# Manuscript Title:

# Dementia and revivalist Islam: New perspectives to understanding dementia and tackling stigma

**Short Title:**

**Dementia and revivalist Islam**

Authors:

Dr Muhammad Zakir Hossain Keele University, UK

Email: [m.hossain@keele.ac.uk](mailto:m.hossain@keele.ac.uk)

#### **ORCID iD** <http://orcid.org/0000-0002-4939-1597>

Dr Faraz Mughal Keele University, UK

Email: [f.mughal@keele.ac.uk](mailto:f.mughal@keele.ac.uk)

#### **ORCID iD** <http://orcid.org/0000-0002-5437-5962>

# Corresponding author(s) name and contact details:

Dr Muhammad Hossain, PhD, AFHEA, MA, MSS, BSS

Health Services Researcher,

Room: DJW 1.76,

Primary Care Centre Versus Arthritis,

School of Primary, Community and Social Care,

Keele University,

Staffordshire, ST5 5BG,

United Kingdom

Tel: +44 (0)1782 733905

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# Abstract

The notion of stigma and its influence on the understanding of dementia has commonly been recognised as a big challenge to seeking healthcare services for South Asians in England. The aim of this commentary piece of paper is to examine how Muslims view and understand and tackle dementia stigma in the context of revivalist Islam, especially its growing popularity among Bangladeshi Muslims within their communities in Britain. This commentary reflects on the interrelationship between dementia and revivalist Islam among Bangladeshi family caregivers and addresses the question of how revivalist Islam is a significant source of understanding dementia and tackling stigma. Bangladeshi caregivers show a practical attitude towards dementia, which is generally acknowledged as a medical symptom and for which family caregivers voluntarily sought healthcare support. This piece captures underlying principles of their religious beliefs in the acceptance of dementia as a disease and in help-seeking, which was influenced by Qur’anic verses and Prophetic traditions. Bangladeshi caregivers’ religious beliefs intertwine with their knowledge, perception, and attitudes towards caregiving for their relatives with dementia. Religious understandings to deliver care are highly effective among Bangladeshi communities. Revivalist Islam offers family caregivers an opportunity to explore their inner wisdom through the challenging journey of caregiving for their family members with dementia.

Key words: dementia, caregivers, Islam, stigma

# Background

Dementia in Black and Minority Ethnic (BME) groups has been categorised as a concealed dilemma,1-3 whereas Bangladeshi people with dementia are a socially marginalised group and existing research is limited.4 In addition, it is felt that Bangladeshis portray an invisible community.5 Despite growing records, the migrant Bangladeshi public frequently characterises the lowest education rates and highest unemployment rates, and worse socio-economic and health situations among of communities in the UK.6-7 Evidence suggests that there are a few researches that investigated Bangladeshi Muslim populations’ understanding and management of dementia.3,8-9 Therefore, the views and experiences of Bangladeshi caregivers need to be heard to understand their dementia experiences, and to identify any barriers or unmet needs for supporting caregivers.

This paper aims and explores how revivalist Islam is appealed by the British Bangladesh community as a basis of sanction and rightfulness in its strengths to eliminate the perception of stigma associated with dementia. In this paper authors tried to draw out the intersection of dementia and revivalist Islam that has a clear implication for dementia caregiving as well as for understanding of stigma. The stigma issue is very important; however, it is not the part of the cultural or religious issues linked to dementia among the Bangladeshi community in the UK.8 The impact of revivalist Islam is evident in how these understandings are expressed as well as in their implications for understanding of dementia and stigma associated with it. The evolution of revivalist Islam seems to be a far more disputed matter within the Bangladeshi Muslims community than other South Asian Muslims in Britain. The authors argued that revivalist Islam may challenge stigma whereas stigma is not so powerful that may have an impact on the carers of people with dementia. The analysis draws out some new findings that consider explaining the change in views about dementia and thereby dementia caregiving that are very interesting and contrast with previous research. More research needs to be made of these and clarity about revivalist Islam and dementia issues.

# Bangladeshi caregivers

Existing research suggests that the English term ‘caregiver’ has no single or forthright definition,10-11 and there is no such word as ‘caregiver’ in South Asian languages.3,12 The identity of a caregiver can vary between people and cultures. South Asian caregivers provide higher levels of care than any other group in England whereas Bangladeshi caregivers deliver three times higher degrees of care than the overall UK population.13 Nevertheless, Bangladeshi family caregivers are the largely hidden and forgotten group who do not identify themselves as caregivers, but classify themselves as family members.14-16

# Islam and dementia caregiving

Muslims are frequently portrayed in terms of homogeneity and pre-existing collective identities, such as, someone who follows or practices Islam, or born into a Muslim family. Muslim populations in Europe and America are often described as a disintegrated, singular, and a monolithic group.17 Revivalist Islam offers a robust means to uphold a affirmative and unique appreciation of identity among the Bangladeshi Muslim community.18 Revivalist Islam is multifaceted, with a combination of ‘syncretic Bengali Islam’ (representing traditional Bengali spiritual society and social stratification); ‘the fundamental principles of Islam’ (strictly following the Qur’an, and the Sunnah (the words, actions, and tacit approval of the Prophet Muhammad peace be upon him)); and the ‘new Islam’ or ‘European Islam’ (a modern Islam based on the Qur’an and Sunnah, as well as rooted in personal choice and reflection).8, 19-24

A qualitative analysis revealed Bangladeshi participants’ hearty desires to care for their relatives with dementia fall within the family and how the meaning of care, the impact of care, and the interpersonal and religious contexts of caregiving create negative perceptions of the residential home care.8,15-16 The interpersonal motives of the current generation of family caregivers seem far from fading away; maybe the caregiving attitude is inherent within UK Bangladeshi families but is also strongly influenced by religious factors. Young Bangladeshi Muslims in the UK are influenced by revivalist Islam, which is the new, purist Islamic commitment towards family caregiving, friends, religious communities, and neighbours.18 These types of Islamic norms and values contrast with the comparatively composed forms of Islam that were traditionally found back in Bangladesh or among Bangladeshi Muslims in the United States of America (USA).18,25 Islamic values are strong permanent forces within the Bangladeshi community and shape various aspects of caregiving, such as family caregivers’ interpersonal motives, traditional values, and culture.15-16 If family caregivers want to remain good Muslims, they may fear displeasure from God for not providing care for their older family member with dementia. Therefore, family caregivers’ religious beliefs as universal norms and values will consistently appear to increase their interpersonal motives and obligations to provide care from their family home. In other words, it may be possible that their caregiving attitudes were taken for granted, as they believed they would be better off in this world, as well as in the hereafter, by providing care for relatives with dementia. It could be argued that providing care is more valuable for family caregivers than receiving external support for people with dementia, as it is one way to fulfil family caregivers’ religious duties, and aim for felicity in the afterlife. In a similar vein, the idea of sending a family member with dementia to a care home is deemed not only as a last resort, but morally and culturally unacceptable.8-9,15-16

# Revivalist Islam in tackling stigma

Unlike previous studies conducted among South Asian communities, a striking theme has emerged from research regarding stigma among the Bangladeshi community in the UK. 8-9,15-16,26  There was no evidence for stigma, which was consistent with a USA study on attitudes in the African American community, which revealed no stigma related with dementia.27 The signs and symptoms such as memory loss, confusion, inappropriate behaviour, problems with communication, faulty reasoning, hallucination, fainting, and agitation are normally linked to dementia that escalated stigma among other South Asian communities. However, aforementioned signs and symptoms of dementia would normally be expected for an elderly among the African American community in US, and hence, they were non-stigmatised. In this US study, it was revealed that a dementia diagnosis was not considered a stigma among participants, which aligns with previous work on Muslim patients with schizophrenia in Thailand, that showed that schizophrenia was perceived to be due to the ‘will of God’.32,34 The statements that precede this one would suggest that African Americans, Muslim people in Thailand, and the Bangladeshi people in the UK do not have stigma towards dementia in their community. Immediately, the question may arise about how are the Bangladeshi people then different from other BME population in the UK and USA? It may be inferred that Bangladeshi Muslims’ beliefs about dementia and other relevant health issues are heavily influenced by Islam and its two main sources of teaching, the Qur’an (Muslim Holy Book) and the Sunnah (words, actions, and tacit approval of the Prophet Muhammad (pbuh)).

Resonating with earlier studies, Bangladeshi community members professed a strong belief in God and seemed to conform to Kibria’s 18,25 explanation of ‘revivalist Islam’. In a participant sample, it appeared that older people without dementia mostly abided by Bengali and fundamentalist Islam, whereas, young family caregivers of people with dementia were influenced by a new or European Islam.16,26 Under these broad terms, from an implicit sense, revivalist Islam has given the Bangladeshi community a distinct Muslim identity, which can articulate a sense of difference from other Muslim communities in the UK. The revivalist tradition also offers Bangladeshi Muslim communities a typical way of dealing with multiple challenges associated with living in the UK, as posed in all spheres of life, such as health and social care, illness, and treatment.

This commentary reveals that the growing knowledge of revivalist Islam gives Bangladeshi Muslims a power to contest dementia stigma in two ways. First, the belief that dementia is caused by God conceivably alleviates the stigma associated with the development of dementia. Secondly, by shifting the accountability for their relatives’ dementia issues to medical conditions, it may be that the stigma associated with dementia is eliminated. This argument is supported by the Prophet Muhammad (pbuh) who said *‘tie up your camel and then trust in God that it will not run away’* 27 which emphasized on action as well having faith both are important. This view is also backed by research among Bangladeshi Muslims in relation to hereditary diseases, which found that participants believed their children’s illnesses were caused by God’s will, and they were not stigmatised in any of God’s affairs.28 Nonetheless, while earlier studies commonly mentioned that, among South Asians, Muslims believed that dementia was due to bad spirits, it was found that the studies conducted among the Pakistani community revealed how dementia is viewed as being related to stigma, or the ‘evil eye’.29 However, Ibn Sina, more widely known as ‘Avicenna’ (980–1037), a Muslim polymath and the founder of modern medicine, dismissed such a concept thousands of years ago, and gave psychological explanations for mental or somatic illness.30 Therefore, combining action and faith are both important to find a new way which would support the view of revivalist Islam to tackle stigma and seek help and support.

Existing research shows that Muslim communities are not protected from any mental health issues.31-32 They also argued that there may still be some stigma attached to mental health issues in some Muslim communities, but that they were meaningless. Evidence showed that family carers and their relatives with dementia were stigmatised through being perceived by the wider South Asian Muslim community members as being cursed or possessed by evil spirits.3 However, we argue that there are no historic reasons in the Bangladeshi community for feeling stigma towards dementia. We feel a lack of stigma attached to dementia and mental health is not a phenomenon confined to the Bangladeshi Muslim community, but likely to be present in other Muslim communities also.

# Discussion

Islam plays a significant role among Muslim families with anyone suffering from physical, psychological, or social problems.19,31, 33-34 Similarly, the Muslim belief that dementia is derived from God as a test, blessing, or forgiveness, has been shown to be common in recent research. The findings captured underlying principles of Bangladeshi community members’ religious beliefs in the acceptance of dementia as a disease and in help-seeking, which was influenced by Qur’anic verses and Prophetic traditions. The Prophet Muhammad (pbuh) said, ‘No Muslim suffers weakness, illness, worry, sorrow, vexation, or gloom – even the thorn that pricks him - without God thereby expiating some of his misdeeds’.35 The feelings of hopelessness about illness, isolation from larger support groups and communities, and suffering in silence are contrary to the tradition of Islam.

In contrast to some evidence regarding other South Asians, Bangladeshi family caregivers not only sought help and information from general practitioners, hospitals, and social services but also learned details about dementia and caregiving from the internet.8-9 Moreover, Islam considers all diseases, plus mental illness, as a test from God in this life and that such suffering and tribulation will assist in the expiation of one’s misdeeds, which can be applied to being diagnosed with dementia. The wider ethnic group may translate dementia in a different way and may have chosen methods to help seeking, but in the Bangladeshi community, revivalist Islam plays a part in their understanding of dementia and access to services.9 It could be argued that the notion of revivalist Islam as an ascribed identity among the Bangladeshi Muslim community has been developed as a response to the disintegration, negligibility, limitation, as well as to the common assumption ‘they look after their own’.36 The views of Bangladeshi dementia family caregivers and their relatives with dementia are unlikely to be considered in policy making, nonetheless, we argue that these voices can have a marked effect on developing services and creating them to tackle the distinct caregiving demands of the Bangladeshi Muslim community. To engage Bangladeshi community with mainstream services, their clear religious identities cannot be overlooked. The experience of dementia is one of the examples of the ability of religious identity to overcome any stigma-related concerns with disease and address caregiving consequences.

# Implications for research and policy

Despite the increasing number of Muslim communities in Europe and elsewhere, little is known about Muslim beliefs regarding physical, psychological, and social health and healthcare, particularly those of the Bangladeshi Muslim community.19 The healthcare needs of Muslim ethnic minority groups within mainstream services are more diverse than ever before, making it essential that service providers know and understand the complex differences between each and every ethnic group so that all can aim to meet their service needs.37

While more service providers are expected to accommodate ethnic minorities with varying personalised needs, health and social care training programs are often doing little to prepare healthcare professionals to the needs of Muslim ethnic minority groups.38-39 Public stigma regarding dementia and seeking healthcare services has a major impact on other BME people with dementia and their family caregivers. However, recent findings revealed that Bangladeshis in England exhibited a very positive, though realistic, view of dementia, demonstrating that, dementia was a clinical syndrome, and for which family caregivers voluntarily sought support from mainstream services.8 Findings captured underlying principles of their religious beliefs in the acceptance of dementia as a disease and in help-seeking, influenced by Muslim belief.8-9

In this paper we explore that revivalist Islam influenced Bangladeshi community members to integrate with mainstream service providers and to seek religiously sensitive healthcare services. Therefore, more Bangladeshi Muslim people may proactively seek religiously appropriate services from UK health services. Consequently, meeting this need of religiously and culturally appropriate services for ethnic diverse groups may put healthcare services under more pressure where service providers are facing existing pressures from rising patient demand and expectation.

We suggest that research, practice, and policy need to align to build a cumulative knowledge base that focuses on the interests of both Bangladeshi people with dementia and their family caregivers. Clearly, this research Furthermore, it is essential to recognise that any research on any religious revivals can impact action and produce new knowledge applicable to practice and policy. Similarly, this commentary has implications for other BAME Muslim populations worldwide living with dementia, their family caregivers, significant others, as well as healthcare professionals caring for Muslim patients. Future research needs to contextualise findings within the evidence base so that its results can have meaningful implications for practice and policy.

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