Caregiver Strain Among Dementia Caregivers in Bangladesh: An Assessment Using the BRICSI

By

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Declaration

It is hereby declared that

1. The thesis submitted is my/our own original work while completing degree at Brac University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.
4. I/We have acknowledged all main sources of help.

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Approval

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Ethics Statement

This project does not involve any kind of animal and human trial

Abstract

This study investigates the multifaceted strain on caregivers of individuals with dementia in Bangladesh, a lower-middle-income country (LMIC). Using the Benjamin Rose Institute Caregiver Strain Instrument (BRICSI), a quantitative survey assessed four domains: Caregiver Mastery, Relationship Strain, Health Strain, and Social Isolation. Results revealed significant challenges—32.1% reported uncertainty in caregiving (low mastery), 39.3% felt manipulated by care recipients (relationship strain), and 41.1% experienced physical health decline. Clinical risk scores were high, with 48.2% for health strain (>10) and 28.6% for mastery (>8), especially among low-income urban female carers. These findings emphasize the urgent need for targeted support, including stress management and social support programs. The study highlights the link between caregiving demands and caregiver well-being, calling for LMIC-focused policies to address systemic support gaps (Cahill, 2020; Naheed et al., 2023). Although based on a small sample, the study contributes to global dementia care research and calls for further exploration.

Keywords: Dementia, Caregiver strain, Bangladesh (LMIC – Low-Middle Income Country), BRICSI (Benjamin Rose Institute Caregiver Strain Instrument), Quantitative survey.

Dedication

"I dedicate this work with the utmost appreciation to my parents, whose unwavering love, unending support, and innumerable sacrifices helped me along the journey."

Acknowledgement

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List of Acronyms:

BRICSI	Benjamin Rose Institute Caregiver Strain Instrument
LMIC	Low-Middle Income Country
NINS	National Institute of Neuroscience Hospital)
WHO	World Health Organization
QOL	Quality of Life

Glossary

Caregiver Strain:	The burden, stress, or negative consequences experienced by individuals who provide care to someone with a chronic illness or disability, such as dementia. This stress can show up in a variety of issues, such as financial, social, emotional, or medical difficulties.
Dementia:	A general term for a decline in mental ability severe enough to interfere with daily life. Cognitive function (which may include memory, reasoning, orienting, comprehension, calculating, learning capacity, language, and judgement) declines are its hallmark.
Intergenerational Living:	A household structure where multiple generations (e.g., grandparents, parents, and children) live together. In Bangladesh, this is a typical societal pattern.
Patriarchal Norms:	Social systems and cultural expectations in which men hold primary power and authority in the family, community, and society. These standards may have an impact on the duties and responsibilities of carers.
Psychosocial Support:	Assistance that attends to a person's social and psychological requirements. In order to promote mental and emotional well-being, this can involve social support groups, counselling, and other interventions.

Respite care is temporary assistance given to carers so they can take a break from their responsibilities. In-home care or adult day care facilities are two places where this can be offered.

Chapter 1: Introduction

1.1 Background

Alzheimer's disease is one of the top ten most debilitating disorders for the elderly, with over 60 million individuals living with it globally as of 2020 (Naseer et al., 2022). Naheed et al. (2023) found the prevalence of dementia among older adults (aged 60 years or older) in Bangladesh to be 8.0%. The majority of dementia care is provided by family members, frequently without official training or institutional resources, in a nation where family caring is still the primary means of elder support. Caregiving dynamics are shaped by Bangladesh's sociocultural fabric, which is marked by joint family systems and intergenerational living. While responsibilities are shared, this frequently results in role disputes and emotional strain. Systemic problems including restricted access to healthcare, financial limitations, and a dearth of infrastructure tailored to dementia exacerbate these difficulties. Indeed, the lack of robust health systems and psychosocial support structures in many LMICs significantly increases the burden carried by families when conditions like dementia arise (Tabassum et al., 2024). Moreover, the stigma associated with mental health in society continually deters families from getting outside help, which worsens stress and loneliness. Although the Benjamin Rose Institute Carer Strain Instrument (BRICSI) offers a strong foundation for measuring this multifaceted strain, nothing is known about how to apply it in Bangladesh's particular situation.

1.2 Research Gap:

Carer stress has been widely studied worldwide, although less is known about it in low- and middle-income (LMIC) nations like Bangladesh (Poon et al., 2020; Prince et al., 2012). The majority of the material now in publication concentrates on Western settings, where social safety nets and formal care systems lessen some of the responsibilities associated with providing care. On the other hand, Bangladeshi carers work in circumstances with limited resources, where stress is exacerbated by cultural and financial constraints. Key gaps include:

- **Cultural Nuances**: The impact of patriarchal norms and intergenerational expectations on caregiver roles.
- **Economic Vulnerability** The relationship between caring responsibilities and poverty, especially in rural areas.
- **Policy Void**: The absence of national dementia strategies, initiatives or caregiver support programs in Bangladesh, despite calls from global bodies like the WHO. This absence of national dementia strategies, initiatives or caregiver support programs in Bangladesh (Cahill, 2020).

A 2022 scoping review identified only three peer-reviewed studies have been done on dementia caregiving in Bangladesh (Ahmed et al., 2022), highlighting the urgency of localized research – a gap this study, alongside recent national prevalence work (Naheed et al., 2023), begins to address.

1.3 Objectives:

The purpose of this study is to:

1. Implement the BRICSI to assess caregivers stress among Bangladeshi carers in four domains—Mastery, Relationship, Health, and Social Isolation.
2. Determine the sociocultural and economic elements are contributing to the tension in Bangladesh.
3. Highlight the particular difficulties experienced by caregivers in Bangladesh by comparing results with statistics from across the world.

1.4 Significance:

This study has important ramifications for:

- **Policy:** By emphasizing carer needs, it will inform Bangladesh's emerging National Dementia Strategy.
- **Practice**: Assisting non-governmental organizations such as Alzheimer's Society Bangladesh and BRAC in creating culturally appropriate solutions (such community respite care).
- **Global Health**: Contributing to the discourse on caregiver strain in LMICs, where the number of individuals with dementia is expected to increase (Naseer et al., 2022; Poon et al., 2020; WHO, 2023)

This study advocates for equality in global health research by filling a critical vacuum in the literature on dementia care (Ahmed et al., 2022; Poon et al., 2020) by focusing on Bangladesh's sociocultural circumstances.

Chapter 2: Methodology

2.1 Design study

The Benjamin Rose Institute Carer Strain Instrument (BRICSI), which was translated into Bangla and validated by my supervisor to fit Bangladesh's sociocultural context, was used in this study's quantitative, cross-sectional design to measure caregivers' strain among dementia carers in Bangladesh. Data were gathered between [September/2024] to [February/2025], with a focus on four domains: Carer Mastery, Relationship Strain, Health Strain, and Social Isolation/Activity Restrictions.

2.2 Participants

Inclusion Criteria:

- Primary caregivers of individuals diagnosed with dementia (clinically verified).
- Aged 18 years or older.
- Providing care for at least six months.
- Residing in Bangladesh (urban or rural).

Recruitment:

Participants were recruited through in **National Institute of Neuroscience Hospital (NINS)**, **Alzheimer's Society Bangladesh** (a non-partnership study), and community health centers in Dhaka. To contact carers in rural areas, snowball sampling was employed.

Sample Size:

A convenience sample of **56 caregivers** was obtained, reflecting resource constraints common in low-resource settings.

Demographics:

- **Gender**: 68% female, 32% male.
- **Household Structure**: 67% from joint/extended families.
- **Income**: 62% earned <$300/month.

2.3 Data collection

Instrument:

The BRICSI questionnaire was translated into Bangla to ensure linguistic and cultural relevance.

Domains Measured:

1. **Caregiver Mastery** (Questions 1–4): Confidence in caregiving.
2. **Relationship Strain** (Questions 5–9): Conflicts with care recipients.
3. **Health Strain** (Questions 10–14): Physical/mental health decline.
4. **Social Isolation** (Questions 15–19): Reduced social participation.

Procedure:

- Surveys were filled out in person by urban participants at medical facilities.
- Due to accessibility issues, interviews with rural participants were conducted over the phone or in their home

- Google forms were used to electronically record responses

2.4 Data analysis

Statistical Tools:

- **Descriptive Statistics**: Percentages, means, and standard deviations.
- **Score Calculation**: Domain scores (e.g., Mastery = sum of Questions 1–4).
- **Risk Thresholds**: Scores exceeding clinical benchmarks (Mastery >8, Health Strain >10) were flagged.
- **Software**: Microsoft Excel

Cultural Adjustments:

- Open-ended questions captured somewhat insights on stigma and familial pressures.
- Scores were contextualized using Bangladesh-specific poverty and healthcare access indices.

2.5 Ethical considerations

- **Informed Consent**: Participants provided verbal/written consent; anonymity was ensured.
- **Compensation**: No monetary incentives to avoid coercion.

2.6 Limitations

1. **Sample Size**: Small sample (n=56) limits generalizability also accuracy.

2. **Selection Bias**: Urban overrepresentation due to accessibility.

3. **Self-Report Bias**: Subjective reporting of strain

Chapter 3: Caregiver Mastery

3.1 Caregiver Mastery

This domain evaluated caregiver's confidence in providing adequate care. This domain evaluated caregiver's confidence in providing adequate care. Key findings from Bangladeshi caregivers have revealed that:

- **Uncertainty in Care Practices**:
    - 32.1% (n=18) felt *uncertain about caregiving methods* (Question 2).
    - 25% (n=14) doubted if the care recipient received *proper care* (Question 1).
- **Self-Perceived Inadequacy**:
    - 39.3% (n=22) believed they *should do more* (Question 3), while 23.2% (n=13) felt that they *could improve their caregiving* (Question 4).

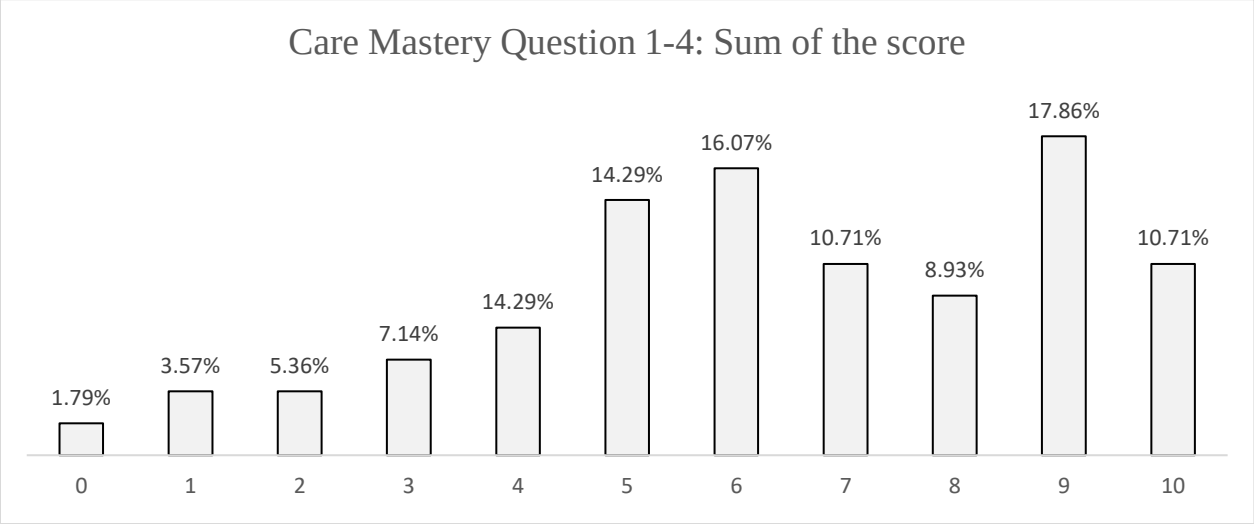
Table 3.1: Caregiver Mastery Responses:

Question	Strongly Agree	Agree	Disagree	Strongly Disagree
1. Unsure about proper care	0% (n=0)	25% (n=14)	50% (n=28)	0% (n=0)
2. Uncertain about care methods	28.57% (n=16)	42.86% (n=24)	19.64% (n=11)	8.93% (n=5)

Question	Strongly Agree	Agree	Disagree	Strongly Disagree
3. Should do more	17.9% (n=10)	33.9% (n=19)	39.3% (n=22)	8.93% (n=5)
4. Could do a better job	23.2% (n=13)	46.4% (n=26)	26.8% (n=15)	3.6% (n=2)

Risk Thresholds:

Figure 3.1 Care Mastery Question 1-4: Sum of the score



28.6% (n=16) scored **>8** (clinical risk threshold), indicating low confidence.

Interpretation:

Significant Uncertainty and Self-Doubt: The findings, especially for questions 2 and 4, indicate that a sizable percentage of this carer group feels they could be doing their job more effectively and has significant uncertainty about how to provide care.

Moderate Feeling of Obligation: Carers in this category also have a propensity to believe they aren't doing enough, albeit in a less overwhelming way (Q3).

Contrast on "Proper Care": It's interesting to note that, despite the rather confusing statistics for Q1, fewer people appear to question if the outcome—proper care being received—is occurring, whereas many question their techniques or performance.

Also, it's noteworthy that 28.6% of carers had a score higher than 8 on the Carer Mastery scale. This score indicates increased risk in accordance with the instrument's criteria.

It indicates that almost three out of ten carers in this group endure significant stress because of: Uncertainty about how to provide appropriate care. Feeling unworthy or as though they need to be doing more. More attention is necessary given their degree of self-doubt and lack of trust in their ability to provide care. The mean quality of life of caregivers of patients with Alzheimer's disease was found to be less than that of caregivers of people without dementia (Naseer et al., 20222). Moreover suggests that in order to reduce this particular kind of carer stress, this subgroup (28.6%) would probably profit from focused assistance, instruction, or resources.

3.2 Relationship strain

Interpersonal tensions were common, followed by Bangladesh's familial dynamics:

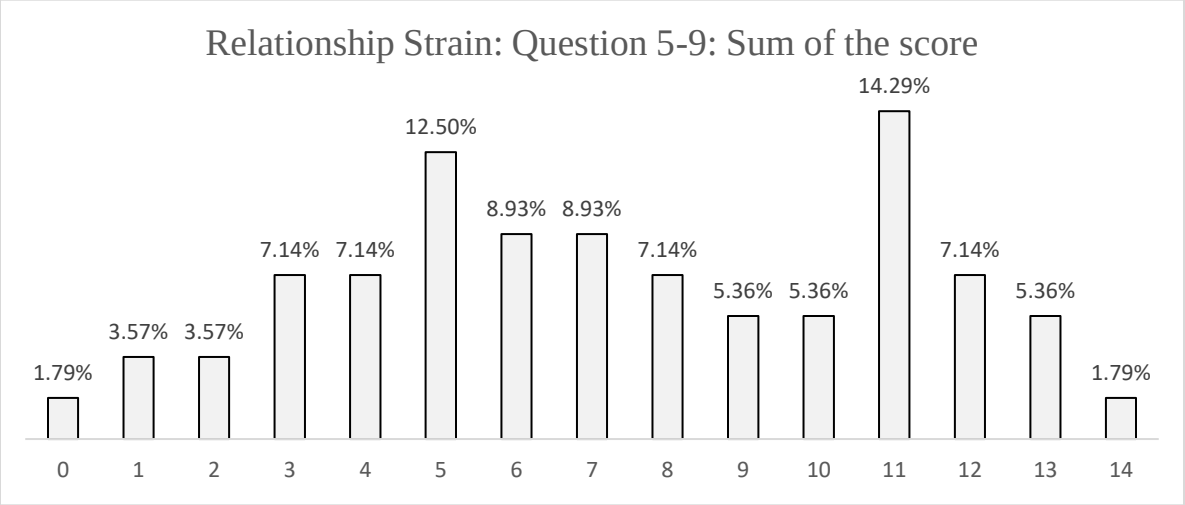
- **Manipulation**: 23.2% (n=13) felt manipulated by the care recipients (Question 5).
- **Resentment and Anger**:
    - 35.7% (n=20) reported *resentment* (Question 8).

- 46.4% (n=26) admitted to *anger* (Question 9).

- **Strained Bonds**: 44.6% (n=25) described *damaged relationships* (Question 6).

Risk Threshold:

Figure 3.2 Relationship Strain: Question 5-9: Sum of the score



28.6% (n=16) scored > 10 (clinical risk threshold),

Interpretation:

This analysis highlights significant interpersonal tension among the caregivers surveyed. Anger (46.4%) and a sense of strained bonds (44.6%) were reported by almost half the group, indicating substantial relationship difficulties. Resentment (35.7%) and feelings of manipulation (23.2%) were also present for a considerable number. Critically, 28.6% (n=16) of caregivers scored above the clinical risk threshold of 10 for Relationship Strain. This suggests that over a quarter of this group experiences a level of strain in their relationship with the care recipient severe enough to warrant further investigation and potential support interventions.

3.3 Health Strain

Physical and mental health deterioration was widespread:

- **Physical Decline**: 41.1% (n=23) reported *worsened health* (Question 10).
- **Mental Health**:
    - 50% (n=28) felt *persistent sadness* (Question 11).
    - 42.9% (n=24) experienced *nervousness* (Question 12).
- **Fatigue**: 64.3% (n=36) had *reduced energy* (Question 13), linked to long caregiving hours.

Table 3.2: Health Strain Overview

Health Impact	**Percentage Affected**
Physical Health Decline	41.1%
Mental Health (Sadness)	50%
Nervousness	42.9%
Low Energy	64.3%

Risk Scores:

48.2% (n=27) scored **>10**, signaling critical health risks.

Interpretation:

The results show a general decline in health among the carers polled. Nearly two-thirds (64.3%) report feeling less energetic, which raises serious concerns about fatigue. Significant effects are seen on mental health, with half reporting ongoing unhappiness (50%) and a sizable percentage reporting elevated anxiety (42.9%). In addition, more than 40% reported a decrease in their bodily well-being (41.1%). Importantly, nearly half of the cohort (48.2%) had a Health Strain score higher than the clinical risk threshold of 10. Given its high incidence, carer health strain appears to be a major problem in this community, highlighting the need for additional evaluation, assistance, and maybe treatments aimed at managing health restrictions, stress, and depression.

3.4 Social Isolation/ Activity Restrictions

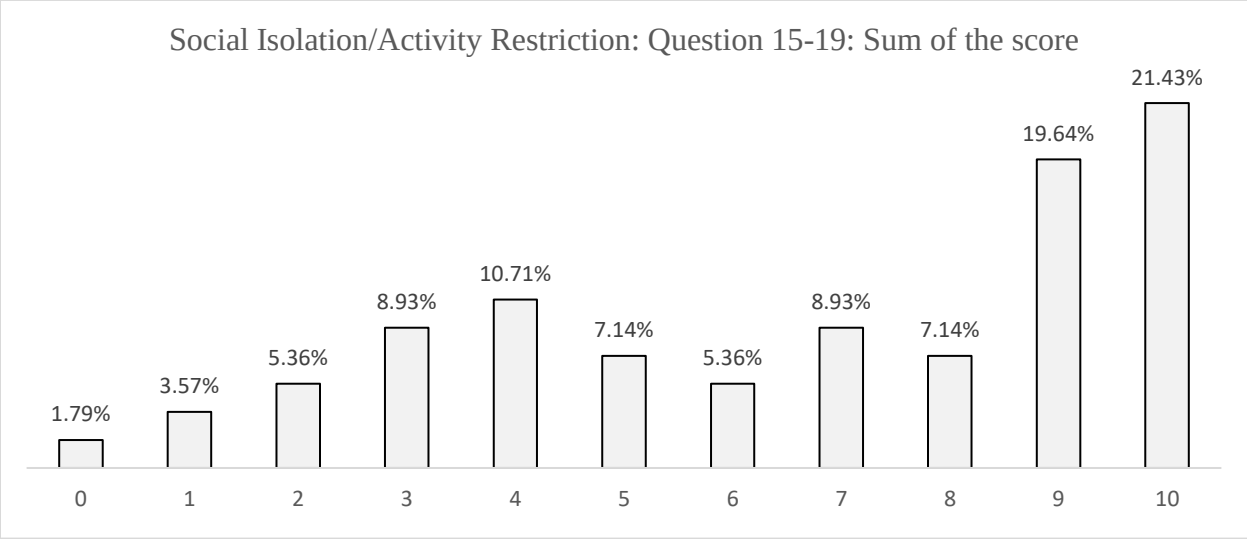
Caregiving disrupted social and cultural engagements:

- **Reduced Social Interaction**:
    - 71.4% (n=40) visited friends/family *less often* (Question 16).
    - 53.6% (n=30) reduced participation in *religious activities* (Question 15).
- **Leisure Deprivation**: 85.7% (n=48) rarely engaged in leisure (Question 19), citing time constraints.

Risk Scores:

62.5% (n=35) scored **>5**, indicating severe social withdrawal.

Figure 3.2: Social Isolation Trends



Interpretation:

The results show that caregiving has a significant effect on the social and personal life of carers. Due mostly to time constraints, 85.7% of people rarely engage in leisure activities like going out, indicating a very high level of leisure deprivation. Social engagement is also drastically reduced; more than half (53.6%) stopped participating in potentially uplifting religious activities, and the vast majority (71.4%) visited friends and relatives less frequently. The fact that the total scores above the clinical danger threshold of five suggests that social isolation and activity restriction are severe and pervasive within this carer group, underscoring the urgent need for help and respite in order to preserve social ties.

3.5 Demographic Variation in Bangladesh

- **Urban vs. Rural**: Urban caregivers faced higher Health Strain (52% urban vs. 38% rural).

- **Income**: 78% of low-income caregivers (<$300/month) exceeded risk thresholds in all domains.
- **Gender**: Female caregivers reported higher Relationship Strain (58% female compare to. 42% male).

3.6 Key takeaways

1. **Most Affected Domain**: Health Strain (64.3% reported low energy).
2. **High-Risk Groups**: Low-income female caregivers in urban areas.
3. **Cultural Context**: Stigma and joint family systems amplified relational and social strains.

Chapter 4: Discussion

4.1 Interpretation of Findings

According to this study, dementia carers in Bangladesh experience multifaceted stress that is influenced by systemic, sociocultural, and economic issues. The results are consistent with worldwide patterns, but are heightened by Bangladesh's particular situation:

1. **Health Strain:**
    - **Physical Decline:** The high rate of deteriorated physical health (41.1%) is consistent with research from Pakistan and India, which shows that time and money restrictions cause carers in LMICs to frequently disregard their health (Hilton et al., 2019). High levels of burden impacting well-being are also documented among caregivers of individuals with schizophrenia in Bangladesh (Tabassum et al., 2024). This neglect of caregiver health occurs despite dementia being recognized as a significant and growing contributor to the national disease burden (Poon et al., 2020; Naheed et al., 2023).
    - **Mental Health:** The psychological toll of juggling caregiving with financial survival is reflected in persistent unhappiness (50%) and anxiety (42.9%), a problem that is less well-documented in high-income nations but resonates with findings of moderate-to-severe emotional burden in Bangladeshi caregivers (Tabassum et al., 2024).

2. **Relationship Strain:**
    - Patriarchal norms and intergenerational living amplified conflicts, with 46.4% reporting anger toward care recipients. This contrasts with Western studies, where

formal care systems reduce familial tensions (Bass et al., 1996). The significance of the caregiver-patient relationship dynamic in influencing burden is also noted in other Bangladeshi contexts (Tabassum et al., 2024).

3. **Social Isolation:**
    - A tendency specific to quickly emerging LMICs, decreased social visits (71.4%) and leisure activities (85.7%) demonstrate how urbanization and young mobility shatter conventional support networks.

4.2 Placing findings in Regional and International Literature

Similarities to South Asia:

- A 2023 study conducted in Dhaka revealed that 68% of carers were under financial difficulty (Khan et al., 2023), which is consistent with the low-income group in this study (62% made less than $300 per month). This aligns with findings that lower income is significantly associated with higher caregiver burden in Bangladesh (Tabassum et al., 2024).
- Because of their less robust social support networks, Bangladesh has higher rates of social isolation (71.4%) than India (55%), according to Hilton et al. (2019).

Distinction from Western Contexts

- Bangladeshi carers have developing mastery deficits (28.6% scored >8) because they are less likely than Western carers to receive counselling or respite care.

- While this study identifies low-income urban females as particularly vulnerable, the first national prevalence study found higher dementia rates overall in females and those with no education, but surprisingly *no* significant difference between urban and rural settings or across socioeconomic strata (Naheed et al., 2023), suggesting the *experience* of caregiving strain might have different demographic drivers than dementia prevalence itself.
- Studies in other LMICs using the 10/66 dementia assessment framework found low education and literacy were independently associated with dementia incidence, but occupational attainment was not (Prince et al., 2012). This contrasts slightly with Western findings where occupation often plays a role but aligns with our finding that basic education (or lack thereof) and potentially income status are critical factors for caregiver vulnerability in Bangladesh.

4.3 Policy and Practice Implications

1. Policy Suggestions:

- National Dementia Strategy: Give rural areas priority while incorporating carer assistance into Bangladesh's basic healthcare system. This aligns with calls arising from national prevalence data (Naheed et al., 2023) and global recommendations (Cahill, 2020).
- Financial Aid: Use initiatives like Elderly Allowance Schemes to provide low-income carers with healthcare subsidies.

2. Community Interventions:

- Respite Care: Create community-based respite centers by collaborating with NGOs (like BRAC). The need for respite and psychosocial support is echoed in studies of caregivers for other conditions in Bangladesh (Tabassum et al., 2024).
- Training Programs: Conduct workshops on dementia care strategies to fill in mastery gaps.

3. Mental Health Support:

- Reduce the stigma attached to in-person visits by using telemedicine to offer counselling. Addressing caregiver burden through community and psychosocial interventions is crucial (Tabassum et al., 2024).

Chapter 5: Conclusion, Limitation & Prospects for Further Research

5.1 Conclusion

The critical need for culturally appropriate interventions to lessen carer stress in Bangladesh is highlighted by this study. Policymakers have the ability to change dementia care from a burden on families to a shared societal obligation by addressing systemic gaps and utilizing community networks (Cahill, 2020; Tabassum et al., 2024). These results highlight LMICs in the conversation about dementia care (Poon et al., 2020; Prince et al., 2012) and promote equity in global health research, building on recent national efforts to quantify the problem (Naheed et al., 2023).

5.2 Limitations

1. **Sample Bias:** Because they were recruited through urban hospitals, urban carers (45%) were over-represented. This contrasts with the national dementia prevalence survey which achieved proportional urban/rural representation and found no difference in prevalence by location (Naheed et al., 2023), suggesting our findings on urban caregiver strain need cautious interpretation regarding national generalizability.
2. **Self-Report Bias:** Subjective reporting may understate strain, particularly among male caregivers adhering to cultural norms of stoicism.
3. **Cross-Sectional Design:** Causality cannot be inferred; longitudinal studies are needed to track strain progression.

5.3 Prospects for Further Research

1. **Increase Demographics:** Add rural carers from each of the eight divisions of Bangladesh, ensuring representativeness as achieved in recent national surveys (Naheed et al., 2023).
2. **Mixed Methods:** Investigate cultural stigma by combining qualitative interviews and BRICSI.
3. **Interventional Studies:** Examine how well community respite initiatives might lessen stress on the body.

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BRICSI

by S. M. Masrakul Islam MEDHA

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