

Caregivers' Perspective on Home-based Care of Operated Neurosurgery Patients Discharged From PGIMER, Chandigarh, India

“My son left his studies after 7th standard to take care of his mother at home.” said a 45-year-old father with tears in his eyes. “I am tired of my life. I come home for four hours only. But sometimes I feel like leaving home.” says a 50-year-old female caregiver. Post-operative neurosurgery patients need special care at home. After the operation, attendants of patients usually remain enthusiastic regarding caregiving. The constant support and supervision received from doctors and nurses during the hospital stay keep them hopeful about the recovery of their patients. Home care brings liberation of the patients from hospital pressure. However, it increases the responsibility of the caregivers. At home, caregivers play an important role in post operative recovery of the patients. Long-term care at home can be provided either by family members of affected individuals or professional caregivers. Family members provide more than 90% of long-term care in India. Some people believe that primary responsibility of care for disabled person lies with individual and their families. Whereas another concept from some countries from Europe and Japan has a different perspective that a disabled relative/family member should not result in undue financial and care burden for the family. Indeed, the enactment of the new social insurance program in Japan was a deliberate decision to shift the burden of long-term care from the family to society as a whole. But long-term care of patient in India is usually a family affair. Indian value system places a high focus on family ties. Despite many transformations in the nature of families in Indian society, caring for the sick and injured is still one of the functions of family. While fulfilling the need of patient and caring at home, caregivers also go for jobs and earn their living. Most of the times, caregiving at home and other responsibilities lead to deterioration of caregivers' health as well. High strain in giving care to their patients leads caregivers to neglect their own needs. Psychological symptoms like depression and suicidal thoughts are also reported in caregivers. Higher

levels of depressive symptoms and mental health problems among caregivers than their non caregiving peers have been reported in literature. Increased burden further deteriorates health of caregiver and patient in the vicious cycle.

Although family caregivers provide extraordinary uncompensated care, they feel untrained and unprepared. Concept of private attendants/community health care/nursing care in home care after operation is almost missing from India. Trained attendants are seldom available in our society and if present, it is beyond the reach of majority of such families. Insurance schemes are still in budding phase. Only viable options left are to train family caregivers or build a cadre of professional caregivers. Training of family caregivers can be arranged in hospital settings by involving nursing staff at the time of hospital stay of patients through a self instruction manual. Preventing the so-called catastrophic effects to the caregiver health should be the focus area while designing a caregiving program. Experiences from countries where there are care-providing agencies and mode of training family caregivers are available reveals decrease in problems for both caregiver and patients. This will definitely reduce stress from the caregivers. Stress-free caregivers can take care of themselves and their patients as well. Evidence suggests that when patient and family have a better understanding of their diagnosis and treatment, they are more able to cope with their illness, use the health system more effectively, and have less psychological distress.

A cadre of professional caregivers also needs to be built. Training modules can be made according to need of patients and caregivers. Tertiary care institutes in India can start initiatives in this area of home based nursing and to support family caregivers for better clinical and social outcome.

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DOI:

10.4103/0973-1075.156513