

Everyday Life of the Caregivers for the Aged with Dementia: A Study in Kolkata

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Abstract: Dropping rates of marriage and fertility, and the growing demands for individual autonomy of the members of the younger generation, have significantly undermined the conventional practice of shared family life in the West, which, despite not having a material crisis, has left the elderly population in the midst of a care crisis. The Western neoliberal democracies have introduced state-initiated care packages to address the crisis. In India, since the last decades of the last century, and particularly in the phase of post-1991 globalisation, the drop in fertility rate, which results in population greying and the dispersal of the younger members within and outside the country, has made a similar care crisis loom large. However, the Indian reality is still significantly different from that of the West on at least three counts: (1) the family bonds, and at times, kinship relations constitute the primary foundation of care, (2) the new neo-liberal phase of withdrawal of state support and rising cost of living because of pro-market reforms and disinvestments, have added to the precarity of the middle class, and (3) the state in India is largely silent on the state-sponsored care packages for the elderly population, who live in serious care crisis. Against this social backdrop, the present paper examines the ground realities of the lives of the caregivers, their problems and sufferings in particular, for the middle-class elderly population suffering from dementia. The findings of the paper are based on an empirical qualitative study of sixteen families with cases of dementia.

Keywords: Elderly population, dropping fertility, family, dispersal of family members, caregivers, everyday life.

Introduction

Caring for oneself and for dependent close family members is a routine social expectation, expressed through everyday practices such as preparing food, managing medication, maintaining the household, and sharing time

and memories with close ones. However, caring for dependent relatives becomes increasingly difficult when younger, able-bodied family members are absent due to low fertility, death, or dispersal for work and career. Even for co-family members sharing the same household, caregiving poses significant material, physical, and psychological challenges, shaped by the caregiver's own capacities and constraints. In response, many urban middle-class families arrange "rational care packages" that substantiate family care with hired assistance in proportions suited to their circumstances and the specific family context.

This paper examines how families of elderly persons with dementia mobilise resources, financial as well as human, reorganise everyday life, and sustain such care arrangements over time, often at the cost of personal routines, commitments, and aspirations. It situates this process within a broader "care crisis" produced by shrinking families and household fragmentation resulting from fertility control and the increasing dispersal of younger members. Drawing on data from an ongoing study of dementia care in Kolkata, the paper analyses how these structural shifts disrupt conventional family-based care and reshape everyday care-giving practices.

Context of the study

An ageing-related condition, dementia, is a growing public health concern in India, with about 5.2 million people living with the condition according to the Dementia India Report (2020), and projections suggesting a rise to 16.39 million by 2050 as estimated by the Alzheimer's and Related Disorders Society of India. A nationwide study published in *Alzheimer's and Dementia: The Journal of the Alzheimer's Association* (2023) estimates a prevalence rate of 7.4% among adults aged 60+, with around 8.8 million older Indians affected. While extensive research has focused on the medical and psychological aspects of dementia caused by conditions such as Alzheimer's, vascular, and Lewy Body diseases, comparatively little attention has been paid to the lived experiences of caregivers who provide continuous support.

At the same time, India is witnessing a steady rise in its ageing population due to declining fertility and increasing life expectancy. The fertility rates have fallen significantly, reaching 2.0 in 2023 and 1.9 in 2026, which is below the replacement level (United Nations Population Fund Report (UNFPA) on *The Real Fertility Crisis*, 2025). Processes associated with modern urban life — such as delayed marriage, career prioritisation, migration, and nuclear family structures — have contributed to the

emergence of lone elderly households and an intensifying care crisis. Many older adults, often living with illness, rely on hired caregivers or old age homes, yet continue to experience insecurity, loneliness, and health anxieties.

The ageing population is socially differentiated by gender, class, family structure, and health status, with those suffering from serious illnesses like Alzheimer's being highly dependent on others for daily care. Dementia not only affects the individual but also profoundly impacts family members who assume caregiving roles, often making career sacrifices and coping with emotional distress. Care involves both the medical dimension, managed by healthcare professionals, and the social, cultural, and economic dimensions, largely handled by families.

In India, the absence of a comprehensive state-supported care policy means that families remain the primary caregivers, sometimes supported by NGOs with limited resources. Family caregivers frequently experience stress, anxiety, and heavy caregiver burden as they struggle to balance household responsibilities, professional work, and intensive caregiving demands. Although some adopt coping strategies such as leisure or personal time, most have limited opportunities for self-care due to the relentless nature of caregiving. This context highlights the profound transformations in caregivers' daily lives, emotional well-being, and social roles as they navigate long-term dementia care.

Methodology

This paper is an outcome of my research on dementia care, which is being conducted in collaboration with the Alzheimer's and Related Disorders Society of India (ARDSI), a non-profit organisation committed to supporting persons living with dementia and their families. ARDSI undertakes a range of initiatives focused on dementia awareness, prevention, and care, and operates a day care centre where persons with dementia participate in structured activities such as physical exercise, dance, painting, and other forms of social and cognitive stimulation.

As part of the fieldwork, I engaged closely with the ARDSI Calcutta Chapter, having meetings with its secretary, visits to its day care centre, and participating in its mobile memory care clinics. Through my association with ARDSI, I prepared a list of the primary caregivers of persons living with dementia in Kolkata and Siliguri, the latter being the second major urban centre in West Bengal. In addition, I identified several respondents independently through my personal network of relatives and acquaintances.

A total of sixteen respondents were selected for the study, and data were collected from them through in-depth interviews

Interviews were conducted exclusively with caregivers who provided informed consent and voluntarily agreed to participate in the study. Most of the interviews were carried out telephonically and, with a few exceptions, did not exceed ninety minutes in duration. 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 home settings, allowing for richer contextual understanding through direct observation and sustained interaction.

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 have been kept true to the participants' voices and lived experiences with minimal possible interpretive abstraction.

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.

Impact of dementia on the lives of the caregivers as viewed by other scholars

A growing body of literature has highlighted the profound and multidimensional impact of dementia caregiving on family members, emphasising the substantial emotional, physical, social, and financial burdens associated with the caregiving role. The National Council of Certified Dementia Practitioners (NCCDP, 2025) notes that as dementia progresses,

caregivers assume increasing responsibilities related to personal care, medication management, household tasks, and continuous supervision. Such responsibilities are physically demanding and emotionally taxing, often giving rise to feelings of grief, frustration, helplessness, guilt, and emotional exhaustion. Moreover, caregiving responsibilities frequently disrupt social relationships, limit participation in recreational activities, and generate considerable financial strain due to reduced employment opportunities and rising healthcare expenditures. Consequently, dementia caregiving has been shown to adversely affect caregivers' overall quality of life and family relationships, particularly among spousal caregivers.

Similar observations have been reported by Sinha et al. (2020), who argue that the progressive dependence and behavioural and psychological symptoms exhibited by people with dementia constitute major sources of caregiver burden. Caregivers often encounter stigma, social isolation, and inadequate understanding from both family members and the wider community. Furthermore, limited awareness of dementia and shortages of trained healthcare professionals frequently result in delayed diagnosis and restricted access to supportive and palliative care services. These challenges compel families to manage the complexities of dementia largely on their own, thereby intensifying emotional distress and financial hardship. The authors emphasise that the economic burden of caregiving is exacerbated by the costs associated with professional caregivers, medical equipment, and home modifications, often resulting in reduced quality of life among caregivers.

Research conducted by Cheng et al. (2025) further demonstrates that the prolonged demands of caregiving significantly restrict caregivers' opportunities for employment, leisure, and social participation. Long-term caregiving has been associated with a range of adverse physical and psychological outcomes, including sleep disturbances, hypertension, chronic pain, anxiety, depression, and feelings of helplessness. In addition, caregivers frequently lack specialised knowledge regarding dementia care and often receive inadequate support from formal healthcare and social welfare systems. Nevertheless, caregivers adopt various coping mechanisms, drawing upon experiential knowledge and relying on support from family members, informal networks, and paid caregivers where available. The authors underscore the importance of respite care, counselling services, support groups, educational interventions, and coordinated support from healthcare professionals and governmental agencies in mitigating caregiver burden.

The importance of supporting caregivers themselves has received increasing scholarly attention. Koufacos (2025) argues that caregivers experience profound emotional distress as they witness the gradual decline of their loved ones and adapt to changing family relationships. Although interventions such as psychoeducational programs, counselling, support groups, and respite services can alleviate some aspects of caregiver burden, they are often insufficient to address deeper emotional experiences, including grief, loss of intimacy, guilt, and self-blame. Consequently, the author advocates for holistic and individualised approaches to caregiver support that attend not only to practical concerns but also to caregivers' emotional and psychological well-being.

The detrimental effects of caregiving on caregivers' physical and mental health have also been extensively documented. Sörensen and Conwell (2011) argue that dementia caregivers experience significantly higher levels of stress, anxiety, depression, and psychological distress than non-caregivers, accompanied by reduced well-being and self-efficacy. Behavioural and psychological symptoms of dementia, including wandering, emotional outbursts, and socially inappropriate behaviours, constitute particularly potent stressors. In addition to psychological distress, caregivers are more likely to experience sleep disturbances, elevated stress hormone levels, impaired immune functioning, increased medication use, and a heightened risk of cognitive decline. These adverse outcomes are influenced by a complex interaction of social, economic, cultural, and personal factors, including gender, socioeconomic status, social support, and access to resources. Accordingly, the authors conceptualise dementia caregiving as an important public health issue that necessitates comprehensive and multidimensional interventions.

Evidence from the Indian context similarly reveals that care-giving experiences are shaped by a complex interplay of burden, resilience, and unmet needs. Lillekroken et al. (2024) observe that family caregivers, predominantly spouses and adult children, shoulder the responsibility of long-term care in the context of limited formal support systems and poor public awareness of dementia. Caregivers frequently experience substantial physical, emotional, and social strain arising from increasing dependency and behavioural symptoms among people living with dementia, while stigma and misconceptions surrounding the condition further exacerbate caregiver burden. These challenges are particularly pronounced in rural areas, where access to healthcare services and professional support remains inadequate. Despite these difficulties, caregiving has also been associated with positive

experiences, including enhanced family cohesion, emotional fulfilment, and a sense of personal satisfaction. Nevertheless, caregivers continue to report significant unmet needs related to information, training, respite care, psychosocial support, and culturally appropriate interventions. The authors therefore emphasise the need for affordable, person-centred, and community-based support systems, particularly in underserved regions.

Taken together, the existing literature consistently demonstrates that dementia caregiving is characterised by significant physical, psychological, social, and economic challenges that adversely affect caregivers' quality of life. At the same time, caregiving may foster resilience, personal growth, and strengthened family bonds. These findings underscore the importance of recognising caregivers not merely as providers of care but also as individuals with distinct needs requiring comprehensive, culturally sensitive, and person-centred support. Greater investment in caregiver education, respite services, psychosocial interventions, and community-based support mechanisms is therefore essential to safeguarding caregivers' well-being and ensuring the provision of high-quality dementia care.

The elderly citizens with dementia and their families

The study comprises 16 dementia patients (10 women, 6 men), reflecting the age-related nature of the disorder. Six patients are aged 66–75, six 76–85, three 86–95, and one is below 65 years. Eight have lived with dementia for less than five years, and eight for more than five years. Occupational backgrounds are diverse and include homemakers (6), school teachers (3), a scientist, a lawyer, a private company executive, an engineer, a railway employee, and two bank employees.

Family composition varies: two patients belong to five-member families, seven to four-member families, six to three-member families, and one is unmarried. Eleven patients live in sub-nuclear households, either alone with hired caregivers or with a spouse, while adult children live separately. One patient each resides in a nuclear, supplemented nuclear, and supplemented sub-nuclear household, indicating urban middle-class nuclearisation and weakening traditional care arrangements.

Among the 16 caregivers, 11 (68.75%) are women, and five (31.25%) are men. Care is primarily provided by wives and daughters, while male caregivers—mainly husbands and sons—more often rely on paid assistance due to employment obligations, reflecting gendered divisions of care labour.

Most caregivers are middle-aged or elderly, well-educated, and middle-class. Household types include sub-nuclear (8), nuclear (3), supplemented sub-nuclear (3), joint (1), and supplemented nuclear (1). Fourteen caregivers are married; one is widowed, and one is unmarried, both demonstrating sustained caregiving commitment.

Female caregivers include teachers (5), homemakers (2), a nursing staff member (1), government employees (2), and a business owner (1). Male caregivers are engaged in law (2), banking (1), and the private sector (3). Twelve caregivers report financial security, while four face financial strain. Thirteen depend on hired support due to work and physical constraints, whereas three provide care personally, citing moral obligation. Financial stability mitigates but does not eliminate the emotional and economic burden of long-term dementia care.

Regarding relationships, 11 patient–caregiver dyads are characterised by cordial and emotionally supportive bonds despite impaired recognition. Three relationships are strained by illness-related stress and caregiver exhaustion, while in two cases, previously poor relationships improved following dementia-related behavioural changes. These patterns provide the contextual foundation for the case studies that follow.

The care arrangement and the caregivers

In this section, we have drawn a field view of the care arrangement for the elderly citizens with dementia and how a long course of caregiving impacts the lives of the caregivers through some case studies.

Case study 1

Mr Pijush Chanda (60) was the primary caregiver for his mother, **Mrs Ashima Chanda** (84), who died in 2021 after a prolonged period of dementia. Following diagnosis, she gradually lost the ability to recognise people and perform daily activities, alongside suffering from hypertension. She remained under the medical supervision of Dr Aniruddha Ghosh from 2015. Mr Chanda lived with his wife and daughter in their ancestral home, redeveloped into apartment-style flats housing extended family members. A graduate employed in a private company, he undertook most care-giving responsibilities, assisted occasionally by his wife, a hired caregiver for bathing and hygiene (especially during incontinence), and a domestic helper for household work.

As Mrs Chanda's condition deteriorated, care-giving demands intensified. For the last four years of her life, Mr Chanda slept in the same room as his mother due to her nocturnal confusion and wandering, and the main door was kept locked to prevent unsupervised exit. During the final one and a half years, she became completely bedridden and fully dependent for bathing, feeding, mobility, and toileting—tasks Mr Chanda performed himself with minimal delegation.

A traditional Bengali widow, Mrs Chanda adhered throughout her life to strict religious and cultural practices, including wearing white sarees, following a vegetarian diet, daily prayers, and using separate utensils. The family consciously preserved these practices during her illness: Mr Chanda's wife prepared separate vegetarian meals using dedicated utensils, and meals remained simple and consistent, facilitating care. Mr Chanda's daily routine revolved entirely around caregiving, beginning early each morning and continuing after work in the evenings, with him sleeping beside her despite severe physical exhaustion.

Mrs Chanda's memory loss followed a typical dementia trajectory. While she forgot recent events, names, and faces—including those of her sons—she consistently remembered her parents, childhood home, and early life in Dinhata and Bamanhata, and repeatedly recalled her father's name, "Nabarun Guha Neogy." Over time, even her participation in worship declined, and she often insisted she had not eaten immediately after meals, reflecting impaired short-term memory. Mr Chanda frequently remarked that he lived in his mother's house rather than the reverse, underscoring her enduring emotional centrality.

Care-giving profoundly constrained Mr Chanda's personal and social life. Friendships weakened, leisure activities ceased, and family travel became rare due to medical risks. During unavoidable travel, his sister temporarily assumed care with hired daytime help. Financial limitations restricted access to professional services, although siblings provided financial assistance during hospitalisations, and his sister ensured medication supplies. Despite exhaustion, Mr Chanda never viewed care-giving as a burden, though moments of frustration—particularly during emergencies involving incontinence—later became sources of guilt, which he reflected upon with remorse.

Mrs Chanda was remembered as a kind and generous person who treated domestic workers and marginalised individuals with dignity. This compassion was reciprocated during her illness, aided by the vigilance of Mr Chanda's

wife. The extended kinship network remained supportive, and despite the shift from joint to nuclear households within the same building, emotional closeness and family harmony largely persisted.

Following Mrs Chanda's death, Mr Chanda continues to experience profound grief and a sense of emotional void, as she had been an anchoring presence for the family. While he regrets aspects of his career, particularly prolonged temporary employment at North Bengal University, he otherwise views his life with contentment, valuing simplicity, dignity, and responsibility. In retrospect, he regards caring for his mother not as a sacrifice but as an expression of filial duty, grounded in love, respect, and sustained commitment—a perspective encapsulated in his enduring belief that he lived with his mother, rather than she with him.

Case study 2

Mrs Sumita Ghosh (59) lives with her husband, **Mr Amit Ghosh (68)**, in their self-owned two-storey house. Following Mr Ghosh's dementia diagnosis after a stroke in March 2024, Mrs Ghosh became his primary caregiver. As caregiving demands have intensified alongside her own declining physical health, this role has become a source of persistent irritation, emotional fatigue, and psychological distress.

Mr Ghosh has severe cognitive and functional impairments and requires constant supervision and assistance with nearly all activities of daily living, including dressing, bathing, eating in an orderly manner, and operating household utilities. He is unable to follow instructions independently and needs repeated, step-by-step verbal prompting even for simple tasks. His confusion, restlessness, repetitive questioning, and inability to complete tasks without guidance significantly contribute to Mrs Ghosh's frustration.

A major source of strain is Mr Ghosh's extreme dependency and separation anxiety. He follows Mrs Ghosh continuously, becomes distressed when she leaves his sight, and demands constant reassurance. This persistent need for proximity severely restricts her mobility and personal space, leaving her without respite and intensifying her irritability and emotional exhaustion.

Mrs Ghosh's frustration is compounded by her own health problems. She suffers from severe knee pain that limits her movement and ability to stand for long periods, yet she continues to perform physically demanding caregiving tasks, including bathroom assistance and constant monitoring. Although knee replacement surgery has been advised, she has postponed

it due to the absence of reliable alternative care, expressing resentment that her own health must be sacrificed. Her recurring question— “Who will take care of whom?”— encapsulates her sense of entrapment and irritation.

The presence of hired help has provided limited relief. Despite employing a cook and a maid, Mrs Ghosh remains dissatisfied with their work and feels compelled to supervise them closely, which adds to her stress. Financial constraints prevent the hiring of a full-time caregiver, reinforcing her perception of being overburdened and inadequately supported.

These cumulative pressures have altered Mrs Ghosh’s emotional relationship with her husband. She acknowledges episodes of anger and verbal outbursts, followed by immediate guilt and self-reproach. Although she understands that his behaviour stems from dementia, this awareness does not prevent emotional reactions. The transformation of her husband from a decisive authority figure into a dependent person evokes grief alongside irritation, as she struggles to reconcile present realities with earlier expectations of marital companionship.

Her daily life is dominated by repetitive and monotonous caregiving tasks— medication management, meal supervision, preparing bathing water, organising clothes, and responding to constant minor demands—leaving little time or energy for herself. Leisure activities offer only brief relief and are frequently interrupted, further deepening her frustration.

Psychologically, Mrs Ghosh reports persistent tension, irritability, and emotional depletion. Prolonged strain has manifested physically in headaches, dizziness, and neuropathic sensations, leading her to seek medical care. While treatment has reduced some physical symptoms, her emotional distress and sense of burden remain largely unresolved.

Overall, Mrs Ghosh’s narrative illustrates the affective labour of dementia caregiving, where irritation, anger, and resentment coexist with duty and moral obligation. Her experience demonstrates how continuous dependency, lack of personal space, physical pain, and inadequate support structures can render care-giving a sustained source of emotional strain marked by recurring frustration rather than overt hostility.

Case study 3

Dr Chaitali Mondal’s (74) life today is profoundly shaped by her role as the primary caregiver of her husband, **Dr Jyotinath Mondal (79)**, who

was diagnosed with dementia in December 2020. Once defined by an intensely active academic and professional life, her daily existence is now structured almost entirely around caregiving routines, emotional vigilance, and constant adaptation to her husband's changing needs.

Her care-giving begins at the most basic level of daily living. From early morning, she prepares food tailored to his needs, often modifying textures into liquid or semi-solid forms because he has difficulty chewing and frequently refuses to eat. Feeding him requires patience and persistence; he may accept only a few spoonfuls at a time, turning his face away after minimal intake. Despite the presence of a trained caregiver, Mrs Mondal prefers to feed him herself whenever possible, believing that familiarity and emotional connection encourage him to eat more. This simple act of feeding has become a central emotional ritual — an expression of care, responsibility, and intimacy.

She also closely supervises his hydration, medication, and hygiene. Earlier, when he lost control over basic bodily functions, she personally cleaned and bathed him, tasks that were physically demanding and emotionally taxing. Although a full-time nurse now assists with these activities, Mrs Mondal continues to oversee every detail, ensuring that routines are followed and that he remains comfortable and dignified. At night, she sleeps beside him while the nurse remains alert, reflecting her constant need to remain emotionally present even when professional help is available.

Beyond physical care, she invests considerable effort in maintaining his cognitive and emotional engagement. She encourages him to listen to music, recite poetry, and participate in simple exercises, often joining him so that he feels motivated. She keeps conversations going even when he does not respond, believing that familiar voices and interaction provide reassurance and continuity. These small acts demonstrate her attempt to preserve his sense of identity and personhood despite cognitive decline.

Her care-giving also extends to managing his social world. She takes him regularly to the day-care centre run by the Alzheimer's and Related Disorders Society of India, where he spends time in a structured environment. She also brings him to social gatherings, family events, and meetings whenever possible, ensuring that he remains socially connected and treated with dignity. In public spaces, she feeds him without hesitation, unconcerned about social judgment, viewing care as a natural expression of love rather than something to be hidden.

This intensive caregiving has required profound adjustments in her own life. Professionally, she has scaled back her commitments significantly. Once a frequent international traveller who attended conferences and delivered lectures worldwide, she now participates almost exclusively through online platforms. Invitations requiring travel are often declined because she cannot leave her husband for extended periods. This shift represents not only a logistical adjustment but also a personal loss of freedom and professional mobility.

Her daily schedule has been reorganised entirely around his routines. She wakes early to prepare meals and coordinate his morning care, manages household tasks during the hours he is at the day-care centre, and resumes caregiving responsibilities immediately upon his return. Even her meals are delayed until he has eaten, reflecting how her own bodily needs are subordinated to his care. Leisure activities such as reading, watching television, and pursuing hobbies have largely disappeared from her life.

Emotionally, the adjustment has been equally profound. She experiences exhaustion, loneliness, and moments of frustration, particularly when he refuses food or fluids or when the physical demands feel overwhelming at her age. Yet she also expresses a deep sense of moral responsibility rooted in their shared history. She often reflects on how he supported her career and feels a strong obligation to care for him with the same devotion. This sense of reciprocity sustains her through difficult moments, even when she questions her own strength.

Hiring a full-time nurse was itself an important adjustment. Initially reluctant, she eventually accepted the need for support due to sleep deprivation and physical strain. The presence of professional help has allowed her some rest and enabled her to maintain her own health, which she recognises as essential for continuing caregiving. Nevertheless, she remains the emotional centre of care, coordinating all decisions and remaining constantly attentive.

Her social life has also narrowed. Travel has ceased, and much of her interaction now revolves around care-giving networks, family visits, and occasional meetings. While she continues to engage intellectually through teaching and organisational work, these activities are carefully balanced with her caregiving responsibilities.

Overall, Mrs Mondal's experience illustrates how dementia caregiving reshapes everyday life through continuous adjustment — restructuring time, redefining priorities, and transforming identity. Her role has shifted from scientist and academic leader to full-time caregiver, yet she integrates these

identities through resilience and commitment. Her care-giving reflects not only practical labour but also deep emotional work aimed at preserving dignity, continuity, and connection in the face of progressive illness.

Case study 4

Ms Kabita Bhattacharya's care-giving for **Mrs Anima Roy** reflects a sustained and multifaceted commitment that combines hands-on care, emotional attentiveness, and careful balancing of multiple responsibilities. Her contribution extends beyond routine support, as she continually negotiates the demands of caregiving alongside her professional duties at school and the everyday management of the household, making care the central organising principle of her life.

In her role as caregiver, Ms Bhattacharya assumes primary responsibility for overseeing Mrs Roy's daily well-being. She manages medication schedules, accompanies her to medical consultations, and closely observes changes in behaviour or mood. She assists with personal care activities such as bathing, dressing, and meals, while maintaining a structured routine that helps reduce confusion and anxiety. Her attentiveness is reflected in the calm and secure environment she creates, ensuring that Mrs Roy remains comfortable and treated with dignity. Through constant vigilance and practical effort, she sustains the everyday functioning of care within the home.

Her care-giving also involves continuous emotional labour. She provides reassurance, companionship, and patient listening, responding gently to repeated questions, memory lapses, and moments of distress. By adapting her communication style to Mrs Roy's changing needs, she helps maintain emotional stability and a sense of familiarity. Her presence offers not only physical support but also emotional grounding, highlighting the relational depth of caregiving.

A particularly significant example of her sensitivity and creativity is her use of **Shib Baba's** name to encourage cooperation with daily routines. Knowing her aunt's strong faith, Ms Bhattacharya wrote a letter in Shib Baba's name, advising her to follow her routine, take medicines regularly, and listen to care-giving instructions. This thoughtful act demonstrates her deep understanding of Mrs Roy's belief system and emotional world, using spiritual reassurance as a gentle way to promote adherence without causing distress. It reflects how care-giving often involves moral judgment and imaginative strategies grounded in empathy and cultural awareness.

At the same time, Ms Bhattacharya carefully balances her professional responsibilities as a school staff member with her caregiving role. Managing school duties requires her to organise time efficiently, often planning care routines around her work schedule and ensuring that Mrs Roy is comfortable and settled before leaving for school. After returning home, she resumes caregiving tasks, attending to household responsibilities such as cooking, cleaning, and managing daily domestic needs. This constant movement between professional work, care work, and household management demonstrates her ability to juggle multiple roles simultaneously, often with little time for rest or personal pursuits.

These overlapping responsibilities have required significant adjustments in her own life. Personal time, social engagements, and leisure activities have been reduced or reshaped as she prioritises caregiving and household stability. Her daily routine is carefully structured around both school schedules and care needs, blurring the boundaries between professional, personal, and caregiving time. This continuous negotiation reflects the extent to which caregiving has become an all-encompassing responsibility.

Emotionally, she has had to cultivate resilience, patience, and adaptability while navigating fatigue and worry. Despite the pressures of balancing multiple roles, she maintains a strong sense of duty and compassion, gradually reshaping her identity around being a caregiver, household manager, and working professional. Her experience illustrates how care-giving transforms everyday life, requiring constant adjustment and emotional strength.

Overall, Ms Bhattacharya's contribution highlights care-giving as a complex and holistic process that involves physical care, emotional support, creative problem-solving, and the management of multiple responsibilities. By balancing her school duties, household work, and sustained care-giving — along with innovative strategies like the letter in Shib Baba's name — she ensures Mrs Roy's comfort and stability while continually adapting her own life around the moral and relational commitments of care.

Case study 5

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. The gradual cognitive decline of Mrs Bina Ganguly profoundly transformed the everyday life of her husband, Mr Krishna Kishore Ganguly,

long before she received a formal diagnosis of dementia. One of the earliest manifestations of the illness was the emergence of persistent suspiciousness and delusional beliefs, particularly her conviction that her husband was involved in an extramarital relationship. Over time, these accusations became a regular feature of their daily life, disrupting the emotional stability and companionship that had characterised their marriage for decades. Routine activities such as attending professional meetings, going out for errands, or even taking a morning walk often became sources of conflict, as Mrs Ganguly interpreted his absence as evidence of infidelity. She repeatedly questioned his whereabouts and intentions, and on difficult days, telephoned him with accusations that left him emotionally distressed and unable to concentrate on his work. Frequently, he found himself abandoning professional commitments and returning home early to reassure and comfort her.

The unpredictable nature of these episodes imposed a heavy emotional burden on Mr Ganguly. At times, his wife accused him of concealing another woman inside their home and publicly refused to share a bed with him. Such incidents caused profound anguish and gradually eroded the sense of mutual trust that had sustained their relationship. Initially unable to understand the pathological basis of these behaviours, he often reacted with frustration, resulting in frequent arguments and emotional turmoil. However, following the diagnosis, he came to recognise these behaviours as symptoms of dementia and gradually adopted a more patient and compassionate approach, responding to her accusations with reassurance and calmness rather than anger.

The consequences of his wife's suspiciousness extended beyond the household and deeply affected his social life and personal dignity. Because Mrs Ganguly was a respected and influential figure within the family, many relatives believed her allegations without question. Consequently, Mr Ganguly experienced humiliation, damaged relationships, and social isolation. Some family members distanced themselves from him, while others questioned his moral integrity. Despite his repeated attempts to explain himself, he found that every defence seemed only to reinforce the suspicions of others. The experience left him feeling helpless and emotionally exhausted, and he later regretted that his preoccupation with protecting his reputation prevented him from recognising the medical nature of his wife's behaviour earlier.

Alongside these emotional and social challenges, caregiving gradually became the central organising principle of Mr Ganguly's daily life. Despite

being in his seventies and managing his own health concerns, he structured his routine around his wife's needs. His day begins with a morning walk, followed by household responsibilities and professional work. He shares breakfast, lunch, evening tea, and dinner with his wife, ensuring that she never feels neglected or alone. Whenever he is at home, he spends time watching television with her, taking leisurely walks around the residential complex, and engaging in light-hearted conversations intended to bring her comfort and happiness.

As dementia progressed, Mr Ganguly assumed increasing responsibility for coordinating every aspect of his wife's care. Although a full-time caregiver assists with household tasks and supervision, he remains actively involved in managing her treatment and well-being. He carefully supervises her medication schedule, ensures that her daily needs are met, and instructs the caregiver regarding bathing, dressing, meal preparation, and safety precautions. His concern extends to seemingly minor details, such as ensuring that her bed is properly prepared, that she is supervised while using the bathroom, and that she remains protected from infections, which could further aggravate her condition.

Mr Ganguly also makes deliberate efforts to preserve his wife's identity and quality of life. Aware of her lifelong passion for music, he encourages her participation in Rabindra Sangeet programmes and often uses music therapeutically during periods of agitation and suspicion. Similarly, despite her diagnosis, he continues to travel with her, believing that journeys and new experiences bring her immense joy and emotional rejuvenation. Their shared love for travel and the frequent visits of their granddaughter remain important sources of happiness amidst the challenges of caregiving.

The cumulative effect of years of caregiving, emotional distress, and social humiliation inevitably affected Mr Ganguly's own well-being. Chronic stress disrupted his sleep and contributed to unhealthy habits, including excessive coffee consumption. Recognising the importance of maintaining his own health, he gradually incorporated morning walks and healthier routines into his life, realising that caring for himself was essential to caring effectively for his wife. Nevertheless, the emotional scars left by nearly a decade of mistrust and public humiliation remained profound. His life was marked not by a single moment of crisis following the diagnosis, but by a prolonged period of psychological suffering and caregiving that began years earlier with the subtle onset of cognitive decline.

Despite the immense emotional pain, social humiliation, and disruption to his personal and professional life, Mr Ganguly never abandoned his role as a husband and caregiver. Rather, his commitment to his wife deepened with time. He continued to prioritise her happiness, dignity, and well-being, providing constant emotional reassurance and unwavering support. His experiences illustrate how dementia affects not only the person diagnosed but also profoundly reshapes the everyday lives of family caregivers, exposing them to chronic stress, social stigma, emotional suffering, and the demanding responsibilities of long-term care. At the same time, his journey reveals the enduring power of marital commitment and the quiet resilience with which many spouses navigate the complex realities of dementia care.

Case Study 6

Following his father's diagnosis with dementia, Mr Arindam Sen's (49) everyday life underwent a gradual yet profound transformation as caregiving increasingly became intertwined with his professional and personal responsibilities. As a human rights journalist whose work demanded extensive travel and frequent assignments across India and abroad, he found it increasingly difficult to reconcile the demands of his career with the growing need for consistent supervision and care. Consequently, he began to reorganise his professional life, reducing long-distance travel and prioritising assignments that allowed him to remain close to his father. What had initially been periodic visits from Bangalore to Kolkata soon evolved into frequent journeys, constant telephone communication, and the meticulous coordination of medical consultations, medications, and caregiving arrangements.

As his father's cognitive decline progressed, Mr Sen made the difficult decision to relocate permanently to Kolkata, recognising that remote management was no longer feasible. His daily life gradually became organised around his father's needs and routines. Alongside overseeing a team of caregivers, he remained actively involved in every aspect of care, ensuring that his father received not only appropriate medical attention but also emotional security and dignity. Night-time episodes of confusion frequently required him to wake up and gently escort his father to the bathroom, reassuring him when feelings of shame and helplessness overwhelmed him. Repeated questions, memory lapses, and increasing disorientation demanded immense patience and emotional resilience, requiring him to constantly adapt his responses to his father's changing condition.

With the progression of the illness, new challenges emerged. Mobility problems, incontinence, and the gradual loss of independence transformed ordinary daily activities into demanding care-giving tasks. Feeding required constant vigilance to prevent choking, while personal hygiene and physical comfort necessitated increasing dependence on professional caregivers. Nevertheless, Mr Sen remained deeply engaged in preserving his father's quality of life. He read newspapers and books aloud, played his favourite music, engaged him in conversations, and even took him on short trips whenever possible, believing that familiar routines and meaningful experiences could provide comfort amidst the progression of the disease.

The caregiving journey was emotionally taxing and marked by persistent anxiety, grief, and feelings of helplessness. Witnessing the gradual decline of a once intellectually vibrant and independent father was profoundly painful. Medical emergencies, sleepless nights, repeated hospitalisations, and the inevitability of cognitive deterioration posed continuous emotional challenges. Yet, rather than allowing frustration to dominate his relationship with his father, Mr Sen consciously cultivated patience, empathy, and acceptance. He came to understand that the repetitive behaviours, confusion, and dependency were manifestations of the disease rather than expressions of intentional behaviour. Consequently, he approached care-giving with compassion and emotional sensitivity, striving to preserve his father's dignity even in the most vulnerable stages of life.

Ultimately, care-giving reshaped not only Mr Sen's daily routine but also his emotional world. It altered his professional priorities, demanded significant personal adjustments, and exposed him to the psychological burden of witnessing the gradual erosion of a loved one's memory and autonomy. Yet, despite the emotional strain and practical challenges, he viewed caregiving not merely as a duty but as an expression of gratitude, love, and filial responsibility. His experiences illustrate how dementia transforms the everyday lives of family caregivers, requiring continual adaptation, emotional endurance, and an unwavering commitment to preserving the humanity and dignity of those living with the disease.

The key observations

The following concluding observations may be drawn from this paper. The findings highlight the complex and multifaceted nature of care-giving, shaped by emotional, social, and structural factors. The cases discussed illustrate how care-giving roles are negotiated within family contexts and how

individuals adapt their personal and professional lives in response to care responsibilities. Overall, the study underscores the significance of resilience, reciprocity, and moral commitment in sustaining long-term care within the family. The key observations are outlined below.

First, Dementia is an age-related, progressive, and largely irreversible neurological–cognitive disorder which is characterised by a gradual decline in memory, reasoning, language, and the ability to perform everyday activities. As the condition advances, it significantly impairs an individual's capacity to function independently, often leading to increasing physical, emotional, and social vulnerability. Consequently, many older adults living with dementia become heavily reliant on caregivers—typically family members—for assistance with daily routines, decision-making, and emotional support, making caregiving a central component of their long-term care. Traditional extended-family care systems are in decline due to smaller family sizes and the dispersal of younger generations.

Second, Care responsibilities are typically borne by one or two family members—often an ageing spouse or close relative—sometimes supplemented by paid caregivers. While hired caregivers play an important role in meeting physical and practical needs, persons living with dementia often place greater trust in family members, whose care is grounded in longstanding emotional bonds. Although paid caregivers may perform their duties with empathy, the unpredictable behaviours and mood changes associated with dementia can occasionally lead to frustration and expressions of irritation. Family caregivers, by contrast, generally strive to respond with greater emotional sensitivity, making conscious efforts to manage their own frustration to protect the dignity and feelings of their loved ones.

Third, Relatives who live apart and away, such as siblings or married children, provide limited yet important support to older adults living with dementia. Owing to geographical dispersion and work and family commitments, their involvement is often confined to periodic enquiries about their parent's health, financial contributions for treatment and medication, and occasional visits. In times of emergency, they may temporarily rearrange their schedules or travel home to assist and, when possible, spend brief periods of meaningful time with their parents.

Extended kin networks similarly offer episodic support, particularly financial assistance during crises, but their relationships often lack depth and regular contact due to distance and competing responsibilities. Their engagement is therefore largely shaped by a sense of obligation and moral duty rather

than sustained emotional closeness. Overall, while extended family members contribute to the broader care network, their involvement tends to be intermittent and less emotionally intensive than that of primary caregivers.

Fourth, Core caregivers experience profound life changes, including reduced social engagement, career adjustments, restricted mobility, and the reorganisation of daily routines. Typically, these primary caregivers are spouses or adult children who must balance employment with caregiving responsibilities. Adult children often seek transfers or new employment closer to home to care for an ailing parent, while spouses negotiate workplace flexibility to manage emergencies.

Care-giving responsibilities significantly curtail social participation and leisure activities, as caregivers prioritise time at home over outings, travel, and social gatherings. Mobility is similarly restricted, with many caregivers foregoing extended travel due to concerns about the comfort and safety of the person with dementia. Consequently, long trips are often abandoned or shortened considerably.

Daily routines undergo substantial restructuring. Adult children frequently assume morning and evening caregiving tasks alongside their professional duties, while spouses take on continuous supervision of health, nutrition, mobility, and sleep, in addition to managing household and external responsibilities. As care-giving intensifies, caregivers' personal priorities, social lives, and even their own health often recede into the background, with their lives increasingly organised around the needs of their loved one.

Fifth, in the first case, a middle-aged son cared for his mother as a sacred duty, accepting personal sacrifices without regret and experiencing deep loss after her death. In the second, a wife cares for her dependent husband despite financial strain, physical illness, and psychological distress arising from his total dependence and cognitive decline. In the third case, a renowned scientist relinquishes her academic commitments to care for her ailing husband, who had long supported her career and sacrificed his own professional opportunities. She devotes herself entirely to caregiving while grappling with profound guilt, reflecting that her earlier career focus limited the time she spent with him and contributed to her overlooking his health needs and early signs of memory loss. In the fourth case study, a schoolteacher assumes primary responsibility for caring for her elderly aunt (*pishi*) living with dementia while also supporting her ageing parents within the same household. Drawing on her professional skills and patience, she effectively balances her occupational duties with her caregiving role by

developing adaptive and creative strategies to maintain her aunt's daily routine, health, and emotional well-being. Alongside these responsibilities, she also fulfils the roles of a single mother, a committed educator, and a caring daughter and niece, managing multiple demands with remarkable competence. Rather than perceiving dementia solely as a constraint, she approaches it with empathy and optimism, viewing caregiving as a meaningful responsibility. Her resilience, emotional strength, and positive outlook emerge as crucial resources that not only sustain her in addressing the complex demands of the caregiving task but also contribute significantly to her aunt's sense of comfort and stability. The fifth case study reveals how dementia-related behavioural symptoms can profoundly reshape the everyday life of a spouse, exposing caregivers to prolonged emotional suffering, social stigma, and the burdens of long-term care even before a formal diagnosis is made. It also highlights how marital commitment and compassionate caregiving enable spouses to sustain their partner's dignity and well-being despite years of humiliation, stress, and personal sacrifice. The last and final case study reveals how dementia caregiving profoundly restructures the everyday lives of adult children, compelling them to make significant personal and professional adjustments while enduring emotional strain and prolonged uncertainty. It also highlights how care-giving becomes an expression of love and filial responsibility, sustained through patience, compassion, and a commitment to preserving the dignity and quality of life of the person living with dementia.

Sixth, overall, the first case shows relatively stable family structures and care values, the second highlights significant stress in both household arrangements and Care-giving norms, the third case shows how care-giving can involve role reversal and sacrifice, and how professional commitments may lead to feelings of guilt and reflection when caring for a loved one. The fourth case illustrates how resilience and a positive attitude help caregivers manage multiple roles and see care-giving as meaningful rather than burdensome. The fifth case study highlights how dementia reshapes the lives of spousal caregivers through emotional distress, social stigma, and long-term caregiving, while underscoring the sustaining role of marital commitment and compassion. The last case study reveals that dementia caregiving profoundly reshapes the lives of adult children, requiring major personal sacrifices and emotional endurance, while reinforcing caregiving as an expression of love and filial responsibility.

Conclusion

In conclusion, this study demonstrates that dementia caregiving within families is a deeply complex social process shaped by emotional bonds, moral obligations, gendered expectations, and structural constraints. As traditional extended-family support systems continue to weaken due to demographic and socio-economic changes, the burden of care increasingly falls on a small number of primary caregivers, most often spouses or adult children. While paid caregivers and extended kin contribute in supplementary ways, the emotional labour and sustained commitment required for long-term care remain largely embedded within close family relationships.

The findings further reveal that care-giving is not merely a set of practical tasks but a transformative life experience that reshapes caregivers' identities, routines, social participation, and professional trajectories. Across the cases, care-giving emerges as simultaneously a source of strain, sacrifice, and emotional hardship, as well as meaning, reciprocity, and moral fulfilment. Variations across cases highlight how differences in family structure, resources, personal outlook, and prior relationships shape care experiences, producing outcomes that range from stress and guilt to resilience and personal growth.

The paper underscores that sustaining dementia care within families depends not only on emotional commitment but also on adaptive strategies, supportive relationships, and the capacity to negotiate competing responsibilities. Recognising both the burdens and the meaningful dimensions of care-giving is crucial for developing a more nuanced understanding of family care, as well as for informing policies and support systems that acknowledge caregivers' vital yet often invisible labour.

Finally, it is for us, the social scientists, to understand that the larger social crises rooted in the larger economic, political and social arrangements impact the lives of the family members who confront ageing-related ailments like dementia and are left to find a care arrangement while performing as the key caregivers. It is for us to understand that the problem that appears minuscule now can turn into a major social crisis, and if the crisis is social (not local or familial), the approach to the solution has also to be grand.

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