**The Sick Elderly People with Neurodegenerative Illnesses and Mental Disorders – the Emerging Challenges and Way Forward for the Church in India**

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1. Introduction

By 2050 in India, due to technological advancement in health care, the elderly segment of the population aged 60 years will surpass the population of children below 14 years. In absolute terms India had more than 91.6 million elderly in 2010 with an annual addition of 2.5 million elderly between 2005 and 2010, which is projected to reach 158.7 million in 2025. The increasing number of the sick elderly suffering from neurodegenerative illnesses like dementia and mental disorders like depression comes with it. By 2050, India will have 43 million of persons aged 80 or over. The situation becomes all the more challenging because 80% of the elderly are in the rural areas, 30% of the elderly being below poverty line, and rising healthcare costs. As per Global Age Watch Index (GAWI), India ranks 73rd out of the 91 countries sampled.

The message of Pope Francis, on the occasion of XXI Plenary Assembly of the Pontifical Council for the Family, is significant in this context, “Children and the elderly are the two poles of life and also the most vulnerable, often the most forgotten. A society that abandons children and marginalizes the elderly severs its roots and obscures its future. Whenever a child is abandoned and an old person is marginalized, is not just an act of injustice, but it also demonstrates the failure of that society. Taking care of children and the elderly is the only choice of civilization.”

This paper gives an overview of what is the status of the elderly in India, especially those who are affected with neurodegenerative illnesses and mental disorders. This paper also gives a special emphasis on the socially and economically marginalized/excluded and vulnerable (women) among the elderly; the emerging challenges for the elderly and for those involved in the geriatric care; how the Church in India responds to the situation, and finally, a way forward for the Church in India.

2. The Elderly - Indian Scenario

The ‘National Policy on Older Persons’ adopted by the Government of India in January 1999, defines ‘senior citizen’ or ‘elderly’ as a person who is of age 60 years or above. Nearly 7.5% of India’s population is presently aged 60 years and above. It is projected to rise to 12.4% of population by the year 2026. By 2050, pursuing the existing trend of longer longevity than men, women over 60 years would exceed the number of elderly men by 18.4 million.

About 65 per cent of the aged had to depend on others for their day-to-day maintenance. Of these, 70% are women. Nearly 40% of persons aged 60 years and above (60% of men and 19% of women) are working. In urban areas only 39% of elderly men and about 7% of elderly women are economically active. In contrast, it is 66% and 23% respectively in rural areas.
As per HelpAge India, 52% of India’s Oldest Old (80 +) have either to be poor or very poor health condition; 80% reported non-availability of support system at community. 12% of the Oldest-Old are still engaged in economic activities.11

31% of older persons reported facing abuse [material exploitation, financial deprivation, property grabbing, abandonment, verbal humiliation, and emotional and psychological torment].12 Most of the cases go unreported in the name family honor and victims are afraid of losing even the minimal support they receive.

3. Provisions for the Elderly in India

Article 41 of the Constitution assures public assistance in old age. National Policy on Older Persons (NPOP), 1999 envisages State support for the elderly. The enactment of Maintenance and Welfare of Parents and Senior Citizens Act, 2007 is to ensure need based maintenance for parents and senior citizens and their welfare. The government through Central Sector Scheme of Integrated Programme for Older Persons (IPOP) encourages Public Private Partnership – supporting non-state actors to maintain/organize various facilities for the elderly. The other measures are old age pensions, income tax exemption/deduction; travel concessions; Geriatric Departments in medical colleges; two National Institutes on Ageing at Delhi and Chennai, etc.

Many of these measures however are not fully implemented. Recently, the National Policy on Senior Citizens 2011, and in line with it, the 12th five year plan and National Mental Health Programme, give special emphasis on senior citizens suffering from severely disabling diseases. This includes various types of dementias including Alzheimer’s, Parkinson’s disease, depression and other psycho geriatric disorders. On the whole, the country is yet to put measures in place to effectively meet the impending scenario of the growing population of the elderly, especially those suffering from neurodegenerative illnesses and mental disorders.

4. The Elderly with Neurodegenerative Illnesses and Depression:

The increased numbers of the sick elderly with neurodegenerative illnesses and various mental disorders will have a marked impact on India’s infrastructures and healthcare systems, which are at present ill prepared in many regions. About 64 per thousand elderly persons in rural areas and 55 per thousand in urban areas suffer from one or more disabilities.13

As per the Ministry of Health and Family Welfare, 1 in every 4 among India's elderly population are depressed, 1 in 3 suffer from arthritis while 1 in 5 can't hear. While 1 in 3 suffer from hypertension in India, almost half have poor vision. Around 1 in 10 experience a fall that results in fracture while 2 in 5 are anemic.14

As per HelpAge India, 30 million are lonely & 1 out 8 elderly feels no one cares they exist & 90 % have to continue to work if they have to survive.15 88 % said loneliness can lead to physical and mental ailments like depression.16 The research suggests that suffering from depression can significantly increase the chances of developing dementia - Alzheimer's disease later in life. In 2010, it is estimated that there are 3.7 million affected by dementia [Alzheimer's disease (AD)
and Vascular dementia (VaD)] in India, and the total societal cost is about Rs.1,470 million. People with Dementia (PwD) are expected to double by 2030, increasing the cost by three times.17

4.1. Care of the Elderly with Neurodegenerative Illness - Challenges:

At present, the sick elderly with depression and neurodegenerative illnesses are taken care of mainly by their families with not much support from public health care system, even at primary care level. The joint family system — the traditional support system for the sick and dependent elderly people - is crumbling because of the migration of the younger generation to the cities in search of better prospects. The advent of nuclear families also adds the woes. The women who traditionally took on the role of caregivers are also working and cannot spend as much time caring for the elderly.18

Neurodegenerative conditions like dementia is considered as a normal part of ageing and is not perceived as requiring medical care. Thus primary health-care physicians rarely see this condition in their clinical work. Private medical care is preferred and this leads to a higher out-of-pocket expenditure for care. Caregivers experience significant burdens and health strain. More than 80% of caregivers are females and around 50% are spouses who are themselves quite old. Most of the old-age homes do not admit people with dementia. The stigma of aging, arising out of neurodegenerative illness like dementia, depression, incontinence, etc., is another social barrier to access to health by the elderly. People with dementia and other types of neurodegenerative illnesses and mental disorders are often neglected, ridiculed and abused.19

4.2. Common Barriers to Health for the Elderly - Accessibility and Affordability

The key barriers to access to health for the Indian elderly include social barriers shaped by gender and other axes of social inequality (religion, caste, socio-economic status and stigma). The physical barrier of reduced mobility declines their social engagement, and limits the reach of the health system. Health affordability constraints include limitations in income, employment, assets and the meager financial protection offered in the Indian health system.20

Social security coverage, such as, employer insurance, pension scheme, etc., covers only a negligible segment of the employed population in organized sectors. The majority of the workforce are engaged either in unorganized sector or self-employed. They are not entitled to formal retirement benefits. As a result, a considerable proportion of the elderly are forced to earn their living by engaging themselves in some work to pull on with their lives.

As 83% of healthcare expenses are private out-of-pocket expenditures,22 the deprivation is severe and crushing for the elderly for whom the need for healthcare increases with age. Even where the care is physically accessible, costs of accessing this care becomes beyond their reach. For the willing caregivers, especially those struggling to meet both ends, the sick elderly becomes a severe economic burden. The growing commercialization of health care and the deficiencies in the public health care system also makes the situation more complex.
Among the elderly, the women suffer most – especially the widows (due to mobility, employment, property, and financial constraints). The predicament of elderly women is aggravated by a lifetime of gender-based discrimination. Ageing women are more likely to get excluded from social security schemes due to lower literacy and awareness levels.

5. Indian Church in Health Sector:

The Church in India, in line with the vision statement of her health policy, firmly upholds the mandate from Jesus Christ, the Divine Healer, to ensure life in its fullness, and inspired by His compassionate love, envisages a healthy society where people, especially the poor and marginalized, attain and maintain holistic well-being and live in harmony with the Creator, with self, with one another and with the environment. Even though the Catholic population of the country is less than 1.5 percent, the Church in India is engaged in various services: 746 small, medium and major hospitals, 2574 health centres, 107 centres for mental health centres, 61 centres for alternative systems of medicine, 162 non-formal health facilities, 165 leprosy centres and 6 medical colleges. There are 615 residential health care centres for the aged. Along with these, there are 678 training centres and 443 rehabilitation centres are involved in the preventive and curative care of the people, which includes the elderly and persons with disabilities. There are 120 nursing schools/colleges, 123 community care centres for people living with HIV/AIDS, including 40 centres for children infected/affected and 60 counselling centres and 82 centres for tuberculosis or terminally ill (palliative care centres). These apart, there are almost 600 institutions that are projects-based. They are focused on certain diseases in collaboration with the government; also, engaged in other social concerns.

One can safely assume that a nearly 0.13 million persons render services in these institutions, consist of the religious, lay workers and volunteers, taking all the facilities together. Women religious congregations and dioceses are engaged in offering medical services, with the contribution of the former being much larger. The medical services consist not only of treatment or surgical interventions but also counselling, conducting camps, awareness and outreach programmes.

5.1. Catholic Health Association of India (CHAI):

As one of the main arm of the Health Commission under the Bishops’ Conference, the Catholic Health Association of India (CHAI), founded in 1943, by Sr. Dr. Mary Glowrey, an Australian nun, is the largest network of nearly 3412 Catholic health care institutions in the country. 84% of them are located in medically underserved areas operating through diocesan and 11 Regional Units across the country. CHAI’s member institutions carry out varied services: 2263 primary care centres, 417 secondary care hospitals, 183 tertiary care hospitals, 5 medical colleges, 18 hospitals offering DNB, 120 nursing schools/colleges, 82 terminal/palliative care centres, 103 mental health centres, 123 HIV/AIDS community care centre, 32 counselling & de-addiction centres, 250 training institutions, 210 disability rehabilitation centres, 121 geriatric care centres and 52 leprosariums.

The network with over 1000 sister-doctors, 25,000 sister-nurses and 10,000 plus religious para-professionals, has been rendering critical health care services to the poor and marginalized –
yearly reaching out to more than 21 million. This includes 5000 HIV patients given per day, around 2000 children affected or infected with HIV being provided institutional care, 15,000 taken care of under community based care, 10,000 children with special needs provided with educational, health & rehabilitation support annually. CHAI member institutions facilitate more than 2 million Self Help Group Members. Over 5,000 Nursing students graduate every year from CHAI member nursing schools.

6. Health Policy of the Catholic Church in India and Care of the Elderly:

The Health policy of the Catholic Church in India recognizes that the elderly have special needs that will be addressed at the individual, group, family and community levels. The Catholic health care facilities will increasingly get involved in the care of the elderly and also work towards creating an enabling environment for them within their own families. The core strategies are to have geriatric departments in the tertiary care system and geriatric services in other health institutions and ensure priority for the elderly in health care facilities and they are with care and compassion. To maintain counselling services and linkages with other institutions to deal with the psychological and social needs of the elderly. The priests, religious sisters and others work with families ensure that the family environment will be conducive for the elderly. The palliative care in hospitals and care homes prepare the elderly for a graceful old age and the final moment of life, and protect the dignity of the dying person. The families and caregivers are made to understand and accept the needs of elderly and to support them with gratitude and respect; that the children are to take care of their ageing and sick parents. Emphasis is also given to training of health personnel in geriatric and palliative care and counseling.

6.1. Action of the Indian Church for the Elderly:

All over India, the Church is having 615 homes for the aged, taking care free of cost of nearly 18500 elderly, mostly sick and abandoned by their families. However, most of these homes are located middle-income level southern States, with nearly 40% very located in the State of Kerala, followed by Karnataka, Maharashtra, Goa and West Bengal. The Church is rendering service to more than 60,000 elderly on a daily basis, including around 18500 in its homes for the aged and 1700 in its palliative care units. This does not include the elderly supported in its project based institutions/organizations and those contacted daily while doing home visits as part of pastoral care. Of late, serious efforts are being taken to train nurses and other frontline health workers in geriatric care.

Compelled by Jesus’ love and His preferential stand for poor and marginalized, Church Health institutions fulfils their obligations to continue and strengthen its services for the economically underprivileged and socially excluded and vulnerable – the elderly, children and women, and extend to more medically underserved areas. The emerging challenges and threats from not-so-friendly external factors – be it technical/professional, new legislations, social, economical and political - call for serious introspection. The Church has to face the lethargic, many a time corrupt, public and prohibitively profit-minded private health care.
7. A suggested Way Forward:

In spite of all the commendable efforts much need to be done regarding the care of the elderly in India. The Church, under the aegis of Catholic Bishops’ Conference of India needs to leverage the full potential of the healthcare networks like the Catholic Health Association of India and that of other Christian denominations and Civil Society Organizations. The Church also needs to do advocacy in the following areas:

1. to recognize neurodegenerative illnesses like dementia, and depression and other mental disorders, especially affecting the elderly, as components of primary healthcare package of the country
2. for the availability of essential drugs for the treatment of the sick elderly with neurodegenerative illnesses and mental disorders at affordable cost
3. to legalize nurse practitioners

Other areas where the Church needs to involve are sensitization, training and research:

1. Sensitizing and educating the public against stigma and discrimination of the sick elderly
2. Creating awareness among the elderly, the caregivers, elders and youth at community level on the National Policy on Older Persons, legislations like ‘The Maintenance and Welfare of Parents and Senior Citizens Act 2007’, and various schemes benefitting the elderly.
3. Providing refresher trainings to primary care physicians to attend the sick elderly suffering from neurodegenerative illnesses, depression and other mental disorders
4. Promoting the significance of ‘task-shifting’ by involving Accredited Social Health Activists (ASHAs), trained birth attendants (Dais) and other frontline health workers under National Rural Health Mission, successful lay/barefoot counselors caring young at risk in many organizations, etc. in making the care for the sick elderly and mental healthcare more accessible and affordable
5. Training and supporting the caregivers/family members to provide home-based care as far as possible to the elderly, especially those suffering from neurodegenerative illnesses and mental disorders
6. Promoting the utilization of modern technology – for instance, telemedicine, and train the frontline health workers to handle them, and thereby making quality healthcare to the elderly more accessible and affordable, especially in the rural and vulnerable areas.
7. Promoting and undertaking research in the field of geriatric care to make it more evidence-based, accessible and affordable for the marginalized/excluded and vulnerable among the elderly.

Inculcating the culture of ‘involving all’ in Christ’s healing ministry, the Church in India has to facilitate the building of local ownership and Caring Communities supporting the elderly towards healthy ageing with dignity and self-respect. The endeavor is to be owned by the elderly themselves, caregivers, community/religious leaders, PRIs, youth, teachers, professionals, frontline health workers/volunteers, etc. As part, the Church has to facilitate the democratization and decentralization of the medical knowledge. This calls for the empowerment of local communities with information and skills to organize, demand and access the rights and entitlements from the perspective of health as a fundamental right, with a special emphasis on the elderly, children and women.
Endnote


11 HelpAge India, *Economic and Health Survey on India’s Oldest Old (80+)*. Available: [http://www.helpageindia.org/pdf/Economic-Health-Survey-on-India's-Oldest-Old.pdf](http://www.helpageindia.org/pdf/Economic-Health-Survey-on-India's-Oldest-Old.pdf)


19 Ibid.

20 Subhojit Dey & Co., 2012


23 Catholic Bishops’ Conference of India [CBCI], *Sharing the fullness of life – Health Policy of the Catholic Church in India*, New Delhi, 2005


26 Data as per the Catholic Health Association of India (CHAI), Secunderabad


28 Many of these institutions carry out more than one role; Hence, the aggregate of these varied institutions does not tally to total number of 3412 mentioned above

29 CBCI, *Sharing the fullness of life – Health Policy of the Catholic Church in India*, New Delhi, 2005

30 CBCI, *Catholic Directory of India* 2013, p. 77-83