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Research Article

Cultural Myths, Superstitions, and Stigma Surrounding Dementia in a UK Bangladeshi Community

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The last three census data highlighted that UK Bangladeshi communities have the worst health outcomes. This includes a higher risk of type two diabetes and heart diseases; both are risk factors for developing vascular dementia. However, little is known about Bangladeshi community members' understandings of dementia, including cultural myths. This paper focuses on the cultural myths, superstitions, and stigma surrounding dementia in an English Bangladeshi community from the direct experiences of people living with dementia, their caregivers, and the views of dementia service providers/stakeholders. This qualitative research was undertaken with three distinct participant groups using semistructured interviews ($n = 25$), who were recruited from community settings. The first and second participant groups explored the experiences of people with dementia ($n = 10$) and their family caregivers ($n = 10$). The third group examined stakeholders'/service providers' views ($n = 5$). Interviews were recorded digitally and transcribed verbatim. Findings were reached using an interpretive approach, emphasising the sense people make in their own lives and experiences and how they frame and understand dementia. The study revealed that participants with dementia and their caregivers have "alternative" knowledge about dementia and do not necessarily understand dementia in a Westernised scientific/biomedical context. Misconceptions about dementia and belief in various myths and superstitions can lead people to go to spiritual healers or practice traditional remedies rather than to their GPs, delaying their dementia diagnosis. This paper concludes that there is a lack of awareness among the Bangladeshi participants and a need for targeted awareness about dementia to help dispel cultural myths and combat the stigma surrounding dementia within the Bangladeshi community.

1. Introduction

Dementia is the leading cause of death in the UK [1]. Coronary heart disease is the second preceding cause of death in England and Wales, which is a significant risk factor for dementia (https://www.bhf.org.uk) [2]. It is estimated that approximately 944,000 people are living in the UK with dementia (https://www.dementiastatisticss.org) [3]. By 2051, this number is predicted to rise to 2 million [4]. The cost of dementia in the UK is currently £34.7 billion a year, with an average annual cost of £32,250 per person with the condition (https://www.alzheimers.org.uk/).

Census data highlighted that the UK Bangladeshi, Pakistani, and White Gypsy communities have the poorest health outcomes across a range of indicators [5]. The average health of 60-year-olds belonging to Gypsies or Irish Travellers and Bangladeshis was like that of a typical 80-year-old [6]. In the last three decades, statistics show that Bangladeshis have the highest rates of illnesses in the UK of any ethnic group (https://www.kingsfund.org.uk) and Higgins [7–9]. There is also evidence to suggest that the Bangladeshi community has the highest risk of developing type 2 diabetes and heart diseases, both of which are important indicators for the development of vascular dementia in old age [8]. Despite the rapid growth in the number of aging Bangladeshi people living in the UK, very little research has sought to understand the experiences of people with dementia and their cultural understanding of dementia among this minority ethnic group. Previous research has highlighted aspects of caregivers' knowledge of dementia in the Bangladeshi community in England; however, people with the condition were not included in that research; therefore, the voices of people who have been diagnosed with dementia were not heard [9]. Although Hossain [9] aimed to understand the knowledge and attitudes of people with the condition, his study did not include those individuals with dementia. Despite increasing recognition amongst researchers that people with dementia should be included in the research as active participants [10], people with the condition within the Bangladeshi community are underrepresented in research. In addition, there have been limited prior studies exploring views about dementia among British Bangladeshis.

2. Context

The UK Bangladeshi community refers to those people in Great Britain who migrated or were born here with roots in Bangladesh. Bangladesh was part of India until 1947 [11]. When British colonial rule ended, the province of Bengal (within India) was partitioned into East Bengal and West Bengal. East Bengal was renamed East Pakistan again in 1947; it eventually gained independence in 1971 from Pakistan and became the sovereign nation of Bangladesh [11]. Due to a shortage of labour in Great Britain, Indians mostly migrated in 1948, as noted by Spencer [12]. In subsequent years, the large-scale settlement of the Pakistani community commenced in 1960 and 1966, while for the Bangladeshis, it was initiated in 1971 following the liberation war [12]. Presently, out of 59.6 million of the total population of England and Welsh, 3.1% of Indians, 2.7% of Pakistanis, and 1.15% of Bangladeshis live in the UK [9]. Although people from these three nations are commonly categorised as South Asians (SA), they have significant ethnic, sociodemographic, and cultural differences. Studies indicate significant disparities in health, education, and income among them Marmot et al. [13]. Notably, the Bangladeshi community has poorer health compared to all ethnic groups in the UK, although 52% of Indians, 51% of Pakistanis, and 47% of Bangladeshi origin people in England and Welsh reported in the last 2021 Census "very good" health (https://www.ons.gov.uk; [9, 15]).

The Bangladeshi and Pakistani people are around twice as likely to be in the bottom fifth of incomes than average and have the lowest median household incomes (https://commonslibrary.parliament.uk/income-inequality-by-ethnic-group/). According to the 2021 census, 78% of Indians, 68% of Pakistanis, and 58% of Bangladeshis reported being economically active; 42% of UK Bangladeshis lacked a regular income [9]. In terms of household overcrowding, the Bangladeshi community exhibits the highest rates (at 22.5%), while Pakistani households follow at 13.5%, in contrast to the lowest rate of 1.7% observed in white British households (https://www.ethnicity-facts-figures.service.gov.uk/housing/) [15].

Further ethnic discrepancies are notable at the occupation level. In 2022, 39.8% of workers from the Indian ethnic group were in "professional" jobs," the highest percentage out of all ethnic groups in this type of occupation in comparison, while the combined Pakistani and Bangladeshi ethnic group had the lowest representation at 21.9% (https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/) [16].

Dementia means different things to different people depending on their social context [17]. Research shows that people from the SA communities (including Bangladeshis) remain underrepresented in specialist dementia services [18] and receive a later diagnosis [19]. They also have misplaced beliefs about dementia, which may keep them from diagnosis and treatment [20, 21].

Parveen et al. [22] have noticed that when participants with dementia of South Asian origin do not find a word to express dementia, then they refer to it as "memory problems," and they commonly note "memory loss" and being "forgetful" as symptoms of dementia. Botsford and Dening [23] stated that there is no word for dementia in the Urdu, Gujarati, Bangladeshi, Hindi, and Punjabi languages. Likewise, Hossain [9] found that there is no synonymous word for "dementia" in Bangla. However, Bangladeshi people often use several Bengali terms to understand dementia, e.g., *"smoron-shokti Thakena" or "smoron-shokti harano" or "mon-bhula"* (memory lost) [9].

Some literature studies suggest that people in SA communities often consider dementia a mental health problem. For example, Atcha [29] mentions that almost all her research participants have reported that the concept of dementia is unfamiliar to South Asians; therefore, a person living with dementia is commonly referred to as having gone "*Pagal*" (insane) or "mad." Moreover, Atcha [29] explores the finding that many participants view dementia as a *jinn* (spirit) possession, and an individual with dementia is "possessed," "taken over," or controlled by external forces. Likewise, Rozario [30] states that Bangladeshi Muslim families often categorise all illnesses into two types, either "*Daktari*" (biomedical) in nature or *"Upri"* caused by *Jinns* or *spirits*. They also take the view that medical doctors should treat medical problems, and the Imams or other spiritual practitioners can generally treat "*Upri*" issues [30].

The third research question guiding this study aimed to understand the experiences of dementia stigma by the people with the condition in the Bangladeshi community. Existing literature suggests that people with dementia from the UK Bangladeshis, along with other Black and Asian Minority Ethnic (BAME) communities, are heavily stigmatised. Stigma not only harms self-esteem and may cause distress but also affects social inclusion and can delay the diagnosis of dementia [21]. Although Hossain [9], Hossain et al. [31], and Hossain and Khan [27, 28] stated that participants in their study believe that there is no stigma attached to dementia in the Bangladeshi community, their findings contradict the majority of South Asian studies, including Parveen et al. [29], Mukadam et al. [21, 30], Atcha [29], Mackenzie [31], Giebel [32], Regan [20], Kenning et al. [33], and Blakemore et al. [34]. Ahmed et al. [35] argued that dementia is considered in the Punjabi and Gujarati communities as a "taboo" subject, resulting in stigma and social isolation. There are some similarities between Punjabis (of Pakistan), Gujaratis (of India and Pakistan), and Bangladeshis in lifestyle, food habits, and culture, as historically, Bangladesh was part of India (until 1947) and part of Pakistan (1947–1971) [11].

3. Method

The study used a constructivist epistemology grounded in the interpretivist approach of social constructivism. It relies upon the participant's views and experiences [36]. A qualitative research approach was adopted to gain deeper insights into people's lived experiences and the meanings that people make of the events and practices in the contexts they are experienced within [37].

To recruit dementia service providers/stakeholders, senior managers of seven organisations providing dementia services in the research area were contacted via e-mail and telephone. Five participants participated in the face-to-face semistructured interviews, while two declined due to their busy schedules. To recruit people with dementia and their family caregivers, posters were displayed inside mosques, temples, and shops with the appropriate authority's permission. Some Imams/faith leaders and community leaders helped in recruiting participants for this research as gatekeepers. The snowball sampling strategy was also used with the help of some participants and via reference and gatekeeping help.

This study drew up clear inclusion criteria for the participants with dementia and their family caregivers who were eligible to participate in the research study. Table 1 provides these criteria.

Table 1: Inclusion criteria.

(1) Overs 18 years old
(2) UK Bangladeshi living in the research area only
(3) Family caregiver who has been directly involved in the day-to-day activities of the person with a dementia diagnosis given within the previous 2 years
(4) Capacity to provide consent to be included in the study
(5) Male, female, transgender
(6) People of any faith or no faith
(7) Dementia service providers/stakeholders from the research area

Semistructured interviews were conducted in three distinct phases with a total of 25 participants. This number was sufficient to answer the research questions with this in-depth qualitative research. According to Crouch and McKenzie [38], 20 or less can be a fair number for qualitative research study.

This paper examines the knowledge and belief about dementia in a UK Bangladeshi community from three perspectives. (1) Participants with dementia and (2) their family caregivers were interviewed to explore their knowledge, beliefs, and experiences relating to dementia. (3) Those of the stakeholders and service providers were asked to express their experiences and perspectives on understanding of dementia in the above community.

Ten people living with dementia from a UK Bangladeshi community have participated in this research study. All were born in Bangladesh and Muslims by faith. Six were male, and four were female. Participants were interviewed alone. An average length of interview with that group was about 45 minutes. All these people with the condition willingly participated in the research, verbally consented, and signed the consent form. The first author had informal discussions with the carers before the meeting to better understand these participants' health conditions. All those participants with dementia had the capacity to give consent. Table 2 presents the demographic information of individuals with dementia from the Bangladeshi community who participated in the research investigation.

Ten caregivers of people living with dementia from eight different families from the same community participated in this research. Six were male, and four were female. Seven care partner participants were born in Bangladesh but raised in the UK, and three carers were born in England. Like participants with dementia, all family caregivers were Muslims. Table 3 illustrates the demographics of those family caregivers of people with dementia from the Bangladeshi community who provided care for their loved ones and participated in this research.

Five service providers comprised participant-group three from the research area participated in this phase of the study. Four were Muslims, and one service provider was Hindu by faith. Three were British Bangladeshi, one was British Pakistani, and another was of British African-Caribbean origin. All were male. Interviews were conducted in English and Bangla, and data were transcribed and translated by the first author. The average length of the interview with the family caregivers and stakeholders/service providers' carers was 60 minutes. Table 4 presents the demographics of those dementia service providers/stakeholders who participated in this study.

Prior to each phase of data collection, participants' consent was gained using a participants' information sheet and consent forms that delineate issues such as the purpose of the study, how the results will be presented, the confidentiality and anonymity procedures, data storage, and the participants' right to withdrawal from the interview if they want to. Participants were fully informed of the study and any attendant risks in all three research phases. The information sheet and consent form were sent to each potential interviewee via e-mail/post and through gatekeepers.

This study was designed before the COVID-19 pandemic, and ethical approval was obtained from the University of Salford on 2 June 2020. Then, ethical amendment applications were sought and granted twice following the pandemic. Data collection from stakeholders/service providers was completed in-person following 1 metre of social distancing protocol. In compliance with the government's COVID-restriction guidance, the family members who provided care for the persons with the condition were interviewed remotely via telephone and Microsoft Teams. Finally, face-to-face interviews were done with participants with dementia when pandemic restrictions were lifted. The information collection, storage, and disposal followed the

Table 2: Demographics of the participants living with dementia.

PLwD/pseudonyms ($n = 10$)	Gender	Age range
Salam	Male	
Jabbar	Male	
Amina	Female	80–85 = 3
Hasan	Male	75–80 = 2
Yusuf	Male	70–75 = 1
Hajira	Female	65–70 = 1
Alom	Male	60–65 = 2
Nisa	Female	55–60 = 1
Sharifa	Female	
Fozlu	Male	

Table 3: Demographics of the caregivers who provided care for their family members who have dementia.

PLwD/pseudonyms ($n = 10$)	Gender	Relationship with the person who they cared for	Born in	Age range
Akram	Male	Son and father	Bangladesh	60–65 = 1 55–60 = 1 50–55 = 1 45–50 = 2 40–45 = 1 35–40 = 3 30–35 = 1
Hafsa	Female	Daughter and father	England	
Shahid	Male	Son and father	England	
Bilkis	Female	Spouse	Bangladesh	
Akhlaq	Male	Son and father	England	
Shuman	Male	Son and mother	Bangladesh	
Muslima	Female	Spouse	Bangladesh	
Mustaque	Male	Son and father	Bangladesh	
Tahira	Female	Daughter and mother	Bangladesh	
Jamil	Male	Son and mother	Bangladesh	

Table 4: Demographics of the stakeholders/service providers.

Stakeholders/pseudonyms ($n = 5$)	Services	Age range	Ethnicity	Religion
Montu	NHS health professional			
Kadir	Dementia service provider	40–45 = 3	British_Bangladeshi = 3	Hindu-1 Muslim-4
Usman	Chairperson of the interfaith network	55–60 = 1	African-Caribbean-1	
Shamsul	Senior manager of a dementia care service	60–65 = 1	Brithish Pakistani-1	
Abrar	Dementia trainer			

GDPR 2018 carefully. Strict protocols were maintained to keep the participants' data secure and confidential. Data stored electronically were saved onto an encrypted device in a password-protected computer at the University of Salford, accessible only to the research team. Table 5 presents the topic guide utilised in the semistructured interviews conducted with the participants of this research study.

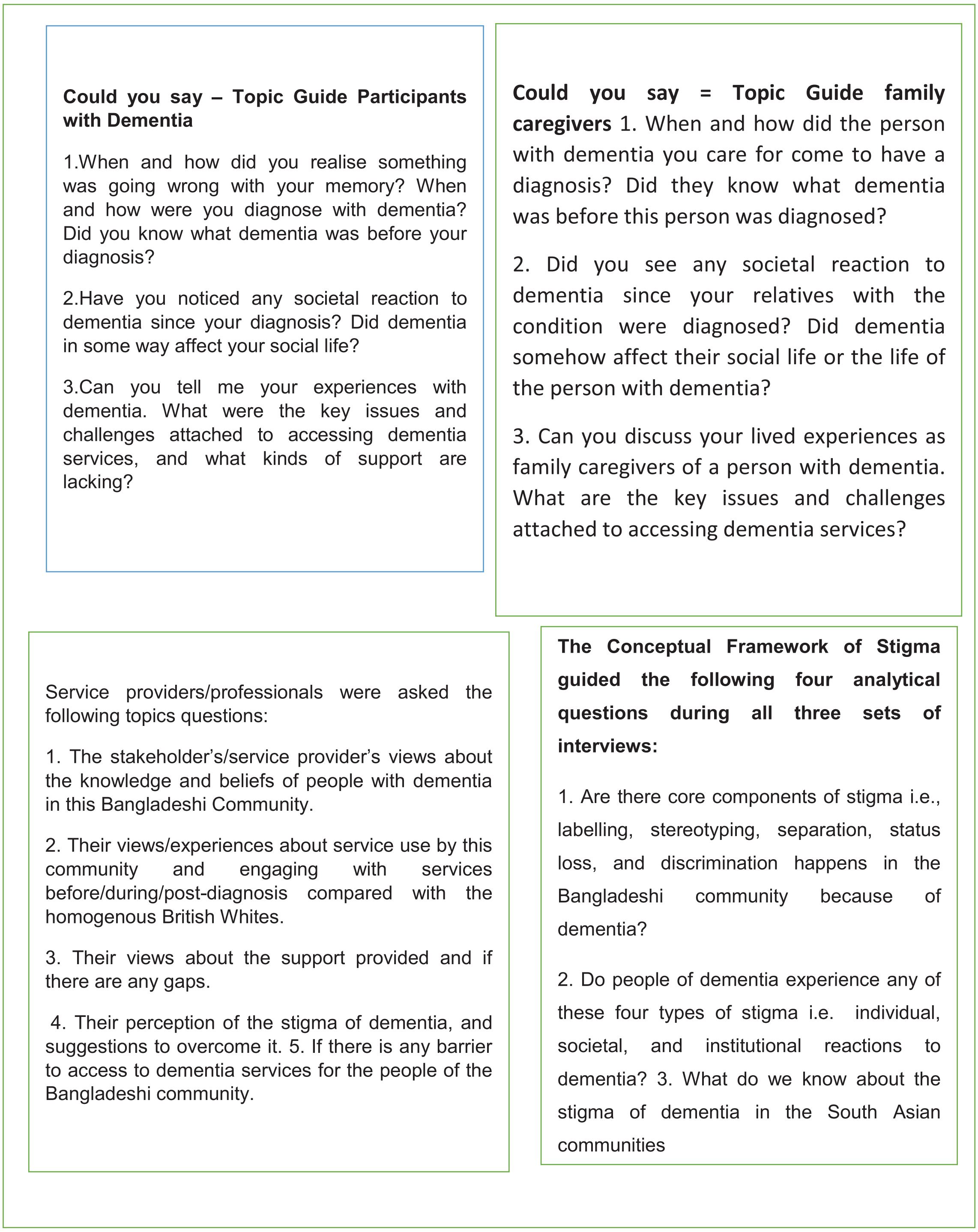
The data were analysed using the thematic inductive approach. The themes identified summarised the data themselves [39]. No prescribed codes or themes were prepared before analysing the data [40, 47]. Pseudonyms were used to anonymise all research participants. The first author was responsible for data management and analysis under the direct supervision of the two coauthors. He transcribed and translated all interview data into English, where the Sylheti-Bangla language was used during the interview. His background and experiences enabled him to relate to and build rapport with his research participants, which was crucial for gaining access to the research samples. His positionality and multilinguistic skills facilitated him collecting, translating, transcribing, interpreting, and analysing the data from the research participants directly, all of which have been invaluable in limiting translation difficulties and improving the quality of the transcribed data [48]. The first author speaks English, Bangla, and Sylheti dialects fluently and was born in the Sylhet division, where most UK Bangladeshi immigrants originate. These factors facilitated accessible communication and accurate translation of the data.

4. Results

The findings from the thematic analysis of all three participant groups are presented in two broad themes: (1) misconceptions, superstitions, and myths and (2) stigma surrounding dementia.

4.1. Theme 1: Misconceptions, Superstitions, and Myths. Findings suggest that most participants' understanding of dementia is limited, and they do not necessarily understand what dementia is from a Westernised scientific/biomedical viewpoint. Many participants with dementia and their

Table 5: Topic guide used in these semistructure interviews.



Could you say – Topic Guide Participants with Dementia

1.When and how did you realise something was going wrong with your memory? When and how were you diagnose with dementia? Did you know what dementia was before your diagnosis?

2.Have you noticed any societal reaction to dementia since your diagnosis? Did dementia in some way affect your social life?

3.Can you tell me your experiences with dementia. What were the key issues and challenges attached to accessing dementia services, and what kinds of support are lacking?

Could you say = Topic Guide family caregivers 1. When and how did the person with dementia you care for come to have a diagnosis? Did they know what dementia was before this person was diagnosed?

2. Did you see any societal reaction to dementia since your relatives with the condition were diagnosed? Did dementia somehow affect their social life or the life of the person with dementia?

3. Can you discuss your lived experiences as family caregivers of a person with dementia. What are the key issues and challenges attached to accessing dementia services?

Service providers/professionals were asked the following topics questions:

1. The stakeholder's/service provider's views about the knowledge and beliefs of people with dementia in this Bangladeshi Community.

2. Their views/experiences about service use by this community and engaging with services before/during/post-diagnosis compared with the homogenous British Whites.

3. Their views about the support provided and if there are any gaps.

4. Their perception of the stigma of dementia, and suggestions to overcome it. 5. If there is any barrier to access to dementia services for the people of the Bangladeshi community.

The Conceptual Framework of Stigma guided the following four analytical questions during all three sets of interviews:

1. Are there core components of stigma i.e., labelling, stereotyping, separation, status loss, and discrimination happens in the Bangladeshi community because of dementia?

2. Do people of dementia experience any of these four types of stigma i.e. individual, societal, and institutional reactions to dementia? 3. What do we know about the stigma of dementia in the South Asian communities

family caregivers had misconceptions about dementia that can be linked to their cultural and religious beliefs. Three people with the condition believed that they had *"upri bemar"* (possession by supernatural entities). Two participants with the condition believed that they had some *jinn* within them, whereas another interviewee reported that some people did *"challan"* (black magic) on them due to jealousy. All three participants went to many spiritual healers in Bangladesh and in the UK. A male with dementia said that

> *"To be honest, I have "upri bemar"[supernatural interventions], nothing [to do] with bio-medical problem. But I go to doctor just because of the pressure of my wife and children. However, I know that no medicine will work on me, as it is upri* (Yusuf)."

One female with the condition reported that

> *"Many of our extended family members suggested I go to any spiritual healers as I thought I might have some "*upri*" problem. However, my son works for NHS, and some of our relatives are nurses who explained that this is not "*upri*". Therefore, I did not go to that line. Otherwise, I might go to them* (Amina)."

One family caregiver said that

> *"You may know that we Bangladeshi see the spiritual side first. When this spiritual treatment finishes, then we see the medical side. Sometimes these spiritual lines come to you automatically."* (Shuman).

Another caregiver reported that

> *"Everyone in my family said we should call* Mulla/Molovi *[i.e., Imams and spiritual healers] to give him a "*foo*" [blowing on any patient after reciting some verses of the Qur'an or any supplication]. We did many different treatments in the line of spiritual therapy. When none of these treatments was working, we told our GP everything in detail about our father. Later, we understood from his GP that he has dementia."* (Akhlaq).

Interview data revealed that some participants considered their memory problem to be due to dementia, but other behavioural symptoms, such as mood changes or being aggressive and urinating/soiling in the bed or on the floor, were "*upri.*" Therefore, when the health condition of a person with dementia (Hasan) deteriorated and he used to urinate or soil himself often on the floor or in bed, his family members took him to a spiritual healer.

> *"Around 6/7 years ago, I went to a spiritual healer in Birmingham who was an Indian Gujarati Imam. My dementia had suddenly worsened. I could not control my urine or toilet at that time. My children bought a new house, and I used to get scared when we moved into this new house. Therefore, my wife and children thought I had* Jinn *with me. So, they took me to Birmingham to this imam to see me. He had blown on me, gave "*pani pora*" (blessed water) and "*suta pora*" (blessed fibre)* (Hasan).

According to some participants, some spiritual healers in the UK do not have any qualifications relating to dementia but take large amounts of money from the people with the condition in the name of *jinn* removal. One participant with dementia described how the spiritual healer treated him:

> *"He (the healer) drew some lines and told us that just above my bedroom, and in the loft, some* Jinns *are living there. These* Jinns *caused me to do excessive toilets and urine. He also said that this is nothing with dementia; but an upri problem. The healer also advocated that if we sell our house and move to different houses, the Jinn will move to the new house. So, we decided not to sell the house, rather we paid four thousand pounds to this healer for Jinn exorcisms. However, the healer could not solve this problem* (Hasan)."

One family caregiver reported that his mother went to Bangladesh for jinn extortion. When she came back from Bangladesh, her health condition had not improved. She was confused whether the *tabiz (amulet worn for protection)* she had (from a spiritual healer of Bangladesh) was the correct one for her issues, and later, she showed this *tabiz* to one of their local Bangladeshi spiritual healers in the UK who told them that

> *"This is a dangerous* tabiz *which will harm you. Someone made "Chalan" [black magic] on you for jealousy. Put this tabiz into hot water; then all bad reaction will be removed."* (Shuman)

This caregiver also added that his mother and their family trusted this healer and followed all his advice. Later, the healer gave her another *tabiz*; however, the family did not see any improvement.

Like those caregivers, all five service providers/stakeholders reported that there are various misconceptions and myths about dementia amongst many of the Bangladeshi people. For instance, one service provider stated that

> "*Some people think that someone has done some form of black magic on them, which is making them feel that way, and they would go to a religious scholar, and they would get blessed water or talismans to wear around the neck, and they would deal with that way* (Usman)."

4.2. Theme 2: Stigma Surrounding Dementia. Participants of this study experienced all four aspects of stigma: self, social, structural stigma, and stigma by association [49]. Most people with dementia and their family tended to hide this information and stayed away from the public view. One participant with the condition reported that

> *"I tell my friends and extended family members that I cannot remember things or forget recent events. However, I do not tell them that I have dementia; people will not understand what dementia is, and they may judge me. People are not educated. People might say-"e beti pagol oi gese" [she has gone mad]; then the whole community may gossip about my family and me," which may damage my family's "*izzat*" [honour]* (Amina)".

Many participants with the condition have reduced contact with their extended families or broader community from fear that if other people knew their condition, they might start gossiping in the community and that might harm the wider family's reputation. Consequently, many participants became socially isolated.

> *"Since [the] last ten years, I never went out to spend time with friends. Most of the time, I am lonely at home. No one comes to visit me apart from my close family members* (Hasan)*."*

Another participant with dementia said that

> *"I don't go anywhere. I do not even go to the mosque now to pray the daily prayer apart from Fridays. I don't go to any parties or social events. I don't like people. I don't even like to talk to anyone over the phone* (Fozlu)*."*

This participant was prompted further why he did not like that; he then replied that

> *"I get annoyed easily, and my mood changes. I shout to everyone, even my daughters and wife. If I do not behave with others appropriately, other people will take it seriously. Not only that, but people might also say: "e beta pagol oi gese" [this guy has become mad], and then I might be the talk of the town. It might affect my daughters' marriage as well. So, better I stay at home* (Fozlu)*."*

Living in a care home also emerged as a source of stigma in the Bangladeshi community. For example, one woman with dementia (Amina) was asked if her children could not look after her due to their business or job, would she think about going to any care home? She replied that

> "Na-re-shuna-re- *[No way]."*

When asked why, she stated that

> ""Manush-e Kita Khoibo?"- *[what are people going to say?]. How could we show our face to the community? It is not our culture to send older people to the care home. However, my children will also not feel good to send their mum to a care home* (Amina)*."*

Family caregivers found that their relative with dementia became socially isolated because of the social stigma. For instance, one caregiver reported that

> *"People try to hide if their family member has got dementia. In our community, dementia is a taboo subject. Some people consider dementia as madness, and it could ruin family honour and reputation; therefore, people try to conceal it. Brother, what can I say about other people when people in my own family went to imams and spiritual healers rather than a doctor?"* (Akhlaq)

This participant highlighted that people often understand dementia as a mental health problem. Another stated that

> *"There is a massive stigma on this. Not only dementia, with any illness, but people of this community also make stigma on it. For example, if any child is disabled, we hide this from others. However, our family is different* (Jamil)*."*

One carer commented that he did not feel shame in looking after his father. However, he gets embarrassed when his father shows atypical behaviour in public. He said that

> *"Some people think it is embarrassing and shameful, and there is stigma, but we do not feel this. Sometimes when my father speaks out of line in social interaction, we feel bad and embarrassed. But those who know he has dementia do not mind him behaving like this* (Mushtaq)*."*

Some people worry and hesitate if their loved one who has dementia behaves differently as others may say something judgmental about them.

One participant stated that

> *"He does not want to go to the mosque. He does not like any social gatherings. The mosque is just next door to our house. When he was well, he could go to the mosque regularly. Now, he does not want to go. He likes to be alone. Last year before the pandemic, there was a marriage ceremony of his brothers' daughter. We all went there. We requested him so much. However, he did not go there. He said, you go, I don't like to go anywhere."* (Shahid)

This interviewee highlighted that his father with dementia became socially isolated, considering other people might not like him, which may worsen his dementia.

Almost all stakeholders reported that people with dementia among the Bangladeshi community are heavily stigmatised. One participant commented that

> *"When people have got dementia, they start losing their friends as other people avoid them considering that people with dementia are not in the right frame of mind or became crazy."* (Usman)

Another stakeholder said that

> *"People feel embarrassed. So, when people are embarrassed, they try to keep everything under the carpet. Could be socially isolated from the community. . . . They may stop coming to the mosque, or they may not frequently come to the mosque. The activities would change for that person (Usman).*

One stakeholder reported that because of the public stigma attached to dementia, the marriage prospects of a family member of person with the condition can be affected badly.

> "*Suppose my father had dementia, my daughter is 25 years old, and I am waiting for my daughter's good marriage proposal. I will worry; because the family coming to see my daughter will find out my father has dementia or behaves differently. So, they can have a perception that this can gradually go to other members of my family, and everyone will be like this; thus, a good marriage proposal can deteriorate.* (Kadir)*."*

5. Discussion

This research data and analysis suggest that people with dementia and their caregivers have misconceptions about dementia and that these misconceptions occur due to their religious and cultural beliefs. Some participants with dementia and their caregivers went to various spiritual healers in Bangladesh and the UK instead of seeking biomedical treatment. They only went to the doctors when they felt the spiritual intervention had failed, thus delaying the formal diagnosis. This is consistent with other studies on South Asian populations. For example, Atcha [29], Victor et al. [50], and Purandare et al. [51] suggested that in the Bangladeshi, Indian, and Pakistani communities, the underlying cultural aspects, including their beliefs, customs, and practices, link dementia with spiritual causes. Similarly, investigating the experiences of people from some BAME communities with dementia, the All-Party Parliamentary Group on Dementia (APPG) also found that there were myths and misconceptions about dementia where "Jinns" are alluded to by some BAME communities [46].

Some participants living with dementia and caregivers discussed their negative experiences of ineffective religious and spiritual treatments. They acknowledged that some spiritual healers were fraudsters, exploiting them via significant fees for performing exorcisms or other spiritual therapy. This corresponds to previous research about the limits of medical and healthcare knowledge amongst British Imams and potential exploitation based on religious or cultural beliefs [30, 47, 48].

Participants with dementia and their caregivers reported that individuals with the condition have separated themselves from their extended family members and the wider Bangladeshi community. Individuals with dementia and their family carers tried to hide these conditions from others because they felt "*shorom*" (shame) about it, suggesting that "self-stigma" was attached to dementia among these research participants. This is consistent with existing literature that the stigma of dementia is a severe problem in many black and minority ethnic communities [22, 49–51].

Data analysis of all three participant groups suggests that social stigma has caused tension for many participants with dementia and their caregivers. Almost all service providers reported that their service users from the Bangladeshi community are heavily stigmatised. Similarly, people with dementia and their family caregivers expressed that if other people from the Bangladeshi community or their extended family members knew that someone in these families had dementia, they might start gossiping about them, which might destroy their wider family's reputation. Eventually, many became socially isolated because people might label them mad. This echoes Atcha's [29] findings that this withdrawal often occurs when people face negative stereotyping and feel more slowly than other community members think they are. Goffman [52] suggests that the stigma occurs when the anticipated attributes assigned to someone in any interaction are not fulfilled. Thus, a person with dementia or mental illness is reduced in our mind from a whole and a usual person to a tainted, discounted one [52]. Link and Phelan [53] stated that stigmatisation negatively impacts on access to social, economic, and political power. It allows the identification of difference, the construction of stereotypes, the separation of labelled individuals into diverse groups, and the complete execution of disapproval, rejection, exclusion, and discrimination [53]. However, Innes [54] argues that the stigma of dementia is shared across all populations and not just ethnic minorities. It is a common challenge for all; she suggests that attitudes towards dementia in all minority ethnic groups, in general, can be seen to reflect negative views of old age and the stigma surrounding mental health [54].

Parveen and Oyebode [55] argue that the negative impact of caregiving for persons with dementia is more significant for minority ethnic carers. They are more likely to experience multiple jeopardies due to combinations such as the stigma of dementia, being perceived as a migrant, racism, and lower socioeconomic status [55]. Some participants (19) reported that dementia is taboo in the Bangladeshi community. This finding echoes that of Parveen et al. [29] who suggest that among Punjabi (Pakistani), Gujarati (Indian), and some African communities, dementia is considered a "taboo" subject. However, this study contradicts [9] claim that there was no evidence of stigma among England's Bangladeshi community. In all three participant groups of this paper, most interviewees reported many components of stigma in the Bangladeshi community.

Findings from all three participant groups suggest that people with dementia and their families kept information about dementia diagnosis secret as they might be stigmatised by broader community members, which severely threatened their daughters' marriage prospects. Some participants with dementia reported reduced contact with people and even avoided telephone conversations because if people knew they had dementia, it might jeopardise their daughters' marriage proposals. This echoes Mohammad's [56] work that explored how dementia was an obstacle to arranging marriages for the children of participants with dementia.

Findings from this study suggest that the misconceptions about dementia and beliefs in various myths are the biggest pertinent challenge for the Bangladeshi community. Raising knowledge and awareness about dementia among this community may help reduce these problems and remove the stigma surrounding dementia. To do this, the following recommendations are proposed:

(a) Health and social care commissioners, care providers, and support services should run a pilot project to increase awareness within the Bangladeshi community, educate people about dementia, remove the stigma, and dispel the myths about dementia through community events and talk-shows on community TV and radio channels.

(b) A group of dedicated Imams/faith leaders could be trained first on understanding dementia and deliver that knowledge during their weekly/Friday sermons. They can also be involved in arranging some seminars/symposiums locally, regionally, or nationally and discuss Islamic perspectives about dementia.

(c) Health and social care commissioners should recruit some outreach workers with Bangladeshi backgrounds to raise awareness through campaigns. All information leaflets/booklets should be written in Bangla and English.

(d) Mosques/faith centres can be used as significant venues for dementia awareness events, where more community members can be encouraged to attend.

6. Limitations

The study is limited in its sample size, though this is cognizant of other qualitative studies that seek to explore lived experiences' context. Moreover, due to the impact of COVID-19, it was impossible to fully execute the original plan that the first author made before the pandemic to collect data and recruit participants. Adoptions were made to data collection and participant recruitment strategies. For example, he undertook telephone interviews with the family caregivers instead of in-person interviews; therefore, he missed nonverbal communication. This impacted the ability to build rapport with participants quickly during face-to-face interactions.

7. Conclusion

This paper has shown how some people living with dementia from the Bangladeshi community in the UK have alternative knowledge and lack awareness about the condition. They did not understand dementia solely in the Western/scientific biomedical context; therefore, this contributed to delays in accessing dementia support services. Participants with dementia and their caregivers visited spiritual healers instead of biomedical doctors, considering dementia symptoms to be caused by possession by supernatural forces. Several participants reported that they went to these healers because of pressure of their extended family members and because of stigma associated with dementia. This paper demonstrates that stigma surrounding dementia, coupled with cultural superstition and misinformation, influenced the understandings about dementia and experiences of participants. The findings of this study show that it is vital for the health and social care providers and the policy makers to raise awareness of dementia, dispel myths, and remove the stigma surrounding dementia from the Bangladeshi community.

Data Availability

The interview data used to support the findings of this study are restricted by the University of Salford Ethics Committee, as participants were given assurance that their data would be used only for this study. Therefore, these data cannot be released.

Additional Points

What Is Known about This Topic? UK Bangladeshis have a higher risk of developing type two diabetes and heart disease; these are risk factors for developing vascular dementia. However, the voice of the people with the condition is not often heard. Cultural understandings of dementia in this community are limited. Little is known about the experiences of stigma surrounding dementia in the Bangladeshi community. *What This Paper Adds?* New insights into misconceptions about dementia and beliefs in various myths and superstitions that exist within a UK Bangladeshi community. Data about how stigma surrounding dementia impacts dementia service use in this community. Makes recommendations for policy and practice about how to support living with dementia in the Bangladeshi community in the UK.

Disclosure

This paper is based on the doctoral work of the corresponding author [57] PhD thesis, University of Salford, available at https://salford-repository.worktribe.com/output/1562045, https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.879636 (Accessed: March 2023).

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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