**Manuscript Title:**

**Barriers to access and ways to improve dementia services for a minority ethnic group in England**

**Short Title:**

**Barriers and facilitators to optimise dementia services**

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### ABSTRACT

**Rationale, aims and objectives:** Much emphasis has been placed on the lack of awareness and understanding of dementia that exist within the ethnic minority groups in the UK. There has been a continual dearth of research, however, among the ethnic minority carers about reducing barriers to accessing services and optimising engagements with religiously tailored interventions. This paper reports findings from a qualitative study that examined the barriers to healthcare service use in Bangladeshi ethnic minority population.

**Method:** This analysis piece draws on findings from a doctoral level research study of understanding dementia among the Bangladeshi community in England. The doctoral research which informed this paper was gathered in two distinct phases: 1) focus group discussions and 2) semi-structured qualitative interviews. All data were audio-recorded and analysed using thematic analysis. The NVivo qualitative software was utilised to simplify the thematic analysis, including transcribing, coding, and interpreting the emergent themes.

**Results:** Some barriers arose out of their religious and cultural beliefs and practices, other barriers related to the complexity of the healthcare system. Gender based caregiving interferes with their religious ideologies while religiously appropriate services are of precise importance when investigating access to services.

**Conclusion:** The findings provide understanding into the development of seeking healthcare services within the mainstream services and it may serve to give a useful direction to future enquiry.

*Keywords: dementia, carers, coping, barriers, ethnicity, healthcare*

### INTRODUCTION

The number of people living with dementia globally is currently estimated at 50 million [1-2]. However, the global number of people living with dementia is steadily increasing and this figure is likely to reach 150 million by 2050 [3]. People with dementia generally require high levels of care, most care for people living with dementia is provided by family carers. There are nearly 700, 000 informal carers (friends and family members) in Britain provide care to their relatives with dementia [4]. Without caregivers’ support, people with dementia would find it very difficult to cope with their symptoms and changes in behaviour as well as performing their day-to-day tasks. Caring for a family member with dementia is linked with increased burden and strain. Family caregivers of people with dementia sometimes become invisible, often called the ‘hidden patients’ within the family due to their demanding and stressful caring responsibilities [5]. Able to understand and effectively managing with the adversities and difficulties of caring may help to avoid caregiver burnout and reduce the effects of stress. Despite the demands of caring, available evidence suggests that compared to their White counterparts, the uptake of formal support services is very low among the Black and Minority Ethnic (BME) carers [6-7]. The BME caregivers’ specific needs and barriers to accessing services may be complex and different from their White British counterparts which remain largely unknown as little research has specifically focussed on BME caregivers.

#### Bangladeshi ethnic group in the UK

British Bangladeshis are the fastest-growing ethnic minority population in the UK [8]. International migrants from Bangladesh are inclined to live permanently in the Western developed world, i.e., the UK followed by the United States, Canada, Italy, and Australia and so on. Currently, the number of Bangladeshis is estimated to be some 451,529 in England and Wales [9-10], which is a 57% increase from the 283,063 recorded in 2001. Bangladeshi immigrants are mostly concentrated in the inner London boroughs such as Tower Hamlets, Newham, Camden and Southwark. There are also large numbers of Bangladeshi population living in Birmingham, Manchester, Oldham, Luton, Bradford, Cardiff and Portsmouth.

#### Religion and caregiving

More than 90 per cent Bangladeshis are Muslim in the UK [11]. Understand religion is an integral part of understanding contemporary social life, health and ageing among the Bangladeshis, either in the countries to which they immigrated or in their countries of origin. Religion is a real and continuing social force in the lives of the Bangladeshis, with greater emphasis on their public rituals and festivals [12]. Religion has also a strong influence in public culture and social change in Bangladesh including politics, gender relations, socioeconomic inequality and health. In Britain, religious beliefs intertwine with their knowledge, perception, and attitude towards mental health and other conditions [13-14]. Religion adequately reflects the ethnic and cultural diversity about dementia or other mental illnesses among the Bangladeshi community.

Religious obligation to care is a strong influential element in the dementia caring role among South Asian communities. Evidence found that most South Asian traditional carers possessed strong religious values. These religious values offered internal personal support and peace of mind for the family carers through the difficult journey of caring for their loved ones with dementia [15-20]. These studies reported that family carers were fulfilling religious duties toward their elderly relatives with dementia as well as toward God by providing care, which was the normal and expected thing to do as a truly religious person. Previous studies also found that South Asian community whenever to talk about the services they needed, they always wanted to get the services at home [16-17, 21]. However, there is a paucity of research about the challenges experienced by Bangladeshi family carers in their roles caring simultaneously for elderly relatives, husbands, and children. An earlier study found that British-Bangladeshi family members were more willing to provide family care than British Indian and Pakistani family members [22]. Although family carers acknowledged some difficulties along their caregiving journeys, this did not discourage them from providing care.

#### Rationale for the study

Barriers to accessing dementia services or reasons for low uptake may be relevant to all BME carers, notwithstanding of the physical, psychological and social well-being concerned, but the situation is likely to be compounded for Bangladeshi family carers. Family carers from the Bangladeshi community may face additional burdens accessing the British healthcare system. Some barriers may arise out of their religious and cultural beliefs and practices, other barriers may relate to the complexity of the healthcare system [23]. In some cases, there may be a need to integrate cultural and religious considerations into service to support appropriate care and access to mainstream services. Therefore, this study aimed to identify and examine the underlying factors which may contribute to family carers’ reluctance to uptake mainstream services in England.

### METHODS

#### Study design and setting

Altogether, twenty-seven participants were recruited from two different cities in the UK, Portsmouth and London, using both purposive and snowball sampling techniques. Purposive and snowball sampling were planned to achieve demographic variation. Data gathered in two phases through in-depth individual interviews and focus groups. In phase one, in total, twenty-one adults of Bangladeshi origin across all age groups (18 years or older, with no upper age limit) and socio-economic backgrounds took part in the two focus group interviews (twelve men were in the male focus group and nine women were in the female focus group). In phase two, semi-structured, audio-recorded interviews were conducted with six Bangladeshi family carers. Apart from gender represented across the two phases, multiple variations such as gender, marital status, and sexual orientation were used to capture information from a diverse population of men and women from the Bangladeshi community.

#### Data collection

Before data collection, full ethics approval was obtained from a local independent research ethics committee. Focus groups and interviews were lasted between 1 hour and 1 hour and 30 minutes and carried out using an interview topic guide with open-ended questions. Focus groups and interviews were recorded with the participants’ permission using a digital voice recorder. Following data collection, all audio files were securely entered into the NVivo qualitative data analysis (QDA) computer software.

#### Data analysis

Data were analysed using thematic analysis. Thematic analysis was chosen as the most appropriate method to analyse and interpret the data obtained during this research project. Although other qualitative approaches are incredibly diverse, complex, and nuanced, Braun and Clarke’s [24] thematic analysis method is useful for rich, detailed, and complex data, given that qualitative data is diverse and complex in nature. Besides, thematic analysis is reasonably suitable for hard-to-reach populations or where qualitative researchers use relatively small sample populations [25]. Thematic analysis can be used with a relatively small sample size and can gain insight without further intrusion into that hidden population [26]. Therefore, thematic analysis was selected as the most suitable analytical method for this research, as it fitted well with the primary research purpose.

Thematic analysis began once all the data was collected. The first author (MH) developed the core idea and design of the study and conducted all interviews. MH prepared the texts for the NVivo analysis. Also, transcripts were read and coded by MH. Themes agreed through discussion by both authors (MH, HK). MH wrote the first draft and the final manuscript and HK made important contributions to the manuscript. All authors read and approved the final manuscript. The breadth and scope of this method allowed the authors to draw unequivocal themes from both focus group discussions and semi-structured interviews, which is consistent with the aim of the current research.

### RESULTS

The study highlighted the perceived challenges that Bangladeshi family members faced when caring for a person with dementia. The study uncovers the state of the Bangladeshi family carers’ caregiving support and helps with their service needs and barriers. Many participants discussed their excruciating experiences with the people with dementia or without dementia and the practical challenges in dealing with psychological, physical, and financial factors which had a profound impact on their personal lives. However, most of the community members were hesitant to seek help and support for their caregiving roles. Considering the data that emerged from this study mainly focused on their support needs and barriers. The themes are presented as unique and consistent categories below.

### Theme 1: Barriers to seeking and accepting help

This theme brings together the results to observe what coping strategies were associated with the family carers’ barriers to seek and accept help. The analysis considered the issues that were most important for the carers to seek and accept support and what negatively impacted their caregiving situations. The findings revealed that seeking help was one of the most complex decisions the family carers made.

#### Subtheme 1.1: Family care management

The focus groups participants were initially encouraged to share their current experiences with barriers to health care access, the perceived barriers to accessing support services, and what those barriers represent to the participants, would shape how ethnic Bangladeshi people live and cope with any illnesses in the UK. The findings emphasised that the participants’ perceived barriers to healthcare access for people with dementia and their carers were influenced by a core set of essential cultural and religious values, such as familism, collectivism, and emotionalism.

It seemed that the participants’ deep understanding of and beliefs in familism serve as major barriers to accessing health care services, particularly as these participants represent the husbands, wives, adult children, and grandchildren from the wider Bangladeshi community. When asked, the participants spontaneously replied that family should be the first choice when providing care for people with dementia; furthermore, care should be provided in the family home. One male responded stated that people with dementia should turn to family first when requiring support (e.g., receiving support from one’s husband, children, or others). This reflects the various power roles within the family, particularly as the husband, adult children, and others need to make fully informed decisions about how they will obtain or provide support for people with dementia. Nevertheless, in extenuating circumstances, if the family is unable to provide support for the person with dementia, that person may wish to consider all of the alternative services available to them.

*If my wife gets dementia as a husband I am there, my children are there. If I cannot look after my wife then I will seek help from elsewhere. Maybe not for dementia but generally, we know how to get help before we need it. If we cannot look after that is different thing.* (Focus group participant 7, male)

On the other hand, the analysis considered the issues that were most important for the Bangladeshi family carers to seek and accept support and what negatively impacted their caregiving situations. The results revealed that seeking help was one of the most complex decisions the family carers made. Some underlying issues played a part in the underuse of healthcare services. The first issue was self-management as an essential means of providing care, which was partly responsible for the family carers’ delay in seeking help. The family carers sought help when they could no longer cope with themselves or when the hospital doctors recommended and referred them to social workers for help. They began seeking help after a lengthy period of 2 to 10 years after the experiences of the first strain, during which the family carers heavily relied on coping strategies that involved managing stress on their own. One of the six family carers actively managed by herself for 10 continuous years without receiving any help.

*I did not ask or receive any support from anyone. The support I was asking for was for my husband. If he gets better, then everything is better. He cannot say ... if he needs any help. That's why I ask [for] support for him only.* (Interview participant 3, female)

There were mixed findings of whether seeking help from close or extended family members or neighbours triggered an opportunity to ask for help from more formal sources, such as health and social care services. Five out of the six family carers expressed great concern about receiving help from their family members. Most of the family carers said that they were unlikely to obtain practical and emotional caregiving support from their extended family members. Most of the family members did not live near the person who needed care and the family carers, and they had their responsibilities as they had their own families.

*Who would you ask for help except your own family? We cannot ask [for] our extended family's help. They would say they are busy with their lives and their own family. They have [more] responsibility for their own families than [for] my family.* (Interview participant 3, female)

Self-esteem and sensitivities of not understanding dementia caregiving problems were likely to hold the family carers back from seeking help from their neighbours. The family carers stressed that seeking and accepting help from their neighbours would be a burden on them. There was a fear of embarrassment and feelings of inferiority as well as uncertainty among two family carers who thought that their neighbours would refuse to offer help. The family carers had negative perceptions about their neighbours; hence, they were reluctant to share their dementia caregiving problems with them.

#### Subtheme 1.2: Unaware of services

There were various findings regarding the barriers to accessing services among the participants. This research highlighted that these obstacles were present at many levels, not just from the perspective of the participants, but also from that of the service providers toward the Bangladeshi ethnic minority. The findings suggest that the service providers could also bridge the gap by improving their engagement with the Bangladeshi ethnic minority. The family carers from Portsmouth indicated that the Alzheimer’s Society of Portsmouth was unaware that dementia was a problem in the Bangladeshi community. Four out of the six Portsmouth based family carers replied that they had not heard from the Alzheimer’s Society of Portsmouth.

*No, I did not contact [the] Alzheimer's Society of Portsmouth neither [did] they contact me. I knew a nurse who mentioned [the] Alzheimer's Society of Portsmouth, but I never heard of anything from [the] Alzheimer's Society of Portsmouth.* (Interview participant 1, male)

Furthermore, the focus group findings represent the current lack of knowledge and understanding of the nature of dementia services. They highlight that there is a need to increase dementia literacy and training among the participants, as well as to the wider community. Perhaps the scarcity of knowledge about dementia indicated that the wider community was not aware of what services were available for the people with dementia or what was involved when caring for someone with dementia. Some participants in the focus group discussion mentioned that they were aware of mental health, but not dementia:

*I don’t know, I can’t say. We have heard of mental health but we never heard of dementia.* (Focus group participant 16, female)

#### Subtheme 1.3: Negative perceptions of care homes

Although the participants mentioned some uncertainties about seeking help from their close and extended family members, neighbours, and the wider Bangladeshi community, they were sceptical about sending their relatives with dementia to a residential care home. The family carers felt that according to their culture and religion, looking after people with dementia in their own homes would be the least restrictive option. All of the six interviewees strongly agreed that placing their relatives with dementia in a residential care home was the last resort option.

*Social services offered me ... residential care services for my mother. But we didn't accept that offer because I did not think they would be able to keep her in a care home. It would be very difficult. Even when [the] carer comes in the house I need to be with her all the time, otherwise the carer cannot manage alone.* (Interview participant 1, male)

Islamic teachings and beliefs, cultural practices, customs, manners, etiquette, and the values of Bangladeshi Muslim family carers play a significant role in help-seeking behaviour. The family carers described that their religious beliefs and cultural practices place a strong emphasis on caring for their relatives with dementia in the home and that a residential care home was not a feasible solution.

*As a Muslim, we have many things to follow which care homes will not follow. We like to look after our elder parents, family comes first. As a Muslim, we have many problems [in] sending our parents to a care home e.g. halal food, cleanliness, medicine time etc. Plus, they will give him food but he will not eat. Many problems, language problems, communication problems etc.* (Interview participant 5, male)

Nevertheless, the focus group participants did not believe that care home staff would be able to deliver their religiously chosen services; hence, they were reluctant to send their older parents with dementia to care homes.

*Halal food plus cleaning both are main reasons Bangladeshi community don’t send people with dementia to a care home. Carer don't clean the patient according to Muslim religion... So that's why all the Bengali people and Muslim people they would not send their parents with dementia to the care homes. Because this is the main reason.* (Focus group participant 12, male)

The participants alleged that health and social care workers were not aware of *halal* and *haram* (forbidden) foods, and that represented another reason why the participants would not seek help from care homes for people with dementia.

#### Subtheme 1.4: Negative experience of healthcare in the past

This research found that a previous involvement with healthcare services had intensified a female family carer’s frustration, which might have negatively influenced her subsequent help-seeking behaviour. Previous negative experiences created misunderstanding and distrust among carers that lead to an unwillingness to engage with the residential care home services. An important point to note here is that the family carer’s poor experience was related to hospital nurses and services, which negatively impacted the carer’s perception of residential care home services. This research examined the potential effects of institutional racial discrimination on inhibiting the carers’ help-seeking behaviour. A female family carer reported that she experienced racism and witnessed discrimination against her father. As such, she believed that the same could happen to her mother. The family carer felt that her mother could get better services from home, which is a safer and more caring environment than the services she would receive in a care home. Exposure to institutionalised care and racial discrimination triggers feelings such as vulnerability, discouragement, and dejection.

*You know, when my dad was in Mile End hospital, they did not change my dad's nappies. So, he had blisters on his bottom. Can you imagine [the] agony I was going through for my dad? It was 8 months [of] a nightmare for me. One night he was so cold; they didn't [even] give him a blanket. That kind of experience has taught me, I would never give my mom to give to anybody like that, I wouldn't trust them. It doesn't matter how much they said they can pay good care. They wouldn't be able to give the care that I give to my mom, the love that I give, the support that I give, the comfort that I give.* (Interview participant 2, female)

One more caregiver also experienced similar labelling circumstances and she felt discontented with the way service providers responded on several occasions.

*[The] council gives pads to my husband. They asked me, everyday how many pads I used for my husband? I said four, then they said I used too many pads. I went mad after listening to that. What would I do with [the] pads if I [didn’t] need them? If he is OK then I don't use more pads. Similarly, [the] hospital upsets me many times this way. Their behaviour I don't like, they are not treating us well.* (Interview participant 3, female)

### Theme 2: Key opportunities for improvement

The problems articulated in this theme are the following: issues with a culturally inappropriate assessment; a shortage of culturally appropriate support and services, which included the unavailability of Bangladeshi Muslim same-sex carers; a lack of cultural and religious knowledge among the agency respite carers; a lack of flexibility and choice in home-based respite care services; and the fact that family carers felt that the respite services were insufficient or inadequate in meeting their caregiving needs. As a result, Bangladeshi family carers faced triple jeopardy due to the growing shortage of same-sex Muslim carers, the scarcity of Bangladeshi same-sex carers, and the overall scarcity of same sex-carers in the UK.

#### Subtheme 2.1: Culturally appropriate care

The findings suggest that ethnic homogeneity was related to home-based respite care service satisfaction. There was an overwhelming consensus among the participants that having a Bangladeshi respite carer option available would be the most preferable option. Participants also expressed concern that in most cases the respite care service providers were not familiar with or failed to recognise the importance of the concept of ethnicity in the care of Bangladeshi people with dementia. The findings suggest that the family carers confronted a complex situation in which they requested a home-based respite carer. The research also found that when requested, the respite carers’ gender was given priority over religion and ethnicity. Most of the family carers emphasised that they would allow a respite carer from a non-Muslim background, but they must be the same-sex carer, rather than a Bangladeshi or Muslim carer of the opposite sex. The research discovered that the family carers indicated a hierarchy of respite carers for their relatives with dementia. The priority was given to a Bangladeshi same-sex Muslim carer, followed by a non-Muslim Bangladeshi same-sex carer, then any non-Bangladeshi Muslim same-sex carer. The least priority was given to the same-sex carers, regardless of their cultural, ethnic, or religious background.

*[An] agency carer cared for my mother but there was a huge cultural gap. We did not allow them to send a male carer to our house, first of all. Second thing is, even the female carer [did] not know how to work between two cultures. The female care did not know how to work for a Bengali Muslim person with dementia. We could not find a Bengali carer who [could] come and look after my mom.* (Interview participant 6, male)

The only reason why the family carers requested and accepted home-based respite services was to deal with their relatives’ incontinence and to maintain their hygiene. Although they accepted respite services, they could not rely on them. They had to be vigilant and be present with the respite carers whenever they visited the person receiving care. Religious Bangladeshi Muslims are adamant about personal hygiene and the family carers explained that they had to follow strict hygienic rules. The respite workers had to also follow similar stringent requirements for cleanliness. However, most of the family carers (4 out of 6) were dissatisfied with how their relatives with dementia were cleaned by the respite workers.

*It was not appropriate at all. Then I had to ask how they should do it. And eventually they did it. Because they used to use only wipers to wipe. They didn't use water. But if you use water after [the] wipe; that cleans much better. They need to understand each culture. If you want to work with other people you need to know their culture. That's why I have been doing this for mom.* (Interview participant 6, male)

The key issue that most of the family carers found with the home-based care service was that the care workers did not spend enough time with the people with dementia. Four family carers expressed their deepest concerns that the level of respite care received was inadequate to meet their needs.

*[The] carers service gave six hours [of] care every week, but we requested more hours.* *They [were] unable to give us more than 6 hours of care.* (interview participant 1, male)

Four family carers expressed that they had no family support whatsoever. While dealing with incontinence and performing personal caring tasks influenced help-seeking for culturally appropriate sources, the help they received from the home-based respite services was not enough. Besides, for cultural reason, one carer’s wife was not allowed to provide personal care to his father with dementia. Therefore, he had to pay privately for supplementary culturally appropriate services not covered by his home-based respite care services. As he was working part-time, he hired an additional carer for his father’s incontinence care and some housework so that he could go to work.

*Moreover, for cultural reason my wife cannot look after him alone and cannot take him to the toilet which is not appropriate. That's why I have to pay someone to look after my father. […] The caring agency was giving their maximum support but that was not enough for me. And I cannot ask for more as they can't give so I paid for a carer.* (Interview participant 5, male)

There was another concern raised by most of the family carers (5 out of 6), about the relationship between the respite care workers and their care recipients with dementia, particularly when home-based respite service providers sent different respite care workers every time. The family carers expressed that knowing their respite workers would enhance the experiences of their relatives with dementia and would help to build a rapport between them. Changing the respite workers not only confused, upset, and frightened the person with dementia but also resulted in instability of care, especially when receiving intimate care.

*When [a] new carer comes, he does not know them, he does not want to communicate with new people.* (Interview participant 3, female)

Findings discovered that some female participants felt that they would need additional carer support to reduce their caring burden. None of the men directly mentioned that carers needed support, but most of the women participants explicitly specified that they currently suffered from a lack of support in the family. Caregiving for the person with dementia would be more burdensome; therefore, the participants believed that home-based respite care services would be essential for them:

*We’ll need carer support. If anyone from our Bangladeshi community helps us that will be best for us.* (Focus group participant 14, female)

A lack of interpreter facilities was another reason for the low usage of health and social services among the Bangladeshi community.

#### Subtheme 2.2: Learning and development

The family carers were overwhelmingly keen to stress that the cultural values and religious beliefs of people with dementia should be recognised and respected. A need for better staff training was identified, especially in how to treat older people with dignity and respect. They expressed the concern that most of the respite workers were not culturally and religiously experienced, skilled, or that they did not have any written care guidelines or care plans for Bangladeshi people with dementia. Carers generally agreed on the need to offer education and training opportunities to agency carers so that they would be able to provide culturally appropriate care.

*Because every culture works differently. Maybe they need to do [a] bit of research about Bangladeshi culture. So, the learning and developments could be for them [to gain] knowledge and [understand] importance of halal food for Muslim patients, cleanliness to not only provide tissues after using the toilet but there should be proper management for using water afterwards.* (Interview participant 5, male)

Another family carer identified some key factors which could build positive relationships and a bridge between healthcare services and Bangladeshi people in the UK, such as engaging with better communication and the recruitment of care staff from the Bangladeshi community. Expressing and sharing information by speaking the same language was seen as a key issue for engaging with Bangladeshi family carers and people with dementia. A family carer suggested that the service providers should create opportunities for the care staff to learn Bengali to deal with Bangladeshi clients. Therefore, this would help the family carers convince themselves that their religious and cultural background was fully recognised and accepted into the mainstream health care services, rather than being overlooked.

*Because of the language barrier, there is no good communication between the agency carers, patients, and family members. They need to learn the Bengali language. However, this problem can be solved if the carers’ agencies recruit more Bengali carers for Bangladeshi families with dementia.* (Interview participant 1, male)

There is no easy way or shortcut to learning about Bangladeshi culture and religion, as sensitive issues in religion and culture should be handled deftly. Dealing with a non-Bangladeshi respite carer might be disruptive, however, clarifying those issues with proper discussion and negotiation could minimise the problem.

#### Subtheme 2.3: Developing a specialist provision

The findings indicate that most of the participants were concerned about the overall Bangladeshi population growth in the UK as well as the increasing number of older people with dementia which has put a strain on family carers. The participants pointed out that the UK health and social care services need to find a solution for the service needs of the older Bangladeshi people with dementia to minimise the increasing pressure. Presumably, developing specialist service provisions for the Bangladeshi ethnic minority would circumvent their negative perceptions about care homes, such as same-sex caring issues, halal foods, cleanliness, and language barriers. At the same time, the participants suggested that such facilities would build greater trust and understanding about the UK healthcare services and social care services across the Bangladeshi community.

*I think, we should have a culturally appropriate service for [the] Bangladeshi community in Portsmouth. It would be ideal, if they [had a] caring service who [could] provide the language and religious background knowledge. We don't have this kind of service in Portsmouth but in London.* (Interview participant 6, male)

While relatively few focus group participants had indicated that they would seek alternative services for support, family support was their first priority. Consequently, some of the participants mentioned that they would consider seeking social services or home care services if they provided culturally appropriate services. The participants also worried that the social services carer would not be able to deliver the sort of care a person required from his or her family members. The female participants expressed concern about accepting care from non-Bangladeshi carers, who would not be able to provide more sensitive services that incorporated ethnicity, culture, religion, language, specific tastes, gender, sexual orientation, personal values, or various preferences.

*Maybe if a carer help a family member towards their caring roles will be helpful. Otherwise, a formal carer will not be enough to look after an older people in the Bangladeshi community…Or if anyone from our Bangladeshi community will help us that will be the best for us. Again we don't know yet, we'll think about our future in the future. We will see what our old age will bring for us in this country.* (Focus group participant 21, female)

### Discussion

There is a scarcity of research about help-seeking behaviours among Bangladeshi family carers of their relatives with dementia. Bangladeshi family carers may be among the most neglected and underserved BME communities concerning dementia and other health services in Britain [27]. Although data from the current study suggest that it is vital for service providers and home carers to be of the same religion and cultural identity as the persons with dementia, there were conflicting results concerning the advantages of having ethnically similar healthcare professionals and family carers. Consistent with previous research involving South Asian family carers, the current study found that having healthcare staff from the same community who speak the same language did not necessarily improve family carers’ satisfaction [28]. In London, family carers were receiving support services from BME service providers and they identified that some factors, e.g., carers arriving late, rushing the patients, shouting and other hostile attitudes affected their service satisfaction. Since most health professionals have more authority than family carers, regardless of their ethnicity, power differentials, as well as the conflict between service providers and service users, are inevitable [29]. Also, family carers were unable to override the decisions of local authorities about how they wanted to care for their relatives with dementia to be delivered.

Available evidence highlighted that there was a fear of the consequences of seeking help, such as stigma was related to the issue of seeking help. Perceived religious causes of dementia (*‘karma’*, or bad deeds earlier in life) have been documented as a source of stigma in the previous studies conducted amongst South Asian communities. It was thought that dementia was God’s punishment for previous sins. The stigma and shame of dementia within communities generate a barrier to seeking support within the community and healthcare providers [16,30]. Negative religious perceptions of dementia as karmic retribution or punishment presented a barrier to help-seeking, as it was believed that seeking support from service providers would humiliate the families and would threaten families’ position in the community [16,19,30]. Despite efforts to develop healthcare access in the South Asian community, this often led to families hiding the person with dementia [20]. Therefore, management of the caregiving task was described as hiding the person with dementia due to possible consequences from family members as well as the wider community [31]. In contrast to most previous studies, where researchers identified stigma as one of the most salient barriers to seeking healthcare support for their relatives with dementia, the current study found no trace of the stigmatisation of dementia.

There were consistent overarching themes that applied to all barriers identified, and a range of additional justifications was specified. Some barriers could be overcome simple solutions, such as providing same-sex carers or a carer from the same religious group. However, due to the lack of same-sex carers from the same religious group, this issue is quite complex: healthcare services are less equipped to support the Bangladeshi community. Despite this, high expectations of receiving culturally and religiously appropriate services were quite common among the participants. The current study discovered that there were good intentions to supply Bangladeshi family carers’ religious needs by healthcare providers in Portsmouth, but in the end, the facility and the resources available were inadequate to accomplish this. The Bangladeshi community in Portsmouth has been represented disproportionately in dementia services, given its comparative presence in the general population [21]. Historically, healthcare services are less equipped to support the religious needs of South Asian ethnic minorities and so deliver care of a lower standard to those groups than they can to White groups [32]. In other words, service providers working with ethnic minority family carers may make inappropriate assumptions about them because of their cultural and religious identities, leading to covert discriminatory practices. It is often, in fact, stated that ethnic minorities looked after themselves and do not need outside help and resources, which undermines the support provided.

The current study challenged the general claim that Bangladeshi families looked after their own. This research has not discovered a sweeping decline in the sense of accessing and accepting government services. Rather, family carers sought help from service providers and tried hard to shield their relatives with dementia from the difficulties they faced in managing caring arrangements with services providers. Specifically, they wanted to ensure that their relatives with dementia were given culturally appropriate services. Family carers also informally educated and trained the agency carers that they believed would help to increase agency carers’ knowledge about culturally appropriate services and promote a better understanding of the needs of the Bangladeshi people. Current research results are consistent with the outcome of Katbamna, Ahmad, Bhakta, Baker, & Parker’s [33] study, which found that British-Indian and British-Pakistani family carers had scant aid and support within the family and were unwilling to look for support from extended family members. Katbamna et al.’s [33] study also reported that the South Asian family carers had a very negative attitude toward service providers and family carers were reluctant to seek support. However, family carers in this current study sought and received formal support from service providers. Themes that emerged in the present study identify significant cultural and religious dissimilarities in the usage of healthcare services. For most of the South Asian family carers, access to support services (health or social care) occurred as an outcome of acute hospital admission [17]. However, in this study, for opposite-sex caring issues, family carers accessed caring services. Also, previous studies reported that the lack of knowledge was the main reason not to access healthcare services among South Asian family members with dementia [31,34]. However, this was not the case for the Bangladeshi participants in this study and the lack of appropriate cultural and religious services was the main reason for withdrawing from the services.

### Strengths and limitations

This is the first study that explored the perspectives of Bangladeshi adults without dementia as well as the experiences of the family carers of relatives with dementia. As a first study, this research covered the areas that it projected to in an efficient way. However, there were a few limitations in this study and future research in the Bangladeshi ethnic minority community may look to expand on these areas. There were limitations in the representativeness and significance of the findings. The participants’ age and gender between phases one and two of the study were different, meaning that the participants were not truly representative of each other. The male focus group was attended by a much older age group than those recruited in both the female focus group and the dementia family carers’ group; moreover, all the focus group attendees had a lack of knowledge of dementia and caregiving. Therefore, the findings from the focus groups may not be fully transferable across the entire population, nor among dementia family carers. Nevertheless, this study also had a minimum age criterion of 18 years of age; as such, the results are not readily transferable to younger populations.

### Conclusion

Although Bangladeshi family carers are vital to maintaining a quality of life for their relatives with dementia, a minority of studies on caregiving in dementia focus exclusively on BME family carers. The true levels of caregiving burden and strain, barriers to accessing healthcare services have been highlighted in this study. Cultural or religious interventions can overcome these barriers and thereby improve the quality of the life of ethnic family carers of people with dementia. Family carers of persons with dementia in the Bangladeshi community may be at risk of developing physical and mental health issues attributed to the barriers linked with accessing healthcare services and service dissatisfaction. The current complexities of caregiving burden experienced by the Bangladeshi family carer, and the problems associated with access to dementia services, raise the question whether the healthcare system is discriminatory towards the Bangladeshi ethnic group in the UK.

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### Acknowledgement:

The authors would like to thank all the interviews’ and focus groups’ participants, community and faith leaders, and the community development key workers from all voluntary organisations who were involved in the recruitment process.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding acknowledgement:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.