Review Article

Dementia Care in India should be spearheaded by Mental Health Professional (Psychiatrist)?

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Abstract

Dementia is a chronic debilitating condition with multiple cognitive deficits characterised by deficits in memory, learning, attention, language, perception, motor and social functions of an individual. More than 90% of causes are degenerative brain diseases and altering the progressive course (reversal) of the disorder is not possible.

Only a clinician well versed with Psychopharmacological & Psychological approaches will be able to do justice in such cases as it asks for innovation in, tailor made psycho therapy, concurrent counselling, and Psycho-educative interventions to patient & care givers. In such situations Psychiatrist is one of the important member among the team of Medical & paramedical professionals involved in Dementia Care.

Introduction:

It is estimated that over 3.7 million people are affected by dementia in our country. This is expected to be double by 2030. It is estimated that cost of taking care of a person with dementia is about Rs.43, 000 annually; much of which is met by the families. The financial burden will only increase in the coming years. With improving healthcare reaching wider strata of people leading to longitivity, the numbers of persons with dementia will double every 5 years of age and so India will have one of the largest numbers of elders with this problem. The challenges posed by dementia as a health and social issue are of a scale we can no longer ignore. Despite the magnitude, services for people with dementia are sparse and there is lack awareness among the family members as well as in the community. At present , there are no special policies for patients living with dementia and there are very few agencies working for better quality of life for these subjects.

There are hardly any standard practice guidelines and treatment centers in India and the current health and social care system is characterized by a widespread failure to support Persons with dementia and their families. Currently dementia remains a largely hidden problem in India, especially in those disadvantaged parts of India where poverty and illiteracy levels are high.

It is well known that the dementia is not a part of aging and is caused by a variety of diseases. We now have a range of option to treat the symptoms of dementia and offer practical help to those affected.

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Invariably the cognitive deficit results in significant loss of social and occupational functioning. Only 2% of cases start before the age of 65 years. After this, the prevalence doubles with every five years increment in age. Thus, Dementia is one of the major causes of disability in late-life.

The common causes accounting for 90% of all cases of Dementias are as mentioned above. These are degenerative brain diseases and altering the progressive course (reversal) of the disorder is not possible. In-fact we don't have a treatment plan to reverse the inevitable process of ageing and restoring the continuing cognitive deficit.

Scope of the Problem

Major disorders resulting in dementias include, Alzheimer's disease, Frontotemporal degeneration

Lewy body disease, Parkinson's disease, Vascular disease, Traumatic Brain injury, Substance induced.

It is estimated that over 7.5 million people will be affected by dementia in our country by 2030. Despite the magnitude, services for people with dementia are sparse and there is lack awareness among the family members as well as in the community. At present , there are no special policies for patients living with dementia and there are very few agencies working for better quality of life for these subjects.

At present the treatment care for Dementia is based on two main pillars,

A. Slowing of the cognitive decline process and
B. Treating the psycho-socio–biological symptoms which keep on evolving due to cerebral degeneration.

Dementia is in-fact a basket of neuro psychological disorders which have Depression, anxiety at one end and

delirium & psychosis at the other extreme along with co-morbid physical disorders and it poses real challenge to treat.

For care giver, and arguably, for people with dementia, it is the (BPSD) behavioral and psychological symptoms linked to dementia and the deficits in the activities of daily living(ADL) that are most relevant and impact most on the burden and the quality of life. Caregiver interventions can be provided at low cost and have shown an effect on decreasing caregiver strain. A large literature attests to the wide-ranging potential benefits of care giver interventions in dementia.

Only a clinician well versed with Psychopharmacological & Psychological approaches will be able to do justice in such cases as it asks for innovation in, tailor made psycho therapy, concurrent counselling, and Psycho-educative interventions to patient & care givers. In such situations Psychiatrist is one of the important member among the team of Medical & paramedical professionals involved in Dementia Care.

The Course and Outcome of Dementia

Dementia affects every person in a different way. Its impact can depend on what the person was like before the disease; his/her personality, lifestyle, significant relationships and physical health. The problems linked to dementia can be best understood in three stages. The duration of each stage is given as a guideline; sometimes people can deteriorate quicker, and at other times more slowly.

The most common course of dementias begins with a number of subtle sign that may, at first, be ignored by both the patients and the people close to the patient. Although the symptoms of the early phase of dementia are subtle, they become conspicuous as the dementia progress, and the family members may then bring a patient to a physician attention.

Diagnosis & Role of Care-Giver:

When making a diagnosis, clinicians focus their assessment on impairment in memory, other cognitive functions and loss of independent living skills. The focus is on the ABC symptoms of dementia i.e.

1. Activities of Daily living (ADL),
2. Behavioral and Psychological Symptoms of Dementia (BPSD),
3. Cognitive and memory symptoms (C&M).

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BPSD occur most commonly in the middle stage of dementia and are mistaken by care givers as deliberate behaviours.

Problem behaviors include agitation, aggression, sleep disturbance, wandering, apathy, anxiety, depression, delusions and hallucinations. Most studies indicate that BPSD are an important cause of care giver strain.

However, symptomatic treatments in Cases of Dementia may delay the relentless course of the disease, ameliorate the troublesome behavioral symptoms and timely support can help people with dementia and care givers.

Management

The Management of Dementia which include standard treatment goals are :-

1. Early diagnosis
2. Optimization of physical health, cognition, activity and well being
3. Detection and treatment of BPSD
4. Educating care giver and providing long term support to the patient.

Early Stage	first year or two	Language problems Getting lost in familiar surroundings Difficulty in making decisions Mood changes Loss of interest in usual activities apathy
Middle stage	second to fourth or fifth years	Frank memory disturbances Restriction in physical activities Pronounced motor deficits Increasing dependence on care-giver for ADL
Late Stage	Usually fourth year and after	Loss of autobiographical memory Confinement to bed Incontinence Lack of self care

At present the treatment care for Dementia is based on two main pillars, slowing of the cognitive decline process and treating the psycho-socio –biological symptoms which keep on evolving due to cerebral degeneration.

Current evidence-based treatments for Dementia

Partially effective treatments are available for most core symptoms of dementia. These treatments are all symptomatic, that is, they can ameliorate a particular symptom, but do not alter the progressive course of the disease.

Treatment basically is directed towards the management of the cognitive, behavioral and the ADL symptoms of dementia. The two broad interventions for management are:

a) **Pharmacological Interventions**

There are a number of drugs available for the management of dementia like Donepezil, Rivastigmine, Galantamine and Memantine.

b) Psychological Interventions

Research has shown that cognitive stimulation and psychological interventions can provide benefits in the early stages of the disease.

In the later stages, they are not of much use for the cognitive symptoms.

Caregiver interventions can be provided at low cost and have shown an effect on decreasing care giver strain. A large literature attests to the wide-ranging potential benefits of carer interventions in dementia.

Dementia is in-fact a basket of neuro psychological disorders which have Depression, anxiety at one end and delirium & psychosis at the other extreme along with co-morbid physical disorders and it poses real challenge to treat Dementia cases.

Only a clinician well versed with Psychopharmacological & Psychological approaches will be able to do justice in such cases as it asks for innovation in

1. Tailor made psycho therapy
2. Concurrent counselling
3. Psycho-educative interventions to patient & care givers.

In such situations Psychiatrist is one of the important and best suited member of the team Medical & paramedical professionals involved in Dementia Care.

Dementia patients especially in early stages are about 15-to 20 % of all patients who are cases of Pseudo-dementia or Reversible Dementia (psychological factors underlying dementia like picture). Thus a Psychiatrist is well trained to diagnose & judge the co-morbid conditions in Dementia Patients and then call for liaison practice to work with concerned speciality.

Indian Scenario

In India, PwD (Patient with Dementia) continue to live with their families. Dementia care is usually a joint effort by the adult members of the family who stay in the same household. The 10/66 Dementia Research Group's multicentre pilot study (10/66 Dementia Research Group, 2004) included 179 care giver from six different locations in India (Bangalore, Chennai, Goa, Hyderabad, Thrissur and Vellore). Most of the primary care givers were women (75%) and majority of them were co-residents (98%). Most PwD lived in large households, with extended families; one quarter to one half of households comprised three generations, including children under the age of 16 years.

None of the care giver received any care giver benefits. It is important to recognize that other family members and friends are often routinely involved in providing care. Paid caregivers were not involved in dementia care from the Indian centers. There is increasing demand for paid care giver, more so in urban India. Though there are no formal training programmes, there are agencies that help families to hire workers. Formal short training programme for these workers are very much needed. The placement agencies need to be registered and regulated.

Impact of Dementia care- Psychological and physical health of caregivers:

The negative consequences of care giving have been widely studied. The levels of care giver strain in low and middle income countries were found to be as high as those seen in the European EUROCARE project. Home-based care received no formal support from existing services.

Care giver generally do not have access to information or advice about dementia care.

Even literate caregivers tend to misinterpret symptoms of dementia as deliberate misbehavior. Current support systems are grossly inadequate and need reinforcement.

All the six 10/66 pilot study sites reported high levels of psychological morbidity, which ranged from 40 % to 72%. On an average, 60% of the 179 care giver had evidence for adverse mental health impact indicated by the high scores on GHQ.

Independent effects of dementia, compared with other chronic diseases, on Care giver strain:

Dementia makes the largest independent contribution of any chronic disease to dependence (needs for care). There is also evidence to suggest that, among older people

needing care, caring for a PwD compared to caring for older people with physical health conditions, places greater demands on the care giver, and leads to more strain. The World Alzheimer's Report 2009 examined this issue further, using data from the 10/66 Dementia Research Group population based studies, to assess the independent effect of dementia, depression, stroke and physical impairment upon care-giver/co-resident psychological morbidity.

In almost all sites, after adjusting for the effects of stroke, depression and physical impairment, there was a strong and statistically significant association between the presence of dementia in the older person and risk for psychological co-morbidity in the care giver/co-resident. The pooled estimate across sites suggested that the care giver/co-resident was twice as likely to have significant psychological morbidity in the presence of dementia.

Conclusion:

Making a diagnosis of Dementia by few tests is comparatively an easy task, than to provide emotional touch, empathetic care and psychological healing to those grey and white haired patients with failing eyesight, restricted walk, artificial dentures, abandoned relatives, empty homes, decreased self esteem, melancholic mood, crying spells, severe helplessness and failing hope like their memory.

Practicing psychotherapy, counselling care givers and applying psychopharmacology in Dementia care is an art which can be learned only when one is psychologically inclined and empathetic in his approach.

So undoubtedly all Mental Health Professional should gear up and start building a team to counter the growing impact of Dementia in Indian subcontinent and set a example to be imbibed by rest of medical fraternity.

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