Review Article

Social aspects of dementia : Indian scenario

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Dementia are becoming a major health problems in elderly due to increasing lifespan in developing countries. So, it's aptly called "Silent epidemic of 21st century". Dementia primarily affects those areas of brain which regulate the executive functions of a person, the ability of doing skill activities are grossly affected. Patients suffering from early-onset dementia (EOD) are particularly susceptible to loss of occupation and thus imposing greater economic strain. They include agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering, and a variety of socially inappropriate behaviors. Caregiver burden is one of the most important issues. Early diagnosis and interventions can still halt the progression of the disease by modifying the risk factors and improve the quality of life of the patients by Creating dementia awareness among the general public. Educating and training health care professionals, specialized dementia care services.

A state level dementia strategy and dementia care policy should focus on issues like legislation and financial assistance. Understanding the burden and costs of dementia is crucial to guide future health care and socioeconomic policy. Though dementia usually a disease of old age with huge social impact but it is managable by comprehensive health care approach which should be done by intervention at various aforementioned level.

[*J Indian Med Assoc* 2017; **115:** 76-80]

Key words **: Dementia, Social aspects.**

Dementia, usually a disease of the elderly is characterized by progressive loss of memory and other mental faculties such as language, judgment, and planning, impairment of daily activities, and deficiency in social interaction[1]. Apart from imposing difficulties on patient's livelihood, it reduces life span, induces caregiver's strain and imposes burden on health care facility[2]. It is expected that the burden of dementia will be increasing owing to increase in longevity, at leastin developing countries.According to the World Health Organization (WHO) report, about 75% of the estimated 1.2 billion people aged 60 years and older will reside in developing countries by 2025[3]. It is estimated that the number of people living with dementia will almost double every 20 years to 42.3 million in 2020 and 81.1 million in 2040 and the rate of growth will be the highest (around 336%) in India, China, South Asia, and western Pacific regions.4Epidemiological studies on cognition carried out in India show marked variability in prevalence rate across different zones of the country. The critics have attributedthese differences toadoption of different methodology, screening instruments, defining criteria, multiethnicity, multicultural and environmental factors[1].

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Cognitive Difficulties-still an Under-recognized Problem in India:

India has a unique situation characterized by rapid epidemiological transition leading to increasing aging population and higher prevalence and incidence of non-communicable diseases.Although India has to bear a great burden of dementia, it remains largely a hidden problem.So, it's aptly called "silent epidemic of 21st century"[5,6]. The number of studies on awareness of cognitive decline is meager in India. Available evidences show that awareness of dementia and need for consultation with physician is poor among common different Indian communities and South-East Asian regions at large[7-11]. Indian social scenario, forgetfulness in the elderly is often recognized as normal variation of aging.Commonly, the responsibility of instrumental activities such as marketing, office work, monetary transaction etc is shouldered upon next generation family members. Consequently, earlier problems like mild cognitive im-

Editorial Comments :

- **Dementia affects the area of brain having exececutive function.**
- **Progressive loss of memory and imparement of language judgement planning daily activities are key features.**
- **Dementia poses huge social impact and care giver burden.**
- **Dementia awareness, specialised dementia care services, support of family members & voluntary organisations are integral tool in management of dementia.**

pairment (MCI) remain unrecognized. When it is recognized, it is often in advanced stages[1]. On the other hand, both poverty and illiteracy are risk factors for dementia and they are also major hindrances for detection of this disease.Another important hurdle in recognizing early cognitive declineis to get proper and chronological history[1]. In a multilingual country like India with huge proportion of illiterate people, formulating and validating different evaluation scales and questionnaires is a challenging task.

Cognitive Symptoms of Dementia and its Social Impact :

As dementia primarily affects those areas of the brain which regulate the executive functions of a person, the ability of doing skilled activities is grossly affected. Loss of independence of daily living could be the very first symptom of MCI[12]. Patients suffering from early-onset dementia (EOD) are particularly susceptible to loss of occupation and thus imposing greater economic strain[13]. Fragmented identity and feeling of extreme loneliness become major hindrances for meaningful existence[14].

Behavioral & Psychosocial Symptoms of Dementia (BPSD) and its Social Impact :

Although symptomsrelated to cognitivedomains are central regarding diagnosis and management of dementia, in recent years thereis growing importance of BPSD particularly from the point of caregiver's burden, quality of life, and outcome of dementia[15]. BPSD are defined as signs and symptoms of disturbed perception, thought content, mood, or behavior[16]. They include agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering, and a variety of socially inappropriate behaviors[17]. BPSD are the most complex, stressful, and costly aspects of care. They are associated with excess morbidity, mortality, hospital stays, and early placement in a nursing home[18].

10/66 group reported that at least one BPSD was present in 70.9% of cases and the commonest psychiatric abnormalities were depressive syndrome (43.8%) followed by anxiety neurosis (14.2%) and schizophreniform/paranoid psychosis (10.9.19Study from western India has documented varied BPSD such as irritability (15.1%), agitation (9.3%), apathy (8.1%), hallucination (8.1%), depression (7%), disinhibition (5.8%), and somatic symptoms such as poor sleep (5.8%), poor appetite (2.3%), and suspiciousness (2.3%)[20]. Pattern of BPSD differs depending on the subtypes of dementia. Pattern of BPSD differs depending on the subtypes of dementia[21-23], but mean total psychopathology scores increased in tandem with dementia severity regardless of dementia type.

Early identification of BPSD is particularly important as they may actually appear before the appearance of cognitive symptoms (particularly, in case of frontotemporal dementia) and have the potential to mislead the diagnosis[24].

Caregiver Burden :

Caregiver burden is one of the most important issues in dementia care as people who have to take care of demented patients have to bear the brunt of the dementia patients, not only just physically or financially, but also psychologically[25]. Like most of the developing countries, in India, the majorities of the caregivers is women in 70% of cases, and are mostly wives, daughters, and daughters-in-law[26,27]. The prime sources of caregiver strain are dependency, BPSD and incontinence[27]. Strain is exacerbated by the lack of supportive response from local health services and of family support resulting from adverse behaviors from other family members, and they suffer significant mental strains. A study from West India[28] has shown that community-based interventions have considerable potential to improve the quality of life of the caregivers and the subjects with dementia. Home-based care is preferred to daycare program for the caregivers of persons with dementia. It has revealed that the use of locally available, low-cost human resources in tune with socio-culturally acceptable method is feasible and leads to significant improvement in caregiver's mental health and burden of care.

Caring for Dementia—The Kerala Model:

Compared to the national figure of 8%, in Kerala, people above the age of 60 constitute 12.6% of the population. This has to be seen in the backdrop of a declining population growth. While India's population grew by over 17% between 2001 and 2011, the growth rate in Kerala was just under 5%. In addition to the growing number of elderly, the numbers of young people to look after them continue to decline. The traditional safety net for elderly care in the form of multigenerational joint families in Kerala is fast disappearing due to urbanization, modernization and economic migration, resulting in more nuclear families[29]. There have been few studies estimating the prevalence of dementia in Kerala[30-32]. A 2012 reportfrom Alzheimer's and Related Disorders Society of India (ARDSI) estimatedthat there wouldbe nearly 2lakhs people with dementia in Kerala[33]. The widely acknowledged Kerala model of health care, which is a remarkable achievement at par with that of many developed countries, may also prove to be the best launch pad to develop a dementia care initiative[29]. The rest of this paper will be discussing the way forward to combat the burden of dementia keeping the state of Kerala as model.

The Way Forward :

Although at presentthere is still lack of curative treat-

ments for dementia, early diagnosis and interventions can still halt the progression of the disease by modifying the risk factors and improve the quality of life of the patients. Much can be done to reduce the burden of the disease on the persons and the families by early interventions like improved awareness and medical, psychosocial and behavioral interventions.

- Creating dementia awareness among the general public: In the first place, the public should be made aware that symptoms of dementia are not a part of normal ageing, but signs that tell them to seek medical help. Lack of understanding leads to stigma and negative attitudes, which in turn results in families not seeking medical help or assistance.
- Educating and training health care professionals about dementia management: Families frequently report the difficult journeys before receiving a diagnosis of dementia, emphasizing the need for specific training in dementia for all health and social care professionals, including doctors, nurses, community health workers and social workers. We need a breed of professionals who are confident in understanding and addressing the problems faced by families of dementia patients. Though diagnosis of the condition and prescription and monitoring of memory medications are specialist skills, we strongly believe that the general care of dementia is a responsibility all healthcare professionals should be ready to shoulder. All health care staff should be educated on when to suspect dementia, as all of us are bound to see someone with dementia wherever we work or whatever we do, even if we do not provide specialist dementia care.
- Developing services to diagnose and manage dementia with equal emphasis on medical and psychosocial care: There should be joint efforts by the health, social welfare and social justice sectors to design a service stream for people with dementia. We have learned from the experience of other countries that comprehensive intersectoral collaboration is essential to effectively address the problems in dementia care. The course of the illness, from onset of symptoms to the final stages, can aptly be called a "dementia journey" which the family does along with the patient. There should be support available at all points in the dementia journey, which starts from the first symptoms like lapses in memory and changes in mood and personality. When they arrive for a consultation even at a primary care level, the professionals should have the skills and knowledge to complete an assessment. It is extremely important at this early stage to rule out any reversible causes of dementia. Most of these patients would need a specialist referral to confirm the diagnosis and start medications if appropriate, and their mental status, cognitive functions, behaviors, level of functioning, and care needs will need monitoring.
- There is a need to develop specialized dementia care services, and this can be done using the existing infrastructure in general hospital settings. Specialist assessments can be conducted in Memory Clinics (dementia clinics). Currently, very few such facilities exist. Memory Clinics are multidisciplinary teams led by specialist. As the disease progresses, families will need advice on managing challenging behaviors and deteriorating activities of daily living. While the medical specialist takes a lead role in prescription and monitoring of medications, nurses can advise the families on various nursing aspects of dementia care. Other members of the multidisciplinary team, including social workers and psychologists, can play a major role in psychosocial interventions.
- Developing a pool of communityworkers and dementia friends to provide care and support at the point of need.
- As the dementia journey continues, families often find services like day centers increasingly helpful. As the social landscape of our family systems is undergoing massive changes, with disappearance of joint families, migration, and increasing prevalence of families just comprising of an older couple, the relevance of domiciliary care, respite centers, and 24-hour care centers is increasing. This is an area which needs close attention of government and non-governmental organizations. Alzheimer's and Related Disorders Society of India (ARDSI) has been in the forefront as a registered national, non-profit, voluntary organization engaged in the care, support, training and research of dementia since its inception in 1992. ARDSI is actively involved in developing services — currently there is a Day Centre (Cochin) and three full time care homes (Cochin, Kunnamkulam, Calicut) for people with dementia run by the national office in Kerala, and another center is being run by the Trivandrum Chapter. The viability of a business model in this sector has drawn many major players into the scene, and probably the future depends on the strength of the social commitment as well. The societal attitude towards care homes for the elderly has been on a changing course. Many now are open to the reality that it is not only acceptable, but in some situations essential, to look into such options to provide quality care for the elderly.
- Dementia, by nature, is a progressive illness, and the condition of the sufferers is bound to deteriorate over a few years' time. Palliative care in advanced dementia has been receiving attention all over the world. It is essential that we acknowledge the need to discuss this important issue, and deliberate on vital aspects like how invasive should the management be in someone with a terminal condition.
- Voluntary organizations play a close collaborative role in dementia care. Training of existing lay health care workers is an important strategy found useful elsewhere.

Programs can be successfully integrated with existing government schemes like Vayomitram, which provide health care and support to elderly people, if properly conceived with provisions forappropriate training. A horizontal integration of District Mental Health Program (DMHP), which is now functional in all districts in Kerala, with Palliative Care Program, supported by the local self governments, is a model scalable across the state. There are several examples of effective collaborative approaches across the world in creating dementia friendly communities (DFC). A notable example is from the United Kingdom where the Government has joined hands with the Alzheimer's Society and other key partners in defining and developing this concept. The program focuses on improving inclusion and quality of life of people with dementia. Despite the magnitude of the problem and the enormity of the challenge, dementia has not yet received the due attention at a sociopolitical level. However, recently there have been several positive responses from the government in recognizing the need to support dementia care and services in Kerala in the form of Kerala State Initiative on Dementia (KSID). This is the time to gather momentum to tackle the challenges of dementia through partnerships. There should be a concerted effort to educate public, train professionals, and develop services to improve the quality of life of those affected by dementia. We have to use an asset based solutions strategy, working on to build on existing manpower and resources for the program to be successful. Commitment and belief in the cause will be the major determinants of the progress of any strategy to address this problem we can no longer ignore.

- Working towards a state level dementia strategy and dementia care policy which should also focus on issues like legislation and financial assistance

Understanding the burden and costs of dementia is crucial to guide future health care and socioeconomic policy. Policymakers need evidence to prioritize and plan appropriately for the rapidly growing numbers of older people with dementia and other chronic diseases. Low public awareness, under-diagnosis, and under-treatment could be addressed by national mobilisation strategies to increase awareness and specialized training for health professionals and authorities through mass media, scientific reports, and special activities, and by the setting up of open clinics in communities.

Close collaboration with all stakeholders, including government and non-governmental organizations, voluntary sector and private partnerships.

Conclusion : Dementia though usually a disease of old age with huge social impact, increasing due to increase in median survival of ageing population is managable by comprehensive health care approach which should be done byintervention at various aforementioned level than we can only be able to decrease the social burden and at least can able to offer streak of light at the end of the tunnel.

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