

Long Term Care of Older Indians: Emerging Scenario

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Older Indians prefer to live and age at the place where they have spent most of their lives. While health services are available in public health or private health services, the care of the elderly is a responsibility of the family. Families still have the resilience to take care of its old and infirm despite lack of resources. At some point of time every individual especially in old age would lose his or her ability to survive independently due to limited mobility, frailty, decline in physical health due to various acute or chronic disease or dementia. With loss of autonomy, the individual is dependent on others for pursuing basic activities of daily living and may require assistance some form of long-term care. It has been a common observation in clinical practice that older people prefer to die in their homes rather than in hospital or hospice. A recently concluded ICMR study at All India Institute of Medical Sciences revealed that 70% of patients who died after attending the emergency department died in their home indicating the importance of developing home care services for sick older persons.¹

As per 60th Round of NSSO, 8% of those above 60 years and 27% of persons above the age of 80 years are home bound or bed bound.² Extrapolating these figures to current population one arrives at a figure of 8 to 10 million Indians, who are home or bed bound. There is a need to distinguish home bound persons from bed bound persons. While the home bound persons are likely to be disabled with locomotor or visual disability, the bed bound persons are most likely to be completely or partially dependent on care givers. The care requirement in each group would differ substantially. The home bound persons would require assistance in instrumental activities of daily living (IADL) while a bed bound person would require assistance in basic activities of daily living (BADL). However, in either case these individuals are in need of assistance and care from family members and formal care givers.

Long-term care of the bed-bound elderly is a challenging task in view of the variable length and quantity of such care. It is more so if the patient has dementia or a paralytic disease. Even a frail elderly with intact cognitive capacity may need intense care. Three issues are of great importance in long-term care: i) assistance in activities of daily living, especially personal hygiene; ii) treatment of chronic diseases and disabilities; and iii) acute health problems which are often unanticipated and disturb the stability of the care mechanism.

Institutional long-term care is virtually nonexistent due to cultural and economic factors. In Indian society, inter-generational relationships, caring, ill health, etc. are considered private issues and generally kept within the confines of the family. Thus, long-term care is mostly home-based. The family with or without paid help would provide the physical care whereas the local general practitioner is the main source of medical care at the community level. The sustainability of such a model has been a matter of debate as well as concern in view of the rapidly changing societal norms. The economics and logistics of institutional long term care are often unmanageable. Following issues related to long term care need to be considered in Indian context.

- The quantum of care depends on whether the patient is cognitively intact or not. Dementia patients need greater volume of care and are difficult to manage.
- Both public and private hospitals being acute care set up with pressure on bed availability do not participate in long term care.

- Old age homes do a detailed health assessment before admitting older persons. In the event of the individual suffering from a major health problem and loosing independence, many of these homes would force the family member/ next of kin to withdraw the inmate from their service, while charitable homes would continue to care.
- Hospices are available in India but mostly for cancer patients.
- There is virtually no institution that admits dependent person requiring minimal medical care and maximal nursing care for unforeseen period of time, except charitable organizations and hospices that to only those persons who are likely to die in foreseeable future.
- Day care services are very few and there are very few takers for such service.
- There is no financial mechanism for supporting long-term care in India.

Resources permitting, most families in this situation would employ a formal care giver. Retaining such workers for long period of time may not be feasible in view of the monotonous nature of work. In recent years, providing care givers who may be considered as contractual labor has turned into a commercial venture. There are institutions that train care givers and organize their employment. The social defense policy of the Ministry of Social Justice and Empowerment has supported financially such institutions for training of care givers. However, most of these programs have been difficult to sustain.

There has been a recent surge in interest of private corporate hospitals in old age care including long term care. Some innovations by private/NGO sector operators in long-term care are worth examining, though none of these have been independently substantiated.³⁻⁷ These services come with a considerable cost and no independent assessment has been carried out for quality assurance and cost effectiveness of their services. But most of these services are heavily medical-intervention oriented and in reality mean prolonged post acute care rather than long term care.

Home care and long term care for older population have attracted young entrepreneurs as business opportunity. Several startup companies with different business models have been launched in last two years and many more are joining. One of the common models is to target older relatives (parents and grandparents) of non-resident Indians located in Western Europe, North America and Australia. The firm would offer guaranteed 24 x 7 services for all health and social problems for a fee. The emigrant family members would be assured that their relatives would be cared for. The other model which is purely health service oriented provide all services available in a hospital (except invasive interventions) through their web site and "Android or Google Apps". These services can be generic for all age groups or age specific. Unlike the earlier model no long term relationship is created. It is too short a time to assess their impact on home care and long term care, but the model makes sense from health care provider's point of view.

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