro community clusters) who have their own distinct cultural circumstances and needs.
19. Service managers and clinicians should recognise that spirituality needs to be considered as part of a whole-person approach to the care and treatment of an individual; service users should be asked about their spiritual and religious needs.
20. Develop a cultural awareness programme for specialist Dementia care homes so that they become more inclusive.
21. Ensure the STARS care team have received cultural awareness training so that they are more prepared for the needs of diverse communities.
22. Promotion of services needs to reflect the way in which the various communities access information. Not everyone has access to the internet, while other may prefer information

via the internet as opposed to speaking to a social worker or call an automated phone line.

23. The carer's assessment should be carried out as soon as the cared for is referred to the Memory Service. This would speed up the process of providing support to carers and the person they care for.
24. Provide culturally sensitive respite for carers, as spending some time away so often would help 'recharge their batteries' and provide some much-needed space. Carers should be involved in decisions about ongoing care, to ensure that any decision-making is an inclusive process
25. Ensure end of life care programmes integrate values and preferences from minority ethnic groups instead of only those from the dominant culture/community.
26. Involve direct interaction with BAME communities (such as outreach or recruitment of healthcare workers and volunteers from BAME and faith groups.
27. Develop information and provision for hospital consultants and GPs about available palliative care services for BAME communities
28. Develop a BME Dementia Nursing Home to accommodate the religious, cultural and language needs of an aging BAME community.

Appendix 2: Sharing Good Practice from Rochdale

Rochdale Context

In Rochdale, the local authority in its Joint Health and Wellbeing Strategy (2012-2015) reported that people are living longer and there is an increasing elderly population. The population aged 65+ in Rochdale is expected to increase by 34.6% between 2008 and 2025. It further states that 28% of the borough's population is of Asian origin; worryingly there is a 10 year gap in life expectancy between the most deprived males and females compared to the most affluent groups.

Following the many recommendations from the All Party Parliamentary Group 'Dementia does not Discriminate' report on Dementia and in partnership with Cartwheel Arts, BME Health and Wellbeing (a community group based in Rochdale) co-ordinated and arranged awareness raising sessions at several community organisations in order to allow accessibility (as practicably possible) to members of the south Asian communities (mainly Pakistani, Kashmiri and Bengali) in Rochdale.

'PURANI YAADEIN'
Come along and join us for a FREE afternoon snack to share your old memories
...and improve your understanding of
DEMENTIA

IF YOU HAVE ANY MEMORABLE PHOTOGRAPHS OF PLACES AND FAMILY OR EVEN OLD PHOTOS FROM YOUR HOME COUNTRY - WE WOULD REALLY LIKE TO SEE THEM AND USE THEM IN OUR DVD AND PUBLICITY MATERIAL.
PLEASE BRING THEM TO ANY SESSION

| AVAILABLE DATES / TIMES & LOCATION | | | |
|---|--|---|---|
| Tuesday 04th May 2014 10am to 3pm Crescent Community Centre Tumbale Street, Rochdale | Wednesday 7th May 2014 10am to 3pm Crescent Community Centre Tumbale Street, Rochdale | Thursday 08th May 2014 10am to 12pm Mandak Youth Project Unique Centre, Dalfield Road Rochdale, OL16 2LP | |
| Monday 12th May 2014 10am to 3pm Mandak Community Centre South Street, Rochdale | Thursday 15th May 2014 10am to 3pm MBCP 145 Railway Street, Rochdale | Thursday 22nd May 2014 10am to 3pm Mandak Youth Project 145 Railway Street, Rochdale | Thursday 29th May 2014 10am to 3pm Mandak Youth Project Dalfield Road Rochdale |

Just come along on the day or call Sarah or Kim on 07968 99 222 / 07978 908 710

Supported by BME Heywood, Middleton and Rochdale Clinical Commissioning Group's social investment fund.

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Regional Clinical Commissioning Group

اپنی پرانی یادوں کو ہمارے ساتھ شیئر کریں۔
بہتر سمجھیں اور جانیں۔۔۔
ڈی مینشیا (جھولنے کی بیماری)
اگر آپ کے پاس کوئی پرانی یادگار تصویریں ہیں تو ان کو اپنے ملک کے پرانے ٹی وی اور ٹی وی پر سٹور کیا گیا ہے۔
ہم ان کو دکھانے کے لیے ان کو ہمارے ساتھ شیئر کریں گے۔

اس دن آئیے ہماری یادوں کو شیئر کریں۔
07519 818222 / 07878 908719

স্মৃতিচারণ
আপনার আত্মকথা আমাদের সাথে শেয়ার করুন।
আপনার স্মৃতি আমাদের সাথে শেয়ার করুন...একটি মুহূর্তই হয়।

ডিমেনশিয়া
উচ্চ বয়সী ব্যক্তিদের জন্য

আপনার মনে যদি কোনো পরিচিত স্থান বা ব্যক্তির স্মৃতি থাকে তবে আমাদের সাথে, হাসপাতাল, পরিবার বা অন্য কারো সাথে এসে বা স্থানীয় পরিষেবা থেকে আমাদের সাথে পরিচয় করে জানতে পারুন।
আমরা আপনাকে বিভিন্ন ধরনের পরিষেবা বা সহায়তা করতে পারি।
আপনার স্মৃতিতে যে ছবি বা ছবিগুলি রয়েছে সেগুলি আমাদের সাথে শেয়ার করুন।

বিগিটিং টেলিফোন লাইন: ০৭৫১৯ ৮১৮২২২ / ০৭৮৭৮ ৯০৮৭১৯
১০:০০ - ১৫:০০

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In addition to the bi-lingual (Urdu & Bengali) leaflets (above) and posters being distributed in all communities and displayed at all the community venues; there was an intensive (bi-lingual) advertising campaign on Crescent Radio (community radio station) and also several interviews on BBC Radio Lancashire, Radio Manchester and on the BBC Manchester Radio Indus (Asian) show.

The workshops sessions were aimed at and within local communities; designed flexibility so anyone can drop in to learn more about Dementia and share their 'Purani Yaadein' (Old Memories).

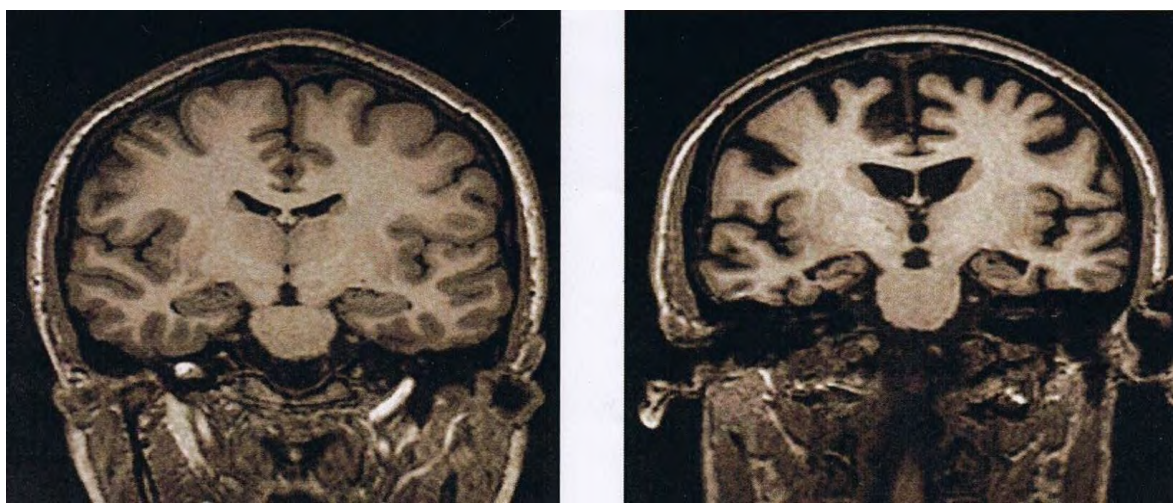
It is important to remember that the dynamics in relaying key messages within the South Asian community is very different to the indigenous community; the approach has to be very flexible when reaching out to 'need to reach' communities.

Many weeks were spent working and engaging with community workers/activists leading up to the road shows in talking about the pertinent issues relating to Dementia i.e. increase of vascular Dementia within the South Asian community and the associated stigma attached to mental health.

To work with the Pakistani, Kashmiri and Bengali communities directly; a series of awareness raising workshops and road shows were organised in order to challenge the stigma surrounding the condition. The talks were delivered in Punjabi, Urdu, Kashmiri, Bengali and English, supported by the Alzheimer's Society.

This project linked traditional Dementia services in the borough with targeted South Asian services in culturally appropriate ways i.e. language, hospitality, culture, religion and the utmost respect.

The workshop planning, design and material was kept low-key and very informal due to the subject area but more so because of the target audience were more likely to be less literate in English and also their own language. The workshops discussed subjects such as how dementia can be identified and managed within the context of the community i.e. highlighting issues with local Mosque Imams and community elders and 'activists'. What was particularly effective in explaining Dementia as a disease of the brain was the Alzheimer's Society's brain scan picture – it is very visible and made an instant impact.



Pic 1. Healthy Brain

Pic 2. Brain with advanced Alzheimer's

'Mein Pagal Nahin Huin' (*I'm Not Mad*) Role-play

During the planning of the 2014 BME Rochdale Dementia Open Day, much discussion took place on how best to deliver a 15 minute message to the 250+ members of the (predominately) south Asian audience on how people living with dementia and their families are affected by this disease. Often misunderstand, people with dementia or any other mental health problems are referred to as 'Pagal' (Crazy/Mad) and therefore there is still a huge stigma attached to condition.

So, apart from delivering talks in community venues or speaking on Radio shows, the decision was made to consider an innovative approach that was visual and audible; something that the audience could understand and relate to and would guarantee an instant response. The role-play was a huge success, it was conceptualised and directed by Shahid Mohammed of BME Health and Wellbeing; and the volunteer 'actors' were all in fact carers. The uniqueness of the role-play was that it was delivered in English and Punjabi.

BME Health and Wellbeing also produced a DVD on 'Purani Yaadein' (old memories) to raise awareness of Dementia amongst the south Asian community in Rochdale and to capture the 'Purani Yaadein' of the first generation of south Asians who settled in Rochdale.

The making of the film was inspired by the team's personal experiences; whose parents arrived in the UK in 1960's to fill the labour shortage in the textile industry. The film recorded a number of old memories of people of that early generation as part of the project, which also included community based reminiscing workshops.

The film features interviews from health care professional including Dr Shanu Datta, Consultant Psychiatrist for Older People at Rochdale's Birch Hill Hospital and Julie Mann, Dementia Advisor from the Alzheimer's Society.

It is acknowledged through research that DVDs tend to be more popular than leaflets, especially among those who have limited literacy in their primary language or in English (Moriarty and Manthorpe 2012). Other organisations have created DVDs in different languages (Scottish Dementia Clinical Research Network 2010) as an alternative or to supplement written information.

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South Asian Community Dementia Project

Recognising Dementia within the South Asian Community

✔ **What are the symptoms?**
Whilst dementia can affect different people in different ways, there are some common signs to look out for, such as:

- Loss of communication skills (reading, writing or speaking)
- Forgetfulness
- Finding it hard to Remember things
- Not Recognising people or family members
- Changes in Behaviour or Personality
- A change in Eating and Sleeping pattern
- Losing sense of Time or Place
- Repeating the same thing over again
- Confusion
- Apathy and Withdrawal
- Loss of ability to do everyday tasks

Many carers and families may not identify or fully understand that these symptoms could be early signs of Dementia.

If you are worried about your memory or any of the above symptoms, or know someone who is, contact us for more information:

Shahid Mohammed (BME Dementia Care Navigator)
Mobile: 07516 818 222
Email: info@bmehaw.co.uk | @bmehaw

English

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সাত্বি় এশীয়ান কমিউনিটি ডিমেনশিয়া প্রজেক্ট

ডিমেনশিয়া বিডি়নজনকে বিডি়নভাবে আক্রান্ত করতে পারে

ডিমেনশিয়া বিডি়নজনকে বিডি়নভাবে আক্রান্ত করতে পারে, তবে কিছু সাধারণ লক্ষণ বা উপসর্গ খোঁজা রাখা দরকার, যেমন:

- ছায়া আদান গ্রহণ বা যোগাযোগের দক্ষতা কমে যাওয়া (শুধা, লেখা, কথা বলা)
- বিধ্বস্তি, ভুলে যাওয়ার অভ্যাস, অমনোযোগিতা
- কোনকিছু মনে রাখা কঠিন বা কষ্টকর মনে হওয়া
- আচরণ বা ব্যক্তিত্বে পরিবর্তন
- যাওয়া দাওয়া এবং ঘুমের প্যাটার্নে পরিবর্তন
- সময় বিভ্রাট হতে অমনোযোগের কমজ্ঞা হারানো
- একই জিনিস বারবার পুনরাবৃত্তি করা
- বিভ্রান্তি বা পুসিয়ে ফেলা
- অসীম, ঔপাসীনা
- দৈনন্দিন কাজকর্ম করার ক্ষমতা হারানো

অনেক কেয়ারার এবং পরিবার ডিমেনশিয়ার এই আগাম লক্ষণগুলোকে ডালাভবে চিহ্নিত করতে বা বুঝতে নাও পারেন

আপনি যদি আপনার স্বস্থি কিংবা উপরোক্ত লক্ষণগুলো নিয়ে চিন্তিত হন বা এমন কাউকে জানেন, তবে বিস্তারিত জ্ঞাের জন্য আমাদের সাথে যোগাযোগ করুন:

শাহিদ মোহাম্মদ (BME ডিমেনশিয়া কেয়ার নেভিগেটর)
মোবাইল: 07516 818 222
ইমেইল: info@bmehaw.co.uk | @bmehaw

Bangla

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ساؤتھ ایشین کمیونٹی میں ڈیمینشیا کی پہچان

علامت کیا ہیں

ڈیمینشیا کے اثرات مختلف لوگوں پر مختلف انداز میں اثر انداز ہو سکتے ہیں مگر کچھ عام نشانیوں سے بھی ہو سکتی ہیں۔

- بات چیت کرنے کی صلاحیت کا کچھ ہلا ہونے، لکھنے اور بات چیت کی صلاحیت کچھ ہلا ہونا
- بول چال ہلکا ہونا
- چیزوں کو یاد رکھنے میں دشواری
- کچھ کے اثرات اور لوگوں کی پہچان کا کچھ ہونا
- عام رہنے میں تبدیلی آنا، رہنے میں تبدیلی آنا
- کھانے پینے اور سونے کے وقت میں تبدیلی آنا
- وقت اور جگہ کے نشانیوں کو سمجھنے میں دشواری
- ایک ہی بات کو بار بار دہرائے دینا
- اچھی طرح یاد رکھنے کی صلاحیت کا کچھ ہونا
- اچھی طرح یاد رکھنے کی صلاحیت کا کچھ ہونا

بہت سے گہرے رد و اثرات کے اثرات انداز میں اس چیز کو سمجھ سکیں کہ اوپر درج شدہ علامات (نشانیوں) اصل میں ڈیمینشیا کے شروع ہونے سے پہلے نمودار ہونا شروع ہو سکتی ہیں۔

اگر آپ اپنی یادداشت کے بارے میں گہرے رد و اثرات کی علامات سے کسی ایک کے بارے میں بھی سوچیں، لکھیں، تو مزید معلومات کیلئے رابطہ کر سکتے ہیں

شہید محمد (ڈیمینشیا کیئر نیویگٹر)
Mob: 07516 818 222
Email: info@bmehaw.co.uk | @bmehaw

Urdu

Dementia information leaflets in English, Bangla & Urdu produced by BME Health & Wellbeing

Appendix 3: Faith and BAME Groups End of Life Care (EoLC) 'Discussing the Unthinkable' Conference.

The main focus of this conference was to increase the awareness of Black, Asian & Minority Ethnic (BAME) and Faith communities on issues relating to End of Life and Palliative Care and Advance Care Planning. We know from research that BAME and faith communities have not previously had the opportunity to discuss this sensitive issue in a safe environment; which is why **BME Health & Wellbeing** decided to hold this conference at the heart of the BAME community.

We spoke to user groups prior to the conference about any prior experiences of palliative care and were able to share our team member's own experiences of EoLC. We also talked about the support that is available from EoLC providers and care homes. Based on our preliminary work; we discussed the need to raise the awareness of 'End of Life' care amongst BAME and faith groups with Kim Wrigley and other SCN colleagues – who completed supported the idea of holding a conference.

Our discussions with Julie Halliwell, the Chief Executive of Springhill hospice in Rochdale were also very positive; particularly in light of the '*Bridging the Gap*' report on how hospices can do more to engage with Muslim communities. Julie was very keen to work together on this project. A link to the report: <http://www.hospiceuk.org/media-centre/press-releases/details/2015/11/12/new-report-calls-for-action-on-data-gaps-to-increase-access-to-hospice-care-services-for-muslims>

The culmination of our work with professionals and the community capacity building sessions was the successful Faith & BAME Groups EoLC conference that took place on the **24th March 2016 at 'Apna Ghar' KYP in Rochdale**. We had over 130 people in attendance, with representation from BAME and faith groups, care homes staff, hospice staff, religious leaders, EoL community transfer nurses, community members and local activists.

The conference was facilitated by Maqsood Ahmad (NHS Manager) and led by BME Health & Wellbeing Founder, Shahid Mohammed. There were several speakers, included Dr Amir Hannan who talked about his personal experiences of end of life care for a family member.

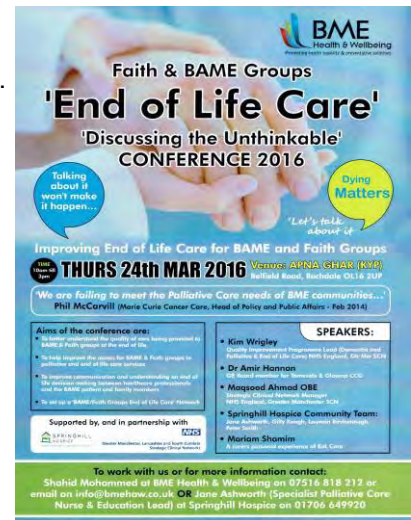
BME Health & Wellbeing worked with several BAME user groups and community activists at a local level leading up to the conference to understand and explore the issues around End of Life Care within the South Asian and Muslim community in Rochdale, as this subject has never really been talked about. We wanted to hear from them on whether or not they have made any decisions about their health, future care or advance planning.

The local focus groups were also an opportunity to find out about the south Asian community's end of life care needs and to do carry out some capacity building work.

Please email info@bmehaw.co.uk if you would like a copy of the full report.

During the Faith and BAME Groups End of Life Care (EoLC) 'Discussing the Unthinkable' Conference organised in Rochdale by BME Health & Wellbeing for the NHS-SCN on 24th March 2016. The following key issues were raised:

- There is a wish/preference for family to care for them at the end of life.
- BAME women and men equally worry about what happens after death.
- Women wanted female carers and men would want male carer if wife is not available would prefer same sex for personal care.
- A worry that if they ask for help wishes won't be adhered to.
- In change of culture not many women are comfortable with caring, due to commitments e.g. working full time etc.
- When death certificate is not written correctly and it can cause delays in registering the death
- When a death is referred to the Coroner and a post mortem is needed; which may not be sensitive to cultural and religious norms.
- Information from GP not always passed onto out of hours' services, can be especially problematic at weekends, statement of intent not always completed
- Engagement with community does not always take place due to fear and misunderstandings.
- Dealing with distress, how to cope with distress - can often feel alone, let down, don't recognise the situation
- The shame aspect of people going into a nursing/care Home or hospice – more awareness needed.
- Post mortems: Muslims need it done quickly and non-intrusive, but coroner can be slow causing delays.
- Information booklet needed on resources available, in different languages.
- A healthcare information centre should be based in the community, professionals need to outreach from the centres and hospitals. They should work with closely with the third sector, groups like BMEHAW.
- Meaningful and appropriate engagement with the community - not everyone has access to social media/email.
- Simplified translated material should be produced.
- Death certificates need to be available immediately.





‘Shahid Mohammed’s dedication to making a difference to people with dementia and their care givers from the South Asian community, and BME communities in general is inspirational’

Anya Ahmed, Senior Lecturer, Social Policy, University of Salford