

## **Shared Silence: The Lived Realities of Spouses of Older Adults With Dementia in Kolkata**

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### **Abstract**

The greying population of modern society live in a deepening care-crisis as the primary care unit, the family, is passing through an existential crisis shaped by declining fertility, declining family size and growing dispersal of family members. For the elderly citizens suffering from degenerative ailments such as Alzheimer's or Parkinson's disease, who need round-the-clock care, the crisis is even deeper. Although ideally, dementia care demands a network of doctors, nurses, domestic aides, and relatives, the primary responsibility lies with the family members, the spouses, in particular. Care arrangement and the quality of care vary depending on the age, physical agility, economic condition, the mental makeup, and the value-resolve of the spouses. This paper examines how dementia caregiving reshapes the everyday lives, emotional well-being, and social identities of elderly spouses who serve as primary caregivers. The paper, based on a study of 16 families with elderly citizens suffering from Alzheimer's in Kolkata, highlights the psychological strain, erosion of personal autonomy and the sacrificial adjustments and compromises that the spouses as caregivers make in their lives. Conducted in collaboration with the Alzheimer's and Related Disorders Society of India (ARDSI), Calcutta Chapter, the study adopts an ethnographic, descriptive phenomenological approach. Drawing from detailed case studies, the paper illustrates the lived experiences, endurance, and resilience of aged dementia caregivers in modern urban India.

*Keywords:* family, elderly citizens, dementia, care crisis, care-givers, sacrifice, sufferings

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## Introduction

Mutual care has been one of the universal functions of the family all over the globe; this holds good even for the Indian family system. However, with increasing geographical dispersion of families, ageing, and declining health, providing care has become more difficult. Over the past two decades, traditional joint families have given way to nuclear or single-member households due to urbanisation, migration, and broader socio-economic shifts driven by liberalisation and neo-liberalism. These changes have reshaped education, employment, family structure, and old-age planning, while reducing state support in key sectors, thereby placing greater responsibility on individuals and families.

In this context, the ageing population—especially in urban middle-class settings like Kolkata—faces a growing “care crisis.” The situation is particularly difficult for elderly individuals suffering from degenerative conditions such as Alzheimer’s and Parkinson’s disease. With the number of dementia patients in India rising rapidly, the burden of care falls largely on family members, especially spouses.

Despite extensive medical research on dementia, the lived experiences of caregivers remain underexplored. Care-giving involves intense emotional, physical, and social challenges that significantly reshape caregivers’ daily lives, well-being, and social relationships, making it essential to study care not just as a medical issue but as a deeply social and relational process.

## The Context of the Study

Statistics indicate that dementia affects 5.2 million people in India (Alzheimer's and Related Disorders Society of India, 2020), a figure projected to rise to 16.39 million by 2050 (figure portrayed in the website of Alzheimer’s and Related Disorders Society of India, Calcutta Chapter). A nationwide study published in *Alzheimer’s and Dementia: The Journal of the Alzheimer’s Association* (Lee et al., 2023) estimates a 7.4% prevalence among adults aged 60+, with 8.8 million elderly Indians living with dementia. While extensive research has examined the medical and psychological aspects of degenerative conditions such as Alzheimer’s, vascular, and Lewy Body dementia, far less attention has been paid to caregivers, who provide continuous support to affected older adults.

At the same time, India is witnessing a steady rise in its ageing population due to declining fertility and increasing life expectancy. According to the *State of the World Population Report 2018* by UNFPA, despite population growth from 566 million in 1971 to 1.35 billion in 2016, fertility rates have fallen, with the total fertility rate dropping to 2.0 in 2023—below the replacement level of 2.1 (Choudhary, 2018). Within a neoliberal, market-driven context marked by economic uncertainty, individuals increasingly make calculated life choices—such as delayed marriage, career prioritisation, controlled reproduction, and migration—that are more pronounced in urban India. This rationalisation of life has led to the rise of nuclear and lone-member households, intensifying the care crisis for the elderly. Many older adults, often living alone, rely on professional caregivers or move to old age homes. Yet, emotional, social, and health-related insecurities, shaped by isolation and separation from family, persist.

Elderly citizens are differentially positioned by gender, class, family structure, and health, with health being a key determinant of quality of life in urban India. Those with minor ailments are better placed than those with severe conditions, who depend on others for daily care. Individuals with complex diseases like Alzheimer’s are almost entirely reliant on caregivers.

The illness not only affects the patients but also deeply impacts family members, who often make career compromises while coping with the emotional strain of witnessing a loved one's decline. Even hired caregivers must bring empathy and compassion to their role. Thus, the lives of elderly persons with Alzheimer's have two dimensions: (1) the medical aspect, managed by professionals, and (2) the socio-cultural-economic aspect, handled by family members. In India, the absence of a comprehensive state-supported care policy places the primary responsibility on families, despite limited support from NGOs with constrained resources.

This paper examines the impact of caregiving on family members, focusing on changes in everyday life, emotional well-being, and social roles in the context of long-term dementia care. Primary caregivers often experience significant stress, anxiety, and burden as they balance household responsibilities, professional commitments, and intensive care demands. While some adopt coping strategies such as personal time, leisure, or hobbies, for most, opportunities for self-care remain limited due to the relentless nature of care-giving.

### **Methodology**

This paper draws on ongoing research on dementia caregiving conducted in collaboration with the Alzheimer's and Related Disorders Society of India (ARDSI). Fieldwork involved close engagement with the ARDSI Calcutta Chapter through meetings, extended observation, and participation in memory clinics. Access to caregivers in Kolkata was facilitated through ARDSI, supplemented by respondents identified via personal networks.

Interviews were conducted exclusively with caregivers who provided informed consent and voluntarily agreed to participate in the study. The majority of interviews were carried out telephonically, each running over sixty to ninety minutes. In addition, in-depth, face-to-face interviews were conducted with five respondents at their residences. Given their proximity and preference for personal interaction, these interviews were conducted in naturalistic settings, allowing for richer contextual understanding through direct observation and sustained interaction. Clarifications and elaborations were sought from the respondents on repeat calls at the time of writing transcripts.

All interviews were guided by a pre-designed interview schedule and were audio-recorded with participants' permission. To date, data have been collected from sixteen respondents and subsequently transcribed for analysis. As the study is ongoing, further data collection will continue over the coming months. The narratives presented in this paper are largely descriptive in nature and aim to preserve the participants' voices and lived experiences with minimal interpretive distortion.

As the experience and progression of dementia vary from person to person, the experiences of caregivers in providing care and comfort to their loved ones also differ significantly. Capturing the complexity of dementia caregiving through a fixed set of parameters is inherently challenging, as caregivers' journeys are shaped by diverse emotional, relational, and contextual factors. Nevertheless, for this research and to develop an ideal-typical understanding of the caregiving experience, this study conceptualises caregivers' lives through a set of analytical categories. These include the emotional burden of caregiving; changes in everyday routines; transformations in conjugal relationships; alterations in leisure activities and opportunities for time alone; and, finally, the emergence of moments of happiness and emotional meaning within the context of dementia.

## The Families of the Patients

Of the 16 patients in the study, 10 are female, and 6 are male. Reflecting dementia's age-related nature, 6 are aged 66–75, 6 are 76–85, 3 are 86–95, and 1 is below 65. Eight patients have lived with the condition for less than five years, and eight for more than five years. In terms of occupation, 6 were homemakers, 3 school teachers, and one each was a scientist, lawyer, private company executive, engineer, and railway staff member, while 2 were bank employees.

Of the 16 patients, 2 belong to five-member families, 7 to four-member families, 6 to three-member families, and 1 is unmarried. Eleven reside in sub-nuclear households—either living alone with hired caregivers due to spousal loss or with a spouse while children live elsewhere. One lives in a nuclear household, one in a supplemented nuclear, and one in a supplemented sub-nuclear arrangement. This reflects the ongoing nuclearisation of urban middle-class families, indicating a declining capacity of the family as the primary care unit, further weakened by dispersal and work pressures.

Among the sixteen caregivers interviewed, 5 (31.25%) are male and 11 (68.75%) females. Women—especially wives and daughters—predominantly assume primary caregiving responsibilities, even when not co-residing with the care recipient. In contrast, male caregivers, mainly husbands and sons, tend to rely on paid support due to their role as primary earners and work pressures. This reflects persistent gendered divisions of labour, where care-giving remains feminised and male participation is viewed as an exception, typically in the absence of an able-bodied female family member.

Dementia, in most cases, catches the individuals aged 65 and above, while most caregivers are either middle-aged (9) or older people (6) or adult children (1), many of whom are themselves ageing and balancing multiple health, personal, and social obligations. A majority of the caregivers (15) are well-educated, have access to health information and are of middle-class background, who are capable of informed decision-making. The families that came under the study were nuclear (3), sub-nuclear (8), joint household (1), supplemented nuclear (1) and supplemented sub-nuclear (3) households. Most caregivers (14) are married, with spouses viewing care as a moral and emotional responsibility, even as marital relationships become reshaped by dependency, strain, and loneliness; the few widowed (1) and unmarried (1) caregivers likewise demonstrate resilience and strong commitment despite personal vulnerability.

In terms of occupation, among women caregivers, 5 are teachers, 2 homemakers, 1 nursing staff member, 2 government employees, and 1 runs a business. Male caregivers are employed in law (2), banking (1), and the private sector (3). Twelve caregivers belong to financially secure or upper-middle-class households, while 4 report financial insolvency. Seven live separately from care recipients and provide remote supervision through hired caregivers; 4 reside in the same city but in separate households and offer direct oversight. A majority (13 out of 16), irrespective of gender, rely on hired caregivers due to work commitments, while ageing spouses also depend on paid assistance. Only 3 respondents prefer not to hire caregivers, citing moral commitment. Overall, financial stability alleviates but does not eliminate the economic and emotional burden of long-term dementia care, which often still requires extended family support.

Among the 16 patients, 11 share cordial and emotionally supportive relationships with their primary caregivers, maintaining meaningful interaction even when recognition is impaired. In

contrast, 3 have strained relationships, where the combined burden of illness and caregiving leads to emotional exhaustion, irritation, and reduced quality of interaction. In one case, a caregiver continues to struggle with accepting her husband's condition and, at times, perceives him almost as a stranger. There are also two cases in which the relationship between the patient and caregiver had been poor before the onset of dementia. However, after cognitive decline—particularly when the patients became calmer and more subdued—the quality of their relationship improved notably.

### **Changes in Spouses' Lives After Dementia**

In this study, 13 of 16 respondents reported that a loved one's dementia diagnosis profoundly transformed their lives, reshaping family roles, emotions, and social and work engagements. Caregivers assumed responsibilities for care, supervision, finances, and emotional support, leading to role redefinition, emotional strain, and social withdrawal. Despite grief, fatigue, and "ambiguous loss," many adapted over time through coping strategies and continued to view caregiving as a moral commitment grounded in compassion and enduring relationships.

Mrs Sumita Ghosh's (69) life has undergone a profound transformation following her husband's dementia diagnosis, as she has become the primary caregiver, managing his daily needs, household responsibilities, and constant supervision despite her own health challenges. The demands of caregiving have left her physically exhausted and emotionally strained, marked by grief, sadness, and a sense of loss as she witnesses the gradual decline of her once independent and strong partner. Her social life, personal interests, and self-care have significantly diminished, and although she finds brief moments of solace in music and routine activities, her life is now largely shaped by responsibility, isolation, and continuous adaptation to her husband's increasing dependence.

This case study shows that spousal dementia caregiving is a deeply transformative and burdensome experience, marked by physical exhaustion, emotional strain, and social isolation. It highlights how caregivers gradually reorganise their lives around responsibility and loss, while continuing to adapt with resilience despite limited personal well-being.

### **Balancing Professional Responsibilities With Care-Giving**

In this study, 5 of 16 respondents reported considerable difficulty in managing professional responsibilities alongside the intensive demands of caregiving. The dual burden of employment and sustained care created persistent time pressures, role conflict, and emotional strain, as caregivers were required to constantly negotiate between workplace expectations and the unpredictable needs of a spouse with dementia. This often resulted in compromised work performance, reduced efficiency, and heightened anxiety, alongside physical exhaustion.

To manage competing demands, caregivers adopted adaptive strategies such as hiring professional help, delegating household tasks, seeking support from family, and adjusting work commitments. While these measures offered partial relief, emotional and supervisory responsibilities largely remained with the spouse. Despite fatigue and stress, most caregivers continued to sustain both roles, guided by a strong sense of duty, emotional attachment, and moral obligation, often internalising caregiving as an integral part of marital commitment.

Over time, this prolonged engagement in dual roles became a transformative experience. It reshaped caregivers' priorities, often leading to the reevaluation of career ambitions, social

engagements, and personal aspirations. Simultaneously, it fostered the development of emotional resilience, patience, and adaptive coping capacities. Many caregivers reported a deepened understanding of care as an ethical and relational practice, as well as a more nuanced appreciation of family bonds, responsibility, and interdependence.

Thus, while the simultaneous management of professional and care-giving roles generates significant strain, it also contributes to processes of personal transformation, highlighting the complex interplay between burden, adaptation, and meaning within the care-giving experience.

### **Conjugal Life After Dementia**

Dementia profoundly reshapes not only the daily routines of family caregivers but also the relational dynamics between caregivers—particularly spouses—and persons living with the illness. As dementia progresses, previously reciprocal relationships, especially spousal relationships grounded in mutual emotional exchange and shared decision-making, are gradually transformed into asymmetrical arrangements characterised by dependency and sustained care. Spousal caregivers increasingly assume roles as managers, protectors, and emotional anchors, marking a fundamental reconfiguration of spousal and familial roles and responsibilities.

This relational shift is further intensified by behavioural and personality changes in the person with dementia. Spouses living with dementia may exhibit altered emotional responses, including withdrawal, passivity, suspicion, or agitation, challenging caregivers' earlier perceptions of their spouse's identity and shared marital history. Such changes disrupt relational continuity and compel spousal caregivers to renegotiate emotional bonds, expectations, and modes of interaction within an evolving caregiving context.

The erosion of reciprocity constitutes a central emotional challenge in spousal dementia care. As cognitive and emotional capacities decline, caregivers' expectations of recognition, emotional response, and appreciation often remain unmet, generating profound feelings of grief, loss, and emotional dissonance. Nevertheless, many spousal caregivers continue to provide care with patience and empathy, redefining spousal love and commitment beyond conventional notions of mutual exchange and companionship.

At the same time, dementia caregiving may also function as a site of relational transformation. In certain cases, sustained spousal care-giving fosters renewed emotional closeness, softening previously strained relationships and enabling new forms of intimacy grounded in empathy, attentiveness, and everyday care practices. Thus, dementia care is not solely a narrative of relational rupture but also one of redefinition and potential renewal, where care becomes a medium for emotional resilience, moral devotion, and rediscovered connection.

Krishanu Ganguly (73), a retired advocate of the Kolkata High Court, lives in Salt Lake with his wife, Mrs Bani Ganguly (73), diagnosed with dementia in 2021. Their relationship had begun deteriorating nearly a decade earlier due to her behavioural and cognitive changes, including mistrust and delusional accusations, leading to emotional distress and loss of intimacy. The situation was compounded when uninformed family members believed her claims, causing stigma and isolation for MrGanguly. Although he now recognises these as symptoms of dementia, allowing some reconciliation, he regrets the delayed diagnosis that prolonged their suffering.

The case highlights how dementia caregiving profoundly transforms spousal relationships over time. As the illness progresses, marriages grounded in mutual companionship and reciprocity are gradually reconfigured into relationships marked by asymmetrical dependence and sustained emotional labour. Spouses increasingly transition from partners to primary caregivers, assuming responsibility for daily care, decision-making, and emotional management.

Intimacy is redefined through acts of care, patience, and vigilance rather than reciprocal exchange. While this shift is accompanied by loss, strain, and grief for the partner's former self, it may also foster new forms of closeness rooted in compassion, commitment, and enduring emotional bonds. Dementia care-giving does not simply erode spousal ties but reshapes them, creating new forms of intimacy grounded in care, responsibility, and ethical commitment. In this context, love becomes an enduring practice—sustained through presence, sacrifice, and emotional effort—rather than merely a shared feeling.

### **The Caregivers' Pursuit of Leisure and Emotional Renewal**

A critical yet under-examined dimension of spousal dementia caregiving is the erosion of personal time. Caregivers become deeply embedded in the continuous physical, emotional, and logistical demands of care, leaving limited scope for self-care. Even when brief periods of respite are available, they are typically devoted to rest and recovery rather than meaningful leisure or self-development.

Consequently, activities that once sustained a sense of identity and personal fulfilment are progressively marginalised. The cumulative effects of fatigue and sustained responsibility produce monotony, emotional depletion, and a gradual attenuation of individual subjectivity.

Nearly all caregivers (15 of 16) demonstrated resilience by attempting to carve out limited personal time despite intense caregiving demands. Following the diagnosis, their daily routines and lifestyles were significantly disrupted. While many made deliberate efforts to include brief periods of rest or emotionally restorative activities alongside work and household responsibilities, most reported substantial curtailment of hobbies, travel, and social interactions due to caregiving obligations and concerns for their partner's safety.

In some cases, caregivers consciously sustained small leisure practices as coping mechanisms to preserve emotional well-being and a sense of self beyond the caregiving role. Overall, the constrained and negotiated nature of personal time emerges as a critical factor shaping caregivers' resilience, identity, and everyday caregiving experience. Here are some illustrations:

Arup Chatterjee (60), the primary caregiver of his wife Rina Chatterjee (60), diagnosed with dementia in 2020 and under treatment in Srirampur, has very limited personal time due to caregiving demands. Social interactions are irregular and contingent on care arrangements, while shared leisure and travel remain largely unfeasible due to her restlessness and need for constant supervision. Consequently, his mobility and autonomy are significantly constrained. Although he occasionally seeks personal respite, her condition limits such possibilities. As a coping strategy, he engages with online caregiving resources, reflecting his ongoing negotiation between duty, emotional commitment, and restricted autonomy.

Like Mr Chatterjee, Mrs Chaitali Mondal's (74) everyday life is largely structured by the demands of caregiving, leaving limited scope for personal pursuits. Nonetheless, she engages in small practices of self-care, such as solving Sudoku, taking brief walks, and maintaining social connections through digital platforms, which serve as sources of emotional support. Despite persistent fatigue, she continues to sustain an emotional bond with her husband, who occasionally demonstrates recognition through words or gestures, thereby reaffirming their enduring relational connection despite cognitive decline. Care-giving has also entailed significant personal sacrifices, particularly the curtailment of travel, as unfamiliar environments tend to heighten his anxiety and disorientation, leading her to gradually accept the long-term constraints imposed by dementia.

These cases show how spousal care-giving becomes an all-encompassing moral and practical responsibility, progressively constraining personal time, mobility, and social life. Everyday life decisions come to revolve around the needs of the partner with dementia, narrowing caregivers' personal worlds and blurring the boundaries between care and self.

Caregivers experience an ongoing tension between emotional commitment and personal autonomy, often leading to isolation and a sense of constraint. At the same time, they adopt coping strategies such as digital engagement and small acts of self-care. Despite cognitive decline, spousal bonds often endure through recognition and everyday gestures, reflecting a complex interplay of loss, resilience, and continuing intimacy.

### **Silent Suffering, Emotional Changes and Sacrifice**

Caregivers often encounter significant difficulty in balancing professional obligations, personal needs, and social relationships alongside the demands of caregiving. The intensive and time-bound nature of care work frequently leads to the marginalisation of leisure, rest, and social engagement, resulting in increasing isolation and limited opportunities for physical and emotional recuperation.

In this study, 12 out of 16 respondents reported experiencing persistent stress and anxiety, reflecting the cumulative psychological burden associated with continuous caregiving. This strain is not only a product of physical exhaustion but also of emotional labour, uncertainty, and the long-term trajectory of dementia.

Moreover, prevailing cultural norms that frame caregiving as a moral and familial duty often inhibit caregivers from articulating their distress. Expressions of fatigue, frustration, or emotional strain may be perceived as a failure of commitment or devotion. Consequently, caregivers tend to internalise their struggles, rendering their suffering largely invisible and insufficiently acknowledged within both familial and social contexts. Here is an illustration:

Mrs Sujata Neogy's (67) experience highlights the profound emotional burden of long-term dementia caregiving. Following her husband's diagnosis in 2020, she became his primary caregiver, a role that led to sustained exhaustion, emotional strain, and psychological distress. In 2024, his admission to a specialised care home ensured better safety and professional support; however, this transition did not alleviate her burden. Instead, it gave rise to complex emotions such as guilt, loneliness, and a deep sense of grief over the gradual loss of their shared life. Her experience underscores that the impact of care-giving extends beyond active care, leaving enduring feelings of loss and moral ambivalence.

Mrs Neogy's case shows that the impact of dementia caregiving continues even after active care ends. While institutional care ensured her husband's safety, it left her with feelings of guilt, loneliness, and grief. Her experience highlights the lasting emotional effects of caregiving and the need to recognise and support caregivers beyond the period of direct care.

### **Moments of Happiness in Caregiving**

Spousal dementia care-giving constitutes a highly demanding and time-intensive form of labour, encompassing not only physical care but also the ongoing management of progressive cognitive, emotional, and behavioural changes. As the illness advances, caregivers frequently reorganise their daily routines, priorities, and social lives around the needs of their partner, while simultaneously undertaking substantial emotional labour in contexts marked by limited or inconsistent reciprocity.

The cumulative burden of caregiving often results in persistent fatigue, stress, and emotional exhaustion. Caregivers may experience moments of frustration or irritability, often followed by guilt, as they recognise these reactions stem from the partner's condition rather than intent. Despite this, care-giving retains meaning: 13 of 16 respondents reported moments of emotional connection—such as shared smiles, recognition, or familiar routines—which provide vital emotional sustenance. Though brief, these moments reaffirm relational continuity and sustain caregivers' sense of purpose and motivation.

In contrast, 3 out of 16 respondents reported a decline in overall happiness following the diagnosis, attributing this to emotional loss, diminished reciprocity, and the gradual erosion of shared memories and companionship. This variation highlights the heterogeneous nature of caregiving experiences, shaped by factors such as coping capacity, the prior quality of the relationship, and the progression of the illness.

While moments of connection can mitigate emotional strain, caregivers' well-being often becomes closely intertwined with the comfort and condition of their partner, necessitating significant personal sacrifice. Opportunities for self-care and leisure, when available, offer important—albeit limited—relief and contribute to emotional regulation and resilience. However, their absence may intensify the perceived burden of care, leading to further psychological strain.

Overall, these findings underscore the complex interplay of burden, meaning, loss, and resilience within spousal dementia caregiving, highlighting the critical need to recognise and support caregivers' emotional well-being to sustain their health and the integrity of their relationships.

### **Support From Extended Family Members**

Support from extended family—once central to the traditional Indian joint family system—has significantly declined in contemporary caregiving. While joint families historically shared emotional, financial, and physical responsibilities, urbanisation, migration, and the shift toward nuclear households have weakened these intergenerational support structures.

In the present study, a majority of respondents (11 out of 16) reported minimal or no involvement of extended family in caregiving, neither receiving nor expecting financial or emotional support beyond the immediate household—indicating a normalisation of reduced

kinship obligations. Respondents noted that relatives are often geographically dispersed across cities or abroad, limiting their involvement, and transforming extended family ties from functional support systems into largely symbolic relationships. Among the remaining respondents, only 5 out of 16 reported occasional expressions of concern from extended family members, which were largely limited to phone calls or sporadic inquiries about the well-being of the patient. Furthermore, 3 out of 16 respondents indicated that contact with relatives was largely confined to festive occasions, suggesting a ritualistic rather than supportive engagement. Strikingly, only 1 out of 16 respondents reported receiving consistent and meaningful support—whether emotional, financial, or practical—from extended family members.

Taken together, these findings point toward a broader shift in the structure and functioning of kinship networks in contemporary Indian society. The erosion of extended family support has led to an increased concentration of caregiving responsibilities within the nuclear family, often placing considerable strain on primary caregivers. This transformation not only reflects changing socio-economic conditions but also signals a redefinition of familial roles, obligations, and expectations in the context of long-term care.

Mrs Bani Ganguly's (73) pre-diagnostic phase was marked by severe behavioural changes, including delusions that led to accusations against Mr Krishanu Ganguly (73, retired advocate), causing social humiliation and isolation. Following the formal diagnosis, relatives began to recognise the illness, though this shift came after reputational damage. Subsequently, a few close family members offered emotional support, reflecting a delayed but important re-engagement of familial support.

Mrs Sumita Ghosh (59) reports limited contact with extended relatives, particularly from her husband's side, who seldom inquire about his health. Her sister and brother-in-law visit occasionally, and her daughter, who lives in Bally, visits approximately once every two weeks. In contrast, neighbours—especially young men in the locality—play a supportive role by regularly engaging Mr Ghosh in conversation and encouraging his evening routine. Over time, these neighbours have come to function as an important source of emotional support, akin to family members.

The case studies indicate that support from extended kin is limited and largely supplementary, with most caregivers relying primarily on themselves or immediate family members due to changing family structures and urban living. While extended kin may offer occasional emotional, financial, or temporary assistance, such support is irregular and insufficient to significantly reduce the caregiver's overall burden.

### **Difference Between Male and Female Caregivers**

The study reveals a clear gendered pattern in the organisation and experience of caregiving, shaped by differential roles, expectations, and access to resources within the household.

*Reliance on hired caregivers:* Male caregivers (n = 5) tend to rely heavily on paid caregivers, adopting supervisory roles focused on coordination and monitoring rather than direct care. In contrast, female caregivers (n = 11) are less likely to depend on external support, often due to dissatisfaction with its quality and a strong sense of personal responsibility, leading them to undertake most caregiving tasks themselves.

*Direct care-giving involvement:* Women remain more actively engaged in the day-to-day care of their spouses, including assistance with personal hygiene, feeding, medication management, and constant supervision. Their caregiving role is continuous and physically demanding. Men, by comparison, provide more limited direct care, often stepping in only when necessary, while continuing to emphasise oversight and coordination rather than sustained physical involvement.

*Household responsibilities:* A clear gender divide is evident in the management of domestic work. Male caregivers are generally exempt from routine household responsibilities, contributing mainly through tasks such as errands, purchases, and bill payments. In contrast, female caregivers shoulder the dual burden of managing the household—cooking, cleaning, and organising daily routines—alongside intensive caregiving, significantly increasing their workload and limiting time for rest or personal well-being.

*Financial and managerial roles:* Men generally exhibit greater familiarity and confidence in managing financial matters such as banking, bill payments, and formal procedures. Women, particularly those with limited prior exposure, often report anxiety or lack of confidence in these areas. However, they demonstrate stronger competence in supervising domestic help and managing household functioning, reflecting their long-standing engagement in these domains.

*Emotional and social outcomes:* These structural differences shape distinct emotional experiences. Female caregivers report higher levels of stress, fatigue, frustration, and social isolation due to heavier, continuous workloads and limited support, with restricted mobility further reducing social interaction. In contrast, male caregivers, often relying on hired help and less involved in daily care, retain greater access to social spaces and tend to experience comparatively lower emotional distress.

Overall, these findings highlight how caregiving is deeply embedded within gendered divisions of labour, with women bearing a disproportionate share of both physical and emotional responsibilities, while men occupy more managerial and less intensive roles.

## Conclusion

The study has found that spousal dementia caregiving in urban India is a deeply transformative social and emotional experience that extends far beyond the domain of medical responsibility. With the gradual decline of the traditional joint family system, dispersal of family members and weakening of kinship relations, the burden of care primarily falls on the spouses. The caring spouses, who are ageing as well, experience physical exhaustion, emotional strain, and social isolation, and, in the process, reshape their sense of self, everyday routines, and relationships. Caregivers frequently experience anticipatory grief, a prolonged process of mourning characterised by the gradual erosion of emotional reciprocity and companionship, alongside the decline of physical and mental health of the patient.

However, some of the caregivers develop forms of emotional resilience and adaptive coping, often deriving meaning from small, everyday moments of connection, recognition, or shared suffering and emotive coexistence. Reflecting on the shared happy memories rooted in mutual empathy and love keep the caregivers going. These moments, though fleeting, play a crucial role in sustaining caregivers psychologically and rejuvenating their resolve and purpose.

The burden of caregiving is, at times made heavier, with broader structural constraints. Limited public awareness about dementia, inadequate institutional support systems, and the absence of comprehensive policy frameworks in the Indian context leave caregivers with minimal external support. As a result, care-giving remains largely privatised, with families navigating complex challenges in isolation.

Hence, the study underscores the urgent need to reconceptualise dementia caregiving as a broader social issue rather than a purely private or familial responsibility. It calls for greater recognition at the policy level and the development of accessible support mechanisms, including community-based services, caregiver support programs, and institutional care infrastructure, which are currently absent in India.

### **Declaration of Generative AI and AI-Assisted Technologies in the Writing Process**

The theme and subject of this paper are original, and the work is based exclusively on data derived from my fieldwork. The manuscript has been written in my own words; however, I have utilised AI tools, particularly Chat GPT, for the purposes of editing, enhancing clarity and precision, and improving the overall quality of the language. Other than Chat GPT No other AI tools have been used in writing this manuscript.

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