




# Equity in care and support provision for people affected by dementia: experiences of people from UK South Asian and White British backgrounds

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## ABSTRACT

**Objectives:** To explore the care and support received and wanted by United Kingdom (UK) South Asian and White British people affected by dementia and whether access to it is equitable.

**Design:** Semi-structured interviews using a topic guide.

**Setting:** Eight memory clinics across four UK National Health Service Trusts; three in London and one in Leicester.

**Participants:** We purposefully recruited a maximum variation sample of people living with dementia from South Asian or White British backgrounds, their family carers, and memory clinic clinicians. We interviewed 62 participants including 13 people living with dementia, 24 family carers, and 25 clinicians.

**Measurements:** We audio-recorded interviews, transcribed them, and analyzed them using reflexive thematic analysis.

**Results:** People from either background were willing to accept needed care and wanted competence and communication from carers. South Asian people frequently discussed needing care from someone with a shared language, but language differences could also be an issue for White British people. Some clinicians thought South Asian people had a stronger preference to provide care within the family. We found that preferences for who provides care varied across families regardless of ethnicity. Those with more financial resources and English language have more options for care that meets their needs.

**Conclusions:** People of the same background make differing choices about care. Equitable access to care is impacted by people's personal resources, and people from South Asian backgrounds may experience the double disadvantage of having fewer options for care that meets their needs and fewer resources to seek care elsewhere.

**Key words:** dementia, carers, memory clinics, service delivery, social work

## Introduction

All people affected by dementia should have equitable access to services, care, and support which meets their needs and enables them to achieve the best health outcomes (World Health Organization, 2017). However, people from minority ethnic (ME) groups tend to present to dementia services when their symptoms are more advanced (Lin *et al.*, 2021,

Mukadam *et al.*, 2019) delaying access to treatment, care, and support. In England and Wales, 14% of the population are from ME backgrounds including over 5.3% from South Asian backgrounds making this the largest ME group excluding White minorities (Office for National Statistics (ONS), 2011).

In England, people living with dementia typically receive the diagnosis in National Health Service (NHS) secondary care memory clinics which are the gateway to treatments, advice, and other health and social care services. There has been considerable work on barriers to dementia diagnosis in South Asian communities, but very little is known about

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post-diagnostic care and support. A 2021 scoping review did not identify any studies about access to and use of post-diagnostic services in this community (Jutla, 2021). Barriers to help-seeking in South Asian communities highlighted in qualitative studies include an expectation or preference to provide care within the family; beliefs that seeking outside help may bring shame upon the family; and a lack of culturally and linguistically appropriate services (Giebel *et al.*, 2015; Hossain *et al.*, 2020; Mukadam *et al.*, 2015). It is unclear whether these factors also impact the use of post-diagnostic services, care, and support.

Few studies have compared experiences of post-diagnostic care in UK-based South Asians to the White British majority. This makes it difficult to say whether experiences of and barriers to service use are more common in or specific to South Asian populations or if they are universal. In this study, we aimed to explore the care and support received and wanted by UK South Asian and White British people affected by dementia and investigate whether access to care and support is equitable.

## Methods

### Ethics

Leeds West Research Ethics Committee (20/YH/0338) approved this study.

### Recruitment

We recruited people living with dementia from South Asian or White British backgrounds and family carers and clinicians from any background from eight memory clinics across four NHS Trusts: three in London and one in Leicester. We included people diagnosed with dementia between September 23, 2019 (six months before the first English national lockdown due to COVID-19) and April 4, 2022. We purposively recruited a maximum variation sample of participants with a range of characteristics including dementia type, gender, socioeconomic status (SES (ONS, 2018a)), relationships, religions, countries of origin, and memory clinic clinicians with various job roles. We recruited until we reached conceptual depth (Nelson, 2017).

### Data collection

We collected sociodemographic information: age, gender, relationship of person living with dementia/carer, religion, country of origin, occupation, and for participants living with dementia, information from their electronic health records about dementia type and severity. We classified SES according to occupation: higher (those who work or worked in managerial, administrative, professional, or intermediate occupations) and lower (routine or manual

occupations). For people who had never worked, we classified them according to their spouse's occupation.

We conducted semi-structured interviews with people living with dementia and their family carers using a topic guide developed with patient and public involvement. Interviews were done face-to-face at people's homes or by telephone depending on people's preference between December 2021 and April 2022. Clinicians were interviewed remotely by video using a different topic guide between June and September 2021. Interviews were audio-recorded. Clinical researchers at one site recruited and interviewed local participants and TJ conducted all other interviews. We offered to arrange professional interpreters for those whose first language was not English and offered all participants a £10 voucher.

### Data analysis

TJ transcribed interviews, or fidelity-checked interviews, transcribed using NVivo auto-transcription software. We used reflexive thematic analysis to analyze the data which involves identifying patterns and themes in the data and requires researchers to consider and discuss their own context and how it influences data generation and analyses (Braun and Clarke, 2022). To facilitate reflexivity, TJ kept a diary throughout data collection which included reflections about any issues or unexpected topics arising, or how her position or characteristics may have impacted participants' responses. She discussed her reflections regularly with the research team which included one South Asian researcher (NM). We followed Braun and Clarke's (2022) six phases for reflexive thematic analysis: 1) familiarization with data and writing familiarization notes; 2) coding; 3) generating initial themes; 4) developing and reviewing themes; 5) redefining, defining, and naming themes; and 6) writing the report.

TJ listened to audio recordings, read, and re-read all transcripts. For both data sets, TJ read several transcripts and developed some initial codes. All authors then read different transcripts and coded them. We met to discuss and develop a preliminary coding framework inductively from the data. Codes were similar for both data sets. TJ coded all remaining transcripts using the frameworks, adding codes as she identified them in the data, and generating initial themes. We used NVivo to code data. TJ, NM, AS, and GL met regularly to discuss and develop the final themes.

## Findings

### Sample and interview characteristics

We interviewed 23 (49%) of 47 families approached. Reasons for not taking part were that people were

too busy ( $n=2$ ), uncontactable ( $n=5$ ), not interested ( $n=7$ ), stopped responding ( $n=7$ ), changed their mind ( $n=2$ ), and for one South Asian family, the person living with dementia was in their home country, not the UK. Seventeen of 24 (71%) not interviewed were South Asian. Most clinicians approached were interviewed (25/28; 89%). We interviewed 62 participants across 48 interviews. All clinicians ( $n=25$ ) were interviewed individually. Interviews with people affected by dementia were made up of either: a person living with dementia and one family carer ( $n=10$ ), a person living with dementia and two family carers ( $n=2$ ), a family carer alone ( $n=10$ ), and for one interview, the person living with dementia was interviewed with a paid carer who was not included as a participant.

### Demographic information

There were 6 South Asian and 7 White British people living with dementia; and 11 South Asian and 13 White British or other family carers. Seven (64%) South Asian family carers and nine (69%) White British or other family carers were female. The mean age of South Asian family carers was 54.4 years and White British or other carers 65.4 years. White British or other carers were mostly retired spouses of the person living with dementia ( $n=8$ , 62%). Six (55%) South Asian family carers were children of the person living with dementia and five (45%) were working. Three South Asian participants required interpretation for the interview, but all chose to have help from family members rather than a professional interpreter. Twelve interviews were with people with higher SES (four South Asian and eight White British) and eight with lower SES (four South Asian and four White British). For three South Asian families, the person living with dementia had lower SES, but their family member had higher SES. We interviewed 25 clinicians, 19 (76%) of whom were female, from a variety of specialties, ethnic backgrounds, and religions. Tables 1 and 2 show sociodemographic information for people affected by dementia and clinicians, respectively.

### Thematic analysis

We generated six themes under two headings (see Table 3). We provide contextual information for quotes: PLWD = person living with dementia; FC = family carer; C = clinician.

### What people want from their care

#### CARER CHARACTERISTICS

Some people had preferences about homecare workers' language, gender, and religion. People from South Asian backgrounds often wanted carers who spoke their first language to enable

communication when the person living with dementia did not speak English well. Clinicians cited language as the main reason people may want care from someone from their own background and judged that people would receive a lower quality of care without a shared language:

*"If someone speaks English, it's very easy, but if someone hasn't grown up in England and doesn't speak English, it's harder. The rapport is different."*

C4, social worker, White English, no religion, female

Preferences around language were not exclusive to South Asian people. Some clinicians and carers reported that White British people wanted care from someone whose English they understood:

*"We have a lot of Somali speaking carers, and that can be difficult for some of the White British population [...] maybe there's a bit of a language barriers there as well."*

C5, nurse, White English, no religion, female

*"[The carers] are from all different places. My husband gets a bit upset if he can't understand them."*

FC7, White English, Christian, wife

Some South Asian families talked about the importance of receiving care from someone who can cook the right food for their religious practices:

*"I think when it goes worst, we probably need help with cooking. I don't know whether we could get somebody vegetarian, Jain cook. I don't think they have it in their services."*

FC8, Indian, Jain, husband

Having a shared religion was preferred but less important to people affected by dementia:

*"She said same religion is ideal, because they would understand her better, but if it's another religion, it's not a major issue."*

PLWD1, Bangladeshi, Muslim, female (interpreted by her son)

For others, religion did not matter at all:

*"[My parents] wouldn't mind. As long as the carers are doing the job properly, it doesn't matter whether they're Christian, Muslim, Buddhist."*

FC2, Bangladeshi, Muslim, daughter

Clinicians reported a similar pattern. A preference for shared religion may reflect a wish to receive care from someone with shared interests, values, and understanding. Clinicians suggested similar reasons when asked why someone might want care from someone from the same background as them:

*"I suppose it's about feeling more comfortable with someone from your own background. Feeling that they'll understand you better. Maybe you'll have more in common with them and they'll understand your customs, your beliefs."*

C6, nurse, White English, Christian, female

This was the case for several families in this study:

*"I think from my husband's point of view, it would be an Irish lady [...] that could talk to him about Ireland, or have some of the old interests."*

FC6, White Scottish, Christian, wife of Irish man living with dementia

For women from both backgrounds, it was important to receive care from a woman:

*"When the social worker was arranging the care, I just said mum is only going to agree to female carers. I know some people like people from their community, but my mum's ok with anyone as long as they're female."*

FC3, Bangladeshi, Muslim, daughter

Clinicians reported this too:

*"Often females from South Asian and White British backgrounds ask for females for personal care. Males are less fussy."*

C4, social worker, White English, no religion, female

### Good quality care

Some families said the carer's background was unimportant if they provided good care:

*"If it's a Black, White, Asian person, it really doesn't matter, as long as they do the caring properly, that's fine with me, my parents won't have any problems either."*

FC2, Bangladeshi, Muslim, daughter

When asked what qualities are desirable in a carer, people living with dementia discussed personable characteristics:

*"Someone who is caring and, you know, understanding, companionable, all those sorts of qualities."*

PLWD2, Sri Lankan, Christian, female

Family carers from both backgrounds described wanting care from someone they can trust, particularly because of the vulnerable nature of dementia. Beliefs about who can provide trustworthy care varied across individuals. For one family, social services were perceived as able to provide someone trustworthy:

*"If it's from the local authority or NHS or wherever, those people are vetted, so we're confident they're not going to do naughty things with us."*

FC8, Indian, Jain, husband

Another doubted the trustworthiness of carers provided by social services and preferred to find their own care:

*"I need someone reliable, so I thought of a relative [...] but if [social services] were to provide somebody, I'd be a little hesitant. I'd probably have to be there to keep an eye on them."*

FC2, Bangladeshi, Muslim, daughter

For one family in which the person living with dementia requires 24-hour care, no level of outside help was acceptable and although home carers were offered by social services, the family chose to do the care themselves:

*"I don't trust people to clean my husband the way I clean him."*

FC9, White English, Christian, wife

Family carers felt it was important to the person living with dementia to have the same carers coming, and that this made receiving care more acceptable. Being able to choose who provides care means that needs around language, gender, food, religion, shared interests, and consistency are more likely to be met than when social services provide care.

### What helps or stops people from receiving care and support

#### FAMILIES, RELATIONSHIPS, AND ATTITUDES TOWARD CARING

Use of services, care, and support was strongly influenced by family input, relationships, and attitudes toward caring. Some clinicians felt that South Asian people had a stronger preference to provide care within families than White British people, while others described White British families accepting more outside help due to having "no other option":

*"Asian families tend to have large family support, bigger networks, relatives, multigeneration households. Elderly English people often live on their own or as couples, so they often don't have the resources."*

C1, psychiatrist, White English, no religion, male

Interviews with people affected by dementia suggested that preferences about provision of care varied from family to family rather than by ethnicity. Some clinicians agreed:

*"I don't see systematic differences in use of social care. I think there might be this feeling that South Asian families are more likely to not want external help, and while there might be some truth in that, there's variability, and often White British families want to provide the care."*

C2, psychiatrist, White English, Christian, male

Most people affected by dementia were receiving some input from family or friends, but its extent varied. Some people of either ethnicity described caring for their relative with dementia as a reciprocal act:

*"My parents did the best they could for me when I was younger, it's now time for me to support them."*

FC1, White English, Jewish, son

But this did not mean they did not want outside help. Some people from either background mentioned family as a reason for needing outside help as people living with dementia and their partners described not wanting to bother their children with their “own lives”:

*“We don’t want to burden them because they’ve got very stressful jobs.”*

PLWD3, Indian, Jain, female

For some families from either background, outside help was not perceived as necessary or acceptable for personal care:

*“If worse comes to worse, I can go and do that myself because I know my dad’s not going to be happy with someone else doing that.”*

FC2, Bangladeshi, Muslim, daughter

For others, outside help was necessary as it was not appropriate for personal care to be provided by family members:

*“She would not allow me to look at her private parts. It’s just a cultural thing, for us Asians. Mum would prefer if somebody else was helping with personal care than me.”*

FC3, Bangladeshi, Muslim, daughter

Particularly family members of a different gender:

*“[My son does not help with] washing or dressing because we still adhere to, I’m female and he’s male.”*

PLWD4, White English, Jewish, female

Individual families differed in what they wanted and what is acceptable. Several clinicians recognized this:

*“It can be easy to fall into that assumption that the family are there, they’re supporting, they’re making sure they’re safe when it may not be the case. So it’s about exploring that, and not just assuming that family will take on that role.”*

C3, occupational therapist, White English, Christian, female

#### MONEY MEANS CHOICE

Several clinicians highlighted that South Asian people were more likely to have a lower SES, and that people with lower SES have fewer options for services and care:

*“A lot more South Asian families are working class and have issues with residency and access to benefits and pensions [. . .]. Whereas White British is a lot more middle-class, so they have easier access to paid services, which are flexible and easier to find, whereas for working class people who don’t have the money, it’s a lot more inflexible.”*

C7, dementia support worker, White English, no religion, female

Some people affected by dementia from higher SES chose their own care and paid privately:

*“Rather than moving somewhere, which I don’t really want to do, we started getting support here. So I have a cleaner that comes. We have a gardener. These are all services obviously that I pay for.”*

FC10, White English, Christian, wife

Those with lower SES felt if they paid for care themselves, they would have more choice and say over what they received:

*“If I paid the carers, I could find someone that he gets on with, and that would be willing to take him out and do gentle exercises to help him.”*

FC7, White English, Christian, wife

For several families, what social services offered was not what they wanted, so it was preferable to arrange care privately:

*“My mum can help dad with having a shower. [. . .] But as for the cleaning and cooking, [social services] said it’s most likely they won’t send anyone to help her, so we might have to hire somebody ourselves, privately.”*

FC2, Bangladeshi, Muslim, daughter

For those with low income, receiving direct payments means they could choose suitable services:

*“[The social worker] mentioned [direct payments], and I think in terms of what she was saying, you know, ‘we keep going round in circles, we need to get something set up for you that’s going to be acceptable’.”*

FC6, White Scottish, Christian, wife of Irish man living with dementia

Clinicians recognized the benefits of direct payments so the family can pay someone suitable to do what they want when they want.

#### GETTING TO SERVICES

Money, mobility, local transport, access to cars, knowledge of how to use transport, and family support can impact people’s ability to physically access services. Those with family support or money to pay for private transport are more likely to be able to receive services. Those with low income and poor mobility may have to depend on hospital transfer services which can be stressful and unhelpful:

*“They arranged transport there, but we had to make our own way home. That was so traumatising, because that was two buses and a long walk for him. I’m never doing it again [. . .]. How can you expect us to do all the appointments? I can’t keep doing these by cab.”*

FC9, White English, Christian, wife

Those that are housebound due to mobility and housing design are likely to miss out on services including day centers and Cognitive Stimulation Therapy (CST), a group-based psychosocial

**Table 1.** Demographic information of people living with dementia and family carers

		PEOPLE LIVING WITH DEMENTIA ( <i>n</i> = 13)		FAMILY CARERS ( <i>n</i> = 24)	
		SOUTH ASIAN ( <i>n</i> = 6)	WHITE BRITISH ( <i>n</i> = 7)	SOUTH ASIAN ( <i>n</i> = 11)	WHITE BRITISH OR OTHER ( <i>n</i> = 13)
Ethnicity – <i>n</i> (%)	Bangladeshi	2 (33)	0 (0)	6 (55)	0 (0)
	Chinese	0 (0)	0 (0)	0 (0)	1 (8)
	Indian	2 (33)	0 (0)	4 (36)	0 (0)
	Pakistani	1 (17)	0 (0)	1 (9)	0 (0)
	Sri Lankan	1 (17)	0 (0)	0 (0)	0 (0)
	White English	0 (0)	7 (100)	0 (0)	10 (77)
	White European	0 (0)	0 (0)	0 (0)	1 (8)
Religion – <i>n</i> (%)	White Scottish	0 (0)	0 (0)	0 (0)	1 (8)
	Christian	1 (17)	3 (43)	0 (0)	8 (62)
	Hindu	2 (33)	0 (0)	3 (27)	0 (0)
	Jain	1 (17)	0 (0)	1 (9)	0 (0)
	Jewish	0 (0)	1 (14)	0 (0)	1 (8)
	Muslim	2 (33)	0 (0)	6 (55)	0 (0)
	No religion	0 (0)	3 (43)	1 (9)	4 (31)
Gender – <i>n</i> (%)	Female	5 (83)	3 (42)	7 (64)	9 (69)
Age (years)	Mean	75.5	74.5	54.5	65.4
	Range	65–86	64–85	22–87	50–78
Job status – <i>n</i> (%)	Full-time	0 (0)	0 (0)	3 (27)	0 (0)
	Part-time	0 (0)	1 (14)	2 (18)	3 (23)
	Retired	5 (83)	6 (86)	4 (36)	8 (62)
	Not currently working	0 (0)	0 (0)	2 (18)	2 (15)
	Never worked	1 (17)	0 (0)	0 (0)	0 (0)
Occupation classification – <i>n</i> (%)	Higher managerial, administrative, and professional occupations	1 (17)	1 (14)	2 (18)	3 (23)
	Intermediate occupations	1 (17)	4 (57)	4 (36)	6 (46)
	Routine and manual operations	3 (50)	2 (29)	3 (27)	4 (31)
	Never worked or long term unemployed	1 (17)	0 (0)	2 (18)	0 (0)
Socioeconomic status – <i>n</i> (%)	Higher	3 (50)	5 (71)	6 (55)	9 (69)
	Lower	3 (50)	2 (29)	5 (45)	4 (31)
Stage of dementia – <i>n</i> (%)	Mild	4 (67)	4 (57)		
	Moderate	2 (33)	3 (43)		
Type of dementia – <i>n</i> (%)	Alzheimer's disease	4 (67)	4 (57)		
	Lewy body	0 (0)	2 (29)		
	Mixed Alzheimer's and vascular	1 (17)	0 (0)		
	Posterior cortical atrophy	1 (17)	0 (0)		
	Vascular	0 (0)	1 (14)		
Relationship to the person living with dementia – <i>n</i> (%)	Wife			1 (9)	8 (62)
	Husband			3 (27)	2 (15)
	Daughter			5 (45)	1 (8)
	Son			1 (9)	1 (8)
	Granddaughter			1 (9)	0 (0)
	Brother			0 (0)	1 (8)

intervention recommended in clinical practice guidelines for dementia in England and Wales for people with mild and moderate dementia (NICE, 2018, Spector *et al.*, 2003):

*“They offered mum to go to a daytime activity. But the problem is, I can't get her out the house [...]. She has difficulty walking, and gets very fatigued.”*

FC1, White English, Jewish, son

**Table 2.** Demographic information of clinicians

Gender – (%)	FEMALE	19 (76)
Job role – n (%)	Assistant Psychologist	1 (4)
	Clinical Psychologist	2 (8)
	Dementia support worker	5 (20)
	Nurse	6 (24)
	Occupational therapist	1 (4)
	Psychiatrist	9 (36)
	Social Worker	1 (4)
Ethnicity – n (%)	African	1 (4)
	Chinese	1 (4)
	Indian	2 (8)
	Pakistani	1 (4)
	White English	15 (60)
	White European	5 (20)
Religion – n (%)	Christian	11 (44)
	Hindi	1 (4)
	Jewish	1 (4)
	Muslim	1 (4)
	No religion	11 (44)

**Table 3.** Organisation of headings, themes, and subthemes of the thematic analysis**What people want from homecare workers**

Carer characteristics

Good quality care

**What helps or stops people from receiving care and support**

Families, relationships, and attitudes towards care

Money means choice

Getting to services

Availability and accessibility of culturally sensitive services

Clinicians highlighted the greater difficulty that people from South Asian backgrounds may face in traveling to services:

*“They can’t travel, especially the women, they’re not so independent to be traveling on their own on public transport [...]. So if they’re to attend any of these groups they wouldn’t be able to go on their own, and family often work or have other commitments.”*

C8, nurse, White European, no religion, female

#### AVAILABILITY AND ACCESSIBILITY OF CULTURALLY SENSITIVE SERVICES

Services also need to be provided in a suitable language. While people affected by dementia discussed the importance of a shared language for homecare, they rarely discussed it for other services. This may be because people are less likely to be offered and therefore aware of services which are not in their language. Clinicians, however, described

language as the biggest barrier to people from South Asian backgrounds receiving wanted and needed care and support. If people do not understand the language in which they are spoken to, they are unlikely to achieve the full benefits:

*“Everyone’s entitled to the same thing, but because there’s the language stuff, people don’t get the same things. People are entitled to have a social call from social services, but is it really a social call if you can’t speak with them?”*

C9, dementia support worker, White European, no religion, female

Some services had clinicians who spoke South Asian languages and others used interpreters to facilitate post-diagnostic support. Some memory clinics were unable to access interpreters at the start of COVID-19 and once it was possible for remote appointments, this was sometimes judged as unsatisfactory:

*“[Doing appointments virtually] exacerbated inequity in assessment and feedback massively because it was impossible trying to do them on the telephone or video through a translator. None of the assessments or feedbacks I tried to do with people from South Asian backgrounds were in any way clinically satisfactory.”*

C2, psychiatrist, White English, no religion, male

While NHS memory clinics have access to interpreters, clinicians explained that not all voluntary and community services do and that therefore, people who do not speak English well are less likely to be able to receive their support. Clinicians discussed a lack of information available in other languages, although there are ways around this:

*“Even the resources online, it’s limited in other cultures. It’s much more readily available for English cultures. But with a translator, we can send a document and they’ll write it in a different language. But it’s not all out there.”*

C10, dementia support worker, White European, no religion, female

There are likely to be specific services set up in areas with large populations of one community. One memory clinic with a large local Bengali community, for example, has adapted CST for Bengali speaking people and in an area with a large Indian population, CST is offered in Hindi. In other places, and more commonly, CST is only offered in English:

*“We can’t offer CST to people who don’t speak English. We don’t have any facility for that, and we don’t have enough of one specific population to make it viable.”*

C11, psychiatrist, White English, Jewish, female

Regardless of your background, if you are a minority, you may be less likely to receive services that meet your needs due to, for example, age, gender, religion, or language:

*“There is a dementia stay near us, but I was concerned that a) they were predominantly ladies and b) they were quite a bit older. He’s still relatively young, whereas there’s a lot of people in their 80s, 90s.”*

FC6, White Scottish, Christian, wife of Irish man living with dementia

*“She spoke Bengali, but she was a Hindu, she wasn’t a Muslim so she couldn’t take part in [the Bengali day centre]. Because she was vegetarian, and their prayer routine is different from hers, she just felt that she had nothing in common with them.”*

C8, nurse, White European, no religion, female

Clinicians highlighted that existing specialist services for South Asian people may be inaccessible because of location and transport:

*“The other problem is that there’s only one South Asian day centre. It’s completely the opposite end of the borough to most of our Asian populations. So they’re going to be on a bus for well over an hour each way and for some of them, that’s just too much.”*

C12, clinical psychologist, White English, no religion, female

Some people were willing to travel to access services that meet their needs:

*“There is a dementia group, not where we live, but where our daughter lives, and my daughter makes sure she takes both of us to the group [ . . . ]. Because in that group they have Indian songs, Indian food, and exercise.”*

FC11, Indian, Hindu, husband

But this may not be possible for people who are less able to travel.

## Discussion

This study aimed to investigate whether access to dementia care and support is equitable by exploring experiences of UK South Asian and White British people affected by dementia, and clinicians working with these groups. We found that people from South Asian or White British backgrounds were willing to accept help and support, although this varied from family to family. A person’s ability to access support, however, is influenced by their personal resources including money, transport, and mobility, and the available support was not always perceived as being able to meet people’s needs around, for example, religious and language requirements. This reflects findings from previous studies of South Asian communities (Jutla, 2021; Willis *et al.*, 2016) but in our study, this was also true for some of the White British majority population which, to our knowledge, has not previously been explored.

It is important to consider language, religion, and cultural practices for all people affected by

dementia, not only in those with ME backgrounds. It was important for South Asian and White British families that the person providing care was trustworthy, female (for women living with dementia) and had a shared language to allow communication. In areas with large South Asian communities, it is sometimes possible to receive care from someone who speaks your language, but this may be less likely in areas with smaller South Asian populations and workforces. White British people in this study discussed language less frequently, but clinicians highlighted that there could be communication difficulties for White British people living in areas with large ME communities and workforces due to language differences. While it is desirable to provide information and support in a person’s preferred language, this may not be possible due to the variety of languages (Gove *et al.*, 2021).

Ethnicity and SES are closely linked. In England and Wales, people from ME backgrounds have, on average, lower SES and likely fewer financial resources than the White British population (ONS, 2018b), although there is variation between different ME groups. A person’s ability to access post-diagnostic dementia services, care, and support that meets their needs is impacted by their ability to choose and pay for individual carers and services, or access transport to travel to services. People from ME groups may experience the double disadvantage of mainstream services being unable to meet their needs, while being less likely to have the resources to seek tailored services and support elsewhere which may be costly and further away or sometimes not available, therefore contributing to health inequities (Watson *et al.*, 2022). This suggests that UK post-diagnostic dementia care is inequitable.

A strength of our study is the inclusion of clinicians who provided additional insight into the nature of and reasons for the behavior and choices of the people they care for. Some clinicians suggested that South Asian families were more likely to provide care themselves. This reflects findings from previous qualitative studies which highlighted a preference or expectation in South Asian communities for family members to provide care (Lawrence *et al.*, 2008; Mukadam *et al.*, 2015), however, all but one South Asian family in our study who needed help from outside the family were trying to access it. Even if there is an expectation for families to provide care, not all families may be willing or able to do this (Zarzycki *et al.*, 2022) and may therefore still want and will still be entitled to other support including respite, additional home care, psychological support, and carers allowance. This highlights the importance of informing individuals about care and services for which they are eligible so they can make a choice rather than assuming that South



Asian families want and are able to provide care themselves (Dodd *et al.*, 2020).

Another strength of our study is the inclusion of people living with dementia who are often excluded from research (Murphy *et al.*, 2015). We used purposive sampling to gather views from as many different people from each background as possible. We were, however, only able to recruit one family from outside London. The remaining recruitment sites included seven memory clinics across three ethnically and economically diverse London boroughs, so the results are likely to be generalizable to England and other ethnically diverse nations with similar health systems. Most people in this study used or were willing to use help from outside their families, and all participants were recruited from memory clinics and had therefore had some contact with services. There may, however, be a group of people who would not seek a diagnosis for dementia or use outside help that were not captured in this study, such as the 24, mostly South Asian families who were approached but declined to take part. None of the researchers collecting data were from South Asian backgrounds which may have influenced South Asian peoples' decision to take part, or what those who participated felt able to talk about. To mitigate this, we consulted a South Asian lay researcher to develop the study documents, and one researcher involved in data analysis (NM) is from a South Asian background. Lastly, our findings may reflect more limited use of services and support as many interviews were during the COVID-19 pandemic.

## Conclusions

South Asian and White British families were willing to use services. Several South Asian and some White British families found it was difficult to find or access services that are culturally sensitive to their needs. There was an intersectionality between ethnicity and socioeconomic status where those with more money were more able to find and access services appropriate to them. To promote equity, it is important to address increased financial demands in accessing tailored service and tackle misconceptions amongst clinicians.

## Conflicts of interests

None.

## Description of author roles

TJ, NM, AS, and GL formulated the research question and designed the study. TJ collected most of the

data and 13 interviews were conducted by clinical research assistants at one recruitment site. NM, AS, and GL supervised data collection. TJ analyzed all interview transcripts, and NM, AS, SBC, and GL analyzed two transcripts each. TJ wrote the first draft of the paper, and all authors revised the paper critically for intellectual content.

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