

Caregiver Burden and Stress in Caregivers of Stroke Survivors: Relevant but Neglected

With approximately 150 billion population and rapid urbanization, India has become the hub of noncommunicable lifestyle diseases. In a large cross-sectional study with a sample size of over a million, Pascal Geldsetzer *et al.*^[1] found the point prevalence of hypertension and diabetes to be 25.3% and 7.5%, respectively. Notably, they found the prevalence of hypertension in the 18- to 25-year-old age group to be 12.1%. This highlights the risk of stroke in the Indian population as a whole and among the young population. Stroke is one of the most common neurological disorders with a higher prevalence in India than in the United States or Europe.^[2,3] Unlike any other chronic disease, stroke is often associated with significant disability and improvement of functional status requires a long time. In addition, there is a significant financial burden too. What is often neglected in stroke care is caregiver burden and stress. Earlier studies have implicated various patient- and caregiver-related factors, which contribute to caregiver burden and stress. However, many of the factors are related to the sociocultural habits of the region where the studies were conducted.

In a study conducted by Anand Kumar *et al.*^[4] in a tertiary care hospital in India, patients with first-ever stroke were followed up periodically for up to 6 months and caregiver stress and burden were assessed with established questionnaires. It is an interesting analysis considering the different social, cultural, and demographic scenarios in the subcontinent compared with Western countries. The World Health Organization (WHO) definition of stroke was followed, and both ischemic and hemorrhagic strokes were included. 251 subjects with first-ever stroke were recruited, of whom 141 completed 30-day follow-up and 119 completed 6-month follow-up. The caregivers were around 20 years younger than the patients. Spouses were the caregiver in most instances followed by children and daughter-in-law. Spouse and children were the primary caregiver in most published studies.^[5] However, daughter-in-law is a major group of caregivers in this study, which is likely due to different social structures in the subcontinent. Previous studies from India also showed a similar trend of caregivers.^[6] A Higher National Institutes of Health Stroke Scale (NIHSS) score and more disability at 30 days were associated with greater caregiver stress, which is self-explanatory. Among caregiver factors, the requirement of prolonged time of care, sleep disturbance, and financial burden had a significant impact on caregiver stress. Oberst caregiving burden score assessing areas where patient needs to be supported, showed providing nursing care, emotional support, transport facility, managing finance and managing behavioral issues were associated with significant caregiver stress. The caregiver strain index showed that all adjustments

made by the caregiver are associated with significant stress, which decreases steadily over time. With time, the caregiver adjusts to the condition, and also, there occurs improvement in the functional status of the patients, which explains this trend. In terms of factors associated with caregiver burden, both patient- and caregiver-related factors are similar in previous literature with little difference related to customs and society.^[5,6]

In developing countries like India, it is financially and logistically not possible for most to keep a patient for long in a healthcare facility for rehabilitation and supportive care only. So, a caregiver at home plays a major role in long-term care and rehabilitation in most of the cases. Indian culture and tradition of joint family are a boon in this aspect, as a shared responsibility among many family members in looking after the stroke survivor may decrease the individual burden. However, with urbanization, the nuclear family is increasing rapidly. As physicians, while treating stroke we often miss to address caregiver burden and stress, and in the long term, this can be counterproductive to patient care and outcome. Training the caregivers regarding feeding, tracheotomy care, mobilization, and communication in aphasic patients during the hospital stay itself may help alleviating anxiety and burden up to some extent. It would be beneficial to counsel the family to involve multiple family members in providing care of the patient to avoid the burnout of a single caregiver. It is important to set realistic goals regarding mobility, and attaining independence in self-care of the patient and family members should be involved in setting those goals. This would prevent caregiver fatigue to some degree. The involvement of community health centers in the reinforcement of physiotherapy and emotional support of caregivers may help. Caregiver burden and stress in stroke are one of the deciding factors in good outcome for the patient and would require the involvement and willingness of all stakeholders—treating physician, all family members, and community health services to address this very relevant but neglected issue.

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