



REVIEW ARTICLE

ROLE OF FAMILY AND HEALTHCARE IN DEMENTIA ---- COMPARISON OF THE PRESENT
SCENARIO IN A DEVELOPED COUNTRY AND A DEVELOPING COUNTRY

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ARTICLE INFO

Article History:

Received 23rd January, 2017
Received in revised form
07th February, 2017
Accepted 19th March, 2017
Published online 20th April, 2017

Key words:

Dementia, Care giving,
Developed country,
Developing country.

ABSTRACT

In present days dementia is one of the fast emerging major public health problem in many developing as well as developed countries. As the generation grows older, more number of people enters old age and as a consequence, the number of dementia patient increases, as this is mostly found in the older populations. Though biology of human being is almost same in each and every part of the globe, but the quality of life varies significantly in different socio cultural backgrounds regarding healthy aging. As often, people ignore early symptoms and signs of dementia, so all dementia cases are not reported and this is more so in developing countries. As curative treatment for majority of dementia is still elusive, care giving is an important component of the management of dementia, whether it is delivered by family members or by other trained healthcare personnel. This article aims to compare the present scenario of dementia care in a developed and a developing country.

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Citation: Kallol Kumar Bhattacharyya, 2017. "Role of family and healthcare in dementia ---- comparison of the present scenario in a developed country and a developing country", *International Journal of Current Research*, 9, (04), 48919-48922.

INTRODUCTION

Dementia is the progressive deterioration of cognitive functioning, which means the loss of the ability to think, remember, or reason, as well as behavioral abilities, in a gradual manner, to such an extent that it interferes with everyday life and activities of a person. While every human being in the globe loses some once-healthy nerve cells (neurons) in the brain, as they age, people with dementia experience far greater loss. Dementia may be reversible or irreversible. In reversible type symptoms may be caused by one or more medical conditions which can be treated. These may be drug-induced, vitamin B1 deficiencies, alcohol abuse, depression and brain tumors can cause neurological deficits that resemble dementia. Most of these causes respond to treatment. But in many dementia-causing diseases, the damage done to the brain by the disease cannot be reversed. Such dementia is called "irreversible dementia". Medicines for irreversible dementias try to reduce the symptoms. They cannot change the underlying disease. Irreversible dementias are most common in tauopathies (in Alzheimer's disease, amyloids or tau proteins deposited in neurons), dementia in Parkinson's disease, dementia with lewy bodies, vascular dementia and mixed vascular-degenerative dementia. Alzheimer's disease is a degenerative brain disease and the most common cause of

dementia (Wilson *et al.*, 2012; Barker *et al.*, 2002). The underlying disease process is still unknown, but there are several risk-factors like increasing age, alcohol and tobacco use, illiteracy, atherosclerosis, diabetes, Down syndrome, genetics, hypertension, mental illness, stress, nutritional factors etc. In a study, marriage was found to be a protective event regarding development of dementia (Saldanha *et al.*, 2010). Married individuals tend to have better physical and psychological well-being than the unmarried or divorced. Similarly, living in an extended family is also a protective factor and these collectively lower the numbers of dementia patients in India. In recent studies on animal it has been shown the protective effect of curcumin, a yellow curry paste (turmeric) which is very frequently consumed by Indians. Curcumin has antioxidant and anti-inflammatory effects, which also decreases amyloid protein synthesis. Presence of this protective factor in the diet may be a causative factor of lower prevalence of dementia among Indians (Mishra and Palanivelu, 2008). Some recent research revealed that, some cognitive activities such as exercise, gardening, listening to music, word games and cooking show good prospective results in management of dementia (Cochrane Summaries, 2014). One of the main differences between caregiving in the developed and developing countries is the living arrangements. Persons having dementia in the developing countries like India live in much larger households with extended families (Brodsky and Donkin, 2009) than those of developed countries like USA. The mean age at presentation in India is about 66.3 years, about one

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decade younger than in developed countries. The proportion of patients with early-onset dementia was high (49.9%), compared to 7-30% in developed countries (Nandi *et al.*, 2008).

Prevalence of dementia in population

Recently some studies have been done by the 10/66 group in the developing countries including India (Ferri *et al.*, 2004), where they suggested that at least one behavior and psychological symptoms of dementia (BPSD) was present in 70.9% of cases and the psychiatric abnormalities they found were depressive syndrome (43.8%), anxiety neurosis (14.2%) and schizophreniform/paranoid psychosis (10.9%). Whereas a study from USA revealed that 61% patients had exhibited one or more mental or behavioral disturbances, where apathy (27%), depression (24%), and agitation/aggression (24%) were found in subjects with dementia (Lyketsos *et al.*, 2002). Thus, higher incidence of depression in developing countries may be related to cultural and socioeconomic factors (Das *et al.*, 2012). Often, people ignore early symptoms and signs of dementia, because they confuse these with some symptoms which are part of normal old age. The persons facing problems and their family members, even sometimes doctors think this. While family doctors may do some initial check-up, the complete diagnosis is usually done by specialists like neurologist, psychiatrist, or geriatrician. Early diagnosis is useful particularly in case of reversible dementia. While we get older it definitely worsens our abilities, but the changes in dementia are to some extent different from those seen as a normal part of aging. Symptoms and signs of dementia are caused by damage to the brain cells. Many people live into their 90s and beyond without any signs of dementia.

At the country level, the countries are home to over a million people with dementia in 2015, US (4.2 million) holds the 2nd and India (4.1 million) the 3rd spot behind China (9.5 million) (Alzheimer's Disease International, 2015). According to the Alzheimer's disease International (ADI) Delphi consensus study, by 2040, the current number of dementia patient is likely to increase by 300% in the next four decades (Ferri *et al.*, 2005). A recent report has given a revised prevalence data. In India there are about 4.1 million (41 lakhs) persons with dementia in the age group of people more than 60 years, in the year 2015. 3.7% people above 60 years age have dementia. Dementia cases in India are actually a tip of iceberg where only 1 in 10 gets diagnosed, treatment and care (Alzheimer's Disease International, 2015). Though the trend is same worldwide, but percentage of non-identification of dementia is higher in India. As per a study in 2010, an estimated 3.7 million Indian people aged over 60 have dementia (2.1 million women and 1.5 million men). The calculated total societal cost of dementia for India was estimated to be US\$ 3.415 billion (INR 147 billion). While informal care which is mostly the care given by family members, is more than half the total cost (56%, INR 88.9 billion), nearly two-thirds (29%) of the total cost is direct medical cost (INR 46.8 billion). The total cost per person with dementia is US\$ 925 (INR 43,285) (The national body for dementia in India, 2010) and the informal care cost per person in urban area (US\$ 257) was two and half times more than those in the rural area (US\$ 97) (Alzheimer's & Related Disorders Society of India, 2010). Looking towards the other part of the globe, studies suggest, of the 5.1 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.9 million are men (Hebert *et al.*, 2010). The total payment made by persons with dementia in the USA for

the year 2010 was estimated to be US\$ 172 billion (Alzheimer's association, 2009) (The national body for dementia in India, 2010), whereas the total payments in 2015 (in 2015 dollars) for all individuals with Alzheimer's disease and other dementias are estimated at \$226 billion. Medicare and Medicaid are expected to cover \$153 billion, or 68 percent (Alzheimer's Association. 2015). The economic value of the care provided by unpaid caregivers of those with Alzheimer's disease or other dementias was \$217.7 billion in 2014 (Alzheimer's Association. 2015). North America has highest cost per person (US\$48,605) and South Asia region has the lowest (US\$903): a difference of nearly 53 times.

CAREGIVER ISSUES

Family

Persons with chronic health problem like dementia, need constant care and assistance from others. These support provided almost entirely by co-resident family members, who are unpaid and not part of the formal health-care system. These caregivers may be of different ages (from teen to aged), different sex (male/female), having different relations with the diseased person (spouse, offspring, sibling, son/daughter-in-law or friend), of different mentality (passion comes from love, responsibility, guilt or even greed), but in every case the responsibilities are more or less same. In developing countries like India, though the illiteracy is high, but the works of these informal caregivers are comparatively easier from the perspective of the extended family (caregivers can work in a collaborative effort) and slower pace of life, where as in developed country like USA, this care is tougher due to more numbers of nuclear families and faster pace of life. On the other hand, in India, these caregivers become easily frustrated because even after their ingenuous effort often the diseased gets criticism of being stubborn and crazy and the family may be criticized as cruel and negligent by the society. This is because of poor awareness of the society resulting in stigmatization. This causes a health burden on the caregiver particularly increasing stress and depression, which is not so common in USA. Even now, the majority of caregivers are women (Shaji and Reddy, 2012). But now-a-days an increased percentage of women are taking up employment outside their homes to supplement their family income. Therefore, on one hand the unpaid caregivers are decreasing, and on the other hand paid caregivers (they may be women also) are increasing in the present socio economic Indian scenario. Caregiving itself can be viewed from a public health perspective (Talley and Crews, 2007). If the caregiver remains healthy, then quality of life of the care recipient will be better. Most caregivers derive personal satisfaction while caring for someone close to them and that enables them to cope with the stress and burden of care. In USA, about 15.7 million adult family caregivers care for someone who has Alzheimer's disease or other dementia (Alzheimer's Association, 2015). In India, though the exact number of adult family caregiver is not available, but it can be assumed that the number is much higher.

Healthcare

Health-care is the services provided by doctors, nurses and other paramedical health professionals. In India, gerontology is a relatively new speciality with very limited scope of specialized training and very few professional in this field. There are only less than 6000 specialized person to take care of

Table 1. Comparison of Population and their percentage aged 60 or over, in India and USA in 2015 (estimated), 2030 and 2050 (projected)

year	India (total number of dementia patient, in thousand)	India (% in population)	USA (total number of dementia patient, in thousand)	USA (% in population)
2015	116 553	8.9	66 545	20.7
2030	190 730	12.5	92 906	26.1
2050	330 043	19.4	108 326	27.9

Data Source: United Nations, Department of Economic and Social Affairs, Population Division (2015). World Population Ageing, 2015 (ST/ESA/SER.A/390).

elderly persons. Among them psychiatrists, neurosurgeons, neurologists, psychiatric nurses, psychologist, social workers are there (only 0.43 for 10,00,000 dementia patient) (The national body for dementia in India, 2010). While in United States there are currently 7,428 certified geriatricians and 1,629 geriatric psychiatrists available in this field (The American Geriatrics Society, 2016). Among other manpower, less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics (Institute of Medicine, 2015). Similarly, although 73 percent of social workers serve clients age 55 and older, only 4 percent have formal certification in geriatric social work (Institute of Medicine, 2015).

The role of doctors and healthcare professionals in the training of informal caregivers of dementia patients

Proper training of informal caregivers has important beneficial effects on the society. The result of a study conducted on 200 clinicians in California, USA suggests that though majority of the clinicians routinely done neurological interventions for patients, only a small number of them actively implemented caregiver support practices (Ham, 1999). On the other hand, the public awareness about dementia in India is very low. This general lack of awareness has serious consequences, such as delayed diagnosis and not seeking help from formal medical care services. Not only general public that suffers from this poor awareness, but primary care doctors also do not encounter many cases in their practice. Overall there is no special emphasis on dementia diagnosis and management in the training of healthcare professionals. This is because there is no structured training on the recognition and management of dementia at any level of health service (The national body for dementia in India, 2010).

DISCUSSION

Dementia patients are practically a burden to their family members in present socio-economic structure, where these elderly patients found themselves helpless. Currently there is no significant social welfare program in India that offers practical assistance to these elders. The only response to their emergency health problem seems to be hospitalization. The onset of aging is a life changing event, signifying the beginning of what will be for most, a process of adapting significant physical, psychological, social and environmental changes. India is a developing country, where the population is humongous and increasing day by day. Here the people are of different culture, ethnicity, religion, but one thing is common to all is the declining attentions towards the elderly people. Majority of them feel neglected themselves, both in their family and in the society. They found themselves very lonely from the surrounding world. These are to some extent due to their reduction in work efficiency, declination in earning capacity, due to suffering from some chronic diseases, memory

loss, increasing number of nuclear family and as a consequence gradual communication problem with next generation. Modern treatment protocol extended life span of human beings and thus this social problem is increasing day by day. A large number of older adults are waiting with a critical demand for healthy aging, but there are only a limited number of professionals in the field of gerontology. Therefore everyone should assure our elderly a secure and comfortable environment that includes human enrichment and more interactions with the community. If the health and family welfare sector was better funded, better equipped and better managed with clear and effective policies, these kinds of suffering could have been avoided. Government has a major role to play in this situation. They should implement some policies and programs focusing dementia, to spread more awareness by advertisement and campaigns with collaboration with NGOs, to take effective measure to train more professionals in this field and lastly to counsel and support the families having dementia patients. The situation is more or less same in the developed countries, to that of a developing country. But the difference is in the outlook, the proper and advance planning and their implementation. Population density is also a big factor in this regard.

CONCLUSION

Advancement in diagnosis of diseases and their treatment protocol has resulted in increased longevity of human life. As a result, number of the aged population is increasing day by day. But as definitive treatment for majority of dementia is still unavailable, caregiving is an important component of dementia management, which requires a variety of skills that include awareness (information and education) on dementia as a central one in caregiver intervention. Clearly, more awareness and more resources will make life better for persons having dementia and their families. Awareness and support from unpaid family caregivers will enable early diagnosis, but the treatment and other support, which mainly come from paid healthcare providers, will ease the life of the diseased. People who are not aware of dementia assume it to be the same as aging. This affects the way they support and treat persons with dementia. Until recently nobody considered caregiving as a public-health matter (Talley and Crews, 2007). Researches on both family and health caregiver should move on and address public health issues related to long-term care, like in dementia. The issues like cost of management and effect of caregiving should be an important part of this research. We should search for the types of caregivers and the exact number of them in the population to formulate proper policies related to elders. Also we have to consider the negative impacts on their physical and mental health. Lastly, we cannot leave the sole responsibility of dementia care on the concerned families only, but caregiving should be an equal responsibility for individual, family, society and the government.

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