

Briefing Sheet

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Supporting South Asian People with Dementia: Lessons from the 'Jeevan' Project



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This paper draws on the experience of the 'Jeevan' Project¹ in providing dedicated support to South Asian people with dementia and their families/carers. It will provide an insight into some of the issues encountered by the project and the responses that were developed to address them.

The project is jointly funded by the Scottish Government and the Robertson Trust. Currently in its second year of operation, the project is unique in Scotland.

Dementia, in its many forms, continues to pose significant challenges to policy makers and practitioners tasked with ensuring that individuals and families affected by the illness have access to timely, appropriate and effective support, so much so that in 2012, the World Health Organisation (WHO) declared it a public health priority. In 2015, there were an estimated 46.8 million people worldwide living with dementia and this figure is expected to nearly double every 20 years reaching 74.4 million in 2030 and 131.5 million in 2050².

UK comparable figures for 2015 estimated 850,000 people with dementia or 1:79 of the population and 1:14 of the 65+ population. By 2025, the total number of people with dementia in the UK is forecasted to exceed 1 million and by 2051, to exceed 2 million³.

¹ www.mecopp.org.uk

² <https://www.alz.co.uk/research/statistics>

³ Alzheimer's Society (2014) Dementia UK Update Report

Scottish data for 2016 estimates 90,684 people with dementia of which 31,282 are male and 59,402 are female⁴. Figures by local authority are set out in the table below:

Local Authority	Male	Female	Total	Local Authority	Male	Female	Total
Aberdeen City	1,142	2,229	3,372	Inverclyde	469	1,020	1,489
Aberdeenshire	1,558	2,631	4,189	Midlothian	508	894	1,402
Angus	864	1,584	2,448	Moray	621	1,136	1,757
Argyll & Bute	671	1,254	1,925	North Ayrshire	891	1,679	2,571
Clackmannanshire	285	517	803	North Lanarkshire	1,661	3,079	4,739
Dumfries & Galloway	1,226	2,110	3,336	Orkney Islands	169	265	434
Dundee City	824	1,684	2,508	Perth & Kinross	1,135	2,084	3,218
East Ayrshire	737	1,368	2,105	Renfrewshire	1,004	1,908	2,912
East Dunbartonshire	792	1,432	2,224	Scottish Borders	889	1,512	2,401
East Lothian	661	1,213	1,874	Shetland Islands	147	240	388
East Renfrewshire	581	1,207	1,788	South Ayrshire	867	1,634	2,500
City of Edinburgh	2,467	5,020	7,487	South Lanarkshire	1,792	3,604	5,396
Falkirk	884	1,634	2,518	Stirling	564	1,029	1,593
Fife	2,283	4,184	6,467	West Dunbartonshire	467	947	1,414
Glasgow City	2,463	5,566	8,029	West Lothian	847	1,469	2,316
Highland	1,603	2,849	4,452	Western Isles	208	422	630

Data on the prevalence and number of Black and Minority Ethnic (BME) people with dementia is not available either at a UK or Scottish level although evidence is emerging that suggests a higher prevalence of dementia and earlier onset amongst people of African Caribbean country of birth than amongst White UK born people⁵. This may be related to vascular risk factors such as high blood pressure, cholesterol, overweight/obesity, tobacco use, lack of physical activity and diabetes which are consistently elevated within some BME groups.

The lack of available data has led researchers to apply the same prevalence rate to BME communities as that used within the majority community. If this calculation is applied within Scotland, this would give an indicative figure of 2,671 (based on a total BME population of 211,000) people with dementia and 528 within the 65+ age group.

⁴ <http://www.alzscot.org/campaigning/statistics>

⁵ Simon Adelman, Martin Blanchard, Greta Rait, Gerard Leavey and Gill Livingston Prevalence of dementia in African-Caribbean compared with UK-born White older people: two-stage cross-sectional study. *The British Journal of Psychiatry* (2011) 198, 1–7. doi: 10.1192/bjp.bp.110.086405

Scottish Government Response

Dementia has been a national priority since 2007. In 2008, the Scottish Government set a national target on improving diagnosis rates and by 2012 had achieved a diagnosis rate of 64%, significantly higher than in England and Wales⁶. The first 3 year National Dementia Strategy was published in 2010 closely followed by the Standards of Care for Dementia in Scotland and the 'Promoting Excellence' Framework in 2011. From April 2013 onwards, the Scottish Government introduced a further target guaranteeing a minimum of 12 months post-diagnostic support to each individual newly diagnosed with dementia. The '5 Pillars'⁷ model is used to deliver the 12 months post diagnostic support comprising of: understanding the illness and managing the symptoms; supporting community connections; peer support; planning for future care; and, planning for future decision making.

The second National Dementia Strategy (2013 – 2016)⁸ recognised that specific population groups⁹ may face additional challenges in receiving a timely diagnosis and access to post diagnostic support and committed the Government to:

"... (undertaking) a brief piece of work focusing on the care pathway for these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care coordination – requires modification to take account of the needs of different groups." (Commitment 16)

This piece of work was taken forward by the National Advisory Group on Dementia and Equality culminating in a series of recommendations to the Scottish Government¹⁰.

In exploring issues of race and ethnicity, the above Report highlighted a number of factors which may prevent or inhibit individuals with dementia and their families from seeking a diagnosis or support. These factors were categorised as either knowledge, societal and/or health related.

A review of the available literature found that 'beliefs' about the causes of dementia and in particular, that cognitive decline was a normal part of the ageing process, acted as a deterrent to seeking help. Stigma associated with the illness, cultural expectations that female members of the family would provide care and a reluctance to engage with mental health services reinforced an unwillingness to seek advice and support. Difficulties with assessment instruments used to diagnose dementia were also highlighted as a possible barrier due to their reliance on literacy and/or cultural bias.

"Dementia is part of ... ageing, "is part of growing old" and the word dementia [does] not exist in [our] language."¹¹

"It is very hard to accept help and support because of our culture, caring for relatives' is our responsibility."¹²

"Muslim community do not use the services because of their culture, language barriers and lack of understanding of their needs."¹³

"The stigma connected to dementia has nothing to do with Islam religion, it is more about family culture, lack of education and rural background, and this might be passed on to the next generation."¹⁴

⁶ Alzheimer's Society (2013) Annual Dementia Map

⁷ http://www.alzscot.org/campaigning/five_pillars

⁸ Scottish Government Scotland's National Dementia Strategy 2013-16 www.gov.scot/Resource/0042/00423472.pdf

⁹ Age (younger onset dementia under 65 years of age), race and ethnicity, learning disabilities, LGBT and disability (sensory impairment)

¹⁰ NHS Health Scotland (2016) Dementia and equality – meeting the challenge in Scotland: Recommendations of the National Advisory Group on Dementia and Equality

¹¹⁻¹⁴ *ibid*

The following recommendations were made:

- ▶ Provide, for people with a diagnosis of dementia, an individualised care approach that recognises all aspects of a person's identity, such as race, religion and sexual identity. This is essential for encouraging early help-seeking among different population groups;
- ▶ Build close relationships and trust with different communities – recommend community workers, trained in dementia, to build up relationships and explore and develop appropriate ways of raising awareness of dementia;
- ▶ Provide services for people with a diagnosis of dementia and their families that are culturally competent. A culturally competent service is defined as 'a service which recognises and meets the diverse needs of people of different cultural backgrounds ... It includes, but is not limited to, making provision for religious and cultural beliefs such as worship, diet and hygiene requirements, catering for communication and language diversity';
- ▶ Facilitate understanding of different communities by having staff members from diverse population groups, as well as good relations with a reference group;
- ▶ Provide health and social service workforce with relevant and timely learning and development in order for people to feel confident and competent to deal with language and cultural differences;
- ▶ Use assessment instruments that are culturally sensitive and do not rely on literacy and/or fluency in English or are culturally biased;
- ▶ Work with local communities of different population groups to develop and distribute culturally sensitive information about dementia and available services;
- ▶ Research the most effective ways to raise awareness of dementia among different population groups; and,
- ▶ Highlight and disseminate good practice.

These recommendations, alongside the recommendations for the other highlighted population groups, will be fed into the third National Dementia Strategy (2016 – 2019).

'Jeevan' One Year On

Drawing on the available research, the project identified 7 key areas of activity to be delivered over 3 years: awareness raising and education; supporting access to a timely diagnosis; post-diagnostic support; challenging stigma; information provision; carer support; and, capacity building. The project also sought to test the validity of the '5 Pillars' model as the preferred Scottish Government delivery mechanism for post diagnostic support. The project anticipated that advocacy and casework would be central to the delivery of a number of key project components.

In its first year, the project provided intensive support to 17 people with dementia and their families/ carers respectively (34 beneficiaries in total). An analysis of information gathered on beneficiaries highlights a number of key points:

- ▶ 65% of referrals to the project were self referrals;
- ▶ 100% of beneficiaries were in receipt of no support prior to their engagement with the project;

- ▶ 35% of beneficiaries 'qualified' for the one year post diagnostic support having received their diagnosis post April 2013 but had not benefitted from this commitment;
- ▶ 53% of carers had significant and/or multiple health conditions of their own; and,
- ▶ 100% of carers were providing care in excess of 40 hours per week of which 8 recorded their caring responsibilities in excess of 100 hours per week.

In conducting the analysis of beneficiaries, significant concerns were raised that 65% of carers who had received their initial diagnosis prior to the Scottish Government's commitment to 12 months post diagnostic support, were in receipt of no support or services. The analysis did not extend as to the reasons why no support had either been sought or provided but feedback from the project worker based on conversations with family members, highlights the following:

- ▶ Lack of understanding about the progressive nature of the illness with an expectation that the situation would improve;
- ▶ Lack of knowledge as to where to seek assistance;
- ▶ Lack of confidence in existing services and their ability to meet the specific needs of Minority Ethnic communities;
- ▶ Fears of confidentiality being maintained within the respective communities; and,
- ▶ The stigmatised nature of the condition itself.

The project adopted a variety of approaches to address the above. As one of the stated aims of the project was also to test the validity of the '5 Pillars'¹⁵ model, the lessons learnt have been set out under each of the respective headings. In adopting this approach, project activities have been subsumed under the most appropriate 'pillar'.

Understanding the Illness and Managing the Symptoms

Language and communication barriers have long been recognised as posing significant barriers for people whose first language is not English or who have limited literacy in their mother tongue. The dementia 'journey' begins with good quality, accessible information yet the experience of the project to date continues to demonstrate significant knowledge gaps in understanding dementia and managing symptoms as a foundation for living with dementia.

Whilst various translated resources are available, two issues have been identified. Medical terminology continues to present challenges for accurate translation with many of the terms used to explain dementia from a medical perspective not having an 'equivalency' within the respective community languages. Project beneficiaries have also reported that translated materials do not reflect the colloquial or less formal language used within communities on a day to day basis, with translators defaulting to a 'high' form which is not easily accessible. Lower literacy levels amongst older BME people in their 'mother' tongue can also prevent or inhibit access to translated information¹⁶.

¹⁵ http://www.alzscot.org/campaigning/five_pillars

¹⁶ Advice on producing accessible information materials can be found at: http://www.mecopp.org.uk/resources-mecopp_publications.php?section_id=258.

Feedback from project beneficiaries has consistently highlighted the value placed on being able to speak to a worker about any concerns or fears in their first or chosen language:

“This is the first time I have really understood why my mother behaves in this way. I thought she was being difficult, doing things that were not right but now I understand that she has an illness. I am not frustrated anymore because I know I can ask the worker for help. Being able to speak to the worker has been a blessing.”

One unintended consequence of this has been the role the worker has played in mediating family conflict as a result of behavioural changes caused by dementia. For many of the carers supported by the project, this has been the first and only opportunity to discuss how they are feeling with a worker who can communicate in their preferred language and who understands the cultural context in which these difficulties are arising. The worker has been able to ‘meld’ cultural knowledge with knowledge of the illness to support the family as a whole unit. This has brought an added and valuable dimension to the project over and above the post diagnostic support model.

In addition to providing information on a one to one basis, the project developed and delivered an introductory training course covering understanding dementia; understanding and managing challenging behaviour; and, future planning including power of attorney and guardianship. Whilst this approach is not new, there are a number of factors which distinguish it. Attendance was supported by the trust invested in the worker by participants, course content was developed to reflect cultural norms and values paying due regard to cultural sensitivities and delivered in the preferred language. Comments received as part of the evaluation demonstrate the effectiveness of this approach:

“Challenging behaviour and knowledge on legal documents and power of attorney and guardianship was invaluable and helped me understand the processes”

“I enjoyed learning more about the illness and understanding why my husband behaves the way does, and learning about different methods to apply in my caring role to make things less difficult for us both”

Evaluation results highlighted that on completion of the training/information sessions, participant attitudes had become significantly more positive and knowledge levels had improved.

Supporting Community Connections:

Within the Alzheimer’s Scotland model, this is defined as ‘support to maintain and develop community connections’ by:

“...working closely with people to maintain and build on their existing social networks, to enhance their quality of life and maximise the natural support they receive from those around them, helping to avoid isolation and reducing future reliance on care services.”¹⁷

Whilst the focus on supporting and maintaining community connections is invaluable in ensuring people with dementia and their carers continue to be included within community life, the experience of the project highlights that it poses a number of intrinsic challenges for South Asian people with dementia and their carers’.

¹⁷ Alzheimer’s Scotland (2011) *Getting Post Diagnostic Support (PDS) right for people with dementia*

Project beneficiaries have reported that fear of being isolated from their communities should the diagnosis become 'known' have prevented them from participating in community life. Where connections have been maintained, this has often been at the expense of the person with dementia who has been kept within the home environment. This is particularly apparent as the condition has progressed and behaviour has become increasingly difficult to manage or 'disguise'. Beneficiaries have also reported that their experience has been one of the community withdrawing from them, often at a time when more support is needed. This is, in part, due to the lack of knowledge and understanding of the condition itself and bears out findings of research conducted by MECOPP on behalf of NHS Health Scotland. This research found a range of beliefs amongst Minority Ethnic communities including the belief that dementia was 'catching', that it could be 'cured' or that it was a normal part of ageing.

In contrast to the stated aim of 'avoiding isolation', people with dementia and their carers have become increasingly isolated. However, this has not yet translated into an increased reliance on care services which remain, on the whole, inaccessible and unsuited in meeting their needs.

The lack of an appropriate infrastructure to support South Asian people with dementia and their carers', as with other Minority Ethnic groups, continues to pose a major challenge to service providers and policy makers alike.

Peer Support

It has already been noted that peer support is significantly under-developed within the South Asian community for people with dementia and their carers'. A reluctance to 'come forward' and identify as having dementia or caring for a family member with dementia has meant that project beneficiaries have coped alone from the point of original diagnosis. The impact of this, as reported by beneficiaries, has been a serious deterioration in their own health and wellbeing, particularly as the condition progresses. This has been exacerbated by the lack of support individuals have either been able or willing to access.

Gendered roles within the South Asian community have also meant that the caring role has disproportionately fallen on female members of the household. In the absence of a 'wife', the caring role has been delegated to younger unmarried women who remain within the household. This, coupled with cultural norms relating to accepted standards of behaviour for women, can increase the isolation experienced.

The 5 pillars' model makes specific reference to 'resilience' as a key element of peer support. In this context, 'resilience' refers to an individuals' ability to cope with, or manage stress experienced, as a result of taking on a significant caring role. Personal assets and resources within the individual, their life and environment support their capacity for adaptation and their ability to 'bounce back' in the face of difficult and adverse circumstances¹⁸.

It has been the experience of the project that the stigma associated with dementia, the isolation experienced by both people with dementia and their carers' as a result of this, inaccessible mainstream dementia support services and the lack of specialist provision all serve to erode personal resilience.

¹⁸ Adapted from Bennett, K. M. (2015) *Emotional and Personal Resilience through Life*. University of Liverpool

Planning for Future Care

The project also experienced challenges in this aspect of its work. Within the 5 pillar's model, the emphasis is on supporting the individual to plan their future care based on their choices, hopes and aspirations so that it can be used at a later stage to guide professionals.

Feedback from project beneficiaries highlighted that both individuals with dementia and their families had a very clear preference to 'remain in the present' as it was too 'frightening' to look into the future and the inevitable progression of the illness. When this was explored, concerns over the availability of appropriate services was highlighted with a stated expectation that the family would continue to care for them to the exclusion of formal support services.

This raises a potential dilemma for families as household structures change due to wider demographic influences and cultural 'shifts' between first and subsequent generations which may result in expectations not being met. This, in turn, presents a challenge to both statutory and voluntary sector agencies as to how to meet increasing demand as the population ages.

Late diagnosis and subsequent delays in seeking or being offered support have also compromised the extent to which planning for future care can be truly 'person centered' due to limited capacity. This has placed an additional responsibility on family members to advocate, to the best of their knowledge, what an individual's preferences would have been and how they can best be met within existing service provision.

Planning for Future Decision Making

In contrast to the 'fears' surrounding 'planning for future care' expressed by project beneficiaries, support to plan for future decision making was welcomed. This was particularly in relation to Continuing (money and/or property) and Welfare Powers' of Attorney.

Project beneficiaries stated that financial matters within families and extended families were often very complex and could include property and land overseas as well as money. Ensuring that there were clear lines of responsibility and accountability were seen as beneficial for the individual with dementia and for the family members involved.

Project beneficiaries also stated that having a Welfare Power of Attorney in place meant that they felt more able to advocate on behalf of the individual with dementia, particularly in relation to care and support needs. An underlying theme expressed was that the Power of Attorney acted as a means of re-balancing the relationship between health and social care professionals and the individual with dementia and their family/carer.

The 'Jeevan' Project as 'Cultural Broker'

In working with South Asian people with dementia and their carers', the approach adopted by the 'Jeevan' project can be defined as 'cultural brokerage':

*"...bridging, linking or mediating between groups of different cultural backgrounds to effect change."*¹⁹

The rationale for this approach adopted by the project can be summarised as follows:

- Emergent and projected demographic changes in relation to prevalence and incidence of dementia amongst BME communities;
- Diverse belief systems related to health, healing and wellness;
- Cultural variations in the perception of illness, disease and their causes;
- Cultural influences on help-seeking behaviours and attitudes towards health and social care providers; and,
- The use of traditional health practices amongst cultural groups.²⁰

The role of the cultural broker has four main components, one or more of which may be dominant at any one time²¹:

- Cultural broker as a liaison utilising their knowledge of (i) health values, beliefs and practices within a specified cultural group or community and (ii) their ability to understand and navigate the health and social care system for that cultural group/community;
- Cultural broker as a cultural guide sharing their knowledge of community strengths and needs and how they support or conflict with the systems, processes and structures of health and social care settings;
- Cultural broker as a mediator to 'ease' the historical distrust and lack of confidence that many Minority communities have towards health and social care services; and,
- Cultural broker as a catalyst for change by supporting the transformation of a health or social care setting/service so that it is more inclusive and reflective of the needs of diverse populations.

The benefits of such an approach are borne out by the experience of the project. For the person with dementia and their carer, there has been a significant increase in dementia support services being not only accessed but sustained. There has also been more recognition within the target community that practitioners and services require support to deliver services in a manner that respects and incorporates their cultural perspectives. In year two as word of the project has spread, individuals with dementia are either being referred earlier in their dementia journey or self-referring at an earlier stage. Project beneficiaries also report that they are more able to communicate their health and social care needs with the support of the bi-lingual worker and to better understand the treatment and support options available to them.

¹⁹ Jezewski, M. A. (1990) *Culture brokering in migrant farm worker health care*. Western Journal of Nursing Research, 12(4), 497–513

²⁰ Adapted from National Centre for Cultural Competence (2004) *Bridging the Cultural Divide in Healthcare Settings: The Essential Role of Cultural Broker Programmes* Georgetown University Centre for Child and Human Development

²¹ *ibid*

Conclusion

As the project's learning and development has progressed, two key issues have emerged: the effectiveness of a cultural brokerage approach in working with South Asian people with dementia and their carers; and the limitations of the '5 pillars' model in supporting diverse communities. Some of the problems experienced are beyond the scope of the model and are symptomatic of much wider and more entrenched structural issues. Other factors such as the stigma associated with dementia within the South Asian – and other Minority Ethnic – communities requires a concerted effort to raise awareness of the condition as the first step in 'challenging' negative assumptions and misconceptions. As the population ages and increasing numbers of people from South Asian and other Minority Ethnic communities are diagnosed with dementia, the challenge is twofold: to ensure not only that individuals benefit from the Scottish Government commitment to 12 months post diagnostic support; but, to ensure that the appropriate supports and services are in place beyond this 12 month period.



Case Study

Miss A is a 36 year old woman of dual ethnic heritage who lives with her father. Miss A is the main carer for her father who was diagnosed with Alzheimer's in 2012. Since his diagnosis, neither Miss A or her father have received any support until a referral was made to the Jeevan project. Miss A assisted her father in all aspects of personal care tasks as well as medication prompts. Miss A had to spend the majority of her day with her father to ensure he did not leave the home unsupervised or called emergency services when he became anxious. Miss A found the situation increasingly stressful and her own physical and mental health was being adversely affected. She found that her life was revolving around caring for her father. Although Miss A had siblings, they did not provide any support as they found it very difficult to understand her father's condition. His constant repetition was extremely wearing and he was losing the ability to carry out basic tasks like making a cup of tea.

The worker supported the family through:

- Referrals to social work for community care and carer assessments;
- Referral for occupational therapy assessment (aid and adaptations in place as a result);
- Providing information on self-directed support which resulted in the award of a direct payment enabling the family to employ a personal assistant of their choosing;
- Providing information and advice on a range of services which may be suitable e.g. day-care opportunities;
- Providing information to the carer on Alzheimer's Disease;
- Providing training opportunities for the carer;
- Referral to a community psychiatric nurse;
- Referral to a community brokerage service; and,
- One to one support to the father from a student on placement with a focus on life history work and reminiscence.

The link worker provided one to one support throughout the assessment process including language support and support to the assessor to understand cultural issues. Ongoing support was also provided to members of the wider family. The following testimonial was received from Miss A:

"My dad was in a really difficult place when we were first introduced to (named worker and student), the help and support that we received was excellent. Named worker advocated for my dad and managed to secure a package of care, she managed to refer him to other services within (named organization) and helped navigate a very complex social care system. My father has welcomed the support he has been given, he benefited greatly with the additional one to one support from the student on placement allowing him the chance to reminisce on the past, explore his favorite music and feel valued."