



Art and dementia in the UK South Asian Diaspora

Elizabeth Lynch with Spare Tyre

Art and dementia in the UK South Asian Diaspora

By Elizabeth Lynch with Spare Tyre

About Spare Tyre

Spare Tyre is a leading participatory theatre company producing multisensory, accessible and inclusive work. For 25 years they have created theatre for, with and by older people aged 60 plus and for eight years they have focused projects on people living with dementias. Their interactive and non-verbal flagship show *The Garden* targets audiences at the later stages of dementia and has been highly acclaimed across the UK.

About the Baring Foundation

The Baring Foundation is an independent foundation which protects and advances human rights and promotes inclusion. Since 2010, the Foundation's arts programme has focused on supporting participatory arts with people over the age of 60, particularly those facing disadvantage or discrimination.

Cover image: Women's group at the Highfields Centre in Leicester.

**A separate Executive Summary
of this report is also available at
www.baringfoundation.org.uk**

Contents

Executive summary	3
Part 1: Introduction	7
<hr/>	
Spare Tyre	
Background to this research	
Research questions	
Methodology	
Researchers	
Part 2: Context	9
<hr/>	
What is dementia?	
The prevalence rates of dementias amongst the communities in the UK	
Culture, ethnicity and dementia, desk research summary: literature summary	
Part 3: Conversations about dementia	12
<hr/>	
Knowledge and experience of dementias	
Stigma and culture	
Accessing and sharing information	
End of life	
Communicating with and caring for people with dementias	
Barriers to accessing support	
Part 4: Culture, arts, creativity and dementia	20
<hr/>	
Arts and health context	
Love Unspoken	
Cultural sensitivity and care provision	
Care homes: Spare Tyre's experience	
Care homes: Attitudes in South Asian communities	
Poor expectations of care home provision	
Positive experiences of care homes, difficult decisions	
Culture and the ideal care home	
Arts and culture for people living with dementia	
Part 5: Reflections and next steps	28
<hr/>	
Part 6: Summary and recommendations	29
<hr/>	
Knowledge and awareness of dementia, access to services, stigma	
The role the arts can play	
Recommendations	
Acknowledgements	32
Bibliography	33
Appendix: Research questions	35

“The perceived risk of booking The Garden transformed to revelation as care home managers saw the show’s positive impact on residents and relatives.”

Spare Tyre



The Garden

Executive summary

ART AND DEMENTIA IN THE UK SOUTH ASIAN DIASPORA

There is growing awareness of the intrinsic and therapeutic value of artistic work for people living with dementia and provision for them by arts organisations has expanded. However, this has not reached the South Asian communities spoken to in this research in any significant way.

Performances of Spare Tyre's dementia-inclusive show, *The Garden*, in selected South Asian care homes were successful as managers saw the show's positive impact on residents and relatives.

The number of older BAME people living with dementia is growing. There are important roles for funders, arts organisations and artists to engage with South Asian communities to ensure the benefits of the arts are more widely shared.

BACKGROUND AND CONTEXT FOR THIS RESEARCH

Spare Tyre's interactive and non-verbal flagship show *The Garden* targets audiences at the later stages of dementia and has been highly acclaimed across the UK. However, despite the inclusive nature of *The Garden*, the company have been acutely aware that the UK South Asian diaspora community has not significantly engaged with theatre, arts and dementia.

Spare Tyre are now asking why not?

They are aware of some dedicated residential South Asian care homes that offer dementia care that is culturally specific in terms of faith – Hindu, Muslim and Sikh. They also know that most South Asians living with dementias are living at home, with some accessing South Asian day care services or within a culturally diverse service that often does not meet cultural or religious needs.

South Asian is a broad term for many different communities and Spare Tyre are aware of and sensitive to language, cultural attitudes, behaviours and faith.

This report specifically talks about engaging communities from the Indian, Pakistani, Bangladeshi and Sri Lankan diaspora.

This research was supported by the Baring Foundation and is limited to the UK South Asian Diaspora as a first step to researching with care the 25,000 BAME people living with dementias in the UK.

The Garden's Director, Arti Prashar, wanted to know about the reasons for the lack of engagement with artistic work when the wider society has opened up to creative interventions.

This research asks:

- Is stigma attached to dementia within the South Asian communities?
- Can Spare Tyre use their multi-art form artistic practice to dismantle this stigma by offering creative workshops and engaging artistic experiences for people living with dementias, their families and carers?
- How culturally specific does an arts project need to be for an ageing South Asian population to take part?

During March – June 2019 we interviewed 123 people in eight South Asian community groups and eight individuals working professionally in the dementia field. For context and specific data and commentary on dementias in UK South Asian communities, reading included online material and a range of reports, written between 2009-2018, and literature on artistic work with people living with dementias, e.g. funded by Baring Foundation, Arts Council England, Wellcome Trust and others. In addition, the researchers attended several conferences, symposia and seminars on dementias, health and wellbeing, and spoke to arts and community colleagues working with older people. Spare Tyre performed *The Garden* in five specialist South Asian Care Homes for residents and families.

Whilst material was found on stigma, ethnicity and culture in government, academic and other literature, there was no mention of artistic work with South Asian communities. In contrast, artistic work for people living with dementias has been well documented and is advocated as beneficial for both therapeutic and intrinsically valuable reasons, notably in the All Party Parliamentary Group Inquiry on Arts, Health and Wellbeing, 2017. However, this artistic practice, as Spare Tyre had observed, has not reached the communities we spoke to in any significant way.

“Artistic practice with people living with dementias has not reached the communities we spoke to in any significant way.”

FINDINGS

Dementia, stigma and culture

The findings from our conversations with the groups and dementia professionals supported our literature review. BAME people living with dementia and their carers face difficulty in accessing services and often access services later. Choice in care and support services is limited due to lower levels of awareness about dementia and higher levels of stigma. The communities have different expectations about care and services.

Service providers have often stereotyped BAME communities in terms of ‘they look after their own’. Services are generally not culturally appropriate. In South Asian languages there is no word for dementia, which makes framing and describing the disease difficult. Not planning for the specific needs of BAME communities with dementia can lead to their marginalisation but narrowly focusing on the distinctiveness of their needs can also create exclusion.

In addition to these findings we observed that the knowledge gained from the lived experiences of South Asian families, especially women who take the main responsibility for caring in the home, is a valuable resource for their peers and for professional and volunteer dementia services. Their voices are underrepresented and greater efforts should be made to reach out and engage with them by dementia service providers and artists/arts organisations working in this field.

“The women really wanted to add their voices to those that are normally heard and seen... Once you are able to access those communities we shouldn’t be surprised that they have a lot to say.”

Dementia care professional

Stigma around dementias continues to be prevalent although there are indications that this is starting to shift, especially where targeted health outreach is being undertaken and where GPs are providing good information and signposting support.

Grassroots cultural and community organisations can play a vital role for underserved groups by facilitating access to services and raising awareness of dementia care and support. These groups are often operating with slender resources and have part-time and/or voluntary staff.

The main barriers to taking the initiative to engage with mainstream services or being aware of what is on offer are social isolation, language/communication and trust. These factors are also cited across the specialist literature and the cultural reasons are covered in some detail.

Faith institutions can play a significant role in addressing issues around stigma and dementia and in promoting access to services and support for dementias. They are often important social hubs. Silence by faith leaders on mental health and dementias can contribute to the maintenance of stigma.

The role of the arts

Spare Tyre's offer to discuss stigma, dementias, arts and culture was swiftly accepted by the eight groups we contacted. Three of these groups booked follow up workshops to co-create content for Spare Tyre's new show *Love Unspoken*, which will tour to theatres from Autumn 2019. This new interactive, multi-sensory performance will respond to the research findings and reflect the cultural specificity required to engage an ageing South Asian population in a meaningful way.

“Maybe when people know that music is like medicine then their perception of it will change. Music is medicine, we know this. Even if it is religious music, it is still there.”

Broadcaster working with dementia

All the groups described arts and creative activity as part of their cultural landscape. This varied depending on the faith, social and regional backgrounds of the individuals. Examples given included music – both religious and secular, film and photography, dance, folk arts, food and celebrations to mark festivals and weddings. Content created for artistic activity will need to take into account this cultural diversity in terms of art forms and genres. However there are many artistic and cultural references that are shared between the older generations across the diaspora communities.

“The perceived risk of booking The Garden transformed to revelation as care home managers saw the show's positive impact on residents and relatives.”

Spare Tyre's persistence in reaching out to South Asian care homes was ultimately fruitful. The perceived risk of booking *The Garden* was transformed to revelation as the care home managers saw the show's positive impact on residents and relatives and the opportunity for follow-up professional development for their care staff. Being able to talk about specific cultural content, as is planned for *Love Unspoken*, will make a difference for future approaches to these care homes and encourage other artists to consider a similar approach to making inclusive work.

“I thought to myself, why not try something new just once in our lives.”

Staff member, Bhakti Shyama Care Home, Balham

None of the literature on dementias and the BAME communities mentioned the role arts could play as part of a cultural offer either to engage South Asian communities with information about dementia or to bring enjoyable, inspiring and uplifting experiences to people living with dementias, families and carers. It is hoped that this research and the inspiring model of practice that *Love Unspoken* can shift thinking within South Asian diaspora communities, the services they encounter and the professionals and agencies who work with them.

The qualities, knowledge and insights of Spare Tyre enable their understanding of the creative tension between linking the essential, culturally specific elements to fresh innovative approaches that are respectful of cultural etiquettes. The performers are skilled at understanding the smallest, slightest responses from people living with dementias, often with other complex physical conditions. Through non-verbal communication they can respond in the moment. For carers, family members and loved ones with a dementia, taking part together is something that makes their lives more enjoyable.

RECOMMENDATIONS

The value and role of arts and creativity in health and wellbeing is now widely recognised. National and local arts organisations and individual artists offer a wide range of artistic experiences for people living with dementias,

some of which includes activity that specifically supports physical and mental health and wellbeing. The benefits of artistic activity have been recognised at government level.

01

Strategic private funders, Arts Council England and Care Commissioning Groups need to work better with the Alzheimer's Society, Age UK and similar organisations to connect with BAME communities in order

to consult, engage and share the opportunities and the benefits the arts can bring to the dementia care landscape. Social Prescribing¹ is one avenue to pursue but can only be part of the wider approach.

02

Arts, culture and heritage organisations could direct critical attention and resources to ensure that their programme strategies reach out to, invite and welcome BAME people living with dementias. If South Asian communities are not

engaging with your offer for elders, consult with grass roots community groups to find out what could make a difference. How could the cross-sector system come up with the best ideas?

03

The researchers urge **all artists interested in arts, community, justice and inclusion:**

- to engage with South Asian communities at a local level

- to encourage South Asian artists from the UK diaspora to bring their artistic and cultural sensibilities and language skills to the table for this generation of elders and the next
- to change the stories we tell about dementias involving the people who are living them.

¹ Health Secretary Matt Hancock pushed the arts up the health policy agenda in 2018 by announcing £4.5m investment in GP Social Prescribing. Social prescribing is a non-clinical intervention in someone's life that should enable improved health and wellbeing. It's not like medical or surgical treatment. It can be any activity that a person enjoys that supports their ability to manage their health – from sport and walking to painting and dance to volunteering.

Introduction

[PART ONE]

SPARE TYRE

Spare Tyre is a leading participatory theatre company. The work exists to engage those least involved in the arts and cultural activity. Spare Tyre produces multisensory, accessible and inclusive theatre and outreach activity locally and nationally.

Over the last 25 years they have created theatre for, with and by older people aged 60+. Over the last eight years they have focused projects on people living with dementias including paid carers and family carers. Their interactive and non-verbal flagship show *The Garden* targets audiences at the later stages of dementia – a group rarely engaged with. *The Garden* experience is proof they have produced an accessible and inclusive show that both people with and without dementia respond to in a very positive way.

Spare Tyre receives support from Arts Council England and other charitable trusts.

BACKGROUND TO THIS RESEARCH

Spare Tyre has toured many UK regions including London, Scotland, Hertfordshire, Wales, Surrey and Sussex. Despite the inclusive nature of *The Garden* and its predecessor *Once a Upon a Time*, they have been acutely aware that the South Asian community has not significantly engaged with theatre, arts and dementia.

Spare Tyre are now asking why not? They are aware of dedicated residential South Asian care homes, e.g. in London in the boroughs of Harrow and Wandsworth. These specifically offer care that is culturally specific in terms of faith – Hindu, Muslim and Sikh. They also know that most South Asians living with dementias

are living at home, with some accessing South Asian day care services or within a culturally diverse service that often does not meet cultural or religious needs. 'South Asian' is a broad term for many different communities and any research undertaken should be aware of and sensitive to language, cultural attitudes, behaviours and faith. This report specifically talks about engaging communities from the Indian, Pakistani, Bangladeshi and Sri Lankan diaspora.

This research was supported by Baring Foundation and is limited to the UK South Asian Diaspora as a first step to researching with care the 25,000 BAME people living with dementias in UK.

RESEARCH QUESTIONS

This research project wanted to discover:

- Is stigma attached to dementia within the South Asian communities?
- Can Spare Tyre use their multi-art form artistic practice to dismantle this stigma by offering creative workshops and engaging artistic experiences for people living with dementias, their families and carers?
- How culturally specific does an arts project need to be for an ageing South Asian population to take part?

The small scope and concise focus for this research project reflects the available resource. It was undertaken March-June 2019 by independent researcher Elizabeth Lynch and Artistic Director/CEO of Spare Tyre, Arti Prashar.

METHODOLOGY

Desk research, e.g. online and via Dementia Research UK.

Attendance at a regional symposium and a national conference about arts and dementia. (See bibliography section.)

Conversations with eight community groups, a total of 123 individuals.

The groups were located in Havering, Hounslow, Leeds, Leicester, Slough and Tower Hamlets (three groups). Six groups were comprised of women only and two were mixed, men and women (one was a group for married couples). The groups included: some people working as carers, some individuals living with a dementia diagnosis, 114 women aged 40-80+ and nine men 70+. The groups were identified through the researchers' personal professional networks. The eight groups varied in terms of language, culture, faith, social demographics and country of birth – sometimes within the groups themselves. Individuals included second generation women born in UK, people from India (Gujarat, Punjab, and via Kenya, Uganda), Bangladesh (Sylhet), Pakistan (Punjab) and Sri Lanka.

The conversations were structured around a series of ten questions and conducted both in English and South Asian languages, supported by some on the spot translations by group members and by Arti Prashar. Over samosas, sweets and tea, the discussions began with some shyness and reticence but quickly became open and frank, sharing emotional stories about living with dementias and their own knowledge and insights. It was clear that these group meetings are an important social and support network for their members.

Interviews with eight professionals working with South Asian communities and dementias.

Data on recent targeted approaches and feedback on visits with *The Garden* to Hindu, Muslim Sikh care homes supplied by Spare Tyre.

Spare Tyre's reflections on their use of the arts to introduce themselves to South Asian audiences and make better connections especially in the care homes.

Next Steps: how the research findings support the development of *Love Unspoken*, Spare Tyre's new production for people living with dementias.

We hope that this research will be of interest to:

- health professionals and researchers working in the field of dementia
 - artists and arts organisations
 - trusts and foundations; Arts Council England
 - statutory and voluntary sector organisations who support people living with dementias.
-

Note to readers:

- Quotes from written sources *in italics*.
- Verbatim quotes by interviewees are *highlighted in red*.
- All verbatim quotes are used anonymously.
- Verbatim quotes by interviewees working as medical researchers and other professionals. are attributed to their generic role, e.g. Medical researcher, Community Connector, unless stated otherwise, with permission.

RESEARCHERS

Arti Prashar is a pioneering expert on the benefits of non-verbal performance for people living with dementias. Her work in this field has been recognised through a Winston Churchill Fellowship in Dementia, Ageing and Spirituality, The Wellcome Trust funded project *Created Out of Mind, Timeslips*, and features in the Indian online publication LILA Interactions as 'Renaissance Person'.

Elizabeth Lynch works with artists, communities and organisations as a producer and strategic advisor to create ambitious cultural programmes. She is an Associate Research Fellow, School of Arts, Birkbeck University and a member of the Diversity and Inclusion Steering Group for Wellcome Trust. She was the founding Director of Roundhouse Studios and has worked as a theatre director with artists and communities in India and Pakistan, most recently on the UK/India arts programme *Silk River* 2017 in West Bengal. She is Chair of Theatre-Rites, trustee for Arts Catalyst and Education Advisor for Spitalfields Music.

Context

[PART TWO]

“Globally, the numbers of people living with dementia will increase from 50m in 2018 to 152m in 2050, a 204% increase.”

World Health Organization²

The information in this section was gathered through reading a range of papers, blogs and online resources that refer specifically to research on dementias in UK Black, Asian and Minority Ethnic (BAME) communities. Wherever possible more specific data has been extracted that refers to the South Asian communities who are the subject of this report. A full bibliography of sources is included in at the end of this document.

WHAT IS DEMENTIA?

Dementia is an umbrella term for a set of symptoms that affect cognitive function, such as memory loss, confusion, difficulty with day-to-day tasks and personality change, which get worse over time. Depending on the stage of the progression of dementia and the type of dementia, there will be different symptoms and behaviours exhibited by the person living with dementia. Alzheimer's disease is the most common cause of dementia, accounting for approximately two thirds of all cases. Other forms include vascular Dementia, Dementia with Lewy bodies and Primary Progressive Aphasia.

THE PREVALENCE RATES OF DEMENTIAS AMONGST COMMUNITIES IN THE UK

More than half of the UK population has been affected by dementia. Today there are more than 850,000 people in the UK living with dementia and this number is set to rise to over one million by 2025. The condition has a devastating effect, not only on the person diagnosed with dementia, but also on the people around them....More than half (52%) of adults know someone who has been diagnosed with a form of dementia, typically a family member such as a grandparent (15%) or parent (11%). Yet our results show that large pockets of misunderstanding around dementia still exist.³

At the time of the 2011 Census, 8.4% of the population of England and Wales identifying as Asian were aged 60 years and over. The Indian ethnic group had the highest percentage of people aged 65 years and over (at 8.2%), and the Bangladeshi group had the lowest (at 3.7%).⁴

² *Dementia fact sheet*, World Health Organisation, December 2017.

³ *Dementia Attitudes Monitor*, Alzheimer's Research UK, 2018: www.dementiastatistics.org/wp-content/uploads/2019/02/Dementia-Attitudes-Monitor-Summary-Report.pdf#zoom=100.

⁴ Source: gov.uk published 22 August 2018. Available at: www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/age-groups/latest/asian-ethnic-groups-age-profile.

Those from black, Asian and minority ethnic backgrounds are less likely to recognise dementia as a cause of death (40%) compared to those from a white ethnic group (53%) and more likely to say they do not know what happens in a person's brain to cause dementia (22% compared with 14% of those who are white).⁵

From the 2011 Census data there are estimated to be over 12,400 people in England and Wales of a South Asian ethnic background over the age of 65 living with dementia, over 5,200 (36%) of these living in London.⁶

This number is set to increase seven-fold by 2051 compared to the two-fold increase in the majority population. The main reason for this expected increase is the ageing of some key immigrant populations but better awareness amongst minority ethnic communities and current policy to increase timely diagnosis may also play a part. Furthermore, evidence suggests vascular dementia is more common in minority ethnic groups (particularly South Asian, African and Caribbean) due to higher prevalence of risk factors such as diabetes, hypertension, and cardiovascular disease. Dr Sahdia Parveen and Professor Jan R Oyedbode.⁷

Amongst the BAME communities it is 'Vascular Dementia' that is more likely to exist. This is partly associated with the lifestyle choices amongst these communities – therefore an opportunity exists to work on risk reduction. Mohammed Akhlaf Rauf.⁸

CULTURE, ETHNICITY AND DEMENTIA: LITERATURE SUMMARY

“ They (our community in general) just accept it's more to do with ageing, rather than get the diagnosis. ”

Cultural and social differences can be a barrier for some ethnic communities accessing health and social care services, such as the stigma or lack of understanding of mental health problems. Doctoral student Mohammed Akhlaf Rauf highlights the importance of thinking about dementia from a cultural perspective and managing care related transitions.

For example, as part of our interviews, we asked people if they had a word for dementias in their mother-tongue. The nearest words from Urdu, Bengali and Punjabi translated as 'forgetting illness'. This reflects the research by Rauf.

BME communities are less likely to have a word for dementia in their first language, they are more likely to present with later stages of dementia – usually due to crisis and receive a mis-diagnosis due to a lack of culturally appropriate assessment tools. Mackenzie, 2006, Moriarty, 2011, Mukadam et al, 2013.

Culture and ethnicity are often perceived to be associated with the 'other', the 'immigrant' or 'minority communities'. It is only with recognition that we all have a culture – the language we speak, the food we eat, the dress code we have and the other social norms that we adhere to, that we begin to realise communities fall back on cultural norms as this helps maintain identity. For there to be an ethnic minority, there must also be an ethnic majority. This is a point worth noting as it reminds society that just as we may have our own identity, the minority communities will also have theirs....

⁵ *Dementia Attitudes Monitor*, Alzheimer's Research UK, 2018: www.dementiastatistics.org/wp-content/uploads/2019/02/Dementia-Attitudes-Monitor-Summary-Report.pdf#zoom=100.

⁶ *Black, Asian and Minority Ethnic Communities and Dementia – where are we now?* David Truswell, A Race Equality Foundation Briefing Paper, November 2013. Available at: www.better-health.org.uk.

⁷ Better Health Briefing 46, *Dementia and Minority Ethnic Carers*, A Race Equality Foundation Briefing Paper, June 2018. Available at: www.better-health.org.uk

⁸ See: www.meriyadain.co.uk/information-2.

The Eurocentric view may be perceived by the general public to be centred on the individual or nuclear families, Afrocentric and Asia-centric tend to be more about the collective; families, communities and the greater success of the sum rather than the individual. Forbat, 2003.⁹

*People of South Asian origin in the United Kingdom may recognise symptoms associated with dementia **but not conceptualize these as part of an illness** even when they are severe. They may consider that individual and family efforts will ameliorate symptoms of dementia. Laurence et al, 2008.¹⁰*

"My mother in law and mother – they're old you know. But it's not diagnosed – but they do forget sometimes – but you don't know – this older life, whether they're actually ill or it's just age."

Most of the current generation of minority ethnic elders in the UK moved here as adults, and relatively few have acquired fluency and literacy in English. In one study, 35% of older Asians in a UK city could speak English, 21% could read and write in English, and 73% could read and write in their first language. Any tests requiring numeracy, or literacy either in English or in their first language, may therefore disadvantage these older people....

They will be further disadvantaged by any test item assuming familiarity with a different culture to the one they have experienced while growing up (Dementia Memory assessment and Diagnosis Service for Cornwall and Isles of Scilly). This combination of factors may have a substantial impact on people's experience of ill health and of seeking help. National Dementia Strategy Equalities Action Plan.¹¹



Feltham Asian Women's Group, Hounslow

⁹ Cited in *Why research culture, ethnicity and dementia?* Mohammed Rauf, October 2017. Available at: www.meriyaadain.co.uk/2017/10/05/why-research-culture-ethnicity-and-dementia.

¹⁰ Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry*, 193(3), 240-246.

¹¹ *National Dementia Strategy: Equalities Action Plan*, UK Department of Health. Available at: assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215522/dh_128525.pdf.

Conversations about dementia

[PART THREE]

This section brings together the findings from conversations with South Asian community groups and with individual professionals working in the field of dementia care and research in UK South Asian diaspora. The eight groups and eight individuals were identified through the personal and professional networks of the researchers during March–June 2019.

KNOWLEDGE AND EXPERIENCE OF DEMENTIAS

“If they are old, very old they can forget everything, so we don't worry is it dementia.”

We asked all the groups ‘How much do you know about dementias?’. In our sample of 123 individuals in eight groups, 31 (25%) indicated that they had ‘a little knowledge’ of dementia and 22 (17.8%) indicated that they had ‘quite a bit of knowledge’. For five of the groups, it was the first time that they had discussed the subject during their sessions. What came through strongly from the conversations was that most people knew very little about dementias, but were very keen to know more. We shared basic information about types of dementia and the participants also shared their knowledge of where information could be found in person or online. Most people indicated asking their GP as their first port of call.

The low awareness of dementias sits alongside the issue of stigma and shame around the condition, which we explored with the groups in depth (see Page 16). The interviewees described family members either receiving/ seeking no diagnosis or very late diagnosis

of family members. This has a detrimental effect on their access to high-quality, person-centred support, where this exists.¹² Some of the women we met were socially isolated and saw the group they attended as a lifeline for wider social contact, information sharing and moral support. Getting a diagnosis is an important gateway for health and social care support not only for people with dementia but also their carers, who are in most cases female. It was evident from the discussions that there was good awareness around the relationship between diet, lack of exercise and diabetes. It was also clear that the groups welcomed the opportunity to talk about dementia and they were eager to learn more.

It is important to avoid assumptions that families from BAME communities do not require any outside help. Carers of people with dementia experience greater strain and distress than carers of other older people. The risk of stereotyping is a failure by services to reach out to BAME communities and ensure services are in place to support the wellbeing of carers and individuals with dementia. All-Party Parliamentary Group on Dementia.¹³

¹² Pockets of good practice exist, but in many areas there is lack of support that meets the needs of people from BAME communities. The Department of Health, local governments and the NHS are not ensuring that good practice is disseminated. Families may not seek support because of a desire to care for the person within the family, but also community pressure to do so even when the burden of caring is considerable. There is also a lack of awareness of services, how they might help or how to access them. Previous experience of hostility and racism among some communities may also deter people from seeking help. All-Party Parliamentary Group on Dementia, *Dementia does not discriminate*, 2013. Available at: www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf.

¹³ All-Party Parliamentary Group on Dementia, *Dementia does not discriminate*, 2013.

Knowledge about the symptoms of dementia within the groups was mainly around memory loss: भूलने की बीमारी 'Bhoolane kee beemaaree'

(Hindi) بیماری بھول (Urdu), Bimārī bhula jāṇā (Punjabi) – translated as 'forgetting disease'.

Bardhoykko jonitho karonay sriti sokti lup paichay (Bengali) – loosely translated as 'due to old age, memory is lost or weak.'

"To start with forgetfulness – the older person I used to know would say 'Oh I have had no food for the whole day' even though she had just been fed. Or she would say something that is not true but then you cannot say that she is lying. We thought she is lying but then we get to learn – So now we know she is not lying. We didn't even know it was an illness."

"One minute they will know oh this is the person I have met – the next, few minutes later they say 'Oh where did you come from – I didn't see you all day.'"

People with personal experience of dementias observed other symptoms such as eyesight, hearing loss and other physical deterioration, hand tremor, 'fear of the world', mood swings and personality changes:

"They do go aggressive and angry."

"It's a form of depression."

"They see and hear things that aren't there."

"There's also no concept of time – they don't know whether its day or night, what day it is what month it is."

"And also I would add that not all symptoms for everybody are the same. And for some it's a slow progress, for others it can be a very fast progress as well."

"One man got very angry while I was caring for him. He attacked me. I phoned the office and they said just leave the house and I did. Another woman used to love her handbag and keys and if we ever touched it, she used to get very very angry. She attacked me too."

(Professional support care worker)

"We have to lock the windows, doors and everything. And hide the keys. Otherwise they will just walk out..."

One group described other consequences of either not seeking or, in some cases, not being given a diagnosis. This related to prescriptions for medication being repeated unnecessarily and sometimes leading to further problems.

"I think they prescribe medication 10 years ago for somebody and they carry on. They don't do any research if the person needs it any longer. My mum didn't have any blood pressure but she was still taking blood pressure tablets. She was living in London, so when she got ill and went to Wrexham, they changed her medication and said she didn't need all this. She went back to London – the GP just carried on the same medication. And they had sent a report to say she didn't need them."

"GPs are so quick at just giving medicines. They don't have time for pensioners."

"You try and make an appointment – they want to know what's wrong before they give you an appointment. And I think with the old people they are just happy to push the prescription and that's it."

There were some powerful personal descriptions about living with dementia in one group:

"I can give you my example. I was cooking something and then I forgot I got to switch off the gas as well. Then I realised when the lady came, the kitchen is very, very hot – it is very, very difficult to admit you got dementia. When my daughter told me you can't drive anymore – I said what's the matter? She said you have got dementia... I said look at my record – for the last 20 years I've been driving – I haven't done anything silly. And she was very good – she said but you are not the only person on the road. There are so many others...."

His wife did not feel that there was enough information from the NHS about dementia for her:

"No, no, no – there's no information. They just say he has this, he has this and you have to live with it. There needs to be more awareness."

"There should be more centres like this one – not just one in Leeds. We should have more everywhere. We should know about this. People should know how to handle these people because they are very scared, and also they can be dangerous to themselves and to other persons."

Another described her dilemma as her husband's carer when considering flying to Sri Lanka:

"Sometimes I think, if I fall ill in the flight will he be able to communicate? Because he depends so much on me. He feels so safe with me around, and most probably if I'm not there he might be better. But now at the moment even like walking, I walk at my pace but I keep watching him, but if I'm not there he's a little bit more alert. I find if I'm not there – he'll stop and look to see if I'm coming. So my concern is when I'm going with him on my own (to Sri Lanka) if I'm OK that's fine, but (if not) will he be able to phone someone and say we are here?"

STIGMA AND CULTURE

“The whole concept of dementia is very secretive – we don't like to say or share as we are afraid of what people will say or think.”

We asked all our groups and interviewees whether dementia was a taboo or an embarrassment to talk about in their communities.

"So for instance I didn't tell my family I came here today, I said 'I'm going to a new class'. I came because I wanted to, but didn't openly say to family where I'm going. Well my father-in-law had come – I didn't want to tell him – as it would have confused him and I didn't have time to explain so I just said 'I'm going to a new class' rather than say 'I am going to Dementia Café.'"

From our conversations it appears that the findings of the All-Party Parliamentary Group on Dementia in 2013 continue to resonate six years on:

Evidence shows that knowledge and understanding about dementia in (BAME) communities is very low. There are myths and taboos attached to the condition. Although stigma is attached to dementia in all communities, it is likely that levels of stigma are higher in BAME communities. The stigma and low levels of awareness surrounding dementia make it more difficult for people to get the support they need.

A number of barriers may prevent access to services such as: dementia not being perceived as an illness, shame and stigma being associated with dementia, negative experiences of services in the past, inadequate provision of culturally appropriate services, language barriers and lack of awareness of available services. Parveen et al, 2017; Giebel et al, 2014; Mukadam et al, 2010 & Daker-White et al, 2002.¹⁴

When asked if people in their communities were embarrassed to talk about dementia, and if it was a stigma, the overwhelming majority of the people we spoke to strongly agreed that this was the case.

"I think they find it an embarrassment, that's why they don't talk about it widely or reach out for help. I don't think people understand the extent of what it is. So they just think it's a loss of memory, it happens to everyone. That's the kind of insight people have."

Half of the groups were unequivocal in their agreement that it was a topic that was avoided, evaded and associated with shame. For some there are even associations with black magic/possession by spirits. Some families caring for relatives with dementia did not find it easy to discuss outside the home, or sometimes even with each other.

¹⁴ Cited in Better Health Briefing 46. *Dementia and Minority Ethnic Carers*, Dr. Sahdia Parveen and Professor Jan R Oyedbode, A Race Equality Foundation Briefing Paper, June 2018 www.better-health.org.uk.

"I've got a friend and his mum's quite bad. I've said to him a lot of times why doesn't your mum come to all these group activities – she's too embarrassed to come and even the husband is embarrassed to admit that his wife is losing her memory. And you are thinking 'this is very common, you should be trying to get her out and about meet people, do things' – but no. So she doesn't come anywhere – which is quite sad."

"I feel that even though there is more awareness of dementia and the many issues around this, I do however feel that specific cultural and targeted support for BAME communities is still lacking. I have found that both the dementia sufferer and their carer are working in isolation from the wider community. I do think this is primarily because dementia is still seen as taboo within their culture and community." (Community Connector, Manchester)

We heard some very sensitive accounts of situations where the combination of lack of knowledge and stigma combined to create very poor care conditions, for example forms of domestic abuse and locking people with dementia in their rooms.

"My ex-brother-in-law, he had Alzheimer's, if they went shopping they would lock him up in the room – so he doesn't wander off anywhere."

However, the stigma dial is being turned down and perceptions are changing. Half of our groups contained people who gave a more mixed response to this question. A few felt comfortable talking about dementias (mainly the younger women in their 40s) and

attributed the embarrassment of others to lack of awareness. With older people, they said dementia was a stigma like the one attached to mental illness.

"People who don't know (about dementias) just say they are crazy/mad/stupid."

"Some people feel free to speak about it – others don't. And they have lots of reasons why they don't tell."

"They are more open (now) but I don't think there is full understanding about the illness. (Lots of nodding in agreement). They don't understand – it's very much like 'Oh they forget'. And they don't realise what that forgetfulness is and how it impacts daily life and things that you take for granted. So yes 'he forget' but they don't know what that actually means – you know what that means to family members, in financial terms, to somebody's independence? You know, one day you are making your own decisions and all of a sudden somebody has to make those decisions for you. You know somebody's looking after your money, somebody's making health decisions – things that you and I would take for granted."

One group in particular were very comfortable using the words 'dementia'. They were very open about saying that their loved one has dementia, it's experienced in their community, in their family, amongst their neighbours. Several women mentioned the need to distinguish dementia from being a 'mental health' problem in the eyes of that community and/or a 'just a growing old' problem that cannot be catered for.

ACCESSING AND SHARING INFORMATION

“Once you have knowledge, then you are not afraid.”

All the groups expressed their wish to access more information about dementias and other health conditions either at their group meetings or other trusted venues such as places of

worship and other specialist voluntary sector organisations.¹⁵ This was ascribed to two key factors, trust and language. This finding fits with some recent research:

¹⁵ Interviewees also mentioned libraries, GP surgeries and NHS venues.

Some in minority ethnic communities have expressed a preference for community based services provided by third sector organizations (Parveen et al, 2017) perhaps due to such organizations being more readily trusted and being better equipped to meet cultural needs, for example, many third sector organisations employ engagement workers to work with minority ethnic communities. Dr Sahdia Parveen and Professor Jan R Oyedbode.¹⁶

"Information needs to be accessible – different languages, different methods – using those kinds of things for a better understanding."

All the groups suggested that interactive workshops would be an attractive and useful way to acquire information.

"There also has to be regular workshops around dementias – so there is more education, better understanding. There is very little that happens in community venues where people are brought together and have these kinds of conversations."

"How we can reach those groups? (My) experience would be by a community partner/connector¹⁷ being the bridge to access that community....communities have more of a connection with community members and people already imbedded into that community.... community workers, voluntary groups or even health professionals with already longstanding relationships created. I would go further to say that this works better and quicker if the link is someone within the ethnicity of that community." (Community Connector, Manchester)

"You only find out when you are in the middle of it, or experiencing dementia."

As in any community, people may not engage much with information about dementias until it affects those close to them. Many of us want to delay having to think about all the implications it will have, and the impact on our lives. With a fragmented mass media, mass health campaigns are much more challenging. Therefore health services need to regularly reach out to communities to instigate and maintain conversations about dementias,

and making the subject part of other targeted health awareness campaigns, e.g. diabetes, heart disease.

"The conversations need to happen in community settings that people are aware of and use regularly, so people know where to find you, e.g. drop-in clinics. Rather than expecting people to go to you." (Medical Researcher, Manchester)

"Not everybody is going to go to Dementia society or to their doctor for a particular leaflet on dementia. It's very much about the experiences that people have – also information through word of mouth – everybody's experience and symptoms are different. Diagnosis is important but that information has to be shared at different venues and there has to be some proactive work done to share information."

Information about dementia on mainstream media, such as BBC TV's *Our Dementia Choir with Vicky McClure*¹⁸ does not reach many South Asian audiences, especially where English isn't spoken – 'if it isn't being shown on the Asian channels it ain't happening'.

Several groups suggested that involving faith leaders at gurdwaras, mosques and temples in promoting access to information and encouraging community support for people living with dementia could help to address the stigma. This was also suggested by four of the dementia care professionals we interviewed, based on their situated experiences as South Asians and their own work in the BAME dementia field. Some women, in several of the groups, felt that this would also be a good way to engage men in conversations about dementias.

"Men, they don't talk about it! They don't even go to the doctors! It's very cultural – within the South Asian communities, men tend to talk less about dementia or any illnesses. More often it's left to the women to deal with these issues."

"The men don't see it as their job to care even if it is their actual physical parents they won't necessarily think that it's their responsibility."

¹⁶ Better Health briefing 46. *Dementia and Minority Ethnic Carers*, Dr Sahdia Parveen and Professor Jan R Oyedbode.

¹⁷ A similar role of 'Dementia Navigators' was proposed in *Black, Asian and Minority Ethnic Communities and Dementia – where are we now?* David Truswell, A Race Equality Foundation Briefing Paper, November 2013.

¹⁸ Available at: www.bbc.co.uk/programmes/m0004pyb.

Having visited the groups and listened back to the recorded interviews, it is clear that this research has already achieved one thing. At least eight new conversations about living with dementias have begun, conversations that will be continued both independently by the groups themselves and in further dialogue with Spare Tyre.

"You are doing an excellent job because you are coming to the group – you are not getting this group into your premises. If you were inviting this group, I don't even think half of them would come. So this is an excellent initiative you are taking!"

"I think just getting that conversation going in the community will be an achievement... The problem is that the issue is kept hidden, because of shame or simply because of a lack of awareness of where to go for help."

(Medical Researcher, Manchester)

"Just having you guys here today – I learnt something important about the heart affecting things – I didn't know that before. I assumed (dementia) was hereditary. But knowing that (new information) is really great."

END OF LIFE

It is also worth noting that with about half the groups we raised the issue of end of life, writing wills, and talking about their wishes for health and finances with family members. Many didn't want to talk about it saying it was in God's hands, or it brings death closer. Others engaged with the issues and understood how empowering it could be especially for women.

"There's a belief or an attitude, you are getting ready to die. You have lived your life, worked hard, studied hard, raised your children and they are married and now you are old and going towards your death, things are set and you need to prepare for that. You are not living to live, you are living and preparing towards your end ... it makes me feel scared for my parents when I think about that... I am sure in every culture that the time of their death is not easy to discuss." (Mental Health Professional)

COMMUNICATING WITH AND CARING FOR PEOPLE WITH DEMENTIAS

“You have to acknowledge that you have to be extra patient, that you have to be like really take your time with them – don't rush – don't rush your conversations – and I think it's just being kind and generous.”

Love, respect and kindness can help all of us to think sensitively about communication and care. As one woman said, knowledge removes fear. It could also be said that knowledge invites curiosity. Because dementia changes our loved one's behaviour, we need to change ours.

"I take her out to eat all the things she enjoys, that she used to cook, before I would never walk in Asian eateries with her – now I do."

Whether working with or living with dementias, we all have to learn new and better ways to communicate and to amplify the best of our caring skills. People in the groups cited: patience, taking time, listening, encouraging socialising, agency and independence, being calm, not contradicting facts or reminding them that they have memory loss, being more tolerant.

A woman in one of the groups, who is a professional care worker shared this account:

"This is about my client. If you're calm, then she is looking at you. If she feels you are OK, then she is calm and talking quietly. If you asking 'How are you' then she very angry – 'Why you come here, who are you – go away!' If you are

calm then you can go and sit down slowly, then she is relaxed. Yes very hard working with dementia.” (Professional care worker)

Another woman talked about caring for her father:

“They want to lead the best quality of life that they can without being like ‘Oh no you got illness so we have to take care of you – you know we have to constantly smother you in care’. I think they really appreciate if you’re normal with them, have normal conversations with them and just say ‘Would you like me to help you with this?’ Let them try and do as much as they can for themselves. I think they really appreciate that.”

People had many ideas about activities that could keep the mind stimulated and active and offer either distraction or focus such as social activities and events, music, arts, crafts, puzzle

books, snooker and jigsaw puzzles. The arts activities are covered in more detail in Part 4 of this report.

The interviewees also described the benefits of doing things in same age groups: men being with their friends, ladies going out and about, having tea, going to the park, sitting and chatting, doing exercise, seeing children. It makes people feel better, better than medicine and ‘without the side effects’.

One man living with dementia himself described the importance of doing everyday things to keep him stimulated and to stop depression such as walking and attending the dementia café. He talked about the importance of faith and how going to places of worship, where his community gathers lowers his blood pressure and brings peace.

“Being a part of this congregation – I am so uplifted – going to temple, mosque, gurdwara – people go there to meet and see people.”

BARRIERS TO ACCESSING SUPPORT

“And I think you must make them feel very welcome. Not make them feel they are disabled or something.”

As already outlined, lack of awareness about dementias, stigma in the community and social isolation for individuals and families are all factors that can be barriers to accessing information and support. Some described resistance to attending some social groups (e.g. organised by Mencap) and events for elders citing language and transport as barriers:

“Maybe those people feel they don’t want to go there, maybe they feel they are too old as well.”

“The language barrier is another one for a lot of the Asians, ‘cos if they don’t speak English I don’t think they feel they can go. And another thing is transportation as well.” Some families who are caring for people living with dementias keep them isolated from the wider community and this can be compounded by the fear/lack of awareness of the illness in those around them.

“But most of the time – if people know people who have memory problems, they say no, don’t go to them – don’t want to know them – it’s too much trouble.”

The carers themselves can become isolated when they don’t have a structure of support from their wider family. This is explored in films¹⁹ and a blog²⁰ by Shahid Mohammed, Dementia Dekh Bhaal Project Manager and former carer, Tide:

‘They look after their own’ – a phrase some in the south Asian communities are only too familiar with hearing.... Access to information and services is equal, we often hear, but how many are aware of the shortcomings in equity even before we get to equality.... We know from studies that many mainstream dementia services are not fit for purpose and do not meet the needs of diverse communities... We also know that carers from South Asian communities usually struggle on and only reach out for help

¹⁹ See: www.tide.uk.net/join_tide/experiences-stories.

²⁰ Available at: www.dementiaaction.org.uk/news/29681_a_blog_from_shahid_mohammed_of_tide_on_the_dementia_dekh_bhaal_project.

when in crisis. It is important that south Asian carer voices are heard, but crucially that voices reach decision-makers on service provision.

Although all the people we interviewed spoke about the cultural obligation to care for their elders, it was acknowledged by some that this was not always possible, making it important for service providers to not assume health care services are not required. Half of the people in the sample we met who care at home for parents with dementias have support from visiting care workers.

We had much useful dialogue about how for many of us there is a gradual process of acknowledging that someone close to

you has memory loss and is changing. We have to accept the futility of contradicting or challenging their mistakes and learning how to respond to aggressive or uninhibited behaviours.

“You are right, they do become aggressive, it’s that frustration that comes out because they can’t remember something or it’s on the cusp of remembering – they know it’s there somewhere but they are finding it difficult to articulate themselves or speak or say something – so having a lot – a lot of patience with them – and to give them the time to be able to express themselves as best as they can in that given situation.”

UNDER-REPRESENTED VOICES ARE A VALUABLE RESOURCE

“The women really wanted to add their voices to those that are normally heard and seen... Once you are able to access those communities we shouldn’t be surprised that they have a lot to say.”

Dementia professional

It is evident from our conversation with professionals working in the field of dementia and the UK South Asian diaspora that they are aware that there is very little in terms of diversity of voices from people with dementia in the academic health research landscape.

“My mum would never openly talk about her condition and I kind of became the default spokesperson for mum even though my wife would be the main carer. One of the things we come across regularly is often the male of the family will be down as the main carer, whether it is for social services or council support or whatever, but actually it is the women, the daughters and in many many

cases the daughters-in-law.... Actually the onus when it comes in Islam is on the son to make sure that I have adequate provision in place for the care of my mother. It is not obligatory for my wife to provide that care, she can turn round and say, ‘No it’s not my duty, you need to provide for her’. For her to do it for me is an absolute blessing and we know that God will reward her for that.” Shahid Mohammed

Shahid Mohammed speaks eloquently about the need to capture lived experiences from more South Asian people who are facing day to day challenges as carers, especially the lack of respite that they face. Through Dementia Dekh Baal and Tide he works to communicate these needs so that dementia service providers can consider more innovative ways to support BAME communities.²¹

“Thank you to you, the mums really enjoyed having a voice.”

²¹ Health service support for carers from minority ethnic communities is limited by a wide range of barriers to accessing services. There appears to be a preference for utilising third sector voluntary organisations, and partnership working may be a good strategy for service development. Better Health Briefing 46. Dementia and Minority Ethnic Carers, Dr Sahdia Parveen and Professor Jan R Oyedbode.

Culture, arts, creativity and dementia

[PART FOUR]

“Why, if there is so much evidence of the efficacy of the arts in health and social care, is it so little appreciated and acted upon?”

Rt Hon. Lord Howarth of Newport²²

For this section, it will be useful to bear in mind the wider conversation about arts, health and wellbeing that also offers a context for this research.

ARTS AND HEALTH CONTEXT

The Inquiry Report *Creative Health: The Arts for Health and Wellbeing*²³ has brought wider recognition to the powerful contribution the arts can make to health and wellbeing. Its three key messages are worth quoting here:

- *The arts can help keep us well, aid our recovery and support longer lives better lived.*
- *The arts can help meet major challenges facing health and social care: ageing, long term conditions, loneliness and mental health.*

- *The arts can help save money in the health service and social care.*

The conjunction between arts, health and wellbeing and dementia is treated at greater length in the report because the Inquiry recognised that dementia is ‘a national challenge of outstanding importance’. The Inquiry firmly urges NHS England ‘to include the arts in personalised post-diagnostic care’.

LOVE UNSPOKEN

As one of the leading pioneers of artistic and creative encounters with older adults for over 25 years, Spare Tyre’s questions for this research sought to interrogate stigma around dementia and to explore whether their multi-art form artistic interventions could help to dismantle it. In doing so, Director Arti Prashar’s core objective for *Love Unspoken* is to provide an enjoyable, meaningful experience for people living with dementia that connects with ‘the new person emerging’. Through demonstrating

different multi-sensory and non-verbal ways to communicate and stimulate people with dementia, *Love Unspoken* also seeks to inspire and empower both professional and family carers to develop and expand their interactions with loved ones.

Through asking people about their lived experiences of dementia and care, and exploring their attitudes to home care support and residential care, Arti had the opportunity during our discussions to give some examples

²² *Creative Health: The Arts for Health and Wellbeing*, The All-Party Parliamentary Group on Arts, Health and Wellbeing, July 2017 www.culturehealthandwellbeing.org.uk/appg-inquiry.

²³ *Ibid.*

of creative interventions and engagement. Through visiting specialist care homes and day care facilities with the company's current show *The Garden*, Spare Tyre have been able to observe and receive useful feedback from families and care staff after performances.

Without even asking if groups would like workshops to explore the use of arts for people living with dementias, all the groups asked

for a return visit to deliver a practical session. This response has answered one of our key research questions and enabled Arti to begin to co-create the content for Love Unspoken from June 2019 as this report was being written. Her process is also being informed by the questions we asked our groups and individuals about cultural specificity and what is needed for an ageing South Asian population to engage in a meaningful way with the arts.

CULTURAL SENSITIVITY AND CARE PROVISION

It is widely accepted (but not always implemented) that if we want services that are effective and efficient, a productive approach would be to engage with and consult communities at a grass-roots level, to listen to their advice, their needs and insights. The evidence from our research conversations indicates strongly that services should be culturally sensitive. All our groups talked about the importance of language, food and faith to meet the needs of their elderly loved ones living with dementia.

*Families are reluctant to use services that do not meet cultural or religious needs and try to carry on alone. There is a large ethnic minority voluntary sector providing culturally appropriate support to older people, but its members may not be skilled in providing dementia care. Shared learning between these services and specialist dementia services would improve the support each could offer people with dementia from BAME communities. All-Party Parliamentary Group on Dementia.*²⁴

Many in the world of health and social care conflate person-centred perspectives with a 'one-size fits all' approach, whilst evidence suggests this is the problem that restricts equality of access to appropriate information and services (Johl, 2014, Mukadam et al, 2015). We find that almost all people want something

*similar – e.g. what I want for my Gran will not be too far from what you want for your Gran. Namely to be loved, supported, comfortable, independent, looked after, healthy (as can be) and happy. The same would be true about what we want for our children, irrespective of our individual ethnic or cultural background. Mohammed Akhlak Rauf.*²⁵

As people in the groups, and some of the professionals we interviewed indicated – language, food, clothing, faith and the arts are all highly visible aspects of culture. However in all communities there are codes and behaviours that are unspoken or unconscious, for example – patterns of handling emotions, family responsibilities, collective decision making, roles in relationship to age, sex, class, attitudes towards dependents. Not making assumptions about people and finding out about their lives are useful inclusive approaches for everyone. Negotiation, accommodation, respect and, as Rauf says, finding some common ground should be on the agenda for care provision.

²⁴ *Dementia does not discriminate*, All-Party Parliamentary Group on Dementia, 2013. www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf.

²⁵ See: www.meriyadain.co.uk/2017/10/05/why-research-culture-ethnicity-and-dementia.

CARE HOMES: SPARE TYRE'S EXPERIENCE

“I thought to myself, why not try something new just once in our lives.”

Staff member, Bhakti Shyama Care Home, Balham

During their eight years of making work for people living with dementias in care homes and day care facilities across the UK, Spare Tyre have observed that their offer has not been taken up by care homes that specifically cater to Hindu, Sikh and Muslim faith communities.

As part of their research for *Love Unspoken*, Spare Tyre recently spent several months targeting these specialist care homes with the invitation to book their current show *The Garden*²⁶, an inclusive and multi-sensory show for people living with dementias. They contacted eight London care homes and the show was booked by five homes. Two homes said that they were not interested and one did not follow up on their initial interest.

The company reported that it was at least twice as time-consuming to secure a booking for *The Garden* amongst these care homes. In general Spare Tyre, like other cultural organisations, find communicating with care homes is challenging, especially initially. Getting through to the right manager is always difficult.

“However with the South Asian Care homes if I did get through to the right person I had about 20 seconds to convince them to book the show before they put the phone down. I had to absolutely refine my sales pitch, mainly to let them know: a) it was a non-verbal piece so language was not a barrier; b) that theatre could be for them; c) that the show was funded and there was only a minimal charge.” (General Manager, Spare Tyre)

Subsequently, five to eight phone calls per care home were made to reassure them that the show was going ahead and to ensure that there would be no last-minute cancellation. (Usually only two to three calls are required.) Once interest had been captured, the General Manager recommended also paying a visit in person wherever possible, to ensure the booking is confirmed.

“Although it was tricky convincing the care homes that theatre could be for them, once on board most shows went smoothly.”

(General Manager, Spare Tyre)

The Garden was experienced by 89 residents across the five care homes, plus their care workers, plus family members. Arti Prashar and the company members observed its positive impact on the residents and received very good feedback from relatives and many care staff. Some of the latter requested training in the creative approaches used to communicate and stimulate.

“The mood in the room was good, (the interaction with) fruit was really good. In a discussion at the end residents said they could sit and listen to that forever, it was so calming. They loved the leaves and the clothes hanging up. I want to make some butterflies and get a projector. Everyone enjoyed it.” (Activity Coordinator, Neem Tree Care Home)

As a result of their targeted approach, the main learning for Arti Prashar and Spare Tyre is that the gate-keeping by care home managers is a significant barrier, rather than the content of a show. The managers are not familiar with ‘theatre’ as a cultural offer or as an activity. If the company could talk to them about specific cultural content, as is planned for *Love Unspoken*, could this make a difference?

This response to theatre in care homes echoes Spare Tyre's findings when they first started going into care homes 8 years ago. It's about building a relationship of trust that can be fostered not only with managers but with care staff themselves. The work aids communication and has an impact especially on those at the later stage of dementia.

Spare Tyre has numerous reports where care staff state clients who didn't speak have started to speak, positive behavioural changes have been observed, how staff feel relaxed by the experience, and residents have had a calm afternoon after the morning performance. Spare Tyre is in discussion with a South Asian care home to talk through the possibility of regular creative workshops.

²⁶ See: www.sparetyre.org/watch-and-listen/the-garden-understanding-our-impact.

CARE HOMES: ATTITUDES IN SOUTH ASIAN COMMUNITIES

“Look after them at home. Because they are your parents and it’s your duty.”

As our desk and field research indicates, the overwhelming majority of South Asian people living with dementias are currently cared for by their immediate and extended families for a range of cultural, social and religious reasons. Those who are living in care homes are very frail, with multiple health conditions as well as a dementia and require more care than their relatives are able to provide.

Most of the people we spoke to consequently had no personal experience of the care home sector. Many were aware of the scandals around poor care and abuse in some care homes that have been widely reported in the media and, like many people in the UK, hold a negative image of care home provision.

“Putting them in a care home is like putting them in a box – a dead end.”

“Whether it’s hospitals or care homes there’s a limited time when you can see them, when they can see you. And Asians, if you put them in a care home think you’ve abandoned them.”

One man with dementia, who had been listening to the conversation for 45 minutes before he spoke said:

“I look at my situation and I feel I want to go to a home – check myself in because my family doesn’t care – so I think I will have to go to a care home – I don’t know when – but I love my freedom – to do what I want, when I want, come here, see and speak with people.”

POOR EXPECTATIONS OF CARE HOME PROVISION

“Stripping away the dignity that that individual has.”

The issue of personal care came up in all the groups we spoke to, in relation to the required cultural/religious practices and to the gender of the care provider. Personal care and who delivers it to patients is a sensitive issue for many people, whatever their heritage may be, and in particular it can cause great distress for people living with dementia. A lack of understanding/recognition of cultural practices not being observed contributes to the adverse perception of care, when it is not personalised. It brings additional added stress for the patient/client and their families.

“Their basic care – the bathing, the toileting... if it’s private then that’s different, but NHS will have their set things – they ain’t always gonna follow what you say. Whether it’s hospital or nursing home care – I don’t think they always listen to you. They ain’t gonna follow your daily routine because they have got a thousand more (to do) and they are not bothered and I think that’s why people don’t want to put them in in

the first place. Because the care I’m going to provide, I don’t think they will provide. Because they have a 100 more to attend to.”

“My dad’s dementia was so bad and aggressive that we were advised at the hospital that when he was discharged...he would be taken to a home. That wasn’t gonna happen. As a family, whatever the case maybe, that however aggressive he was, whatever it was, we would look after him at home. So it was about arranging a care plan, that suited his needs, it was about making sure that we had care workers – who are again male – ‘cos he would not allow a female stranger to be anywhere near him – let alone take him to the toilet and help him with personal hygiene. But for us as a family – no matter what the advice was from the health professional we would not consider putting him in a home. For us it was ‘we will work around this as a family’, even if it meant taking turns in who stayed over and who did what, giving people roles and responsibilities – it was going to happen at home. Because we felt. And still feel that understanding isn’t there.”

"When you've lived your life a particular way, going to the toilet, washing yourself – then having somebody else caring for you and not understanding and not doing that for you, that is stripping away the dignity that that individual has. Stripping away then that person. They've lost themselves in this illness. The last thing you want to do is take away the very little independence or the very little things that make them them."

A few people had had poor experiences with care home provision:

"Nobody likes to go into care home. If you are alone then it's fine – you need to go there – as there is no one to look after you. But if you are

living at home – in a family – you have to first think, can any one of us look after them or not? If you can then that's fine, but if you can't, then absolutely send them to a care home. But you have to check to make sure it's a good home. Now take my experience with my mother in law... she was in a care home – the way they were treating her – I will never, ever send her back to one again. She came out like a dead person, they don't clean her, they don't give her a shower, they don't even give her her food properly. And they don't let my family go to see her. They said 'Oh it's some kind of virus around here. Oh, you can't come here'. It's just an excuse."

POSITIVE EXPERIENCES OF CARE HOMES, DIFFICULT DECISIONS ABOUT THE FUTURE

“It is changing – my father-in-law is in a care home, he has dementia. He said he didn't want his children to look after him. He is happy because he has friends there, they treat him well.”

For some families the time came when they had to accept that they were unable to continue to provide adequate home care and facilities. We heard about more positive experiences:

"My mother in law had dementia (and) was in a care home eventually 10 years ago... we couldn't manage her at home. She would get up at night and put the water on and so on. So in the end she had to go into a nursing home. The biggest problem for her was the language barrier. Culturally specific care homes weren't available then. And the ones that are around now – I don't know the standard of care. The one she was in was fantastic really."

"I mean the people who work in these care homes are very patient and they get into those roles because of the caring way that they have."

We asked what people would do if they reach their limit caring for loved ones at home. Apart from the daunting expense cited by some, others suggested discussing the possibility

beforehand, to psychologically prepare themselves so that the decision to go for a care home is less of a shock. They talked about the need to have resilience and to consider the impact of the illness on carers.

"It's not an easy decision – you love them and you want to keep them home."

"I'm caring for two people – it's affecting me, they swear at me, it's very hard. The whole family is upset."

Some older women put themselves in their children's position:

"Our children are great but we understand they need to go to work, look after us, do the shopping – it's hard for them too."

When the care home accommodates the family and the community, culture can be brought to the residents:

"(When my Gran had to go into a care home) we reached out to our temple, there is only one Hindu temple in Leeds, and actually what would happen is that a lot of my Gran's mates a lot of who were widowed, they just bring the cultural stuff to the care home. You wouldn't believe it they just descend en masse and the care home were very accommodating, so my experiences

and my family's experiences are unique. I didn't know they were unique, I thought there was a good understanding but as time has gone on and I have started working in the field a bit more I have learned that is not the case."

"Before cuts – elderly people were taken to clubs. You need funds to take them by car or transport, now they are very isolated at home. Families have to give up their time and can't as they have to work."

CULTURE AND THE IDEAL CARE HOME

“To be able to go out and be enabled by my carer.”

We asked everyone what the ideal care home might look like, for their loved ones, for themselves? How should provision take culture into account and what specific aspects of culture were important to consider for practical, emotional and spiritual reasons?

There was consensus across all the groups about the importance of meeting people's dietary needs for both familiarity and for religious requirements, e.g. halal, vegetarian, vegan. Carers from a similar cultural, ethnic background are important, with knowledge of their language, especially as many people living with dementia who might speak English revert to mother tongue. People from the same or similar background will also know about significant religious festivals, observances and social etiquettes. Sensitivity around gender was often mentioned, 'no male nurse for women's personal care'.

"I would like them to be able to have conversations, so I would to see people in care homes being able to have conversations in their mother tongue. I would like for them to feel like they are being respected because respect is a really big thing in our culture."

The groups all described the importance for themselves and their loved ones of being in an environment that reflected their religious beliefs and enabled worship. In addition to diet and physical cleanliness they indicated places to pray and opportunities to listen to prayers, either live or recorded.

"As a Muslim they need prayer time. My dad even though he was forgetting he still wanted to do his prayers in hospital. Mashallah. So it's important for us to have that."

"For my Gran, we used to put on the Ramayana and stuff like that. Wherever she went in her mind she was very happy and would sing along. Music was a big part of that, when I mean music, I mean religious music ...What was also incredible was that she wouldn't have a clue who any of us were but she knew that word for word... Look at the peace they are in when they are listening to this stuff."

Related to religious customs, cultural etiquette needs some consideration, for example:

"The arrangement of sitting – if it's a mixed group or not. Because most elderly people prefer women only (group/activity)"

"Or men only –"

"Men I don't think would mind."

Several people mentioned the importance of being able to connect with the outside world and to go outside and being able to enjoy fresh air, plants and animals:²⁷

"I know my grandparents loved gardening and because in Bangladesh they had a lot of land, they would look after their own animals, they would look after their own gardens. That would be something that they would really appreciate."

Most of all the people we spoke to wanted to have conversation, individual attention, social interaction and activities. They talked about the staff needing to be kind, caring and patient, and dementia trained – this was equal to the importance of catering for diet and faith.

²⁷ Spare Tyre's observation over the years is that many care homes have gardens but access to them is restricted by the amount of time carers have to take residents outside and some health and safety considerations.

"At home we will give them more time, in care home/hospital, no-one will give them more than 15 minutes. Give the elderly enough time – you will get a lot out of them – I am a psychiatric nurse, speaking from personal experience. You may not share experiences but if you give them the time and attention you will glean much information from them."

"Understand they have an illness – speak lovingly with them – just like you are doing now."

"Care – understanding that people need love, need to be hugged and held, cherished – these things have very positive effects on people. Affection is the most important. Give them 'love'. Make them laugh. Don't just take their money and then disregard them."

They also talked about the relationship between the care home and the family – the family should be able to visit as much as they want to and be involved in decisions about care and activities.

ARTS AND CULTURE FOR PEOPLE LIVING WITH DEMENTIA

“It is very valuable to try and engage people through art. As you are aware, Asians are really into their arts and dramas and that sort of thing.”

“Maybe when people know that music is like medicine then their perception of it will change.”

As most dementia care takes place at home and in community settings, our conversations explored what kind of arts and cultural activities are meaningful for people living with dementia in domestic as well communal environments.

Music was mentioned across all faiths and regional cultures. Music from Bollywood films e.g. from the 1940s – ‘You put on some Raj Kapoor music and you see people just come to life’. Some younger Muslims reminded each other that their Bangladeshi parents enjoyed music and films when they were young and listening could connect them to/evoke youthful memories.

"Music – that takes them back to their time"

"People live public life and private lives"

"So not just religious recitation..."

However some Muslims we spoke to felt that this approach does not suit everyone, for example:

"People I know and have met, they wouldn't take necessarily well to music or Bollywood type music or dancing, which is why Alzheimer's Society's Memory Cafés don't work well. You have singing and dancing and my mum who has dementia, I wouldn't take her there, she would stick out like a sore thumb. It's not her cultural reference point."

However, **film** as a medium to communicate health messages can be powerful. One South Asian community worker described how he had been involved in making films with people from various Muslim cultural backgrounds about their (hidden) lived experiences as dementia carers. The films opened people's eyes to the challenges many families are facing.²⁸

Abdul Khan...said 'After my wife died I was left alone I don't have many friends and my family live far away, I have a great desire for new, creative and engaging projects to be delivered, that empower the community to engage and make changes, My wife had Dementia and I had no idea what to do. If this project was happening then I could have understood my wife's condition better'.²⁹

The power of religious music and **religious readings** was described by both individuals in the groups and professionals working in the dementia field – listening to broadcasts from Mecca during Ramadan, reciting the Hadiths, hearing a passage from the Qur'an, from Hindu mythology, e.g. the Ramayana.

²⁸ Available at: vimeo.com/123566448 Alchemy Arts Manchester.

²⁹ See: www.alchemyarts.co.uk/abdul.

Nearly all the groups described **songs** from youth and childhood being remembered and resonant with their elders, but that these songs were not part of the repertoire in mainstream dementia cafés, care homes or daycare centres.

The many musical activities that we enjoy in Alzheimer's Society cafés also tend to exclude the early Bangladeshi population. Sylheti folk music is very, very beautiful and very, very different from the songs that we might sing – like 'Daisy, daisy' and 'My bonny lies over the ocean' – these songs are just unknown. Alli Anthony, Alzheimer's Society, All Party Parliamentary Group on Dementia 21 March 2013.

"Maybe when people know that music is like medicine then their perception of it will change. Music is medicine, we know this. Even if it is religious music, it is still there." (Broadcaster working with dementia)

Spare Tyre's musicians are skilled at improvising and are knowledgeable about a wide range of musical styles from across the globe. They can pick up on a rhythm and a tune in response to even a fragment of a song. Whilst some people may not want to join in with music or dance activity, they are often happy to enjoy watching others sing, dance and play music. Many of the older people grew up in communities where people celebrated each other's folk and faith festivals, so there is much that is culturally resonant in terms of live arts. **Music and dance** are central to many of the South Asian communities especially at weddings and during festivals.

"I think music helps a lot. It occupies your mind ...music and dancing is very essential..."

"Yes they say that – they said in the news the other day..."

"With music your hormones rise, your endorphins go up (laughter). Your whole body starts moving with it."

In terms of **visual culture**, the iconography for different religions is distinct, but there is commonality in depictions of rural and urban landscape and the natural world, e.g. animals, birds, fish, vegetation and flowers in textiles, furnishings, domestic objects and some folk arts such as fruit carving and floral displays.

Spare Tyre has found the multi-sensory experiences of handling of fruit, vegetables, fresh herbs and spices are a wonderful way to profoundly connect with people living with dementias.

A couple of professionals we spoke to talked about the power of **reminiscence** work but also cautioned that this needs to be handled carefully. For example, some of the current age group who are living with dementia hold harrowing memories of Partition, which can come to the fore as short-term memories decline. Likewise, old memories may be of experiencing racism, isolation and hardship when they first arrived in the UK in 1960s and 70s.

As Dr Karan Juttla (Senior Lecturer, Association for Dementia Studies, University of Worcester) pointed out during the oral evidence sessions, understanding and responding to the unique life history of individuals is part of person-centred care, which is the essence of good dementia care. Person-centred care means valuing each individual and their unique personality, culture, life history and preferences.

During the discussion about culture and what can resonate with people living with dementias, several men and women talked about the importance of being open minded and not making assumptions about their parent, to not limit their options for trying to communicate.

"That's what I found with my mum...there's things that you learnt maybe as a child or that are so much a part of you that never go despite ...that you might lose your memory... there's still bits of you that you've held on to – it might be your faith, it could be anything because we are all individuals."

During our conversations about arts and culture, some deeper cultural behaviours, the unspoken codes and rules emerged. For example handling and expressing emotions with families and patterns of group decision making, gender roles and duties. These conversations led us naturally to discuss the ideas for *Love Unspoken* and resonated with Arti Prashar's personal experiences of dementias and parental care.

Arti Prashar's reflections and next steps

[PART FIVE]

*“Indian people they never say I love you,
only what you cooking?!!”*

The idea for *Love Unspoken* came from a very personal lived experience – Arti Prashar's father had Parkinson's related Alzheimer's and after the recent death of her mother – who had vascular dementia – she asked, 'Do you miss mum?'. He responded with two words 'Oh yes'. Held in those two words was a profound love that she had not witnessed in daily life. It made her curious – how many other Asian men cannot express their feelings openly after death of a loved one? Do they become isolated? Why are we not speaking openly about dementia in the family? It gave birth to the next show for people with dementias, for people within the South Asian Diaspora, but it needed researching.

“It has been profoundly moving to have already touched so many South Asian elders living with dementias during this research. By actively seeking them out, spending time with them and talking about dementia and by winning their trust through creative interventions with The Garden.”

“The non-verbal approach used in this interactive show enabled connections better than I could have dreamed of. They have played with us, imagined with us, laughed with us, thanked and blessed us for spending time with them. Their families did the same – so grateful for the meaningful and respectful way we engaged with their mother or father.”
(Arti Prashar, Artistic Director, Spare Tyre)

From meeting with the groups and mentioning creative workshops it was clear to Arti that the project had to be shared outside care homes, amongst community and cultural groups. It was also clear that as an artist, she would have to work with much sensitivity and care

- to honour the stories and thoughts shared
- to co-create with the cultural groups,
- to give them a platform for their songs, stories and poetry.

“And you know we move away from that as we get older – when we are little you do cuddles – and in Asian culture there's not a lot of hugging anyway – and you need it more and more and you don't realise that.”

The challenge ahead is how to incorporate words into a non-verbal show, how to play with the theme of 'love' when within the diaspora most love stories are tragic.³⁰ However, their responses heartened Arti, and gave her the courage to try things out with dancers and musicians and test it out with a couple of groups to gauge their response.

The journey has begun and *Love Unspoken* will see its debut at The Queen's Theatre Hornchurch in October 2019.

“Yes do the play as it's another source of information – it's a positive response!”

³⁰ E.g. Heer Ranja, Laila Manju, Rama and Sita.

Summary

[PART SIX]

KNOWLEDGE AND AWARENESS OF DEMENTIA, ACCESS TO SERVICES, STIGMA

Our findings support the literature to date on dementias and UK South Asian diaspora communities. The literature reports that:

- BAME people living with dementia and their carers face difficulty in accessing services and often access services later.
- Choice in care and support services is limited due to lower levels of awareness about dementia and higher levels of stigma.
- The communities have different expectations about care and services.
- Service providers have often stereotyped BAME communities in terms of ‘they look after their own’.
- Services are generally not culturally appropriate.
- In South Asian languages there is no word for dementia, which makes framing and describing the disease difficult.
- Not planning for the specific needs of BAME communities with dementia can lead to their marginalisation but narrowly focusing on the distinctiveness of their needs can also create exclusion.

In addition to these findings we observe from our research the following:

The knowledge gained from the lived experiences of South-Asian families, especially women who take the main responsibility for caring in the home, is a valuable resource for their peers and for professional and volunteer dementia services.

Their voices are under-represented and greater efforts should be made to reach out and engage with them.

Stigma around dementias continues to be prevalent although there are indications that this is starting to shift, especially where targeted outreach is being undertaken and where GPs are providing good information and signposting support.

Cultural and community organisations can play a vital role for under-served groups by facilitating access to services and raising awareness of dementia care and support. These groups are often operating with slender resources and have part-time and/or voluntary staff.

The main barriers for these groups in terms of taking the initiative to engage with mainstream services or being aware of what is on offer are social isolation, language/communication and trust. These factors are also cited across the specialist literature and the cultural reasons are covered in some detail.

Faith institutions can play a significant role in addressing issues around stigma and dementia and in promoting access to services and support for dementias. They are often important social hubs. Silence by faith leaders on mental health and dementias can contribute to the maintenance of stigma.

THE ROLE THE ARTS CAN PLAY

'If health is about adaptation understanding and acceptance, then the arts may be more potent than anything health has to offer. More and more of life's processes and difficulties – birth, death, sexuality, ageing, unhappiness, tiredness, loneliness, perceived imperfection in our bodies – are being medicalised. Medicine cannot solve these problems... Worst of all people are diverted from what may be much better ways to adjust to these problems.'

Richard Smith, Editor, British Medical Journal.³¹

01 The arts can play a key role in generating important conversations and in co-creating artistic content that responds to cultural diversity. Spare Tyre's offer to discuss stigma, dementias, arts and culture was swiftly accepted by the eight groups contacted; three groups are booked in for follow up workshops to co-create content for *Love Unspoken – funding dependent*.

02 Arts and creative activity were described as part of their cultural landscape by all the groups. This varied across the groups depending on the faith, social and regional backgrounds of the individuals. Content created for artistic activity will need to take into account this cultural diversity in terms of art forms and genres. However there are many artistic and cultural references that are shared across the diaspora communities.

03 Spare Tyre's persistence in reaching out to South Asian care homes did bear fruit but the extra capacity this requires is not sustainable for most arts organisations.

04 None of the literature on dementias and the BAME communities mentioned the role arts could play as part of a cultural offer:

- to engage South Asian communities with information about dementia
- to bring enjoyable, inspiring and uplifting experiences to people living with dementias, families and carers.

Our dementia professionals could not signpost us to any work in this field.³²

05 Spare Tyre's approach: The qualities, knowledge and insights of Spare Tyre enable their understanding of the creative tension between linking the essential, culturally specific elements to fresh innovative approaches that are respectful of cultural etiquettes. They have the confidence and insight to encourage audiences and participants to try new activities. Some aspects of their interactive artistic practice bring fresh inspiration and many are suitable for replication in care and domestic settings. They have a flexible menu of experiences, e.g. using objects, photographic and film projections, movement, dance, recorded and live music. The performers are skilled at understanding the smallest, slightest responses from people living with dementias, often with other complex physical conditions. Through non-verbal communication they can respond in the moment.

For carers, family members and loved ones with a dementia, taking part together is something that makes their lives more enjoyable.

³¹ Smith R, Spend (slightly) less on health and more on arts, *British Medical Journal (BMJ)*, 325 1432-1433. 2002.

³² We found a couple of examples where documentary films had been made with South Asian carers to raise awareness of issues around dementia. We spoke to a radio station and orchestra based in Manchester who are delivering a significant offer to people living with dementias, but they reported that they had been mostly working with groups who included very few BAME individuals and no dedicated South Asian cultural groups. This scenario was reflected across all the seminars/symposia/conference attended, apart from presentations by Leeds Playhouse, where Spare Tyre are engaged in developing and delivering work with local South Asian groups.

RECOMMENDATIONS

The arts have a part to play in many aspects of dementia, from delaying its onset and diminishing its severity to improving quality of life for people with dementia and their carers. At one of our Inquiry meetings, Dr Sebastian Crutch – a clinical and research neuropsychologist working in the Dementia Research Centre at UCL's Institute of Neurology and on a Wellcome-funded project exploring dementia and the arts called Created Out of Mind – pointed out that there are many different types of dementia and everyone will

*have a different journey, **but creative activity has more flexibility to address that complexity than generic therapies or drugs.***³³

The value and role of arts and creativity in health and wellbeing is now widely recognised. National and local arts organisations and individual artists offer a wide range of artistic experiences for people living with dementias, some of which include activity that specifically supports physical and mental health and wellbeing. The benefits of artistic activity have been recognised at government level.

Recommendation 1

Funders, Arts Council England and Care Commissioning Groups need to work better with the Alzheimer's Society, Age UK and similar organisations to connect with BAME communities in order to consult, engage and

share the opportunities and the benefits the arts can bring to the dementia care landscape. Social Prescribing³⁴ is one avenue to pursue but can only be part of the wider approach.

Recommendation 2

Arts, culture and heritage organisations could direct critical attention and resources to ensure that their programme strategies reach out to, invite and welcome BAME people living with dementias. If South Asian communities are not

engaging with your offer for elders, consult with community groups to find out what could make a difference. How could the cross-sector system come up with the best ideas?

Recommendation 3

The researchers urge all artists interested in arts, community, justice and inclusion:

- to engage with South Asian communities;
- to encourage South Asian artists from the UK diaspora to bring their artistic and cultural sensibilities and language skills to the table for this generation of elders and the next;

- to change the stories we tell about dementias involving the people who are living them.

³³ *Creative Health: The Arts for Health and Wellbeing*, The All-Party Parliamentary Group on Arts, Health and Wellbeing, July 2017 www.culturehealthandwellbeing.org.uk/appg-inquiry.

³⁴ Health Secretary Matt Hancock pushed the arts up the health policy agenda in 2018 by announcing £4.5m investment in GP Social Prescribing. Social prescribing is a non-clinical intervention in someone's life that should enable improved health and wellbeing. It's not like medical or surgical treatment. It can be any activity that a person enjoys that supports their ability to manage their health – from sport and walking to painting and dance to volunteering.

Acknowledgements

Many thanks to the following groups and individuals who took part in and contributed to this research:

Feltham Asian Women's Group, Hounslow

Mohila Ongon, Tower Hamlets

Parents' Group, Mulberry School, Tower Hamlets

Parents' Group, Harry Gosling School, Tower Hamlets

Apna Virsa, Slough

Highfields Centre, Leicester

Touchstone Centre, Leeds

Havering Asian Social Welfare Association (HASWA)

Bhakti Shyama Care Centre, Balham

Neem Tree Care Home, Greenford

Sairam Villa Nursing Home, Harrow

Meera Nursing Home, Kingsbury, London

Karuna Manor Care residential, Nursing, Dementia Home, Harrow

Nusrat Ahmed, South Asia Gallery Community Producer, Manchester Museum

Shabir Banday, Director REACH Community Health Project (SCIO), Glasgow and Honorary Research Fellow, Institute of Health & Wellbeing, College of Medical, Veterinary & Life Sciences, University of Glasgow

Dr. Sana-e-Zehra Haidry, Atlantic Fellow for Equity in Brain Health, Trinity College Dublin

Shahid Mohammed Life Story Network/Project Manager, Dementia Dekh Bhaal

Beena Khetani, Director Sonder Radio, Manchester

Lucy Geddes, Head of Camerata in the Community Manchester

Jahanara Miah, Project Manager, Institute of Brain, Behaviour and Mental Health, University of Manchester

Riplajeet Kaur, BME Dementia Worker at Touchstone Leeds

Special thanks also to Kazi Ruksana Begum



Mohila Ongon Women's Group, Tower Hamlets

Bibliography

SOURCES QUOTED

Dementia fact sheet, World Health Organization, December 2017.

Dementia Attitudes Monitor 2018, Alzheimer's Research UK.

Black, Asian and Minority Ethnic Communities and Dementia – where are we now? David Truswell, A Race Equality Foundation Briefing Paper, November 2013, www.better-health.org.uk.

Better Health Briefing 46. *Dementia and Minority Ethnic Carers*, Dr. Sahdia Parveen and Professor Jan R Oyedbode, A Race Equality Foundation Briefing Paper, June 2018, www.better-health.org.uk.

Creative Health: The Arts for Health and Wellbeing, The All-Party Parliamentary Group on Arts, Health and Wellbeing, July 2017 www.culturehealthandwellbeing.org.uk/appg-inquiry

Dementia does not discriminate, All-Party Parliamentary Group on Dementia, 2013. www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf

Wake Up London! – The case for a London regional investment strategy to develop appropriate information and services for black, Asian and minority ethnic people living with dementia. www.mentalhealth.org.uk/sites/default/files/wake-up-london.pdf

National Dementia Strategy: Equalities Action plan, UK Department of Health. assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215522/dh_128525.pdf

Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry*, 193(3), 240-246.

OTHER READING

Cultural heritage, Cultural wellbeing: the bio-psychological impact of arts and cultural interventions, Professor Helen Chatterjee, University College London.

Prevalence of dementia in population groups by protected characteristics, a systematic review of the literature, Public Health England, 2015.

Risk reduction of cognitive decline and dementia, WHO guidelines, World Health Organization, 2018.

The development of inter-cultural care and support for people with dementia from minority ethnic groups, Alzheimer Europe, 2018.

Who Cares? Museums, health and wellbeing, MLA Renaissance North West.

How galleries and museums can enhance health and wellbeing, Health and culture, 2011.

Information Programme for South Asian Families (IPSAF): an external evaluation. Parveen, Blakey, Oyebode 2015, University of Bradford.

Social isolation and older BAME people in Greater Manchester, Lewis and Cotterell, 2017, University of Manchester.

WEB LINKS

Asian ethnic groups: age profile, Census 2011: www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/age-groups/latest#asian-ethnic-groups-age-profile.

Meri Yaadain website: www.meriyaadain.co.uk/information-2.

Arti Prashar: Pioneer of non-verbal performance-therapy for dementia, ageing and spirituality, Lila interactions, 2018, lilainteractions.in/arti-prashar-pioneer-of-non-verbal-performance-therapy-for-dementia-ageing-and-spirituality.

Forgetting the self but remembering to live: A conversation with Arti Prashar, Lila interactions, 2018, lilainteractions.in/forgetting-the-self-but-remembering-to-live.

Theatre, spirituality and dementia: The soul still knows who they are, Lila interactions, 2018, lilainteractions.in/theatre-spirituality-and-dementiathe-soul-still-knows-who-they-are.

Our Dementia Choir with Vicky McClure www.bbc.co.uk/programmes/m0004pyb.

'Asian parents in care homes', Sarfraz Manzoor, *The Guardian*, 26 February 2011, www.theguardian.com/lifeandstyle/2011/feb/26/asian-parents-care-homes-sarfraz-manzoor.

Tide – together in dementia everyday: www.tide.uk.net/join_tide/experiences-stories.

A blog from Shahid Mohammed of tide on the Dementia Dekh Bhaal project, Dementia Action Alliance, 22 March 2019, www.dementiaaction.org.uk/news/29681_a_blog_from_shahid_mohammed_of_tide_on_the_dementia_dekh_bhaal_project.

The Garden – understanding our impact, February 2019, www.sparetyre.org/watch-and-listen/the-garden-understanding-our-impact.

Alchemy Arts Manchester, films available at: vimeo.com/123566448, www.alchemyarts.co.uk/abdul.

'What my Dad's dementia taught me', by Rajan Datar, *BBC News*, 25 January 2019, www.bbc.co.uk/news/health-46945252.

'Do I see what you see?' A film about dementia, disconnection and seeing the world differently, Created out of Mind, 2018, www.createdoutofmind.org/stories-and-reflections/do-i-see-what-you-see.

DEMENTIA AND HEALTH CONFERENCES

Attended March–June 2019

Creative Interventions in Dementia Care, Queen Mary University, 18 March 2019.

Dementia Strategy Expert Panel: How can the public and private sectors work together to create world-leading dementia-friendly communities in central London and beyond in the next five years? NHS, RBKC and LB Westminster, 19 March 2019.

Arts, Health and Wellbeing: Connecting research, policy and practice, The Culture Capital Exchange, 10 April 2019.

Exploring Ageing in History: Exhibition Launch at Royal College of Nursing 11 April 2019 (Pat Thane, Research Professor in Contemporary British History, explored the myth that ageing is a modern issue).

Arts 4 Dementia: Towards Social Prescribing, Wellcome Collection, 16 May 2019.

Creative Health Conference, Southbank Centre, 10 June 2019.

Spare Tyre's research questions

[APPENDIX]

RESEARCH QUESTIONS

- 01** Is dementia a taboo within the South Asian community?
- 02** Can we use the arts to dismantle this taboo?
- 03** How culturally specific does a project have to be for an ageing South Asian population to take part?
- 04** How can Spare Tyre create multi-sensory, person centred experiences for South Asians living with dementias that resonate culturally and spiritually?
- 05** How can we have better conversations about dementia with institutions, paid carers, families and loved ones?

QUESTIONS FOR THE GROUP INTERVIEWS

About dementia, diagnosis and stigma

- 01** Who is in the room? Who knows someone close to them who has lived with dementias? Who knows people living in care homes with a dementia? Who knows people being cared for at home by their family with dementias? Do they have any support from professional carers in the home and/or attend a day centre?
- 02** Who thinks they know quite a lot about dementias? Who knows a little? What do you know? Why is this?

- 03** Do you think people in your community are embarrassed to talk about dementias? If so why is that? If not, what helps?
- 04** What do you think are some good ways to communicate with people with dementia? What works well? What doesn't work?
- 05** What do you know about memory? If we can't remember things, how can we be better at enjoying the present moment?*

About arts and culture

- 01** Is it important for people living with dementias to be in an environment where they can have familiar cultural experiences? What are these?
- 02** Spare Tyre is making a new show for people living with dementias in South Asian care homes. What would you like to see as part of that? What would be lovely? What would be necessary?
- 03** What would be useful for people living with dementia and relatives/carers to give people ideas and confidence to have better conversations about dementias and give better care?
- 04** As we age, how can we come to accept the care of others as part of the life-cycle? Acknowledge the limits of our independence and dependence on others? 'We are babies twice on our lives'.*
- 05** How do you talk about end of life? What is useful and what is not?*

*We did not always get round to asking this question with all of the groups.

QUESTIONS FOR INDIVIDUALS

- 01** How can we have better conversations about dementia with/between institutions, paid carers, families and loved ones?
- 02** What are your thoughts about how the arts sector could work with your networks to have more joined up conversations and shift thinking/behaviours that are a barrier to better care?
- 03** Spare Tyre is making a new interactive, non-verbal artistic experience, *Love Unspoken*, informed by this research. It will be toured to arts and community venues for South Asian groups and will be suitable for those living with dementias, their carers and families.
In terms of dismantling the stigma around dementias, how could this arts event help to shift/change attitudes and behaviours? What would you like to see illuminated, challenged, opened up?
- 04** How culturally specific do you think dementia care projects have to be for an ageing Asian population to take part?
- 05** How could artists and medical/research specialists work better together?

*“People focus too much on the negative side of dementia....
The focus should be on what you have and what you can do and achieve
and what is still there. It is not the end of the world.”*

Dr. Sana-e-Zehra Haidry, Mental Health Professional



Rehearsal for Love Unspoken.

A separate Executive Summary
of this report is also available at
www.baringfoundation.org.uk

The Baring Foundation

8-10 Moorgate

London EC2R 6DA

020 7767 1348

www.baringfoundation.org.uk

Twitter: @baring_found

December 2019

ISBN: 978-1-906172-46-6