

Dementia Dekh Bhaal

Supporting South Asian carers of relatives with dementia
in Rochdale
Evaluation Report



Acknowledgements

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Tide - Together in Dementia Everyday

Tide is an involvement network for carers and former carers of people with dementia. It is a social movement to further the rights and voices of carers of people with dementia, to give them a voice and the tools they need to transform society. Tide is currently hosted by Life Story Work CIC but will be established as an independent charity by the end of 2019.

For more information about Tide and Life Story Network CIC please visit their websites at: www.tide.uk.net www.lifestorynetwork.org.uk.

You can also sign up for our newsletter online for regular updates of the work we do and the opportunities for carers of people with dementia in your area.

Disclaimer

The views expressed in this evaluation report are those of the evaluator. They do not represent the views of Life Story Network / Together in Dementia Everyday, which hosts the Dementia Dekh Bhaal project.

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Executive Summary

'Dementia Dekh Bhaal', meaning 'to care for dementia', was set up by tide - together in dementia everyday. Tide is a social movement led by carers for carers and campaigns to have better recognition and support for carers, enabling them to have a voice to speak up and influence change. This Project Outcome Report evaluates the success of Dementia Dekh Bhaal in its delivery as commissioned by the Heywood Middleton and Rochdale Clinical Commissioning Group (HMR CCG) and Rochdale Borough Council (RBC).

In 2015 the Life Story Network was commissioned by the CCG and RBC to review their dementia offer. The report '*Strategic Review of Local Dementia Support*' was submitted in March 2016 and included a section on the needs of BAME communities, with a recommendation that commissioners should:

*'Invest in the development of a sustainable programme of work with the local BME communities to identify **BME Community Champions** to establish a coordinated model of education, advice, help and support for their local communities, building on the good practice from Liverpool and Bradford. It is particularly important to ensure that you engage and develop local community champions.'*

In 2018 the CCG and the Council commissioned the Dementia Dekh Bhaal project to address the needs of South Asian carers. Specifically, the three strategic aims of the project were:

1. **Develop and deliver a training package for professionals** to understand more about the approaches to take for BAME people with dementia and their carers to provide more culturally competent care.
2. **Campaign to increase awareness** within the community, general public and public-sector staff around BAME dementia including a suite of material to support local carers in campaigning work and provide them with the knowledge, skills and confidence to do this with impact.
3. the **power of stories to change perceptions** including the creation of a suite of videos capturing the experiences of people with dementia and their carers.

It is clear from this evaluation that a key success of Dementia Dekh Bhaal has been the utilisation of an 'expert by lived experience' to engage and involve the South Asian community in Rochdale. In essence, the 'Story telling' has been brought to the fore via three short films, from three carers with different experiences (home maker, a working professional and a carer with complex health needs himself). The 'Campaigning' has been initiated through the community roadshows, radio work and community engagement, resulting in carers signing up to be involved with tide for networking and personal development. Dementia Dekh Bhaal has also grown the grassroots movement from the initial difficulties of engagement with carers to twenty carers now being signed up to be a part of the tide movement, giving them a voice through training and further learning and development.

Whilst tide has achieved the agreed objectives through its delivery of the Dementia Dekh Bhaal project, it is important that this is not seen as a stand-alone project. Far too often projects designed to support seldom heard groups are regarded as pilots that appear to be time limited and resource limited. Demonstrable good practice needs to be embedded in service provision so as to give sustainability and effective delivery in meeting the needs of the marginalized communities.

It is hoped that the learning from this project will be used by RBC and HMR CCG to review how they can make further progress in meeting the dementia and dementia care needs of the diverse communities in Rochdale.



Introduction and background context

Commissioning Dementia Dekh Bhaal

Tide is a social movement led by carers for carers and campaigns to have better recognition and support for carers, enabling them to have a voice to speak up and influence change. Whilst tide is involved in national work on carer issues, they have taken a decision to develop a strategic thematic focus on the specific needs and voice of carers of people with dementia from Black Asian and Minority Ethnic (BAME) communities, focusing on localised needs to address the complexities that exist within this array of diversity and communities within communities. One such example is Dementia Dekh Bhaal in the borough of Rochdale.

Dementia Dekh Bhaal arose out of the '*Strategic Review of the Local Dementia Support*' commissioned by Heywood, Middleton and Rochdale CCG (HMR CCG) and Rochdale Borough Council (RBC). This strategic review (reported March 2016), undertaken by LSN, included a clear focus on BAME dementia matters, based on the needs identified by the review. Three particular strands of the review, in the context of the BAME communities, included:

- Improved communication with the BAME communities and better reflection of this community in the resources provided by the CCG and the Local Authority (RBC)
- A continued conversation with BAME communities to better understand their various cultural needs
- Improved feedback to the BAME communities following consultation.

The report included a specific recommendation:

*Invest in the development of a sustainable programme of work with the local BME communities to identify **BME Community Champions** to establish a coordinated model of education, advice, help and support for their local communities, building on the good practice from Liverpool and Bradford. It is particularly important to ensure that you engage and develop local community champions'*

Given that the review was based on good practice from elsewhere as well as consultation with local communities, the review was able to make recommendations for a local plan which would bring about improvements for dementia related support under the themes of the CCG and council's new model of care: Thriving and coping, Community Hub, Getting help (Primary and Social Care), Getting more help (high quality intensive community services) and Getting specialist help.

Tide was commissioned by RBC and HMR CCG to propose and deliver on the BAME dementia needs within Rochdale. It was agreed that Dementia Dekh Bhaal would be delivered in two Rochdale wards - Milkstone and Deeplish - with carers also coming from Central and Sparthbottoms. The agreed outcomes for Dementia Dekh Bhaal were to:

- Develop and deliver a training package for professionals to understand more about the approaches to take for BAME people with dementia and their carers to provide more culturally competent care
- Improve knowledge of professionals in raising awareness of dementia to BAME communities - awareness of cultural barriers and issues
- Raise awareness for care and support services to be delivered in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities
- Raise awareness of the need to provide more support for the carers of people living with dementia from BAME and religious minority communities
- Campaign for carers to join Tide, for support, confidence building and networking
- Using the power of stories to change perceptions, including the creation of a suite of videos capturing the experiences of people with dementia and their carers.

The objectives were summarized as:

- Story Telling
- Campaigning
- Training

Funded for a year, the project employed a part-time project manager to deliver Dementia Dekh Bhaal.

A steering group was established to oversee the project, consisting of HMR CCG and RBC representatives, representatives of tide, the project manager and a PhD student undertaking research into the coping strategies of South Asian family carers of a relative with dementia.



Dementia Dekh Bhaal - the context in Rochdale

The model adopted by tide for addressing the needs of South Asian communities in Rochdale in relation to dementia adheres to the principles set out in the 'PHE report on a guide to community-centred approaches for health and wellbeing' (PHE, 2015). Using an 'Asset Based Community Development approach (ABCD), Dementia Dekh Bhaal began by recognising the communities (carers in particular) as a means of strength and able to make informed decisions to facilitate better management of the dementia related information and service needs. 'ABCD' is a methodology used whereby the strengths and opportunities of a community are used as a basis for their further development and sustainability.

As part of the Great Manchester efforts to address the 'under served' communities, Dementia Dekh Bhaal made it a priority to evidence that it can implement this asset based approach, meeting the requirements as expressed in '*The Value of Lived Experience in Social Change*' (Sandhu, 2017). Not only does the Dementia Dekh Bhaal project demonstrate an asset-based approach with a community development perspective, but it also acts as a pre-courser for the programme of work set out by the current task and finish work stream of Dementia United concerning underserved populations, which seeks to improve the dementia related needs of the BAME communities across the Greater Manchester region.

The learning from this project could not only become a catalyst for improving services quickly, but the nuances gauged through the expert by experience and the value of the lived experience approach will evidence the need to drop prejudicial and historical notions of '*they look after their own*' (Katbamna et al. 2004) to one where carers are given an equitable opportunity to access services and information. For example, services should no longer be able merely to say '*our doors are open*' but should ask themselves what they can do pro-actively to improve the uptake of services to support the person living with dementia as well as the family carers.

Dementia care in South Asian families

As the number of older people amongst the British South Asian population grows, the projected increase of dementia in the BAME population is expected to increase by seven to eight fold (APPG 2013; Botsford and Harrison Denning 2015). The Dementia Dekh Bhaal steering group was acutely aware that a number of social, cultural and religious factors that influence carers' awareness, decision-making and ability to access information as well as services may also influence the involvement and engagement of carers with this project.

Whilst Dementia Dekh Bhaal has been mindful of these influences, it recognises that not everyone understands the significance of culture, history, social constructs and influence of faith. Knowing communities was seen to be imperative in how to access carers before beginning to support them - including giving them a voice and a platform to share their story so that other families can benefit from this experience.

A brief synopsis of some of these issues is given below:

Language and Awareness

There is no word for dementia in the five main South Asian languages - so how are carers to discuss or recognise dementia when there is no comparable word? (Rauf 2011).

Migratory experience

The first generation of South Asian migrants came to Rochdale (and other northern towns and cities) to work in the textile industry. Generally speaking, men worked and women raised families. Many experienced racism and discrimination. That leaves a legacy for later life and the perception of statutory services (Uppal and Bonas 2014; Jutlla 2015).

Stigma

Not having a word for dementia has meant that other negative words have been used to describe or associate with dementia, namely 'crazy', 'paagal' and 'mental'. Carers then try to hide the dementia related behaviours of a family member rather than attract attention towards the condition (Botsford and Harrison Denning 2015).

Role of faith

South Asian faiths (Hinduism, Islam and Sikhism) place a great responsibility on the wider family to support and look after their elderly. In a western society, the difficulties of living in extended family structures can place pressure on the immediate family of the actual carer(s) (Rauf 2011).

Culture

Culture combines many things including diet, language, expectations, norms and dress, for example. However, it is the changing dynamics of families and the culture of British Asians that create a complex set of circumstances within which British South Asian carers are looking after a relative with dementia. Many may assume dementia to be a part of the normal ageing process (Johl et al. 2016).

Embedding tide's 'TRUST' model

The section above gives an indication of good practice in being able to embed community engagement and delivery of service delivery through various approaches such as Asset Based Community Development and valuing individual lived experiences. Communities are resilient but they also need to access opportunities. These opportunities can only be provided when there is a two-way relationship between the communities / participants / people using services and those attempting to provide meaningful engagement or service provision.

Tide too has developed a model for reaching out and engaging with people who would participate in tide's projects and training. This has been coined as 'TRUST', an acronym for:

Time
Relationship
Understanding
Sustainability
Trust.

The trust model exists to fully engage with participants in a Theory of Change to allow for a grassroots process of engaging, empowering and facilitating meaningful change from within communities. 'Theory of Change' is a methodology which enables appropriate planning, participation, and evaluation of service / projects, promoting social change.

The Dementia Dekh Bhaal project has used this approach and demonstrated that each of these aspects has been important in building the strength of the core principles in engaging with an otherwise 'seldom heard' group of people – South Asian carers of a relative living with dementia. TRUST is important as it demonstrates a number of particulars:

T (Time) – It is important to put time in to get to know the community you are trying to engage with. This was demonstrated by having a Manager who knew the community that Dementia Dekh Bhaal wanted to reach out to and made sure that efforts were not simply rushed to get to the outputs of the project

R (Relationship) – Building strong relationships with communities or individuals requires humility and the ability to listen, observe and accept that we do not always know best. This is where the lived experiences of individuals must be respected in order to build the capacity to have meaningful engagement. Dementia Dekh Bhaal recruited someone from the community who was able to give the time and build the trust through allowing for a meaningful relationship to be built with individuals as well as community organisations.

U (Understanding) – Any successful delivery of a project needs the delivery agents to have a good understanding of the participants and the community within which they wish to operate. Dementia Dekh Bhaal included an in-depth understanding of the population dynamics and cultural aspects that would facilitate or hinder success as well as the most conducive ways to engage otherwise 'seldom heard' communities.

S (Sustainability) – Tide was asked by HMR CCG and RBC to deliver a pilot project resulting from a review of the dementia services in the borough. The purpose behind the principle of 'sustainability' is to ensure participants and communities feel safe, happy, engaged with and listened to in terms of dealing with the issues at hand. Dementia Dekh Bhaal has demonstrated the success in delivering the aims, but also highlighted the methodologies for engagement, recruitment and participation. This now needs to be reviewed by HMR CCG and RBC as to how it can be sustained so that meeting the needs of these communities can continue.

T (Trust) – Trust is another key component of the TRUST model to create recognition of the fact that without building trust the whole approach fails. Trust is key to building meaningful relationships that allow for understanding and appropriate dialogue or engagement. Dementia Dekh Bhaal has demonstrated tide's TRUST approach by allowing the project time to build this trust with the potential participants.

Dementia Dekh Bhaal

Strategic Aims

The strategic aims of the Dementia Dekh Bhaal were to:

1. **Develop and deliver training package** for professionals to understand more about the approaches to take for BAME people with dementia and their carers to provided more culturally competent care, thereby raising awareness of the need to provide more support for carers and people living with dementia in the BAME / religious communities.
2. **Campaign to increase awareness** within the community, general public and public sector staff around BAME dementia including the development of a suite of materials to support local carers in campaigning work and provide them with the knowledge, skills and confidence to do this with impact.
3. **Use the power of stories to change perceptions** including creating a suite of videos capturing the experiences of people with dementia and their carers.

Objectives

In order to deliver the strategic aims, Dementia Dekh Bhaal undertook to meet the following objectives:

Develop and deliver training package

- A general overview and introduction to dementia related matters (access, services and social constructs).
- Co-produced with carers from BAME communities in Rochdale.
- Interactive with participants engaged through tasks and discussions.
- Developed with technical support from Tide.

Campaign to increase awareness

- Tide support to the Dementia Dekh Bhaal project to increase awareness through the campaign.
- Commence a social media campaign through 'Dementia Dekh Bhaal' identity and branding.
- Online digital actions, direct actions and lobbying. Meeting with decision makers provide carers with information and resources.

A campaigning tool kit developed for BAME carers to access to get their voices heard (co-developed with the ten tide volunteers) Encourage carers to join tide to be members of the network and become actively involved if they wish

Use the power of life stories

- Create carer video stories that highlight some of the issues faced by carers and people living with dementia in BAME communities.
- Record case studies and quotes to use when campaigning.
- Recruit a number of carer activists to support the project and ongoing work.
- Build on the collection of stories, developing the campaign beyond the project via tide.

Methodology for Evaluation

In order to undertake an evaluation of the project, it was important to seek feedback from the steering group, participants and the staff involved in the delivery of the work. Three forms of data collection were undertaken:

- Focus Groups with community organisations.
- Telephone interviews with carers.
- Training feedback forms.

Focus Groups

Two focus groups were held to explore the success and failures of the Dementia Dekh Bhaal delivery and strategy. Participants from the two community organisations - Bangladesh Association & Community Project (15 men – two Pakistani, 13 Bangladeshi) and Pakeezah Women's Group (about 21 women) responded to a series of questions to ascertain their perspectives on the approach used by Dementia Dekh Bhaal. Focus groups are an effective way of conducting research (or asking questions) as it allows participants to reflect on comments by their peers and then to add or to differ from what they hear. Both the focus groups were very positive about the Dementia Dekh Bhaal project and believed that the success lay in their trust and relationship with Shahid as the Programme Manager due to his '*lived experience as a former carer*'. Further feedback is provided later in the report.

Telephone interviews with carers

The three participants in the films produced by Dementia Dekh Bhaal agreed to be interviewed by telephone as it meant that either they were not distracted from care duties or they could be interviewed at work (one participant). Telephone interviews allow the individual to remain free from any obligation to respond in any particular way - either due to body language or bias. However, it is important to mention that the interviews were conducted after an initial contact to explain the role and purpose of the evaluation, thereby giving them time to prepare before the actual interview.

Feedback from the training session

The group training session was designed to seek views from the participants on the content, delivery and length of the pilot training developed as part of the Dementia Dekh Bhaal project. Written feedback was sought through evaluation forms - two forms were used one for and by tide and the other by HMR CCG and RBC for their learning and development.

The original plan was to undertake a group session to go through the proposed training for front-line staff so that it could be refined. However, the timeline was such that the training was delivered very close to the end of the project.

Feedback from the Project Manager

A face-to-face interview was also held with Shahid Mohammed as the Programme Manager to seek his views on what he believed worked well, what could have been done differently and what he thought the learning outcomes were from having managed this project. This would enable HMR CCG and RBC to benefit for any similar projects in the future.



Evaluation Findings

This section covers feedback from:

- Using the 'Expert by Experience' approach.
- Story Telling - Carer 'lived experience'.
- Campaigning.
- Training.

Delivery through an 'Expert by Experience'

From the outset of the project, the steering group agreed that the success of a community project required an asset based community development approach, at the heart of which was an 'Expert by Experience'.

An 'Expert by Experience' is someone who is able to make effective use of their lived experience in a specific field as a means of advancing their approach, empathy and trust with the target audience. In this case Shahid Mohammed was recruited by tide for the purposes of delivering this work.

The strengths Shahid brought to the project leadership included:

- Lived experience as a carer of his mother who had dementia.
- Local to Rochdale - so had good awareness of geography and population demographics.
- Excellent awareness of local politics and influencers.
- The trust of the wider community for his work in the community.
- A long history of professional work in the civil service which gave both a statutory and voluntary sector experience.
- Community language skills.
- Involvement as an expert by experience for a PhD study into the coping strategies of South Asian carers of a relative with dementia.

Given the skills and experiences as the Project Manager, Shahid was able to gain trust in the community, respect amongst the colleagues in the statutory and voluntary sector partner organisations and access to key influencers and the media.

In order to try and gather some practical steps for other similar projects, we asked participants in the project as to what they thought worked well and what could have been improved. Our findings suggest that no one approach worked best.

All three participants in the short films felt that the Project Manager having an empathetic approach and his willingness to listen and hear their stories were the key positives in encouraging them to participate in the project.

The Pakeezah Women's Group reported that the Project Manager was calm, respectful and willing to listen to concerns they raised as women carers - including when they *"off-loaded their concerns of men in the family not always appreciating the work that the women undertake in terms of care."*

Similarly, the Bangladeshi group of men were full of praise saying, *"Shahid is Pakistani but he gave us respect and we respected what he was trying to do."* The significance of this lay in the fact that some of the men initially felt that it should have been a Bangladeshi man talking to them in Bangla rather than a Pakistani man speaking Urdu. This was captured by one man who said, *"language is important but what is more useful is the content and the information. He [Shahid] shared his experiences as a carer for his mum and that made us all realise that we all feel the same when caring for a close relative."*

Asked about any improvements or changes they would have preferred, the women's group said that they had thought it might have been easier if the worker was a woman *"because men usually do not understand the heavy load we have to carry as a wife, carer, mother being a cook, cleaner, carer... we have to keep everyone happy especially when men say that it is easy just being at home."* When asked whether the Project manager was able to understand or empathise with this, they all said, they *"had no problem because he told us how he and his wife faced difficulties within family, community and with services to try and get help for his mother."*

Exploring this further, they were asked if it would have been better if the project manager was a woman. A few commented that they would *"not have had to think about trust as much"* but all agreed that choosing between *"lived experience and just being the right gender should not be about the worker being a man or a woman, but based on knowledge and respect."*

Asked the same question about the gender of the project manager, the people in the films all said that trust was the biggest issue; because they could see that *"Shahid was very knowledgeable, understanding and helpful [they] preferred someone like him irrespective of asking if it was he or a she."*

The Project Manager was also forthcoming in helping to identify the barriers or challenges that could hinder the success of a project such as this. The main obstacle is the time pressure for a part time worker: *"having to build relationships, trust and delivery is difficult in a part time post."* He felt this was because the biggest challenge he saw was *"carers needed to trust people before they can open up their homes and their lives to strangers."*

Another challenge expressed was the difficulty of ensuring there is continuity and sustainability. The Project Manager said he felt that *"a lot of good groundwork is done before you can start to deliver the project and when you are established the funding runs out. What are you meant to say to the carers you have been working with?"* However, he also responded that his strategy was to signpost people to

services to support carers and to tide to stay connected during and beyond the project.

Story Telling – Carer Lived Experience.

Making public their personal experiences can be a huge step for carers of any culture or background. There is always the worry that carers feel judged by others - whether family, friends or the wider community. Dementia Dekh Bhaal aimed to have some South Asian carers share their story on film that would be widely distributed and used in training. The idea of a story bank fits in well with other approaches to cultural appropriateness in communication. Many of the South Asian families have English as a second or third language. Put together with the fact that there is no word for dementia in the main South Asian languages, it was clear that the role of the films would be two-fold: to help raise awareness by educating people about dementia and to help break down cultural barriers or stigma surrounding dementia and dementia care.

The Dementia Dekh Bhaal project was successful in recruiting three carers with varied backgrounds and carer circumstances. Each one offered a unique insight into their lives as a carer and the barriers and facilitators they faced in their role as a carer.

Tahir (Pakistani, male) - a carer with his own ill health (MS) supporting his mother living with dementia. He helps his wife to look after mum, but his wife also has some health concerns of her own. Given his own ill health, his wife also has to support him. A complex situation.

Dewan (Bangladeshi, male) - works in a professional capacity and has been a carer for his dad. Dad was a “*lion in the community*”, and it fell to the family to arrange support within the home without access to care services.

Ansa (Pakistani, female) - a mother, a wife, a daughter in law and a carer for her mother in law. Ansa struggles with coping to care for her mother in law, feels obliged to have to care and wants to care, but fears the future as dementia is progressing.



A number of questions were asked which have been grouped under the four questions below:

1. What made you want to get involved in the project?

- *Trusting Shahid to make sure that what I say is respected and honoured*
- *We have had some real challenges in supporting [my relative]. We don't want other families to struggle as we do.*
- *No one cares about us and I saw this as an opportunity to show that we can and do manage.*
- *Dementia needs to be known in our communities. I agreed that if I do not share my story how do other carers get strength to fight challenges.*

2. What helped in being a part of the project?

- *I would definitely say trusting the project manager. His own story is powerful and that made me think I want to share my story.*
- *Honesty, openness and trust with Shahid meant we can trust our filmed story to be used positively.*
- *I think I understood the need to share our story so that other carers can see that they too have a voice and should not be scared of challenging community stigma. The more people see and hear the better it is for everyone.*

3. Were there any challenges in agreeing to be a part of the Dementia Dekh Bhaal film project?

- *To be honest I was scared: what will my relatives say if they see me on film?*
- *It's embarrassing maybe because no one wants to show their problems for the world to see.*
- *I think the only challenge was making sure I could find the time for the filming because of being busy with [relative with dementia].*

4 Is there anything else you want to add about your involvement or about the project?

- *I want to thank Shahid because he put me at ease.*
- *I feel Dementia Dekh Bhaal should be in every GP practice. I am sure there are many families that are struggling.*

Campaigning

Opening up to a wider audience is always difficult, whether speaking to friends or family about the struggles in coping or to the community about the realities of dementia and its progression.

Carers often feel isolated regardless of their ethnic background. However, there can be various level of jeopardy for some carers. For instance, language barriers coupled with experiencing racism or perceived prejudice along with migratory experiences can make it more difficult to have trust in services, or to speak up about the stigma or struggles of being a carer for a relative with dementia.

Dementia Dekh Bhaal therefore ran a number of activities to create the begins of a grassroots movement to challenge community perceptions and de-stigmatise dementia.

Project Launch

A successful project launch took place in partnership with Pakeezah Women's Group. The launch brought together RBC, HMRCCG, community members, Councillors and some media. Officially launched by the Mayor, Cllr Zaman, this was an opportunity to explain why this work was such an important step for the South Asian community. Tide's CEO, Anna Gaughan, gave a commitment to champion the support needs of carers from the BAME communities.

Asked why the launch was hosted by a women's group, Shahid explained that this was significant for a number of reasons. Primarily, care tends to be done by women so they should be informed and empowered, men have more access to community events and some work had already been done with some men's groups. Shahid also said, *"these ladies were then interested in becoming ambassadors for the Dementia Dekh Bhaal project to challenge dementia related stereotypes in their homes and social circles."*

Community Roadshows

Three roadshows were held to provide information about dementia, the impact on the carer and the help or support available to carers. These took place at Pakeezah Women's Group, Bangladeshi Association and Community Partnership and the Castlemere Community Centre.

The community roadshows were rated a success as they were seen to be fulfilling the sense of outreach to the community. One participant in the evaluation said, *"It was good that Shahid came to talk to us as a group as we learnt together, otherwise we would have said it is of no concern - but be secretly frightened of what might happen."*

These community roadshows also allowed for questions and answers in a friendly environment where the participants felt safe. The ethos of Dementia Dekh Bhaal was clear to see - the speaker was an invited guest and not the lecturer telling people how it was.

Being able to *"laugh at our cultural practices and why we become our own worst enemy is something the younger generation will not allow"* said one lady, *"we worry what others think rather than the trouble and burden we place on ourselves."*

The community roadshows highlighted the need for appropriate engagement. Not all carers go to the community centres, but those that do can become advocates for the change in cultural thinking and behaviours.

Feedback from Roadshow events

1. What was your awareness of dementia before the roadshow delivered by Dementia Dekh Bhaal?

- *We don't have a word for dementia.*
- *We thought it is natural as you get older.*
- *We never saw our parents in Pakistan, India or Bangladesh with dementia as we lived here and they lived abroad.*
- *The thing is whatever comes good or bad comes from god so we just accept it.*

2. Did the Dementia Dekh Bhaal roadshow change your views on dementia - and if so in what way?

- *We learnt that it is not normal to getting old because it affects the brain like having a physical health problem.*
- *We were surprised to learn that Asian people are at more risk of getting dementia early age and because of our lifestyle like diabetes and heart problems.*
- *Shahid said our communities will have seven or eight times increase in dementia. That is terrible news for us and for our children.*
- *I feel I am better able to talk about dementia with family and friends because this is an illness not deliberate by people who get dementia.*
- *We had some really good discussions about how it can affect women more as men don't usually end up being carers but we women do.*
- *Shahid told us that we should try to live healthy lives to prevent chances of getting dementia.*

3. Do you think programmes like Dementia Dekh Bhaal support communities like yours and if so how?

- *We spoke in Urdu and Punjabi and that was really good.*
- *Shahid is a local person and we trust what he was telling us.*
- *I think the fact that Shahid was able to tell us about services that can help carers was really good because I don't think anyone in our group knew.*
- *We didn't know dementia but we understood Dekh Bhaal. I think we need more information and help for people in the community.*
- *Shahid said this was a one year project, why can't you deliver these events regularly as people will need help if more and more people get dementia?*
- *I feel this was a good way to get us to talk about what might happen to us and how we might have to make choices about dementia or as carers if our children are also busy with their lives.*
- *If it wasn't for Shahid I would not have been comfortable in telling the group about how I struggle with looking after my mother. People say she is going crazy, now I know its dementia.*

4. How could Dementia Dekh Bhaal be improved so you have a service or project that meets the needs of the South Asian community in Rochdale?

- *I think is important we can trust the person who tells us the information.*
- *It was good that Shahid came to us in our centre rather than we having to go somewhere to find out about dementia.*
- *We need more of this work in the community because there will still be lots of people who do not know that they can get help.*
- *Many won't know that they are carers because in our culture we care for people, we have to care for our older people.*
- *You should get more people aware about dementia so that carers do not feel that they have to listen to the rubbish that people say to them like their mum is going crazy.*

5. Why do you think South Asian carers do not access mainstream services relating to dementia or dementia care?

- *How can we access them if we don't know about them?*
- *The doctors sometimes say that it is old age.*
- *We have Asian people working in the Council and health - sorry to say but they don't help the community (not sure if this meant information or general comment).*
- *I think it is because we worry about what our relative or neighbours will say. We get scared of them rather than put older people in care homes.*
- *Services are no good if they are far from home or if it takes a long time to get help.*

Radio programmes

The campaign was further supported by taking the voices of carers and the purpose of the work into people's homes - especially those who may not be accessing community centres and places of worship. It was evident from talking to individuals that many felt they would be *"stuck at home if there was no friendship or reason to come out of the house."* Others also stated that for many folk *"home-based responsibilities mean that many carers do not have the opportunity to get out for their own socialising."*

Radio work was therefore an important means through which information could be passed on to carers at home. This was also culturally appropriate as the information was tailored by language and the time of the year. The project manager delivered some community issues by speaking on Crescent Radio, BBC Manchester and Voice of Islam. It is difficult to gauge the exact reach but the feedback from the phone calls into the radio show was excellent. The presenters also commented on how valuable this area of work was for the South Asian communities in Rochdale and beyond.

Buy-in from community champions

For any project or programme of delivery to be successful there needs to be an element of community buy in, securing their trust and confidence. Dementia Dekh Bhaal was fortunate to gain the early support of a local radio station and of the town's Mayor. Both of these helped to normalise the experiences of carers of a relative with dementia, but also to engage in discussions that pushed the responsibility onto the community to reduce the stigma associated with dementia and 'normalise' the need to access support in caring for a relative with the condition.

The Mayor of Rochdale offered his support as he felt that dementia was something that the community needs to be aware of but also to change the stigma from within. Cllr Zaman told us that he valued Dementia Dekh Bhaal as it, *"offers a good opportunity to change community perceptions of dementia, as well as to inform services that they cannot sideline these communities by thinking that they simply look after their own."* Cllr Zaman's support has helped us to access encouragement from people connected to politics, faith institutions and the business community.

Growing a grassroots Movement

At least twenty South Asian carers have been recruited and have signed up as members of tide. This means they will access information, training and involvement opportunities and become advocates with a voice to represent themselves and their communities.

Training

Training for frontline staff

Dementia Dekh Bhaal was tasked with creating a training package for frontline staff. This was to be tested out with some frontline workers to gather feedback on what would be most helpful in their understanding and ability to engage with BAME carers of a relative with dementia.

The main purpose of the training session was for the HMR CCG and Rochdale Council to inform their staff on the difficulties of understanding dementia and dementia care from BAME community perspectives. The content includes the social constructs of dementia and of care, migratory influences, stigma, the influence of faith, generational variances, the impact of organisational culture on acting as gatekeepers or having potential prejudicial reputations and how this impacts the diverse populations of Rochdale.

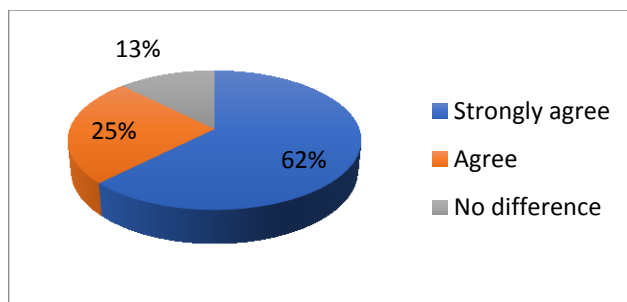
The training was delivered in February 2019. Colleagues at RBC and HMR CCG led on the promotion for the training session. The training was set up on the Adult Care Training System that details all training for adult care staff. It was advertised on an internal "weekly round- up" email. This is an internal email sent to all adult care colleagues to inform them of any training that is on offer. The information was circulated for at least 3 weeks. The course information was sent to CCG communications so that it could be advertised to NHS colleagues.

The low take up by frontline staff could have been due to the course not being mandatory. The remit of Dementia Dekh Bhaal was to run this as a pilot session to learn from the feedback of the participants. It may also be that take up was low due to the fact that RBC also run a cultural awareness training course which may have given the impression that this was a similar course, but we cannot confirm this.

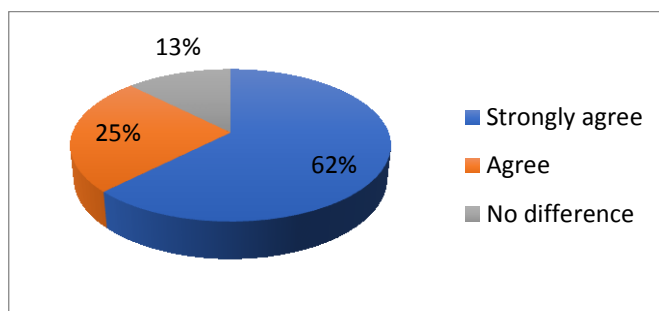
The powerful stories of the three diverse carers were included in the training to share their lived experiences.

Feedback from the training session:

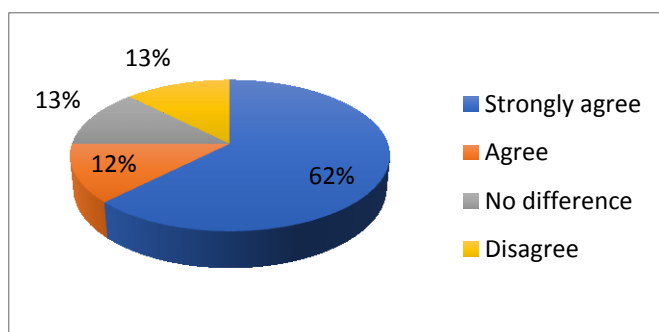
1. Were you satisfied with the training session? 5 out of 8 strongly agreed, 2 agreed and 1 felt no difference



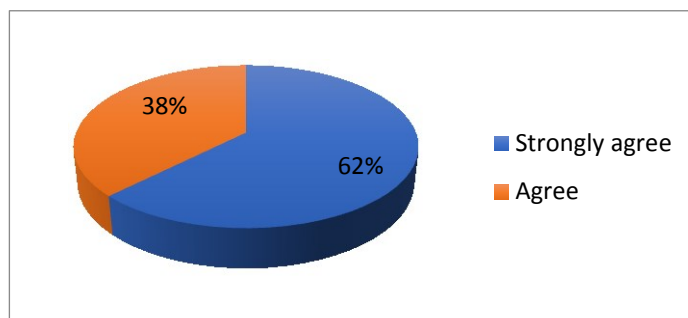
2. Would you recommend this training to others? 5 strongly agreed, 2 agreed, 1 felt no opinion



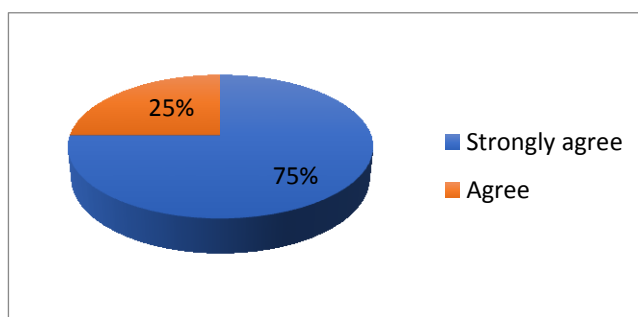
3. Would they want to attend further training sessions? 5 strongly agreed, 1 agreed, 1 felt neutral and 1 disagreed



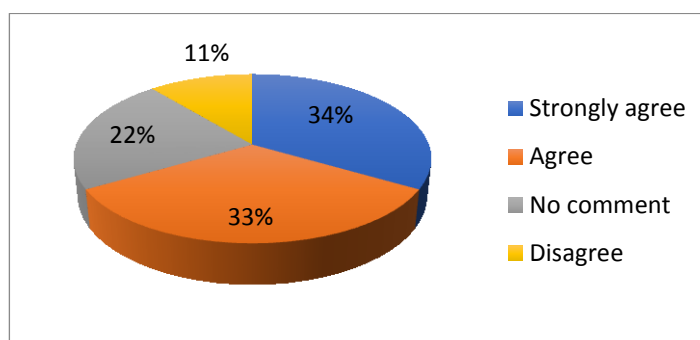
4. Was the information helpful? 5 strongly agreed and 3 agreed



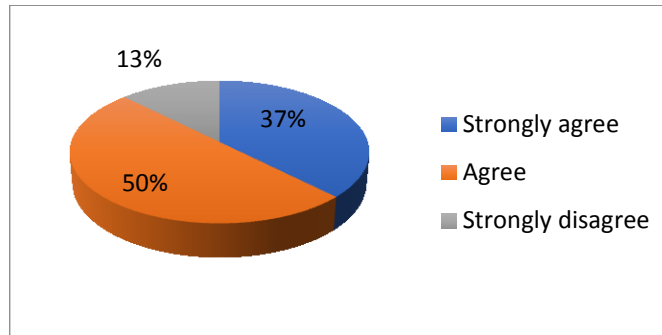
5. Were the speakers easy to understand? 6 strongly agreed and 2 agreed



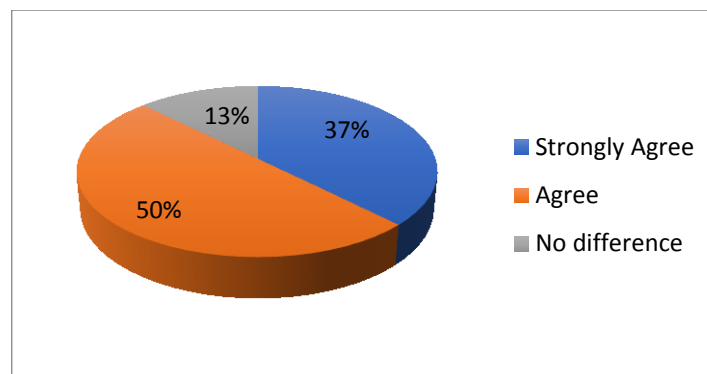
6. Was the session of the right length? 3 strongly agreed, 3 agreed, 1 disagreed and 2 did not comment



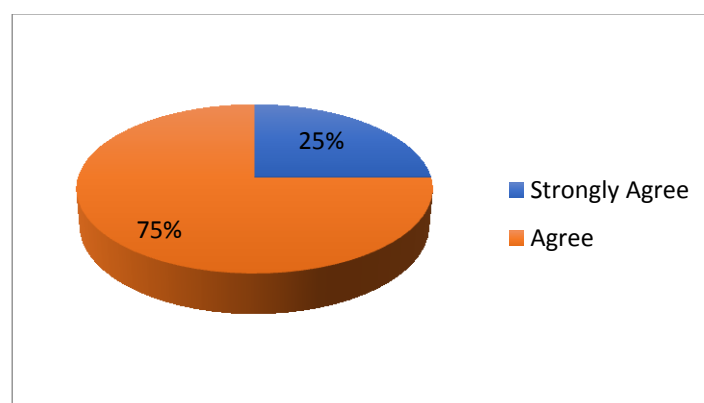
7. Did the training improve participants' understanding of BAME dementia matters? 3 strongly agreed, 4 agreed and 1 strongly disagreed



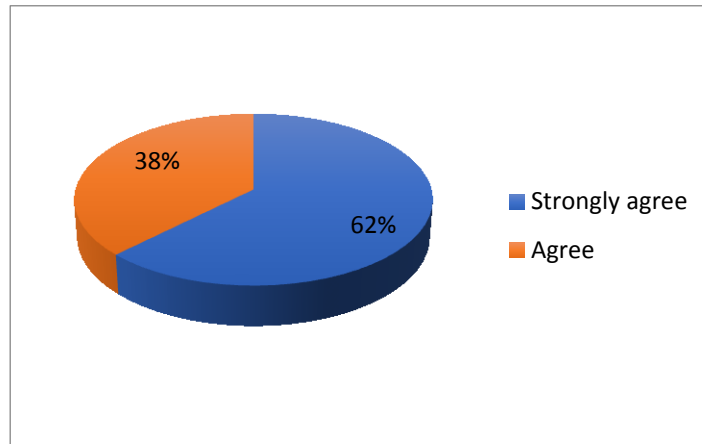
8. Did the training give confidence to participants about BAME dementia issues? 3 strongly agreed, 4 agreed and 1 felt no difference



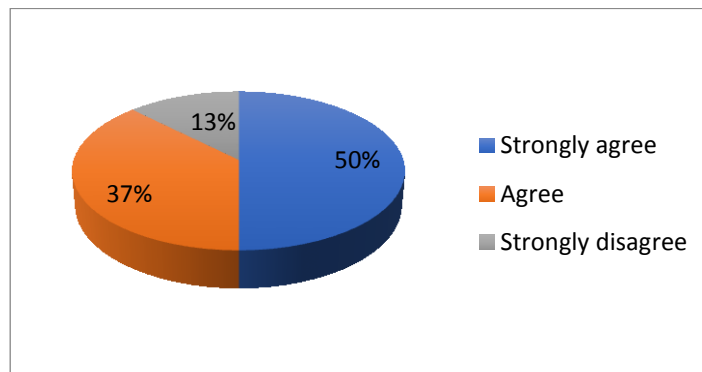
9. Did the training enable participants to better support the needs of BAME dementia matters? 2 strongly agreed and 6 agreed



10. Did participants value this training? 5 strongly agreed and 3 agreed



11. Did the training empower participants to challenge stigma preventing support for BAME people with dementia or their carers? 4 strongly agreed, 3 agreed and 1 disagreed.



What did you value the most from the training?

- *Learning about South Asian cultures and how families aren't able to speak about dementia, also what certain words meant*
- *Learning about cultural beliefs, perceptions and understanding, and how this will support my own learning and interactions with service users*
- *Very interesting project and its goals to get to know that awareness work is being done with all communities*
- *Really enjoyed the course. Loved the real life stories (videos) as it shows how life really is. Really knowledgeable facilitators.*

- *Differences in languages spoken in Pakistan and India, carers experiences, overall the information was good*
- *Identified information regarding re languages within Punjab*
- *Understanding of caring roles within the family unit.*

The training could be improved by:

- *More information on how to support - methods and strategy. I think we ran out of time in the end (want more)*
- *List of the different languages for certain communities on a map*
- *More time*
- *Felt the videos were correct of experiences within the three families, however feel they were all negative*
- *For it to be a full day course as very interested in the culture (would have liked to go into more depth on this) before moving on to the dementia side*

Seven of the eight participants felt that the training would be good for frontline workers to have a better awareness of the potential barriers affecting engagement with services.

Summary

Dementia Dekh Bhaal has taken an Asset Based Community Development approach to meeting the objectives and the aims set out for tide to deliver in Rochdale. From the outset, tide adopted the 'Lived Experience' both for the delivery and the value placed on the carers with whom the project worked. A steering group, which included expertise from field experience, academia, commissioning and the lived experience, enhanced the qualitative input into piloting a meaningful, cost effective and valued project.

It is clear from the feedback of the participants that the 'expert by experience' characteristics of the project manager enabled carers to build trust with him before being able to engage, involve and participate in the various aspects of the project. Having being commissioned as a result of their strategic review of dementia in Rochdale, tide rose to the challenge by incorporating a tried and tested approach to empower carers rather than preach to them. By undertaking a campaign, telling the stories of carers and developing a training package, tide has enabled carers to share their experiences via film, roadshows, signing up for tide membership and beginning to present at events.

The training package developed has incorporated the involvement of carers into the information so that frontline staff can get a good understanding of the issues faced by South Asian carers of a relative with dementia. In addition to the work delivered through Dementia Dekh Bhaal, 21 participants registered to become members of tide. Of these 21 individuals, eight identified themselves as current carers, six as former carers, one person living with dementia and one person just interested in BAME dementia and carer issues.

The challenge now is how these raised expectations can be strengthened, sustained and incorporated into mainstream approaches to meet the needs of diverse communities.



Recommendations

- This approach needs to be embedded in other community engagement projects for the CCG and the Council as it demonstrates good practice for reaching out, engagement and delivery.
- Tide should publicise this pilot project as a successful model of engaging with BAME communities so that the fallacy of *'they look after their own'* can be challenged with evidence from the carers – showing their challenges and struggles. There is a clear opportunity for the wider partnerships (such as Dementia United in Greater Manchester) to adopt the practices and learning from this project across its various towns and cities in the region.
- Dementia Dekh Bhaal project has demonstrated the importance of credible, local experts by experience who can reach out to South Asian communities to gain their trust, tackle stigma and demonstrate that it is ok to talk about dementia. RBC and HMR CCG should take the learning from his project to explore how it can continue to engage directly with these communities to improve awareness and understanding about dementia and enable carers to seek help.

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