

Where to Care Older Adults with Dementia?

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Introduction

Most of the patient with Alzheimer's disease and other dementia may become dependent on the caregivers/family members with the natural progression of the disease severity. In addition, these patients frequently have Behavioral and Psychological Symptoms of Dementia (BPSD), which have been found to be associated with significant caregiver's burden and increased Nursing Home (NH) placement [1]. With the increasing severity of cognitive impairment of the patient and BPSD, the caregiver's burden worsened further [2]. The family members frequently experience protracted stress and physical demands, which consequently leads to psychiatric morbidity, physical health problems and poor quality-of-life among them [3,4].

There are multiple factors demographic characteristics, level of cognitive impairment, physical functioning, Activities of Daily Living (ADL), presence of BPSD, financial status, the need for more skilled care/assistance, characteristics of the patient and caregiver together, socio-cultural issues, the caregivers' health, relationship between the patients and their family members, perceived burden of the care giving and availability of long term care facilities which predict NH placement of the patients with Alzheimer's and other type of dementia [5-8]. A reduced health-related Quality of Life, increased burden of care-giving task and relatively poor health of caregivers are among the most important predictors for nursing-home placement of patients with dementia [8,9].

There are advantages and disadvantages of keeping the patient in NH/long term care facilities versus the individual's home for long term care. "Whether older adults with dementia should be cared at their homes or in NHs/long term care facilities?" is a question or dilemma that frequently prevails in present scenario when the primary caregiver has to decide about the placement of the patient with dementia.

Advantage of Nursing Home

The NHs or long term care facilities have their own advantages as to provide structured and safe atmosphere under the supervision of skilled nursing staff, social worker, dietician, and physicians. Adequate diet, hygiene, regular physical activities and medical checkups may help them to maintain optimal physical health. In addition to multiple health related activities, the residents at NH also have opportunity to interact with the people of same age group along with to have various sources of entertainment. The one of the biggest advantages is that the enormous burden of care has been taken off from the caregivers' shoulders [1]. Consequently, the family members have quality time for their own health and recreation. The NH/ long term care centers also serve as safe haven for those older adults which are victims of abuse by their family members at their own home.

Advantage of Home

Many believe that the home is the best place for the care of these people because they have the opportunity to live with their family members who supposedly understand their needs best both at physical as well as emotional level. The elderly persons even with significant cognitive impairment have a sense of familiarity, comfort and freedom in their own home resulting in less behavioral problems in comparison

to old age homes/NH where they have an institutional feel that may cause stress with many patients. When given the option between the two, the majority of patients will choose to stay home over a facility.

It is not only human beings living in a house, but also various objects related to house, the house itself and its surroundings where an older adult has spent a major part of his/her life are also significantly important to most of the older adults. In many Asian countries like India, China, Bangladesh etc., people prefer to live and die at their home/village during their last years of the lives rather than going to any hospital or institution for long duration. As joint families are common in these counties, the burden of care is shared among the caregivers with least disturbances in their routine activities and jobs. The patients are also benefited because of opportunity for productive interaction with various family members of different age groups.

Disadvantage of Nursing Home

The patients at NH not the equivalent not only lose the freedom but also the opportunity to have frequent interaction with their friends, relatives, family members and neighbors. Many of them face difficulty adjusting in the new environment of NH, and keep longing for going back to their home even when they have moderate to severe dementia. Being in NH means that the patient is kept away from the things/stuff, environment and people to whom he/she is so emotionally connected.

Nursing staff many time act in mechanical way without any emotional input. In addition, frequent turnover of the staff at NH add the miseries of these older patients. Significantly low levels of satisfaction regarding have been expressed by the elderly persons residing in NH as well as their family members [10]. A study also reported accelerated short-term cognitive decline in Alzheimer's disease following NH placement of the patients [11].

While Alzheimer's Type Dementia has profound indirect costs, the combination of a high rate of NH entry and lengthy stays of these patients add the financial burden not only on the individuals but also on the health care system of a country [12]. Moreover, these facilities are either not affordable to the most of the people in developing countries because of inadequate financial recourses and unavailability of insurance policies to cover the cost of care in the NHs or not available in most of the cities.

Disadvantage of Home

There is a dark side as well of keeping the elderly with dementia at

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the home. The caregivers are the ones who bear the brunt of enormous burden of care. In addition, it might be overwhelming stressful, for the caregivers of nuclear family, specifically if all the caregivers are working. Now another important aspect is the severity of disability and medical problems of the patients which cannot be taken care of effectively at home. At times the safety of the family members is also at stake along with the patient's own safety when he/she becomes agitated, suicidal or aggressive. Health of the care givers may also be compromised often while they are dealing with the stress of caring their parents or spouse with dementia. On the other side, it may turn into disaster for the elderly patients themselves to live in their home if their caregivers start abusing them physically, verbally, or by neglecting them.

A Balanced Approach

There is need to adopt a middle path or strike a balance in order to provide the benefit of keeping the patients at home as much as possible and at the same time manage the burden of care in caregivers. Data on predictors of nursing-home placement could help us to shape interventions to avoid or defer NH placement [13]. Although there are advantages and disadvantages of keeping the patients with dementia at their home or NH, however there is no place like home for the most of the patient if adequate and skilled support can be provided at home at least in initial stage of the illness. With increased pressure on health budgets, home health care offers a cost-effective alternative to premature Nursing Home placement. The Department of Health and Children's 2009 Evaluation of Home Care Packages report found that such services are helping elderly and dependent people to live longer at home and prevents unnecessary admission to residential care. Regular home based nursing care by the skilled staff is a viable alternative of NH [14]. If required the patient can be kept in the hospital or NH for short periods to manage of acute medical or psychiatric crisis or for the purpose of respite to the family members.

Difficult behavior (BPSD) patterns are common with dementia leading to institutionalization. And, treating these symptoms might delay or prevent nursing home placement of many patients [15]. However, often these behavior patterns are under-recognized and under-treated by physicians. These BPSD may be treated easily with medications and non-pharmacological interventions. The care-givers can be taught and trained with behavior management/modification techniques with little efforts on the part of physicians or psychiatrists.

As caregivers' stresses and their social, emotional, physical, and financial losses secondary to burden of care of the patient with dementia are among the most vital determinants early institutionalization of dementia patients, our goal should be to minimize these losses [16]. Regular evaluations/screening of the physical and emotional well-being of the care givers and recognition of the problem and underlying cause may help early intervention.

Primary health-care professionals are usually the ones who initially deal dementia patients and their caregivers. They should have the basic competence to recognize BPSD and burden of care in caregivers for early and effective management by counseling, non-pharmacological and pharmacological treatment and to ascertain when to refer the patients to specialists. In addition, they should also be familiar with the community resources available (such as dementia support groups and adult day care programs) to which care-givers can be referred.

A comprehensive program of support and counseling of spouse and care-givers could considerably benefit to caregivers as well as the

patients with dementia resulting in reduced rate of NH placement of the patients [17,18].

Although, there is insufficient evidence till now to compare nursing home/institutes versus home health care for older adults with dementia in terms of quality of life, cost effectiveness [19,20], more research in these areas will provide us better insight and future direction. Till then, our effort should be to help our elderly to live with dignity at a place of comfort and of their choice preferably at their homes within the community as much as possible where they can have opportunity of social interaction, independence, privacy and opportunity of expression their creativeness and enjoy their interests and that is on reduced formal health-care costs [12].

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