

Understanding the Experiences of Post-Diagnostic Dementia Support for South Asians Living In England: The Need for Co-Production

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Abstract

Background: The increase in the numbers of South Asians in the United Kingdom (UK) is likely to lead to an increased need for dementia services yet; they are currently under-represented in dementia services. Furthermore, little is known about the prevalence, experience and treatment of dementia in the UK South Asian population, including their experiences of post-diagnostic support. Consequently, a project was commissioned by Alzheimer's Society in the UK to gather insight into the experiences of post-diagnostic dementia support for the South Asian community in England to identify whether their post-diagnostic support needs were being met and what they needed from post-diagnostic support services.

Methodology/Methods: As this project sought to understand experiences, a qualitative case-study approach was adopted. Twelve South Asian carers of a person with dementia and one South Asian person living with dementia took part in an on-line in-depth, topic-guided conversation. All conversations were audio recorded with consent and analysed using a thematic analysis.

Findings: Analysis revealed that the South Asian community are doubly affected by dementia in relation to post-diagnostic support because 1) they received very little post-diagnostic support and 2) even when they did, it wasn't culturally appropriate and therefore ineffective. Essentially, the lack of culturally inclusive care compounds the lack of access further. Consequently, people discussed current gaps in service provision, making recommendations that will result in better support, and more positive experiences for South Asians when diagnosed with dementia in England. In order to achieve this, South Asians in need of dementia support should be involved in the planning, development and delivery of post-diagnostic support services.

Conclusions: This paper discusses findings that highlight the importance and benefits of co-production whereby people who use services and carers work with professionals in equal partnerships towards shared goals.

Keywords: Dementia, Post-Diagnostic Support, South Asian, Ethnic Minorities, Co-Production

Introduction

There are over 55 million people worldwide living with dementia, with an estimated 900,000 people living with the condition in the United Kingdom (UK) [1]. In 2013, the All-Party Parliamentary Group on Dementia reported there were an estimated 25,000 people living with dementia in the UK from an ethnic minority background [2]. A significant proportion of these people are South Asians, who make up over 5% of the total UK population [3]. In the UK, South Asians include Indians (2.3 per cent), Pakistanis (1.9 per cent), Bangladeshis (0.7 per cent) and other Asians including Sri Lankans, as well as third-generation Asians, Asians of mixed parentage, people from Nepal, Bhutan and the Maldives and some from the Middle East [4]. Most South Asians in the UK come from three areas of the

subcontinent: the Punjab (Pakistan and India), Gujarat (India) and north-east Bengal (Bangladesh) with some Gujaratis and Punjabis who came from East Africa. The main languages are Punjabi, Gujarati, Bengali (or Bangla), Hindi, Urdu and English. The main religions are Islam, Hinduism and Sikhism with some Christians, Jains and Buddhists [4].

Despite the growing numbers of South Asians in the UK; they are currently under-represented in dementia services [5]. Those who do use services have suggested that they are culturally inappropriate due to cultural and language barriers [1, 6-9]. Research with Sikh carers in Wolverhampton highlighted that this was due to a lack of awareness from services about their faith, cultural norms and dietary requirements [10]. A number of road-

shows involving discussion groups about dementia with ethnic minority groups, including British Asians concluded that people made use of religion, as opposed to medical healthcare services, as a form of personal and treatment control [9]. It has also been suggested that people from South Asian communities prefer to draw on community support networks such as mosques, and gurdwaras, rather than dementia-specific services such as those run by the Alzheimer's Society possibly because they did not perceive these as meeting their cultural needs [11]. Other studies have suggested that low service uptake is also due to a lack of knowledge of the services available as well as culturally specific barriers such as language [8, 9, 12]. It has also been suggested that the reliance on community initiatives for support is due to the low representation of staff from a person's own community background in professional health services [1].

Disparities in service provision for people from ethnic communities compared to White British communities within a primary care led dementia service in the UK were investigated [13]. On the contrary, the study suggests that many areas of service provision showed no evidence of inequality however, important differences remain including the time at which people present for assessment and the range of post-diagnostic services which are discussed [13]. Significantly more people from the White British sample were recorded as using or being offered more than one form of community support. The authors were unclear as to whether support offered to South Asian communities was declined based on the perception that these services would not meet their cultural needs. Furthermore, they suggest that the lower recorded level of post-diagnostic support might reflect either fewer culturally appropriate services are available, or such services do exist, but dementia navigators and practitioners are not aware of them. They also suggested the possibility that staff may not recommend the same range of post-diagnostic support for South Asian people due to the assumption that they may not use these services [13]. There is also the likelihood that UK south Asians are not aware of the services available to them following a diagnosis of dementia [7-9, 12].

Due to the dearth of literature, a project was commissioned by Alzheimer's Society, a leading charity in the UK, to gather insight into the experiences of post-diagnostic dementia support for the South Asian community in England to identify whether their support needs are being met, and what they require from post-diagnostic support services [14]. This paper presents the three case study illustrations to highlight experiences of (the lack of) post-diagnostic support and culturally inclusive care, and the need for co-production in the design and delivery of health services for people living with dementia from South Asian communities.

Methods

As this project sought to understand experiences, a qualitative case-study approach was adopted. The case study approach allows in-depth, multi-faceted explorations of complex issues in real-life settings. In light of the COVID-19 crisis, this was an on-line based research project conducted by the first author. The project involved one-to-one in-depth topic guided conversation

either via zoom, Microsoft Teams or over the telephone.

People were contacted in two ways:

1. A Social Media Campaign

Dedicated social media pages were previously developed by the first author targeting South Asian communities living with dementia. These platforms are designed to be interactive with various calls to action such as sharing experiences. A communications strategy including a four week social media campaign was developed to seek South Asian people who have experiences of post-diagnostic support; including appearing on a West Midlands based local radio station to advertise for people who were interested in sharing their experiences.

2. Existing Established Networks

Existing networks known well to the first author were contacted. For example, three West Midlands based support groups that are virtually run by members of the South Asian community consisting of approximately 20 members each were contacted. Prior to the Covid-19 pandemic, these groups met physically but now operate via WhatsApp groups to offer support to those possibly experiencing isolation. These groups are self-funded, organised and operated by volunteers within the community.

A project flyer/advert was developed and shared amongst these networks with details of how to contact the first author, should they want to share their experiences.

In total, 13 people took part in this project: 12 carers of a family member with dementia and one person living with dementia. The project included nine females (eight Sikhs, one Hindu,) four males, (two Muslims, one Hindu, and one Sikh). The youngest participant was 28 years old and the eldest was 78 years old from various locations in England.

The Conversation

Following a consultation with Alzheimer's Society, a series of questions were developed based on the current knowledge gaps. These questions formed the topic guide for the conversations. Conversations took place via Zoom, two via Microsoft Teams, and five via a telephone conversation. Ten conversations took place in English, two in Punjabi and one with both English and Punjabi. Conversations lasted between 30-90 minutes each. Conversations were audio recorded with consent. Consent was also received for the use of direct quotes in the write up of the report and dissemination activities, including publications.

Ethical Considerations

As this project was commissioned by Alzheimer's Society, senior members of the charity's research team reviewed all methods involved in the project ensuring that they were in line with the British Psychological Society's code of ethics and conduct (2018). In doing so, all participants were respected and the author ensured that they acted responsibly and with integrity. They did not mislead participants and remained open and honest about the purpose of this project and intended use of the findings. Consent was received for the use of direct quotes in the write up of the report and dissemination activities, including publications.

Analysis

Analysis of the information collected applied the six phases of thematic analysis outlined by Braun and Clark [15]: (i) Familiarisation with the data; (ii) Generation of initial codes; (iii) Search for themes; (iv) Review of themes; (v) Categorisation of themes and (vi) Production of the report. A number of themes emerged from the conversations including: a lack of information about services and having to work through a fragmented pathway; the lack of culturally inclusive care, lack of support as carers and the need for coproduction. This paper presents three case-study illustrations to highlight some of these challenges and the importance of co-production.

Findings

Following a diagnosis of dementia, all people who took part in this project reported that their loved one was assessed for medical treatment via a memory assessment service but no one person was verbally told by a healthcare professional if any other services were available to them. As all people were using a memory assessment service, if a problem was raised that did not concern medical treatment, they were advised to contact their General Practitioner (GP) for a referral to social services. However, this was only if they raised a concern with the memory assessment service. After several months of navigating a fragmented pathway, people were doubly affected by dementia in relation to post-diagnostic support because 1) they received very little post-diagnostic support and 2) even when they did, it wasn't culturally appropriate and therefore ineffective. To highlight this, three case studies are presented: Balvinder, Sameer and Sukhjinder (pseudonyms have been used to protect their identity).

Case Study One: Balvinder

Balvinder is a 32-year-old Sikh woman, who cares for her mother who was diagnosed with Alzheimer's disease one year ago at the time of the conversation. Balvinder's mother, "got the diagnosis and nothing happened after that." When her mother's health deteriorated, Balvinder contacted the GP to let him know that her mother was refusing to get out of bed. The GP wanted to do a blood test and as she couldn't physically bring her in, the GP referred them a second time to the memory assessment service. When Balvinder explained the issue to the memory assessment service, they referred her to social services as it was not something they dealt with. Months passed before Balvinder was able to get a response during which time her mother's health further deteriorated. Indeed, the additional challenges of the Covid-19 pandemic did not help their situation however, for Balvinder, the concern was more not being able to find her mother appropriate support and being moved around services:

"So, when this stuff was happening where she didn't get out of bed and stuff, the GP, basically, then referred me again to the memory clinic. They were just kind of like, "Okay, well, if your mum's not getting out of bed and she's not eating then we need to refer you through the council and maybe we can get someone in to help you with like incontinence pads and things like that." And I was kind of like, "We're not really having that problem because she actually does get out to go to the bathroom. That's the only thing she probably gets out for. The problem is I can't keep her out... once she gets to the bathroom, I can't keep her out of it, she just runs straight back into bed. So, you know, we

got referred, basically, to social services. And they took ages to get back to us, they just didn't. They just took it really, really slow. It was like weeks or months that we had like replies and stuff from them. In the meantime, my mums not getting out of bed or eating properly."

Consequently, Balvinder "carried on figuring it out." Eventually she was put in touch with a specialist dementia nurse, known in the UK as Admiral Nurses, who she found helpful as "she called every so often and gave a bit of advice on what we could try. Ultimately, though, her answer was, "You need to get a carer in, get a change of face and try that." Balvinder didn't want to rely on the NHS due to the delays in getting support and so went private to find a suitable carer for her mother because "I was kind of at a point where I was like, "I need an answer now. Like she's not getting out of bed, she's not eating. I need an answer now so yeah, we went private for carers."

Balvinder was sent a list of recommended care agencies in the area from someone in social services and contacted them all privately only to be faced with another obstacle – the lack of Punjabi speaking care workers. Even though her mother can speak some English, it was more that her:

"Generation is going to feel more comfortable and a bit more of an affiliation with someone who is a bit more culturally in touch, right? And, you know, who will understand... who will just understand and speak to you in your mother tongue, like it was just comfort, right?"

Balvinder also discussed the challenges of services not understanding the diversity within South Asian communities:

And first of all, a lot of care agencies did not understand that there is a difference between – which is just stupid – that there is a difference between Punjabi, Gujarati and Hindi, like you cannot just send me a Gujarati speaking care worker and say that they understand Punjabi because it's not the same. Because I had that, I had someone send me a Gujarati speaking care worker saying, "Oh, but she understands Punjabi," and I'm like, "That's great but she doesn't speak it." That's not the whole point. I want Mum to feel comfortable and be able to communicate with her in Punjabi, right? That was a massive issue that we faced."

Consequently, for Balvinder, "there's no one who can provide that support or who can speak the language and is a specialist in this." For Balvinder, "getting a diagnosis of dementia is shocking, what's even more shocking is finding out that there is no support available for your Mum because she doesn't speak English." Furthermore, the lack of dementia awareness amongst the South Asian community essentially left Balvinder with "nowhere to go for support."

"Every day I'm losing my mum one bit at a time. Not only is there no one to talk to about this, I don't know how to help her. She hasn't got out of bed for months. My dad doesn't understand why and neither does the rest of the family who think we aren't doing enough. Services can't help us because they don't have the resources or understand our needs. The community aren't

educated enough to provide us with any support. I can't tell you what it feels like to have spent two years of our lives chasing a diagnosis to then be told "okay, crack on now." It feels so disappointing."

The double jeopardy of the lack of culturally and linguistically appropriate services and the lack of dementia awareness amongst the South Asian community highlighted for Balvinder, the need for services to develop "dementia specialists who are from South Asian backgrounds." In doing so, not only will there be more support for people from South Asian communities but, also more opportunities to raise awareness about dementia via such individuals. In addition to needing more dementia specialist South Asian healthcare workers, Balvinder also noted the need for non-pharmacological interventions that "ignites that spark in her brain to get her to do stuff, you know, cultural things that she enjoys." Having such support in place, would also "relieve a lot of tension and stress on the rest of us because then you've, essentially, got a day to yourself or a day back where you can get your errands done. Because that's constantly the thing, isn't it, because someone always kind of needs to be around."

It is the responsibility of policymakers and service providers to include such experts by experience to identify their needs and service requirements for "this is the first time I am talking about my experiences and what needs to change, nobody has ever asked me." Furthermore, Balvinder reflected on the difficulties that older people may face when they have little family support:

"I work as well, long hours, and working from home means I've had to do both. Even though it's been a blessing in disguise, I don't know if it would have been different had my brother and I not actually been around for mum. But, you know, if this was someone else, if it was my parents by themselves, they'd really be struggling, like, they'd be really, really struggling."

Case Study Two: Sameer

Sameer is a 30-year-old Muslim male who carers for his mother who was diagnosed with Alzheimer's disease eight months ago from the time of the conversation. He noticed that his mother "started acting very strange, becoming forgetful and doing weird things." He spoke about this with a colleague at work and was advised to take her to the GP to check that it was not dementia. Sameer had heard of dementia but didn't know exactly what it involved and so,

"I went home that day and started googling it. The symptoms that I read about were quite similar to what mum was doing and so once I got over the shock of it, I took her to the GP, and he was pretty good to be honest. He told me that it could be Alzheimer's disease and made a referral to the memory clinic. He sent her for lots of scans and tests and then after about 6 months I think they confirmed it. Covid happened so although she got the diagnosis 8 months ago I actually went to my GP almost a year before that. I went in feb 2020 and it took until jan 2021 for her to get diagnosed – she has definitely had dementia for a lot longer than that."

Following his mother's diagnosis, Sameer "wasn't given any in-

formation about anything. I have been chasing the memory clinic since things have opened back up and I'm still waiting to hear back from them. That's where the referral was made so that's all I know about." Consequently, Sameer began to do his own online research about what services may be available to support his mother and because his mother does not speak English, he struggled to find a service that would be able to culturally and linguistically meet her needs. Similar to the other people who took part in this project, Sameer reported how time consuming it was trying to find his mother appropriate support:

"To be honest, I'm still dealing with the diagnosis myself and trying to understand it. I spend so much time looking for ways to support her myself at home, because there's no help with anything. It's a tough one because you either spend your time trying to find out what help is available or, you spend your time researching how to help them yourself you know, because you're the one living with them."

Sameer also discussed the lack of emotional support for his mother: "it's so difficult. I'm a bloke you know. We're not as intuitive as women I think. I see to her practical needs you know, medications, making sure she has everything she needs, but emotionally I don't know how to help her." He is currently awaiting an assessment as he "can't help her with her personal care – I just remind her to shower and things like that because she forgets or she thinks she has showered and she hasn't."

For Sameer, the most difficult thing is "not knowing how to help her" and so he would benefit "if someone could come and talk to me about her diagnosis. Just explain to me what Alzheimer's disease is and how I can give her the support she needs. No day is the same and so sometimes I find something that works and then, boooof, the next day it fails. Just like that. It's tiring."

In an attempt to find his mother some support, Sameer noted the need for his mother to be around people like herself: *I can't find anything that supports people with dementia that she would actually be interested in but, wouldn't it be great if there was something for her. It doesn't have to be for Muslims but at least some place or something where an Asian woman would feel comfortable and can be with others like her.* He also talked about the importance of his mother maintaining her independence and having social interaction: "it's not healthy for her, sitting at home all day and because of her dementia she can't go out anywhere on her own anymore."

As a young Muslim male caring for his mother, Sameer talked about the challenges he faces in seeking his own support: "I'm a man, and as you know men don't speak to each other much about emotional things. There's no-one I can speak to, not even anyone at our Mosque because they don't about this condition there, I'm still trying to learn about it myself let alone educate them." Similar to Balvinder, he faces a double jeopardy of no support from services in addition to no support from his community leaving him feeling "alone" and "scared for the future." Furthermore, he stated "it's been hard enough being isolated during Covid but at least then there was nothing to miss out on whereas now

you're sort of sat at home knowing that your friends are out there having a good time."

Similar to Balvinder and others, Sameer discussed the importance of reciprocity with services: *"I don't know a lot about dementia and from what I can see, services mainly cater for white English people so if someone could come and educate me about dementia, I can educate them about the things that are important to my Mum, like her culture and religion."*

Case Study Three: Sukhjinder

Sukhjinder is a 43-year-old Sikh woman who cares for mother who was diagnosed with vascular dementia two years ago at the time of the conversation. Sukhjinder's mother has a history of what she describes as 'volatile and erratic' behaviour; however, when her behaviour became more challenging, she contacted the GP and had to be incredibly persistent in order to get her mother support:

"So, I just pushed and pushed and I said I'm going through a hard time with her. And I think the doctor was just saying well, she's always been like that. And I said, "Well, I need something done." And they were just a little bit reluctant. And then I said, "Well, I want to check her MRI and things." And then, eventually, they, you know, because I was really adamant, then they were like, "Okay." I'm quite a firm person and pushy so I think because of that. Otherwise, I don't think they would have, probably, done it. They just kept for years saying, "Oh, that's just her personality."

Similar to Balvinder, once she had the MRI scan Sukhjinder was then faced 'battling with another service':

"So then we went to the Hospital and we got the MRI scan. And then it took a few weeks and I was calling and saying, "Why haven't we had the results?" And to get the results, that took some time, it really did and I kept pushing, saying, "Where are the results?" And they said, "We're sorry, there's just been a delay." And then they said, "Oh, it had kind of been forgotten," or they suggested that. And I said, "That's not good because that MRI was done months ago and you've just got back to me now."

Consequently, Sukhjinder had to go through the process again and persistently follow up, eventually they received the results of the scan which revealed a vascular dementia. For Sukhjinder therefore, *'the system is really bad. I've spent what's felt like years trying to get to the bottom of this.'*

Following the diagnosis, Sukhjinder was given several leaflets for further information and she felt *"overwhelmed because, you know, you're just trying to process the fact that your mother's got dementia and then I was emotional. I didn't contact them because it was all just all over the place. It wasn't like in one place. They were all different organisations, it was all just too much to take in."* She also felt that *"these services just didn't make sense and seem to be for people in their mid-to-late stages of dementia, and Mums still quite active."*

Sukhjinder's mother was referred to the memory assessment service however; Sukhjinder struggled to get her mother to her appointments on time. As a result of missed appointments, her mother was discharged from the memory assessment service leaving Sukhjinder with social services as her only hope for support. When social services arrived to do the assessment, her mother *"was being erratic so we never really got to what they can help with."* Sukhjinder had done her research prior to the assessment and so *"I told them, this is what I need, I need to apply for this and that."* Similar to the other people in this project, Sukhjinder noted the challenges of a fragmented pathway:

"There are just no processes in place. There might be internally or to write it down so they're, you know, meeting their criteria. But from an external perspective, from someone who is diagnosed or their carer who doesn't know about the system, who doesn't know what's what, there is no system in place to show them, "Oh, you can have this." Whose responsibility is it to tell us? Only when you really talk and find out but that's not always possible."

Following the assessment with social services, Sukhjinder felt that there was no services in place that would cater for her mother's needs and that you have to be in a crisis in order to get some support:

"And then they [social services] said, "Oh, just contact us if she needs any more help," but then I thought, "Help with what? You're not really being specific as to what you could help with. You've basically left me because you're basically saying, "Oh, when she's completely unwell then we might be able to step in." But they don't do the support up to then. All that time spent searching for things, what's the point?"

Although it is important that processes are "charted and written down and simplified" Sukhjinder raises the important point of making such information accessible to people whose first language is not English by considering,

"A digital system so they could interact in languages [...] a chart of what the process is if you think someone's got dementia and who to go to and what service and what the process to finding is out. And then where to go from there and what are those. Maybe in a few sheets, not too... because people aren't going to read it. And then do that in different languages. And then it connects to the digital form so they can put in certain words. Or if they feel they've got a problem, they know who to go to."

Due to her experiences, Sukhjinder feels that *"although we live here, we're still treated as outsiders."* For Sukhjinder, this is because of the way in which the system is set up, causing indirect discrimination to people from culturally diverse communities: *"because everything is always in English first and foremost. You have to then go and ask for things in different languages. Now, with such a multicultural place, I've lived in other countries so, like, for example, in Gambia, it's formed of different tribes and everything is in different languages and so the health system has that in all those languages. So, you think about it, that's just a*

very, very poor country. And here, it's like oh well, first English speaking and then we'll deal with the others later."

Furthermore, organisations may have support available in other languages, however as Sukhjinder pointed out *"in order to know about them, you have to be able to read English because the letters, the leaflets, they're all in English."* Consequently, Sukhjinder felt that the system has failed her mother due to her ethnicity and age:

"because she is capable of learning [English]. But I think it's just because they've been removed from society in some ways because a) they're elderly, b) they're not going to know how to learn. But how are they going to learn if you don't show them? And how are they going to know things if you always put it in English? And then treat them like they're stupid. They're actually brighter than this generation now because they had it hard and they did all the things very... they went through difficult times."

Similar to the others, Sukhjinder has been searching on-line to find ways to support her mother. She joined an on-line chat forum where she could get advice from others, and tips for caring but ultimately *"I have so many ideas for how the system can be improved for our people having now experienced it"* – illustrating the importance and value of the co-production of services with experts by experience.

Discussion

To fully understand people's experiences of post-diagnostic dementia support, one must firstly consider their experiences of getting the diagnosis itself. Supportive of the literature, the people in this study also faced the challenges of working through a disjointed and fragmented pathway making evident the lack of coordination and leadership on dementia. Furthermore, the process of accessing and being delivered the diagnosis set the tone for how people viewed dementia and their resulting pathway which offered pharmacological interventions but nothing to support their (loved ones) cognitive function, independence and wellbeing [16]. Previous research has highlighted that people from South Asian communities are reluctant to use services out of stigma or shame [1, 8, 9]. However, this project has evidenced a generational shift whereby people are seeking services but have been disappointed by the lack of culturally inclusive care available. Community level barriers of stigma and the lack of dementia awareness means that there is an increased need for services but services are ready for this change. There was also no evidence that services were declined based on the perception that services would not meet their cultural needs [13]. For the people in this study, such services did not exist or, they were/are unaware of them.

With such gaps in service provision made evident, many of the people who took part in this project such as those reported in this paper, highlighted the potential benefits of services working in co-production to provide better outcomes for South Asians living with dementia. It is important that experts by experience are able to influence and support services in the way that they are designed, commissioned and delivered, moving towards a more

equal and meaningful role in services. For co-production to be successful, people who use services and carers should work with professionals in equal partnerships towards shared goals [17]. As result of their experiences, the people who took part in this study have already alluded to changes that can result in better support, and more positive experiences for South Asians when diagnosed with dementia in England including: south Asian dementia specialist workers; the involvement of family members to help support healthcare professionals, and; post-diagnostic culturally and linguistically adapted psycho-social interventions.

Conclusions

The increase in the numbers of South Asians in the UK is likely to lead to an increased need for dementia services yet; they are currently under-represented in dementia services. Furthermore, little is known about the prevalence, experience and treatment of dementia in the UK South Asian population. This project sought to gather insight into the experiences of post-diagnostic dementia support for the South Asian community in England and evidenced the difficulties of navigating the dementia pathway and the lack of culturally inclusive post-diagnostic support for South Asians. The people in this study expressed their willingness to support services to better meet the needs of people from south Asian backgrounds. It is important that healthcare services are designed, commissioned and delivered via co-production so that people who use services and carers work with professionals in equal partnerships towards shared goals.

Alzheimer's Society mission is to reach every person with dementia to provide support and enable them to live well with the condition. However, there is a need to understand how dementia is understood and recognised in different ethnic groups to maximise reach. This project has enabled a deeper understanding into the current challenges facing South Asian communities accessing post-diagnostic support. Furthermore, this project has focused a need to work more in partnership with South Asian communities to establish the current unmet needs of this community and to deliver more appropriate, culturally inclusive support through the organisation's services. The project has also played a key role in Alzheimer's Society's 2022 Dementia Action Week campaign, identifying cultural barriers to diagnosis for the Punjabi community. It has enabled the organisation to engage with members of the community through workshops, supported the creation of South Asian-specific diagnosis content, informed external communication approaches, and improved the reach of the campaign through South Asian media outlets.

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Authors' Information

Dr Karan Jutlla is an experienced qualitative researcher and educator dedicated to promoting cultural inclusivity in health and social care, with a particular focus on dementia. As an academic, Karan's research interests in the challenge of dementia care, particularly within ethnic minority groups have spanned over a

decade. She continues to support policy makers, and health and social care service providers to potentially address and deliver superb outcomes for a hitherto neglected but growing part of the community. Karan has a 'grass roots' approach, and is passionate about ensuring that leadership level decisions are reflected in the quality of care received by service users. She has spoken at over 50 national and international conferences and is a Fellow of the Higher Education Academy. For more information about Karan and her work, visit: [HYPERLINK "http://www.drjuttla.com"](http://www.drjuttla.com) www.drjuttla.com

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References

1. Alzheimer's Society. Ethnic minority communities. Increasing access to a dementia diagnosis. 2021.
2. All Party Parliamentary Group. Dementia does not discriminate. The experiences of Black, Asian and minority ethnic communities. 2013.
3. Truswell, D. (2013). Black, Asian and Minority Ethnic Communities and Dementia.
4. Minority Rights Group International. South Asians. 2021.
5. Moriarty, J., Sharif, N., & Robinson, J. (2011). Black and minority ethnic people with dementia and their access to support and services. London: Social Care Institute for Excellence.
6. Atcha, M. (2018). Access to dementia diagnosis and support in a diverse South Asian community: A qualitative study. Lancaster University (United Kingdom).
7. Johnson, M., Tilki, M., Jutlla, K., Kaur, H., Lam, T., Tan, G., ... & Williamson, T. (2019). Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change. Jessica Kingsley Publishers.
8. Jutlla, K. (2015). Dementia and caregiving in South Asian communities in the UK. *Dementia, Culture and Ethnicity: Issues for All*.
9. Parveen, S., Peltier, C., & Oyebode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: A scoping exercise. *Health & social care in the community*, 25(2), 734-742.
10. Jutlla, K. Caring for a person with dementia: a qualitative study of the experiences of the Sikh community in Wolverhampton. Keele University: PhD Thesis; 2011.
11. Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (2018). A grounded theory analysis of the dementia experiences of people from three BME communities: Balancing the need for support against fears of being diminished. *Dementia: the International Journal of Social Research and Policy*, 19(5), 1672-1691.
12. Blakemore, A., Kenning, C., Mirza, N., Daker-White, G., Panagioti, M., & Waheed, W. (2018). Dementia in UK South Asians: a scoping review of the literature. *BMJ open*, 8(4), e020290.
13. Dodd, E., Pracownik, R., Popel, S., Collings, S., Emmens, T., & Cheston, R. (2022). Dementia services for people from Black, Asian and Minority Ethnic and White-British communities: Does a primary care based model contribute to equality in service provision?. *Health & Social Care in the Community*, 30(2), 622-630.
14. Jutlla, K. Understanding the experiences of post-diagnostic dementia support for the South Asian community in England. 2021. Commissioned research by Alzheimer's Society.
15. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
16. Alzheimer's Society. From diagnosis to end of life: The lived experiences of dementia care and support. 2020.
17. GUIDE, S. Co-production in social care: What it is and how to do it.

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