Manuscript Title:

**The costs of caregiving: Exploring the perceived burden of dementia among Bangladeshi caregivers in Britain**

**Running Head:**

**Burden of dementia among Bangladeshis in Britain**

Author:

1. Dr Muhammad Zakir Hossain Keele University, UK

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

ORCID iD: [0000-0002-4939-1597](http://orcid.org/0000-0002-4939-1597)

<https://twitter.com/drmzh>

**Corresponding author name and contact details:**

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

Health Services Researcher, Primary Care Centre Versus Arthritis, School of Primary, Community and Social Care, Room: DJW 1.76, Keele University, Staffordshire, ST5 5BG, United Kingdom. Tel: +44 (0)1782 732936 Fax: +44 (0)1782 734719

# The costs of caregiving: Exploring the perceived burden of dementia among Bangladeshi caregivers in Britain

# Abstract

There are currently 700,000 carers caregiving for 850,000 people with dementia in Britain, with Bangladeshi caregivers three times more likely to provide family care compared with their White British counterparts. However, few studies have been conducted to explore how caregiving for a loved one with dementia affects caregivers in Britain. The purpose of this study was to highlight the impacts of dementia on Bangladeshi caregivers. The roles of the caregivers were physically, psychologically, and socioeconomically demanding, particularly when their relative’s condition gradually worsened. This study will also help improve the advice, care, and support available for other ethnic minority caregivers.

*Keywords: dementia, family caregiving, coping and resilience, ethnic minorities, qualitative*

# 

# Introduction

Worldwide, around 46 million people have dementia, and the number of people with dementia in Britain is estimated to be 850,000, representing 1.3% of the British population (Hossain, Stores, Hakak, Crossland, & Dewey, 2019; Luengo-Fernandez, Leal, & Gary, 2010; Prince et al., 2014). It is projected that in the United Kingdom (UK) more than a million people will have dementia by 2025, with one in three persons born in 2015 expected to progress to dementia in their lifespan (Alzheimer's Research UK, 2019). Dementia is an umbrella term for a decline in mental ability that is severe enough to interfere with daily life. A person is affected by dementia when the brain is damaged by diseases such as Alzheimer’s disease, or by a series of strokes. There are many types of dementia, but Alzheimer’s disease is the most common causes of dementia, accounting for two-thirds of cases in the elderly. Other types of dementia include vascular dementia, which is the second most common cause of dementia, occurring after a series of strokes (post-stroke dementia); dementia with Lewy bodies is the third most common cause of dementia, affecting over 15% of the cases in the UK. Fronto-temporal dementia is the fourth most common cause of dementia and is a relatively rare type of dementia (Alzheimer's Research UK, 2013). There is a plethora of research being carried out on the potential treatments of dementia; however, to date, there are no drug therapies that can cure Alzheimer’s disease or any other common type of dementia.

# Dementia in Ethnic Groups

Dementia among Black, Asian, and Minority Ethnic (BAME) groups has been characterised as ‘a hidden problem’ (Brownlie, 1991; Wilkinson, 2002) since each BAME group is a marginalised group and thus the existing literature is limited (Wilkinson & Bowes, 2003). Numerous recent studies, however, highlighted that the projected number of BAME people with dementia in the UK is 25,000, and this number is forecasted to rise to 160,000 by 2051 (Hossain et al., 2018; Hossain & Khan, 2019; Khan, 2015; Truswell, 2014). Among all the South-Asian ethnic groups in Britain and America, the Bangladeshi population is one of the fastest growing minority groups, and yet they have the lowest education rates and experience disproportionately higher rates of unemployment and overcrowding, poorer socioeconomic status, and worse health than the overall population (Garbin, 2005; ONS, 2013; Patel, Rajpathak, & Karasz, 2012). Recent studies also emphasised that there has been little research on Bangladeshi people with dementia and their caregivers’ understanding and management of dementia (Hossain et al., 2018; Hossain & Khan, 2019). Therefore, the voices of Bangladeshi caregivers need to be heard in order to understand their dementia experiences and to address any challenges or unmet needs for supportive services.

# Rationale for the Study

Despite Bangladeshis being one of the fastest growing immigrant populations among all major ethnic groups in Britain, America, and around the developed world, there is a scarcity of research addressing the effects of dementia caregiving on Bangladeshi caregivers (Hossain & Khan, 2020; OECD, 2012; Patel, Rajpathak, & Karasz, 2012; Sunder & Uddin, 2007). A small amount of research conducted in America mainly focused on African American, Hispanic, Black Chinese, Chinese American, Korean, Korean American, Latino, White, and US-based European Union carers of people with dementia (Botsford, Clarke, & Gibb, 2011; Regan, Bhattacharyya, Kevern, & Rana, 2012). In spite of the growing interest in caregivers’ roles in family needs and support among BAME communities in Western Europe and America, there is a dearth of published research about caregiver burden, physical health, psychological health, economic situation and quality of life in the UK (Milne & Chryssanathopoulou, 2005). Further evidence from the UK and the US shows that BAME carers provide higher levels of care than their White British/American counterparts (Hossain & Mughal, 2020; Hossain, Stores, Hakak, & Dewey, 2019; ONS, 2001; Sayegh & Knight, 2013; Yeandle, Bennett, Buckner, Shipton, & Suokas, 2006). Among all BAME caregivers, Bangladeshi caregivers are the most deprived, neglected, and effectively hidden group (Hossain, Stores, Hakak, & Dewey, 2019). They identify themselves as fulfilling family duties and do not associate family duties with caregiving. Therefore, the rationale for interviewing Bangladeshi family caregivers was to gain their perspective of caregiving and their personal experiences with their care recipients. Further research is required to explore and understand Bangladeshi family carers’ experiences and feelings, and the ways they cope with their caregiving roles.

# Purpose of the Study

A key deficit in the existing research on dementia family caregiving is our understanding of the impact of caregiving on health and quality of life among Bangladeshi caregivers. The purpose of this study was, therefore, to identify factors associated with the impact of caregiving and categorise the effects of caregiving on the health and well-being of Bangladeshi caregivers.

# Materials and Methods

***Design***

Qualitative methodology allows inductive, exploratory research to provide a detailed description of how different ethnic groups feel about dementia and what paths they take to access health and social care services for people with dementia. This approach is appropriate to exploring complex personal narratives and experiences of accessing services for ethnic minority people (Mukadam, Cooper, Basit, & Livingston, 2011). The current study utilised qualitative methods: first, focus group discussions were conducted, followed by one-to-one semi-structured interviews with Bangladeshi caregivers, to collect in-depth information about their perceived burden of dementia caregiving. Qualitative methods provided an opportunity to discuss research issues with the participants. The author used an interview schedule to guide the interview. Purposive and snowball sampling were used to collect data from the caregivers. A combination of purposive and snowball sampling was particularly beneficial for dealing with underprivileged, geographically detached, and hard-to-reach Bangladeshi caregivers in Britain, where no practical sampling frame exists (Eland-Goossensen, Van-De-Goor, Vollemans, Hendriks, & Garretsen, 1997).

***Recruitment***

This study was conducted in two regions of Britain where a comparatively large number of Bangladeshi immigrants have settled permanently. Prospective participants were approached through Alzheimer’s Society, a UK-based care and research charity for people with dementia and their family carers; through local community leaders such as community development workers; and through the mosques’ imams. Initial contacts were made with 38 potential family caregivers; the author contacted them directly or via a male family member or a guardian of a female family caregiver. A total of 22 caregivers expressed an interest in the research. However, the number that finally agreed to participate was lower than had been anticipated. The research thus proceeded with 15 caregivers: 12 of the caregivers were female, and the rest were male.

***Data Collection***

Prior to recruitment, full ethical approval was obtained from a local independent research ethics committee. Written consent was obtained from all participants before data were gathered. An interview schedule was produced based on a qualitative research synthesis (Hossain et al., 2018), which was modified using research evidence and the current research questions. The interview schedule was intended to gain insight into the caregivers’ experiences of caring for a family member with dementia. The topics/questions in the interview schedule provided a frame of reference, rather than an inflexible structured process (Bryman, 2012). All interviews were digitally recorded with the participant’s permission. Participants could opt out of having their interview recorded; however, none chose to do so.

***Data Analysis***

All interview recordings were transcribed verbatim and the author extensively used NVivo 11 computerised software to produce accurate interview transcriptions. Braun and Clarke’s (2006) thematic analysis was chosen as the preferred method to analyse the findings. NVivo was used as an audit trail, and was found to be a good data management and thematic analysis tool. NVivo served to facilitate an accurate, transparent, and trustworthy data analysis process. Thematic analysis is a comprehensive qualitative data analysis process and is deemed to be the most suitable for any qualitative study that pursues an exploration of a phenomenon of interest through the interpretation of data generated through participant interviews (Alhojailan, 2012; Boyatzis, 1998). Thematic analysis was an efficient component of data analysis as it allowed the author an in-depth understanding of the phenomenon under investigation. The author repeatedly read the transcripts to identify a number of recurring concepts, generating initial codes that were developed until primary recurrent themes emerged.

# Results

The major themes that emerged from the data examined caregivers’ perceived physical, psychological, social, and financial impacts of providing care for their family members with dementia. The majority of caregivers lived with the family member with dementia and provided care for them in the family member’s own home. The themes cover Bangladeshi caregivers’ difficult and unpleasant experiences of physical, emotional, and socioeconomic burdens in their caring journeys. It is noteworthy that the manifestation and implication of burden and stress varied according to the family caregiver’s age, gender, and marital status. Themes are described in detail below using participants’ direct quotations as data extracts to demonstrate the themes. Some extracts overlapped across several themes. The participants’ responses from the discussions were not changed. Therefore, any grammatical or unusual wording is an accurate reflection of what the participants said during the discussions. The author chose these specific extracts based on their significance to the main themes and sub-themes.

***Physical Burden***

This theme explores the perceived physical burden when providing care for a person with dementia, which had a powerful impact on the caregiver’s physical health. Participants described that, as the person’s condition deteriorated, they required constant care that was both physically demanding and challenging. Interestingly, most of the focus group and interview participants stated that caring for people with dementia took more effort than looking after a newborn baby.

*Sometime she thinks she is in pain.. so those days would be really miserable. It’s like having a baby, looking after a baby. That you have to change her nappies, feed her, you know you need to do everything for her. That is what physically becomes very difficult. (Participant 2, female)*

The caregivers described that they constantly needed to be with their relatives with dementia and that their lives became a lot more restricted as a result. The participants described their typical days spent caring as tremendously busy, full of fatigue and worry, and involving difficult and often simultaneous tasks. During the interview, one caregiver emphasised the difficulties of dealing with her husband’s incontinence and managing his personal hygiene on a daily basis.

*Every day three times at least I have to clean him. He cannot say when he needs to go for toilet. Time to time I check on him if he needs to go to the toilet. So, in 24 hours I have to clean him two or three times. I have to clean everything, including his clothes, bedsit, carpet, etc. He is heavy; I cannot move him alone sometimes. This is the main problem. (Participant 3, female)*

Half of the caregivers interviewed were suffering from various health issues themselves and lacked the physical strength to continue their caring duties. Caregivers stated that their relatives with dementia required heavy care, involving lifting and physical care, which resulted in strain and physical injury for two caregivers. A wife who was a caregiver, as quoted above, genuinely wanted to provide care for the person with dementia, with whom she shared her entire life. Although she was not suffering from dementia, she was ageing at the same time, as well as lacking the physical strength to provide care. In addition, some participants described that they were deteriorating physically by providing care for their relatives with dementia.

*I have many health problems. I have diabetes, cholesterol, and high blood pressure… this increased for my heavy caring duties for my mother. (Participant 1, male)*

Participants described that because of their complex caregiving tasks they did not get enough sleep at night. Night-time disturbances were common among the persons with dementia, and the caregivers had to stay awake with them. One male caregiver said that his mother’s bed was next to his bed where he slept with his wife, so that he could keep his eye on her.

*My mother needs 24 hours constant care. She sleeps in the same room we husband and wife sleep. Because we cannot keep her in a separate room, it is not possible, anything bad can happen to her anytime. (Participant 1, male)*

Sleep deprivation left caregivers feeling exhausted and another caregiver was given sleeping pills by her doctor. However, she did not want to take the sleeping pills in case anything happened to her husband while she was asleep.

***Psychological Burden***

Some caregivers described how they lost their relatives through dementia. Typically, in an earlier life stage the parent had been the head of the family; they had provided their family with protection and were the principal sources of emotional support for caregivers. Now their roles had been reversed. One caregiver explained that by providing physical and psychological support, she became the mother of her mother with dementia.

*Which really upsets me, you know, as a daughter, because this is the person I used to seek for my comfort. And that person is not there anymore, I lost that person. When you have a problem, you go and tell your mom, but we can’t do it anymore. Because our mom doesn’t understand, our real mom, the person herself is not there anymore. She is a very different person now. (Participant 2, female)*

However, one of the participants reported adopting a more practical, rather than emotional, approach in their role as a caregiver. Specifically, this individual was more likely to deny or cover up any emotional or psychological issues; however, this approach did not necessarily imply that she lacked interest in caring for her father, who had dementia. Rather, she seemed to manage her emotions, which reportedly helped her cope with her father’s condition.

*Umm… (long silence) I don’t know, I’m OK with it. I had to deal with it, I am not an emotional person. I am not sure about my other family members. I know some people find it kind of heartbreaking to see him like that. But I mean, I don’t know, I don’t get anything like that. (Participant 13, female)*

Caregivers who delivered long hours of care continuously over a prolonged period of time had higher levels of stress. One spouse carer described her frustration because she was under tension and stress 24/7 due to looking after her husband. Moreover, the caregivers were particularly concerned about the possibility of the persons with dementia getting lost or putting themselves at risk by, for example, leaving the gas fire on in the kitchen. Some caregivers experienced that on multiple occasions: the person with dementia disappeared from the house when they found that the doors were open. As a result, the caregivers were frustrated, and they had to be vigilant 24/7 in case the people with dementia got lost or started a fire.

*Oh yes, of course, we are annoyed after doing all the hard work. Looking after older people dementia, husband, children, cooking, cleaning etc. are very difficult for a single person. It is not possible keep an eye on everybody, make everybody happy. (Participant 8, female)*

Although agency carers used to come and do the cleaning tasks, most caregivers interviewed stated that they had to stay with the person with dementia while the agency carer cleaned them. The caregivers feared that, due to lack of cultural and religious knowledge, the agency worker would not clean the person with dementia in an appropriate way in line with the caregivers’ cultural standards and values, for example washing their private areas with water rather than wiping with tissue paper or wet wipes. This put greater pressure on the caregivers.

*First, it was not OK. Then I had to ask how they should do it. And eventually they did it. Because they used to use only wipers to wipe. They didn't use water. But if you use water after wipe; that cleans much better. They need to understand each culture. (Participant 6, male)*

One caregiver described that her father with dementia lost the ability to speak English after he was diagnosed with dementia and this caused her extra stress. Another caregiver explained that the final stages of caregiving for his mother with dementia created a unique psychological challenge for him. His caring duties came to an end when his mother died. Losing a parent to dementia was an excruciating experience for him, and the death of his mother had a profound impact on his personal life. Following his mother’s death, he underwent months of loneliness, depression, despair, grief, and loss.

*I was very much devastated by my mother’s dementia condition. I thought no way I could cope with my mother’s condition. I could not my mom go through dementia. When she was suffering from severe dementia and when she died, I was very depressed for three months. I could not do anything. (Participant 6, male)*

*The Risks of Marital Breakdown*

Out of the 15 participants, three were male caregivers and were married with children. One of the male participants had recently got married. All the male caregivers and their families lived in the same household as the care recipients with dementia.

*We’re newly married, I don’t want to give her the burden of my father. Because she would think, ‘What is going on? I have come to your house and now I have got all the burden from your family already’. (Participant 5, male)*

Two of the three caregivers had complex relationships with their wives. The caregivers felt uncertain about their future marital statuses and this led them to experience distress while they were performing their caring duties. The caregivers dreaded that excessive caring duties for the people with dementia would result in frustration and the inability to maintain their marital relationships with their wives. In addition, the lack of time the caregivers had for themselves and their wives had severely affected their married lives. The caregivers described their overwhelming caring duties and that, because of the lack of intimacy, their wives found it difficult to stay with them. Consequently, two caregivers’ marital relationships deteriorated over a period of time and they feared marital breakdown.

*My marriage was almost going to break down. But because of our culture and religious background, my wife… understood what was going on. But I don’t know what will happen in the future in our community. (Participant 6, male)*

The quotations above demonstrate that there was not only a lack of caring attitudes from the caregivers’ wives, but two wives felt threatened by their husband’s caring relationship with the person with dementia. Although the male caregivers’ enormous caring duties decreased the scope for maintaining intimate husband–wife relationships, that did not prevent the caregivers from continuing their caring responsibilities for their relatives with dementia.

On the other hand, female focus group caregivers critically reflected on their experiences that their husbands were uncooperative, negligent, and unhelpful. The husbands’ impact on their experiences had manifested in the caregivers’ portrayals of the meaning of ‘good husbands’, and the caregivers stated they would cope well with their caring duties if they had good husbands.

*Majority of men in our culture do not look after their wives… If wife becomes ill, a brain stroke, dementia, if a husband helps his wife in that difficult time then he is a good husband. (Participant 11, female)*

As mentioned above, most caregivers also perceived that their husbands appeared to hold a steady and negative attitude towards caregiving roles. They said most men do not hold the same caregiving ideologies as women do; none of the female caregivers seemed to have these expectations from the male members of the Bangladeshi community.

*No problem for a wife looking after her husband with dementia. But husband looking after his wife with dementia will be very difficult and marriage will break down. (Participant 14, female)*

Caregivers explained that their current physical and emotional strains were associated with old age, gender issues, their greater carer burden, being busy, and fatigue. In addition, many caregivers reported that they were suffering from functional decline, which profoundly affected their ability to perform caring duties for their family members with dementia. The caregivers also expressed frustration as they continued their caring duties despite their physical strains.

*We women are going through many physical problems, yet we have to do all caring duties in the house. (Participant 9, female)*

Expressions of burden differed from person to person and the intensity of burden that the caregivers experienced in their daily lives often resulted in physical and mental burnout.

*Stereotyping Attitudes from Service Providers*

The caregivers experienced frustration and conflict with the staff from the local authority social services, which placed a greater psychological strain on them. The stereotyping of particular ethnic minorities was perhaps the most significant factor that impacted the ability of Bangladeshi caregivers to fully access health and social care services. Some participants explained that their perception of the local authority’s intentional discrimination and racism against them as Bangladeshi caregivers was the key reason for their negative attitude towards healthcare services. One caregiver expressed her frustration, anger, and fear as she had to contend with discriminatory and stereotyping attitudes from the benefits office staff members on a regular basis. The caregiver felt that being a Bangladeshi ethnic minority who was in receipt of unemployment benefits, as well as living in supported housing, contributed to the perspective that harsh judgements about her caring role were being made by the staff members at the local benefits agency office. At times, the caregiver felt unsupported and unappreciated as the staff from the benefits office undermined her caregiving role for her mother with dementia.

*Most benefit office staff don’t know what dementia is. I told them I’m a 24-hour carer for my mother with dementia. You know the lady in the benefit office was so rude to me, she said, ‘I don’t care if you’re a dementia carer’. They also said, ‘your mother got dementia, so what then?’ They asked me, what I am going to do when my mother has died? (Participant 2, female)*

As a result of being frightened and experiencing the anger and shame of being racially harassed by the staff members at the local benefits agency office, she turned down social support for a few weeks.

*I was horrified and so upset by the benefit people’s attitude towards my mom and me. How can they say that what will I do when my mother dies. This is why I hate going to them, I hate. You know, I hate to take that benefit money. […] It is just because I’ve got mom with dementia and I’ve got three younger children. I don’t have any other option, I’m so embarrassed, so upset. (Participant 2, female)*

Another caregiver, who had been caring for her husband for an extended period of time, experienced similar stereotyping situations. She mentioned that she was dissatisfied and angry with how hospitals and councils reacted. This was not a one-off experience, but rather a record of several experiences.

*Hospital does not give me more than two pads for my husband per day. If I asked more they said government is not giving more. Hospital upsets me many times this way. Their behaviour I don’t like, they are not treating us well. Social workers came and shouted on me one day. Social workers said they would provide care one hour in the morning and one hour in afternoon. But they actually provide half an hour. (Participant 3, female)*

Two further caregivers also reported fears of racial discrimination and hostility from social workers working with the Bangladeshi community. Participants felt that they did not get the practical support they needed from the government. The caregivers recognised the difficulty of distinguishing between racial discrimination and inability to meet their expectations.

*I was very angry that day. I told the social workers I will sue you. Social carers getting money for providing care for my mother but when they come to my house they asked me to do all the work for them. They are not doing their jobs properly, they are not treating us equally as white people. (Participant 10, female)*

This type of perceived racial discrimination acted as a barrier to accessing healthcare services. The following caregiver quotation describes racism from the hospital that prevented her from asking for further services from any hospitals.

*Can you imagine that agony I was going through for my dad? Three times he fell out of bed, one day he left on the floor for 9 hours. It’s discrimination against minority people. These are the people the nurses would target. Its more about your right. They are such a bully there in X Hospital. The nurses will intimidate you in the hospital. Not only my mother, I would not put anybody in there. I would not want my children to put me there, I wouldn’t want to go there. (Participant 12, female)*

However, some caregivers interviewed in a coastal city spoke highly of the service providers and they also appreciated the support delivered by hospital doctors and the reassurance they offered to caregivers and to their relatives with dementia.

*Doctors and hospital, they are very good. They helped me so much. Because every time I took him to the hospital they helped me lot. (Participant 5, male)*

***Socioeconomic Burden***

There are substantial social and financial effects associated with providing care to a person with dementia. Many of the caregivers interviewed described that their caring responsibilities restricted their social lives.

Most of the caregivers interviewed stressed that they were apprehensive as a result of their financial difficulties and social disadvantages. All but one of the caregivers experienced unique employment challenges while trying to maintain a balance between their employment and full-time caregiving responsibilities. Two of the caregivers had worked full-time up to two months before their relatives were diagnosed with dementia. One caregiver had never had paid work. One caregiver left his well-paid job and became a taxi driver. Driving a taxi fitted around his caring role for his mother with dementia.

*Money was a big problem for me. Because I had to leave my well-paid job. I left my job for my mother’s dementia and jumped into a taxi job. (Participant 6, male)*

Two other caregivers also reduced their hours of work because of their heavy caring responsibilities.

*But it is extremely hard for me. I have to go to work at 5 o’clock in the morning. I asked caring agency for a carer to look after my dad while I go to work. (Participant 5, male)*

For one caregiver, after leaving her job entirely, the caregiver’s benefit was her only source of independent income. However, the weekly benefit she received was not enough for her average household expenses and the extra costs her three children incurred. Therefore, she had to cut back on some expenditures as she was unable to meet her children’s basic needs.

*It’s a struggle. I only get £60 weekly carer’s benefit, which is not much. I have got three children, the bills and the expenses for the children. They need more things, they want to do more activities. Sometimes I have to say no to them. I cannot afford that. So financially this not only affects me, affects them too. (Participant 2, female)*

Although some caregivers acknowledged the major financial strain that accompanied their caregiving responsibilities, the following caregiver did not express any financial pressures due to her parents’ financially solvent situation. Instead, financial stability gave them the freedom to purchase their own commodities.

*We have no financial problems because my father suffers from dementia. If he needs incontinence pads and stuff like that we buy it because he uses different types. It has never been a problem. (Participant 4, female)*

# Discussion

Several recent studies have investigated the negative consequences of caregiving, such as strain and burden. Evidence suggests that despite a sense of homogeneity among all BAME groups, they experience caregiving differently (Hossain et al., 2018). Even with the increased caregiving literature, there is still a dearth of research on the effects of caring for a person with dementia on Bangladeshi caregivers. Consistent with previous studies, Bangladeshi caregivers in this study demonstrated that dementia caregiving has placed greater pressure on their health and well-being. Current findings suggest that Bangladeshi caregivers were perhaps more resilient to the negative physical, psychological, and economical effects of the excessive caregiving burden than other BAME carers. This study highlights that Bangladeshi caregivers approach caregiving differently from other BAME groups, adopting more of a religiously appropriate person-centred care. Caregivers exhibited a strong sense of family obligation, religious beliefs, and interpersonal motives to provide care for their relatives with dementia at home. Caregivers appeared to accept and take for granted expectations to fulfil challenging caregiving roles. A scarcity of culturally and religiously sensitive resources for the needs of Muslim patients meant that Bangladeshi caregivers were more likely to provide direct care themselves rather than receiving care from service providers. Sending an older family member with dementia to a residential care home was neither a solution nor a preferred option.

Although there is abundant evidence of poor health outcomes for BAME people, compared to their White British counterparts (Evandrou, Falkingham, Feng, & Vlachantoni, 2016), there has yet to be any published studies on institutional racism as a determinant of ethnic minority carers accessing mainstream healthcare services. The caregiver’s socioeconomic status and perceived institutional racism towards them are intertwined with the carer’s and person with dementia’s health and well-being because institutional behaviour determines access to healthcare and other resources. Much of the available evidence reveals there is an increasing level of racism towards many ethnic minority elders and their carers in Britain and America (Karlsen & Nazroo, 2002; Nazroo, 2003; Russell, Clavél, Cutrona, Abraham, & Burzette, 2018). Although experiences of disadvantage and racism are common among BAME carers, significant differences were revealed in this study in terms of dementia caregiving among Bangladeshi socioeconomically disadvantaged caregivers. Consistent with previous studies (Karlsen & Nazroo, 2002; Yin, 2018), our findings have also confirmed that institutional racism can add extra strain and affect the quality of life of caregivers in many ways, but Bangladeshi caregivers in particular may well be socially excluded as service users because of a shortage of religious facilities in the healthcare services as well as a lack of adequate understanding of the religious requirements of the Bangladeshi Muslim community.

The results of this study will provide an understanding to service providers, policy makers, and researchers of the ways in which dementia and family caregiving are experienced in the Bangladeshi community and why they have remained unreported within the broader BAME communities. Previous research on the experiences of family carers of people with dementia in BAME communities delivered practical understandings of the position of women in households, for example daughters-in-law (Godfrey & Townsend, 2001; Hossain et al., 2018; Hossain & Khan, 2019). However, this research also provided insight into the role of males as family carers and their experiences maintaining their marriages while still shouldering the burdens of full-time, complex caregiving roles. A thorough analysis of this current research postulated not just new knowledge about Bangladeshi daughters-in-law who have shifted their roles, but also, for the first time, the results revealed Bangladeshi women’s autonomy in caregiving decision-making, and its acceptance by their husbands. The shifting role of women, from being traditional daughters-in-law to decision-makers, has allowed them to choose not to be dementia family carers for their Bangladeshi parents-in-law, which has consequences, significance, and validity within the Bangladeshi community as well as in the South-Asian immigrant community and other BAME immigrant communities.

# 

# Implications for Policy and Family Practice

The implications of this study for policy and family practice are explored through clarification of the tensions in Bangladeshi caregivers’ responses to family caregiving for their relatives with dementia. Some of the disputes developed in the current study may be transferrable to BAME family caregivers in the United States, some issues are related to people with dementia and their family caregivers, and others echo with previous research on ethnic minority groups’ general barriers to accessing health services. The results of the current research have important implications for any health and social care service providers working with BAME people with dementia and their family carers. The overall findings revealed that there is a lack of appropriate care for Bangladeshi people with dementia and their family carers living in Britain. Although the current study’s findings and recommendations refer to Bangladeshi caregivers in Britain, they may be relevant to healthcare professionals working with Bangladeshi communities in America. Despite the differences between the British and US healthcare systems and cultural values, knowledge, and understanding of dementia, caregiving burden and coping strategies amongst Bangladeshi family caregivers are transferable between these countries. Health and social care providers should have professional training regarding Bangladeshi Muslim culture, beliefs, and lifestyles when they work with the Bangladeshi immigrant community and they should consider how this affects their consultations and advice to family carers. Relevant healthcare staff should be given colloquial Bengali language training or be provided with interpreters through clinic-based link workers.

# Strengths and Limitations

There were a few limitations in this study and future research on Bangladeshi caregivers may expand on these areas. First, the study was small and geographically restricted in such a way that results may not be generalisable to the population of family caregivers as a whole. The study was not carried out all over the UK and therefore lacked the views of Bangladeshi caregivers outside of the research settings. Sampling issues are a key problem in research involving South-Asian people with dementia and their family caregivers. Historically, South-Asian immigrants have been a closed group in the UK (Bowes & Wilkinson, 2002). Samples are limited by relatively low response rates. Despite these limitations, the current study has some significant strengths. This study is the first to investigate the impact of dementia caregiving among Bangladeshi caregivers using a nationally representative sample from two different large cities in Britain. Most previous studies in this area relied on broad BAME groups rather than a single BAME group. The findings will be applicable outside of the context of the research setting, with implications for other Bangladeshi caregivers, their families, and healthcare professionals.

# Directions for Future Research

Future research should recruit a larger number of participants from more diverse areas of the UK. Since this is the first qualitative study among the Bangladeshi caregivers in the UK, there is no doubt that policymakers, practitioners, and the wider BAME community should expect to see many further studies within this community that examine their various caregiving needs based on their religious needs. Future research can build on this current research, which identifies a clear path to improving caregiving experiences by promoting a religiously appropriate, dementia-friendly atmosphere for Bangladeshi people in Britain and the US. Caregiving accountability among Bangladeshi families does not necessarily replicate the reality of White British or European families; instead, there is an assumption that they tend to look after their own family (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004). There is scope for a research plan that can explore how a carer’s gender role ideology is associated with the carer’s burden and strain. Are same-sex carers keener to accept the roles of family carers and are opposite-sex carers more reluctant to be family carers of their relatives with dementia? While gender-based caregiving interferes with Islamic religious ideologies, further research will benefit from investigating how Bangladeshi Muslims’ religious values influence experiences of caring for a person with dementia and how their religious beliefs affect their access to and experience of dementia care services.

# Conclusion

Dementia caregiving has a negative impact on the lives of Bangladeshi caregivers of people with dementia. However, some caregivers feel positive about their role. Current study findings reinforce the importance of assessing the needs of caregivers who provide care for relatives with dementia. Help-seeking should be initiated during the early stages of dementia to minimise the negative impact of caregiving on caregivers’ health. In addition, service providers should provide religiously appropriate support for caregivers during the period immediately after the diagnosis of dementia. Like other BAME caregivers, Bangladeshi caregivers of relatives with dementia, particularly caregivers with a low socioeconomic status and no caregiving assistance from others, are more likely to feel burdened in the caregiving role. Interventions for Bangladeshi caregivers should be aimed at increasing the caregivers’ religiously appropriate social support. Moreover, providing religiously appropriate services may increase positive feelings among caregivers about sending their relatives to a care home or a day-care centre, resulting in less strain on caregivers as a result of their caregiving roles.

As the BAME population and dementia prevalence continue to surge in Britain and the US, more qualitative research is needed to investigate and better understand cross-cultural differences in the impact on carers of dementia caregiving issues. Therefore, the findings gained from this study have clear and important implications for other BAME populations, Caucasian caregivers, and the healthcare professionals supporting these communities. It is important for healthcare providers to recognise the roles that ethnic, cultural, and religious identities can have in perception of dementia and how that can affect caregivers in help-seeking and coping with the caregiving burden. Future research needs to contextualise findings within the evidence base so that its results can lead to meaningful implications for practice and policy.

# Acknowledgements

The author would like to thank all the caregivers who have contributed to this study.

# Declaration of Interest Statement

The author reports no conflict of interest.

# References

Alhojailan, M. I. (2012, 2012). Thematic Analysis: A critical review of its process and evaluation.

Alzheimer's Research UK. (2013). Types of dementia.

Alzheimer's Research UK. (2019). Perceptions of dementia. Retrieved from <https://www.dementiastatistics.org/statistics/perceptions-of-dementia/>

Botsford, J., Clarke, C. L., & Gibb, C. E. (2011). Research and dementia, caring and ethnicity: A review of the literature. Journal of Research in Nursing, 16, 437-449.

Boyatzis, R. E. (1998). Transforming qualitative information : thematic analysis and code development.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Brownlie, J. (1991). A hidden problem? : dementia amongst minority ethnic groups. Stirling: University of Stirling.

Bryman, A. (2012). Social research methods: OUP Oxford.

Eland-Goossensen, M. A., Van-De-Goor, L. A. M., Vollemans, E. C., Hendriks, V. M., & Garretsen, H. E. L. (1997). Snowball sampling applied to opiate addicts outside the treatment system. Addiction Research, 5(4), 317.

Evandrou, M., Falkingham, J., Feng, Z., & Vlachantoni, A. (2016). Ethnic inequalities in limiting health and self-reported health in later life revisited. Journal of Epidemiology and Community Health, 70(7), 653. doi:10.1136/jech-2015-206074

Garbin, D. (2005). Bangladeshi Diaspora in the UK:some observations on socio-cultural dynamics, religious trends and transnational politics. Human Rights and Bangladesh.

Godfrey, M., & Townsend, J. (2001). Caring for an Elder with Dementia: The experience of Asian caregivers and barriers to the take up of support services. Leeds: Nuffield Institute for Health, University of Leeds.

Hossain, M., Crossland, J., Stores, R., Dewey, A., & Hakak, Y. (2018). Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. Dementia, 1471301218800641. doi:10.1177/1471301218800641

Hossain, M. Z., & Khan, H. T. A. (2019). Dementia in the Bangladeshi diaspora in England: A qualitative study of the myths and stigmas about dementia. Journal of evaluation in clinical practice.

Hossain, M. Z., & Khan, H. T. A. (2020). Barriers to access and ways to improve dementia services for a minority ethnic group in England. J Eval Clin Pract. doi:10.1111/jep.13361

10.1111/jep.13361.

Hossain, M. Z., & Mughal, F. (2020). Dementia and revivalist Islam: new perspectives and approaches to understanding dementia and tackling stigma. Journal of Evaluation in Clinical Practice. doi:<https://doi.org/10.1111/jep.13412>

Hossain, M. Z., Stores, R., Hakak, Y., Crossland, J., & Dewey, A. (2019). Dementia Knowledge and Attitudes of the General Public among the Bangladeshi Community in England: A Focus Group Study. Dementia and Geriatric Cognitive Disorders, 48(5-6), 290-296. doi:10.1159/000506123

Hossain, M. Z., Stores, R., Hakak, Y., & Dewey, A. (2019). Traditional gender roles and effects of dementia caregiving within a South Asian ethnic group in England. Dementia and Geriatric Cognitive Disorders, 48(5-6), 330-336.

Karlsen, S., & Nazroo, J. Y. (2002). Agency and structure: the impact of ethnic identity and racism on the health of ethnic minority people. Sociology of Health & Illness, 24(1), 1-20.

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. Health & Social Care in the Community, 12(5), 398-406. doi:10.1111/j.1365-2524.2004.00509.x

Khan, O. (2015). Dementia and Ethnic Diversity: Numbers and Trends. In J. Botsford & K. Harrison Dening (Eds.), Dementia, Culture and  Ethnicity :  Issues for All. London and Philadelphia: Jessica Kingsley.

Luengo-Fernandez, R., Leal, J., & Gary, A. (2010). Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom. A report produced by the Health Economics Research Centre for the Alzheimer's Research Trust. Oxford: Health Economics Research Centre, University of Oxford.

Milne, A., & Chryssanathopoulou, C. (2005). Dementia Care-giving in Black and Asian Populations: Reviewing and Refining the Research Agenda. Journal of Community & Applied Social Psychology, 15(5), 319-337. doi:10.1002/casp.830

Nazroo, J. Y. (2003). The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. American journal of public health, 93(2), 277-284.

Oecd. (2012). Bangladesh.

Office for National Statistics. (2001). Census 2001. London: HMSO

Office for National Statistics. (2013). Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid-2011 and Mid-2012. Online: Office for National Statistics Retrieved from <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/index.html>

Patel, V. V., Rajpathak, S., & Karasz, A. (2012). Bangladeshi immigrants in New York City: a community based health needs assessment of a hard to reach population. Journal of immigrant and minority health, 14(5), 767-773. doi:10.1007/s10903-011-9555-5

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., . . . Salimkumar, D. (2014). Dementia UK: Update. Retrieved from London: alzheimers.org.uk/dementiauk

Regan, J. L., Bhattacharyya, S., Kevern, P., & Rana, T. (2012). A systematic review of religion and dementia care pathways in black and minority ethnic populations. Mental Health, Religion & Culture, 16, 1-15.

Russell, D. W., Clavél, F. D., Cutrona, C. E., Abraham, W. T., & Burzette, R. G. (2018). Neighborhood racial discrimination and the development of major depression. Journal of abnormal psychology, 127(2), 150-159. doi:10.1037/abn0000336

Sayegh, P., & Knight, B. G. (2013). Cross-cultural differences in dementia: the Sociocultural Health Belief Model. International Psychogeriatrics, 25(4), 517-530.

Sunder, D., & Uddin, L. (2007). A Comparative Analysis of Bangladeshi and Pakistani Educational Attainment in London Secondary Schools. InterActions: UCLA Journal of Education and Information Studies, 3(2).

Truswell, D. (2014). Black, Asian and Minority Ethnic Communities and Dementia–Where Are We Now. J Alzheimers Dis Parkinsonism, 4(152), 2161-0460.

Wilkinson, H. (2002). The perspectives of people with dementia : research methods and motivations. Philadelphia, PA: Jessica Kingsley Publishers.

Wilkinson, H., & Bowes, A. (2003). Innovative methodologies - can we learn from including people with dementia from South Asian communities? Research, policy and planning: the journal of the Social Services Research Group, 21, 43-54.

Yeandle, S., Bennett, C., Buckner, L., Shipton, L., & Suokas, A. (2006). Who Cares Wins: The Social and Business Benefits of Supporting Working Carers. Centre for Social Inclusion, Sheffield Hallam University: Carers UK.

Yin, P. (2018). Racism and Indigenous Health. In: Oxford University Press.