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Burnout in caregivers of patients with alzheimer's disease in India: a case-based approach

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Introduction

Alzheimer's Disease (AD), named after Dr. Alois Alzheimer, who first discovered the disorder in 1906, is among the most common neurodegenerative disorders of memory found in older adults. This devastating disorder characterized by neuritic plaques, neurofibrillary tangles leads to progressive cognitive impairment leaving patients completely dependent on caregivers. Patients initially present with deteriorating memory and thinking abilities. As the disease progresses relentlessly critical cognitive functions are lost making patients unable to perform activities of daily living (ADL). In the later stages of AD, patients develop prosopagnosia, loss of speech, personality and behavioral changes, and disruptive hallucinations and illusions. While clinical trials are ongoing, at present, there is no definitive cure for AD. It can only be *slowed down* with acetyl-cholinesterase inhibitors and cognitive rehabilitation strategies.

Caring for a patient with AD, whether by family members or by trained nurses and healthcare workers, comes at a significant physical and emotional cost. For families, it also causes a significant financial burden. As a result, care

givers frequently report stress and symptoms of burnout. A burnt out caregiver does not only pose a threat to their own physical and mental health, but also to the health of the patient due to lapses in caregiving. In extreme cases, a burnt out caregiver may even consciously or subconsciously abuse the patient (caregiver abuse). Therefore, it's crucial that physicians discuss and address the needs of the caregiver while managing care for the patient with AD.

Case report

A 79-year-old female, hereby referred to as Mrs. Y, was diagnosed with late stage (advanced) Alzheimer's dementia. She had three children – two daughters and one son. One daughter lived close to her and was her primary caregiver (hereby referred to as Mrs. A), whereas the other two children lived abroad and were largely uninvolved in her care. Mrs. A, the primary caregiver was married, working and had a family of her own. On a recent visit to the neurologist, she reported that her mother's condition had advance and she had begun wandering off to neighbors' houses, getting violent with the help (a full time maid and a part time nurse). She was disruptive at times, shouting and screaming, turning on the TV loud at night. During the patient interview, it was noted that Mrs. A appeared exhausted, exasperated and discouraged with respect to her mother's deteriorating condition. During a visit with the neuropsychologist Mrs. A admitted to being under high levels of stress and even admitted to wishing that her mother's life would end soon. She refused the option of admitting her mother to a dementia care centers or an old age home.

Discussion

With increasing life expectancy, the global burded of neurodegenerative disorders of memory such as dementias is expected to rise exponentially. According to the World Health Organization (WHO), globally, 135 million people are likely to have dementia by 2050. This is an exponential increase from 47 million in 2015. In India, the situation doesn't look any better. Being one of the most populous countries, India is headed toward multiple challenges associated with an aging population. According to a 2023 report by NIH's Fogarty International Center, the prevalence of dementia among adults aged 60 and above in India is 7.4%, which means about 8.8 million older adults are currently living with dementia.[1] This is a significant increase from 5.3 million, as per the Dementia in India 2020 report.

Such a rapid increase in dementia prevalence in India brings forth challenges of increased caregiver distress, burden and burnout Caregiving is a physically demanding and emotionally strenuous process, which can and often does lead to burnout. Burnout, as defined by the American Psychological Association (APA), refers to physical, mental, and emotional exhaustion, accompanied by decreased motivation, lowered performance, and negative attitudes toward oneself and the person who is been cared for. While a number of studies have looked at caregiver burnout in the West, few have acknowledged the topic in the Indian context.[2,3]

A glaring problem with respect to dementia in India is that due to lack of education and awareness, the early signs and symptoms of AD are often considered normal age-related memory decline. It is only when the disease has progressed to the moderate and advanced stages, when neuropsychiatric symptoms become prevalent, that family members become alarmed and seek medical attention. These neuropsychiatric symptoms, characterized by apathy, distorted perception and thought content, and mood and behavioral changes, make AD very challenging for caregivers. Research has also shown that caregiving for a AD patient has a detrimental impact on the caregivers' physical, emotional and mental health as compared to caregiving for other chronic illnesses.[4]

Caregiving experiences are profoundly shaped by prevailing social and cultural milieu. The Indian context favors family values, respect and regard for elders, and collectivist philosophy as opposed to the individualist philosophy promoted in the West. As a result, family members take it upon themselves to care for their elders with Alzheimer's or other dementias rather than admitting them to dementia care centers or palliative care homes. Even in the face of burnout and exhaustion, they continue to prefer home-based care for their loved ones, as was the case in Mrs. A caring for her mother Mrs. Y. The biggest concern that is often expressed by caregivers when given the option of care homes, particularly by the children of patients with Alzheimer's in India, is the guilt of abandoning their parent(s) in their time of need.

Caregiving is often seen as a sacred duty of children toward their parents in the Indian context. This strongly held belief of caregiving while experiencing physical, mental, and emotional toll of burnout can create a sort of cognitive dissonance among individuals caring for their parent(s) with AD. This further adds to the stress and psychological maladjustment. More often than not, the responsibility of caregiving falls disproportionately on women in the family (wives and daughters), as was also the case for Mrs. A. However, with family values being a great driver of Indian society, caregiving is not always seen as a negative experience. Grover et al.[5] looked at the positive experiences of caregiving, attributing it to personal and spiritual growth and a way of strengthening familial bonds. On the flip side are the abuse-prone caregiving practices stemming as a result of burnout.[6]

Regardless of whether caregiving is perceived as a positive or negative experience, India desperately needs awareness programs, support and respite services in place for patients and caregivers. Interventions and strategies for managing caregiver burnout involve awareness and training programs to increase education about AD for early detection and management. Positive social support, accessible and adequate public health resources, professional help and supportive counseling services, meditation and yoga are also effective strategies for preventing and managing caregiver burnout.

As scientists and researchers around the world endeavor to find a cure for Alzheimer's, developing interventions and programs to manage caregiver distress remains an equally important task, especially in India. One such undertaking proposed by researchers at the National Institute of Mental Health and Neurosciences (NIMHANS) and National Ageing Research Institute (NARI) is called "Moving Pictures India", a digital media resource to improve dementia care in India.[7]

Conclusion

Caregiver burnout is a significant yet under-addressed issue in the context of Alzheimer's disease in India. The cultural emphasis on familial duty and collectivist values often compels caregivers to prioritize home-based care, even at great personal cost. As seen in the case of Mrs. A, the physical, emotional, and psychological toll of caregiving can lead to profound stress and cognitive dissonance. While caregiving may bring personal growth and stronger familial bonds, the lack of awareness, resources, and institutional support exacerbates the challenges caregivers face. Comprehensive interventions, including education, professional counseling, and public health support, are essential to alleviate caregiver burden and enhance the quality of dementia care in India.

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Conflicts of interest

The authors declare that there are no Conflicts of interest.

Disclosures

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