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

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1 **Manuscript Title:**

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

4

5 **Short Title:**

6 **Barriers and facilitators to optimise dementia services**

7

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1 **ABSTRACT**

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

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

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

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

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

22

23 **INTRODUCTION**

24 The number of people living with dementia globally is currently estimated at 50 million [1-2].
25 However, the global number of people living with dementia is steadily increasing and this figure
26 is likely to reach 150 million by 2050 [3]. People with dementia generally require high levels of
27 care, most care for people living with dementia is provided by family carers. There are nearly
28 700, 000 informal carers (friends and family members) in Britain provide care to their relatives
29 with dementia [4]. Without caregivers' support, people with dementia would find it very difficult
30 to cope with their symptoms and changes in behaviour as well as performing their day-to-day
31 tasks. Caring for a family member with dementia is linked with increased burden and strain.
32 Family caregivers of people with dementia sometimes become invisible, often called the
33 'hidden patients' within the family due to their demanding and stressful caring responsibilities
34 [5]. Able to understand and effectively managing with the adversities and difficulties of caring

1 may help to avoid caregiver burnout and reduce the effects of stress. Despite the demands of
2 caring, available evidence suggests that compared to their White counterparts, the uptake of
3 formal support services is very low among the Black and Minority Ethnic (BME) carers [6-7].
4 The BME caregivers' specific needs and barriers to accessing services may be complex and
5 **different from their White British counterparts which** remain largely unknown as little research
6 has specifically focussed on BME caregivers.

7

8 **Bangladeshi ethnic group in the UK**

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

17

18 **Religion and caregiving**

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

29 Religious obligation to care is a strong influential element in the dementia caring role among
30 South Asian communities. Evidence found that most South Asian traditional carers possessed
31 strong religious values. These religious values offered internal personal support and peace of
32 mind for the family carers through the difficult journey of caring for their loved ones with
33 dementia [15-20]. These studies reported that family carers were fulfilling religious duties
34 toward their elderly relatives with dementia as well as toward God by providing care, which
35 was the normal and expected thing to do as a truly religious person. Previous studies also

1 found that South Asian community whenever to talk about the services they needed, they
2 always wanted to get the services at home [16-17, 21]. However, there is a paucity of research
3 about the challenges experienced by Bangladeshi family carers in their roles caring
4 simultaneously for elderly relatives, husbands, and children. An earlier study found that British-
5 Bangladeshi family members were more willing to provide family care than British Indian and
6 Pakistani family members [22]. Although family carers acknowledged some difficulties along
7 their caregiving journeys, this did not discourage them from providing care.

8

9 **Rationale for the study**

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

20

21 **METHODS**

22 **Study design and setting**

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

34

1 **Data collection**

2 **Before data collection**, full ethics approval was obtained from a local independent research
3 ethics committee. Focus groups and interviews were lasted between 1 hour and 1 hour and
4 30 minutes and carried out using an interview topic guide with open-ended questions. Focus
5 groups and interviews were recorded with the participants' permission using a digital voice
6 recorder. Following data collection, all audio files were securely **entered into the NVivo**
7 **qualitative data analysis (QDA) computer software.**

8

9 **Data analysis**

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

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

28

29 **RESULTS**

30 The study highlighted the perceived challenges that Bangladeshi family members faced when
31 caring for a person with dementia. The study uncovers the state of the Bangladeshi family
32 carers' caregiving support and helps with their service needs and barriers. Many participants
33 discussed their excruciating experiences with the people with dementia or without dementia
34 and the practical challenges in dealing with psychological, physical, and financial factors which
35 had a profound impact on their personal lives. However, most of the community members

1 were hesitant to seek help and support for their caregiving roles. Considering the data that
2 emerged from this study mainly focused on their support needs and barriers. The themes are
3 presented as unique and consistent categories below.

4

5 **Theme 1: Barriers to seeking and accepting help**

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

11

12 **Subtheme 1.1: Family care management**

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

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

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

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

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

16

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

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

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

35

1 **Subtheme 1.2: Unaware of services**

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

11 *No, I did not contact [the] Alzheimer's Society of Portsmouth neither [did] they contact*
12 *me. I knew a nurse who mentioned [the] Alzheimer's Society of Portsmouth, but I never*
13 *heard of anything from [the] Alzheimer's Society of Portsmouth. (Interview participant*
14 *1, male)*

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

22
23 *I don't know, I can't say. We have heard of mental health but we never heard of*
24 *dementia. (Focus group participant 16, female)*

25

26 **Subtheme 1.3: Negative perceptions of care homes**

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

34 *Social services offered me ... residential care services for my mother. But we didn't*
35 *accept that offer because I did not think they would be able to keep her in a care home.*
36 *It would be very difficult. Even when [the] carer comes in the house I need to be with*

1 *her all the time, otherwise the carer cannot manage alone.* (Interview participant 1,
2 male)

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

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

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

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

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

24

25 **Subtheme 1.4: Negative experience of healthcare in the past**

26 This research found that a previous involvement with healthcare services had intensified a
27 female family carer's frustration, which might have negatively influenced her subsequent help-
28 seeking behaviour. **Previous negative experiences created misunderstanding and distrust**
29 **among carers that lead to an unwillingness to engage with the residential care home services.**

30 An important point to note here is that the family carer's poor experience was related to
31 hospital nurses and services, which negatively impacted the carer's perception of residential
32 care home services. This research examined the potential effects of institutional racial
33 discrimination on inhibiting the carers' help-seeking behaviour. A female family carer reported
34 that she experienced racism and witnessed discrimination against her father. As such, she
35 believed that the same could happen to her mother. The family carer felt that her mother could
36 get better services from home, which is a safer and more caring environment than the services
37 she would receive in a care home. Exposure to institutionalised care and racial discrimination
38 triggers feelings such as vulnerability, discouragement, and dejection.

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

9
10 One more caregiver also experienced similar labelling circumstances and she felt
11 discontented with the way service providers responded on several occasions.

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

18 19 **Theme 2: Key opportunities for improvement**

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

29 30 **Subtheme 2.1: Culturally appropriate care**

31 The findings suggest that ethnic homogeneity was related to home-based respite care service
32 satisfaction. There was an overwhelming consensus among the participants that having a
33 Bangladeshi respite carer option available would be the most preferable option. Participants
34 also expressed concern that in most cases the respite care service providers were not familiar
35 with or failed to recognise the importance of the concept of ethnicity in the care of Bangladeshi
36 people with dementia. The findings suggest that the family carers confronted a complex
37 situation in which they requested a home-based respite carer. The research also found that

1 when requested, the respite carers' gender was given priority over religion and ethnicity. Most
2 of the family carers emphasised that they would allow a respite carer from a non-Muslim
3 background, **but they must be the same-sex carer**, rather than a Bangladeshi or Muslim carer
4 of the opposite sex. The research discovered that the family carers indicated a hierarchy of
5 respite carers for their relatives with dementia. The priority was given to a Bangladeshi same-
6 sex Muslim carer, followed by a non-Muslim Bangladeshi same-sex carer, then any non-
7 Bangladeshi Muslim same-sex carer. **The least priority was given to the same-sex carers,**
8 **regardless of their cultural, ethnic, or religious background.**

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

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

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

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

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

33 **Four family carers expressed that they had no family support whatsoever. While dealing with**
34 **incontinence and performing personal caring tasks influenced help-seeking for culturally**
35 **appropriate sources, the help they received from the home-based respite services was not**
36 **enough. Besides, for cultural reason, one carer's wife was not allowed to provide personal**

1 care to his father with dementia. Therefore, he had to pay privately for supplementary culturally
2 appropriate services not covered by his home-based respite care services. As he was working
3 part-time, he hired an additional carer for his father's incontinence care and some housework
4 so that he could go to work.

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

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

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

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

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

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

29

30 **Subtheme 2.2: Learning and development**

31 The family carers were overwhelmingly keen to stress that the cultural values and religious
32 beliefs of people with dementia should be recognised and respected. A need for better staff
33 training was identified, especially in how to treat older people with dignity and respect. They
34 expressed the concern that most of the respite workers were not culturally and religiously
35 experienced, skilled, or that they did not have any written care guidelines or care plans for

1 **Bangladeshi people with dementia.** Carers generally agreed on the need to offer education
2 and training opportunities to agency carers so that they would be able to provide culturally
3 appropriate care.

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

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

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

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

26

27 **Subtheme 2.3: Developing a specialist provision**

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

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

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

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

20

21

22 **Discussion**

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

1 [29]. Also, family carers were unable to override the decisions of local authorities about how
2 they wanted to care for their relatives with dementia to be delivered.

3
4 Available evidence highlighted that there was a fear of the consequences of seeking help,
5 such as stigma was related to the issue of seeking help. Perceived religious causes of
6 dementia ('*karma*', or bad deeds earlier in life) have been documented as a source of stigma
7 in the previous studies conducted amongst South Asian communities. It was thought that
8 dementia was God's punishment for previous sins. The stigma and shame of dementia within
9 communities generate a barrier to seeking support within the community and healthcare
10 providers [16,30]. Negative religious perceptions of dementia as karmic retribution or
11 punishment presented a barrier to help-seeking, as it was believed that seeking support from
12 service providers would humiliate the families and would threaten families' position in the
13 community [16,19,30]. Despite efforts to develop healthcare access in the South Asian
14 community, this often led to families hiding the person with dementia [20]. Therefore,
15 management of the caregiving task was described as hiding the person with dementia due to
16 possible consequences from family members as well as the wider community [31]. In contrast
17 to most previous studies, where researchers identified stigma as one of the most salient
18 barriers to seeking healthcare support for their relatives with dementia, the current study found
19 no trace of the stigmatisation of dementia.

20
21 There were consistent overarching themes that applied to all barriers identified, and a range
22 of additional justifications was specified. Some barriers could be overcome simple solutions,
23 such as providing same-sex carers or a carer from the same religious group. However, due to
24 the lack of same-sex carers from the same religious group, this issue is quite complex:
25 healthcare services are less equipped to support the Bangladeshi community. Despite this,
26 high expectations of receiving culturally and religiously appropriate services were quite
27 common among the participants. The current study discovered that there were good intentions
28 to supply Bangladeshi family carers' religious needs by healthcare providers in Portsmouth,
29 but in the end, the facility and the resources available were inadequate to accomplish this.

30 The Bangladeshi community in Portsmouth has been represented disproportionately in
31 dementia services, given its comparative presence in the general population [21]. Historically,
32 healthcare services are less equipped to support the religious needs of South Asian ethnic
33 minorities and so deliver care of a lower standard to those groups than they can to White
34 groups [32]. In other words, service providers working with ethnic minority family carers may
35 make inappropriate assumptions about them because of their cultural and religious identities,
36 leading to covert discriminatory practices. It is often, in fact, stated that ethnic minorities looked

1 after themselves and do not need outside help and resources, which undermines the support
2 provided.

3
4 The current study challenged the general claim that Bangladeshi families looked after their
5 own. This research has not discovered a sweeping decline in the sense of accessing and
6 accepting government services. Rather, family carers sought help from service providers and
7 tried hard to shield their relatives with dementia from the difficulties they faced in managing
8 caring arrangements with services providers. Specifically, they wanted to ensure that their
9 relatives with dementia were given culturally appropriate services. Family carers also
10 informally educated and trained the agency carers that they believed would help to increase
11 agency carers' knowledge about culturally appropriate services and promote a better
12 understanding of the needs of the Bangladeshi people. Current research results are consistent
13 with the outcome of Katbamna, Ahmad, Bhakta, Baker, & Parker's [33] study, which found that
14 British-Indian and British-Pakistani family carers had scant aid and support within the family
15 and were unwilling to look for support from extended family members. Katbamna et al.'s [33]
16 study also reported that the South Asian family carers had a very negative attitude toward
17 service providers and family carers were reluctant to seek support. However, family carers in
18 this current study sought and received formal support from service providers. Themes that
19 emerged in the present study identify significant cultural and religious dissimilarities in the
20 usage of healthcare services. For most of the South Asian family carers, access to support
21 services (health or social care) occurred as an outcome of acute hospital admission [17].
22 However, in this study, for opposite-sex caring issues, family carers accessed caring services.
23 Also, previous studies reported that the lack of knowledge was the main reason not to access
24 healthcare services among South Asian family members with dementia [31,34]. However, this
25 was not the case for the Bangladeshi participants in this study and the lack of appropriate
26 cultural and religious services was the main reason for withdrawing from the services.

27

28 **Strengths and limitations**

29 This is the first study that explored the perspectives of Bangladeshi adults without dementia
30 as well as the experiences of the family carers of relatives with dementia. As a first study, this
31 research covered the areas that it projected to in an efficient way. However, there were a few
32 limitations in this study and future research in the Bangladeshi ethnic minority community may
33 look to expand on these areas. There were limitations in the representativeness and
34 significance of the findings. The participants' age and gender between phases one and two of
35 the study were different, meaning that the participants were not truly representative of each
36 other. The male focus group was attended by a much older age group than those recruited in

1 both the female focus group and the dementia family carers' group; moreover, all the focus
2 group attendees had a lack of knowledge of dementia and caregiving. Therefore, the findings
3 from the focus groups may not be fully transferable across the entire population, nor among
4 dementia family carers. Nevertheless, this study also had a minimum age criterion of 18 years
5 of age; as such, the results are not readily transferable to younger populations.

7 **Conclusion**

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

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