Manuscript title:
Traditional gender roles and effects of dementia caregiving within a South Asian ethnic group in England

Running title:
Gender roles and dementia caregiving in a South Asian group

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Abstract

Background: Despite the integral role that women play in the care of older adults in South Asian families, limited empirical data are available on the impact of migration from South Asia to England. The purpose of this research was to examine caring for a family member with dementia from a gender role perspective.

Methods: Data were gathered in two phases: 1) focus groups and 2) semi-structured interviews. Focus groups were held with the general public and semi-structured interviews were conducted with family carers. Data were audio-recorded and analysed using thematic analysis. The NVivo qualitative software was utilised to simplify the thematic analysis.

Results: While traditionally family care for frail older adults has been mainly provided by women in South Asian families, this study's samples revealed how women's attitudes towards caregiving are changing in British societies.

Conclusion: There remained a dearth of research about socioeconomic transformations in South Asian women's migration to Western countries which could contribute to deterring them from providing family care. More research is warranted to understand the ways in which migration shapes gender relations in the South Asian families and its impact on care for the frail elderly.

Keywords: dementia, caregiving, gender, ethnic minority, south asian, migration

Introduction

A recent qualitative systematic review indicates that there is no such word for the meaning of 'carer' in South Asian language [1]. Traditionally caring duty falls to the younger family members in the household especially daughters-in-law or unmarried daughters in South Asian community. There is an abundance of literature on South Asian daughters-in-law who are the main caregivers and obliged to look after their husbands' relatives [2–10]. Even outside the South Asian communities, recent trends showed that overall caring duties from daughters-in-law increased [11]. Furthermore, analyses of the British General Household Survey data revealed caring was a major

part of women's gender roles and any justifications were considered inappropriate when they failed to provide care [12]. However, there is a dearth of relevant literature on South Asian women transformations of womanhood through migration. There have been opposing ideas about cultural and religious obligations of care towards South Asian elderly population in the UK [13]. In this study, authors challenge the previous research which was based on a common assumption that contemporary daughters-in-law are ready to meet the needs of older people with dementia, which may not be true. There is a paucity of research about the challenges experienced by South Asian male caregivers in their changing caregiving roles simultaneously for the elderly relatives with dementia and its influence, negative or positive, on daily living experiences.

Aims

The current study aims to highlight the ways in which migration challenges and reshape gender-based arrangements related to caring for the elderly and the frail within the Bangladeshi ethnic minority community.

Methods

The current study utilised qualitative methods to collect data, firstly using focus group discussions to explore Bangladeshi immigrants' experiences and perceptions of caring for people with dementia, followed by one-to-one semi-structured interviews with Bangladeshi family carers of people with dementia. Purposive and snowball sampling were used to collect data from the carers and general public of the Bangladeshi community. General public attended focus groups (n = 21) and individual qualitative interviews (n = 6). living either in Portsmouth and London.

Data collection

Focus groups and individual interviews were conducted in a non-directive means conferring to topic guides with open-ended questions. These qualitative methods allowed 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. These approaches were

appropriate to explore complex personal narratives and experiences of accessing services for ethnic minority people [8].

Data analysis

Braun & Clarke's [14] thematic analysis was used to analyse the data. Both a manual and a computer assisted analysis software NVivo were undertaken. The data collected from both focus group discussions and semi-structured interviews were subjected to inductive thematic analysis that incorporated the realities of Bangladeshi community members' gender specific experiences of caregiving to try to reach a better understanding of the phenomena explored. Thematic analysis delivered an efficient component to data analysis that allowed authors to extensively understand the phenomena under investigation.

Results

The data were organized into four following broad themes:

Perceptions of caregiving

Male participants overwhelmingly expressed that caregiving is a female duty. The male participants explained that culturally, Bangladeshi women are expected to be hushed, obedient, and subservient to the senior members of the family, including husbands, parents, and parents-in-laws; they should also be caring to the children. The following excerpt from a male participant echoes the perceptions and attitudes toward women's gender roles in caring duties.

> *We rely on most of the moms or ladies of the houses in the Bengali communities. This is my view. My wife looks after my son, my wife looks after me, and she would look after my parents as well as (look after) her parents plus my pets. (Man, 76 years)*

Participants perceived that women did not have any choice regarding their caring duties, which were culturally assigned behaviours and expectations based on their gender. When the participant quoted above was asked to clarify his statement, as it seemed women hold many roles within the household, the participant stressed that

this was normal and that most people who were born and brought up in Bangladeshi community had this expectation that women would take on the caregiving role.

Five out of nine female participants also perceived that their husbands appeared to hold steady and negative attitudes toward caring roles. They said that the majority of the male members of the Bangladeshi community in the UK do not hold the same caregiving ideologies as female participants do; none of the female participants seemed to have these expectations from the male members of the Bangladeshi community.

> *No problem for wife is looking after her husband with dementia. But husband looking after his wife with dementia will be very difficult. (Woman, 55 years)*

Despite the burdens and strains of caring, many participants described how they were performing this hard work around the clock, and that sometimes they did not even receive any appreciation from their husbands or from others in the family. As a consequence, the perception of caring for a person with dementia regrettably seems to add to women's subjective burden of caring-related strain, which is already being experienced by family carers of people without dementia and their families.

Denial of caregiving role

Previous theme highlighted that women were under intense pressure to provide care for the older family members, however, while excessive caring duties led a deterioration in their marital relationships, male caregivers came under pressure from their wives to save their marriages. Notwithstanding, wives had complained that their husbands had put their parents with dementia before their wives. There is a wide range of possibilities on the denial of caregiving for the parents-in-law from the current study's sample of daughters-in-law. Current study found that despite women were the main sources of care at home, women work outside the home in paid employment was highly valued by their husbands. However, some women's work have challenged their availability to provide care for their parents-in-law.

> *My wife, she was working as well. That is the main reason I quit my job to care for my mom. (Man, 37 years)*

Current theme found that providing care for parents with dementia harshly penalized their sons' employment as they had to leave their well-paid jobs, but employment status appeared as an excuse for the daughters-in-law for not becoming caregivers of their parents-in-law. It seemed that husband carers appreciated that their wives were deemed unable to provide care for their parents-in-law as they were in the labour force. Therefore, on the one hand, daughters-in-laws' employment served as a justification for not providing care for their parents-in-law. On the other, sons as male caregivers' caregiving responsibilities towards their parents justified them to leave their jobs. Although as a result financial strain was harder, there was a satisfaction among the caregivers about roles. A male family carer left his well-paid job and became a taxi driver. Driving a taxi fitted around his caring role for his mother with dementia.

> *I left the job and jumped into a taxi job. Because I thought I could be more flexible with taxi job. (Man, 52 years)*

Perceived stigma in caregiving

This theme provides a detailed description of how female participants perceived stigma as a family carer, particularly of someone living with dementia, as well as how any stigma related to caregiving might affect the family carers' lives in the wider community. Fear-mongering attitudes toward being a paid carer among Bangladeshi community members prevent these individuals from taking up caring jobs in the UK. Moreover, the participants described that the wider community viewed paid carers with suspicion, which would have a broad, negative impact not only on family carers, but on their families as well:

> *Obviously, Bangladeshi paid carer is hard to find because they're ashamed of doing this job. (Woman, 39 years)*

> *There is a lot of stigmas in the community to work as a paid carer. People will start talking when carers will go over other people houses and do the caring job. That is why nobody want to be a paid carer for a dementia patient. (Woman, 46 years)*

Members of the Bangladeshi community would monitor the carers with suspicion; scepticism would arise regarding the carers' motives, and families would investigate the family carers' affection for, or mistrust their obligation toward, the people with dementia, particularly if the carer was not an immediate family member. The moral duty of caring for someone other than a family member with dementia would be judged negatively by the wider community.

Overcome the barriers to change

The participants described that changing traditional gender role attitudes and perceptions towards caregiving is difficult. They blamed Bangladeshi culture, stating that it deters them from becoming professional carers. The research findings suggest that cultural differences are indeed an influential determinant for becoming a waged carer.

> *This is our Bangladeshi culture, our mentality. We cannot deal with caring jobs for other people like English carers do. (Woman, 60 years)*

The participants said that unlike in English culture, overarching Bangladeshi society values discouraged women from applying to caring occupations. However, some participants were hopeful that the attitudes toward providing care for someone outside the family may change in the future. Stigmatizing attitudes and perceptions related to working as a paid or unpaid family carer can be significantly reduced by learning and training initiatives.

> *You would be able to do that if you had enough training for dementia caring. (Woman, 50 years)*

Discussion

Current study findings highlighted contradictory attitudes and a lack of caregiving preferences among female participants by drawing a clear line between the perceptions and reality of dementia caregiving. The findings indicate that women are being confined by pervasive traditional gender role expectations in the Bangladeshi community. To the current study's women sample, their perceptions and expectations

of caregiving are, however, somewhat paradoxical. They acknowledge, on the one hand, that their positions as decision makers are often subordinate to men, their general health and conditions as caregivers are often so difficult; on the other hand, they want to continue caring for their husbands as long as they are alive. Consistent with previous studies [2, 3, 11, 15, 16], male focus groups' participants' perceptions about daughters-in-law providing dementia care did not align with findings from the family carers' interviews, where no daughters-in-law were the caregivers of their parents-in-law with dementia. The question may arise as to why other South-Asian daughters-in-law expressed the desire, and hence provided care, for their parents-in-law with dementia when the daughters-in-law in the current study adamantly rejected the caregiving responsibility. Certainly, in alignment with other South-Asian communities, the traditional Bangladeshi community also has a pervasive preference for daughters-in-law in providing family care; however, due to modernisation, it is essential not to dismiss the influence of education and financial aspects in determining the caregiving process in Bangladeshi families in the UK.

Evidence shows South Asian women are rapidly increasing their participation in higher education and the labour market [17–19]. The current study also found that women were engaged in employment while their older family members were living with dementia, hence their inability to provide care was justified by their husbands and others in the family. Moreover, perhaps the British-born Bangladeshi daughters-in-law in this study had better education and better language skills than the Indian-born or Pakistani-born daughters-in-law in previous studies. Even though it is not uncommon, British-born Bangladeshi daughters-in-law have better education and language skills than their Bangladeshi-born husbands. It might be possible that British-born daughters-in-law declined their caregiving roles for their parents-in-law, but they extended their roles as spouses or mothers of their children or for their job responsibilities. Therefore, the assumption should not be made that the experience of other South Asian daughters-in-law is applicable to Bangladeshi daughters-in-law in the UK. More empirical research is needed to understand the complex relationships among Bangladeshi daughters-in-law, their husbands, parents-in-law, and their perceived gender roles and burden related to family caregiving.

Conclusion

The current study explored gender expectations of roles and changing roles of male and female carers and how these roles sustained and shaped their life conditions within the Bangladeshi community in England. Older Bangladeshi males primarily turn to female family members to receive support and care. Traditionally, men have higher expectations that women should provide family care, which might not be possible given their busy lives and the demands of living in a modern society like Britain. The government should take further steps to educate ethnic groups to break down gender stereotypes and encourage them to share their caregiving tasks. There is a necessity to broaden the discussion about gender equality within the Bangladeshi families. There is also a need to discuss the reality that South Asian women who were born and raised in Britain cannot avoid being influenced by British values. Although the culture, religious beliefs, and values of individual Bangladeshi communities should be respected and promoted, these are dynamic constructs that change across time. There is a need to hold sensitive discussions and debates about these factors under circumstances where they can be addressed in such a way that does not undermine Bangladeshi culture; rather, these discussions should highlight the importance and changing nature of these constructs to better inform care practices.

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Statement of Ethics

Full ethics approval was obtained from the University of Portsmouth. The main principles that were considered included obtaining informed consent, protecting the participants, and ensuring participant confidentiality, anonymity, and safety.

Disclosure Statement

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Authors contributions

Two authors (MH & YH) collected the data; the first author performed the data analysis and interpretation and writing of the manuscript. All authors read and approved the final manuscript.

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