Dementia in India: it's high time to address the need!

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ABSTRACT

The situation in India with regards to dementia prevalence has not been researched thoroughly though there have been indications of prevalence according to the 10/66 Dementia study which was conducted in seven low and middle income countries in eleven sites which included both rural and urban India. The population trend projects to a rise from 5.63% of older adults in 1961 to 6.58% in 1991 reaching 7.5 per cent in 2001. Men between the age group of 75 - 79 years and women of same age group account to 57% and 157% of dementia sufferers respectively. This figure rises to 11% and 294% when the age group of 80 years and above is considered. The educational background, social status, urban / rural living, understanding of assessment process and validation of the assessment tools used are to be taken into account when diagnosing somebody with dementia. Large families living together for generations in the same house provide supportive care to the elderly they also are affected by the carer burden. This in turn has an effect on the negative economy due to lack of income generation by that member of family in addition to the psychosocial stress faced by them. India is currently spending INR 0.15 to 160 billion per year for care of people with dementia. It is predicted that the current number of people with dementia would double by 2030 (3.69 million to 7.61 million) and the immediate consequence would be that the cost of care would also double.

Key words: Key words: dementia, economy, families, India, population

INTRODUCTION:

‘Dementia’, the term haunting the world, which is dealing with this ever demanding and progressively disabling condition, is defined by the International Classification of Mental Disorders (ICD 10), [1] as a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. The world population is ageing and due to the advancement of the medical fraternity and the state of art scientific technology in the healthcare system fortunately people are living longer. In the United Kingdom (UK), it is estimated that the older adult population aged 65 and over is projected to increase from 16 per cent in 2008 to 23 per cent by 2033 and it is in keeping with rest of the European countries. [2] The ageing population in the UK has been depicted in the figure below, which has been adapted from the National Statistics Office, UK (Figure 1).

Figure 1: Ageing population trends: UK

Prevalence of dementia in India

The situation in India with regards to dementia prevalence has not been researched thoroughly though there have been indications of prevalence according to the 10/66 Dementia study which was conducted in seven low and middle income countries in eleven sites which included both rural and urban India. [3] This study was conducted...
on the background of previous literature that low socioeconomic countries harbour less of dementia compared to higher economic countries (Table 1).

Table 1: The prevalence of dementia in India as in 10/66 Dementia study

<table>
<thead>
<tr>
<th>Age Group</th>
<th>India</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>65-69 years</td>
<td>70-74 years</td>
<td>75-79 years</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Men</td>
<td>2.9</td>
<td>5.5</td>
<td>4.5</td>
</tr>
<tr>
<td>Women</td>
<td>5.5</td>
<td>7.4</td>
<td>8</td>
</tr>
</tbody>
</table>

In assessing and diagnosing dementia there are a number of issues when countries like India are considered. The educational background, social status, urban/rural living, understanding of assessment process and validation of the assessment tools used are to be taken into account when diagnosing somebody with a condition which means little to people but harnesses itself in the most overwhelming fashion. Though the percentage figures from these studies look small in numbers one could imagine the prevalence of Schizophrenia, which is considered to be 1% and still presents with significant psychiatric morbidity costing the Government a fortune.

Ageing population of India

The census conducted in 2001 has shown that the elderly population of India accounted for 77 million compared to 24 million in 1961, 43 million in 1981 and 57 million in 1991. This trend projects a rise from 5.63% of older adults in 1961 to 6.58% in 1991, reaching 7.5 per cent in 2001 (Table 2). [5]

Table 2: Elderly population in India 1961 - 2001 [8]

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>60+</td>
<td>5.6</td>
<td>6</td>
<td>649</td>
<td>675</td>
<td>7.5</td>
</tr>
<tr>
<td>70+</td>
<td>2</td>
<td>2.1</td>
<td>2.33</td>
<td>2.51</td>
<td>2.9</td>
</tr>
<tr>
<td>80+</td>
<td>0.6</td>
<td>0.6</td>
<td>0.62</td>
<td>0.76</td>
<td>0.8</td>
</tr>
<tr>
<td>90+</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>NA</td>
</tr>
<tr>
<td>100+</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>NA</td>
</tr>
</tbody>
</table>

The projections for the ageing Indian population show that the current 'cone' shaped pyramid will swell in the middle and at the top with a huge rise in the older adult population growth.

Figure 2: The ageing Indian population [8]

Table 3: Projected dementia population in the State of Andhra Pradesh by year 2026 [7]

<table>
<thead>
<tr>
<th>Year/age</th>
<th>65 - 69</th>
<th>70 - 74</th>
<th>75 - 79</th>
<th>80+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>35.6</td>
<td>43.5</td>
<td>50.3</td>
<td>54.0</td>
<td>1834</td>
</tr>
<tr>
<td>2011</td>
<td>387</td>
<td>50.6</td>
<td>57.6</td>
<td>99.0</td>
<td>2459</td>
</tr>
<tr>
<td>2016</td>
<td>46.3</td>
<td>55.9</td>
<td>68.9</td>
<td>136.8</td>
<td>3079</td>
</tr>
<tr>
<td>2021</td>
<td>56.7</td>
<td>67.9</td>
<td>77.5</td>
<td>1764</td>
<td>3785</td>
</tr>
<tr>
<td>2026</td>
<td>68.3</td>
<td>84.0</td>
<td>95.3</td>
<td>213.5</td>
<td>461.1</td>
</tr>
</tbody>
</table>

Awareness of dementia in India

The awareness of dementia in general population in India is lacking to the extent of not being able to identify the common symptoms and signs as culturally this symptomatology was considered as 'normal ageing' or 'madness in elderly'. In a number of studies done it was suggested that people were able to identify the typical features of dementia but named them differently like "Chinnan" (literally childishness) in Malayalam language in Kerala, "nerva frakese" (tired brain) in Konkani language in Goa where they also believed that it is caused by "family neglect, abuse, tension and lack of love", and "weak brain" in Hindi in Banares. [10] Though people realized the signs and symptoms of dementia, the suggestion that dementia is an organic brain syndrome and is part of a medical condition was not acknowledged. [10]

A multitude of factors responsible for the lack of awareness of dementia among masses and professionals in India; lack of structured training in recognition and management of dementia among professionals; lack of support for patients and their care givers, and the lack of government healthcare organizations and media in promoting awareness in communities. [11] There are other dynamics such as lack of pressure on the government and policy makers to provide a more responsive dementia care service, [17], and complete lack of support to the family and informal caregivers by any organization or institution. [11]
Caregiver burden for people caring dementia patients

Due to lack of supportive structure in the healthcare system in India specially for people with dementia and their families; the exclusive provider of care would be a member of family who would in-turn lose the job, suffer the carer burden and in many cases emotional and psychological stress. For people to approach services and get engaged with them, they need help and encouragement in accessing services and also awareness which can be increased by information provided by the government, healthcare providers and media (Table 4).

Table 4: Family and financial support for people with dementia

<table>
<thead>
<tr>
<th>Place</th>
<th>N</th>
<th>Government or occupational pension %</th>
<th>Income from family %</th>
<th>Disability pension %</th>
<th>Food insecurity %</th>
<th>Living alone %</th>
<th>Living with spouse only %</th>
<th>No children %</th>
<th>No children within 50 miles %</th>
<th>Income security</th>
<th>Secure living arrangement</th>
<th>Availability of family support</th>
</tr>
</thead>
<tbody>
<tr>
<td>India (urban)</td>
<td>75</td>
<td>13.3</td>
<td>28</td>
<td>27</td>
<td>28</td>
<td>4</td>
<td>13.3</td>
<td>5.3</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>India (rural)</td>
<td>108</td>
<td>26.9</td>
<td>444</td>
<td>0</td>
<td>17.6</td>
<td>15.1</td>
<td>57</td>
<td>8.3</td>
<td>2.6</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is a relatively unique situation in India with the family and extended family set up of supporting the people with dementia and also for many generations to live in the same house at the same time including children less than 16 years of age. Though this provides supportive care to the elderly, it also affects the carer with burden and affects the economy due to lack of income generation by that member of family. An observational study concluded that social engagement, marriage, living with someone to avoid loneliness might be protective for development of dementia. Another study claims that larger household would witness less caregiver burden compared to smaller household.

Older people with dementia cannot in India be viewed as a separate group in society and many a times the patient's and caregivers needs are unmet, which results in the psychological strain and economic disadvantage which in turn will have a negative impact on all family members leading to impoverishment, educational disadvantage, and gender inequality that constitute the major barriers to successful social and economic development. It is true of Indian family systems and also other similar cultures that elders would like to live with their children and children do feel that it is their responsibility and honour to look after their parents and grandparents. If there are more people living in household they will share the responsibility as well and this is true of many developing countries.

Economic impact of dementia in India

The Dementia India Report, 2010 came up with stark figures of economic impact of dementia in India. According to this report in 2010, there were as many as 37 million Indians with dementia and the total societal costs is about 147 billion Indian Rupees (INR), while the numbers are expected to double by 2030, costs would increase three times. The families are the main carers and they need support to play such a pivotal role. The informal carer form more than half the total cost of care (56%, INR 88.9 billion) and nearly two-thirds (29%) of the total cost is accounted for direct medical cost (INR 46.8 billion). Total cost per person with dementia is US$ 925 (INR 43,285). Due to the huge amount of cost of living in urban areas 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).

The deep rural - urban divide in India makes it a daunting task to perform the costing and the cost analysis due to vast variations in the service provision and availability of resources.

India is currently spending INR 0.15 to 160 billion per year for care of people with dementia. It is predicted that the current number of people with dementia would double by 2030 (3.69 million to 7.61 million), the immediate consequence would be that the cost of care would also double but when nominal 5% annual inflation is taken into account this amount would almost treble by 2030.

Current dementia services in India

The services provided for dementia care in India is quite fragmented and patchy depending of the geographical areas in addition to rural or urban locations. The Alzheimer's and Related disorder Society in India (ARDSI), along with other social governmental and non-governmental organizations produced a list of services available to support people with dementia. The paucity of resources in India could be seen when the facilities and services available for people with dementia are analyzed. In a country of growing elderly population and straining socio-economic condition there are 6 Residential care facilities (respite facility, family support); 10 day care centres (medical attention and supervision); 6 domiciliary care services (advice and tips for caring families); 100 memory clinics (provide assessment, support, information and advice) and 10 dementia help lines.

The most significant barrier which emerges when implementing services for dementia are low human resource capacity for the care of those suffering from this progressive condition. Lack of essential human resources such as neurologists, psychiatrists and psychologists for all mental disorders across the continuum of life has been systematically documented in a Lancet series on Global Mental Health.
Some initiatives have been taken by the Government and also ARDSI in implementing training programs for caregiver to help people them care better and also among the professionals to pursue career in geriatrics. They established a six months certificate course in geriatric care, one-year post graduate diploma in geriatric care, training NGOs and functionaries and establishment of ARDSI school of geriatric care.

Undergraduate and post graduate training in psychiatry
In most Indian medical schools the recruitment is based on performance in premedical entrance examination. Minority groups (ethnic and social), which are underrepresented, are recruited with lower cut off scores in competitive entrance examinations. The rotating internship year after completing the final medical exams, usually the fifth year is most of the time used to study and prepare for postgraduate medical entrance examination, \(^{[18]}\) which undermines the experience and usefulness of the internship year.

The need of appropriate undergraduate psychiatric training has been highlighted for a long time but progress has been sluggish. There is a rift that exists between psychiatry and the rest of medicine in India, which is detrimental to both the disciplines and this gap can be filled to a great extent by incorporating psychiatry education in the undergraduate curriculum. Empowering the medical officers with psychiatric knowledge during their undergraduate training can go a long way in increasing psychiatric care in India. \(^{[19]}\)

Psychiatrists are key specialists in managing and supporting psychiatry case loads that are beyond the management skills of general practitioners and have played significant role in driving mental health program and providing mental health care to patients in many countries and India is not an exception. However, their influence is in part a by product of their professional preparation and training received both at undergraduate and postgraduate level. \(^{[20]}\)

There are over 103 medical institutions providing postgraduate training in psychiatry in India, which has been a remarkable achievement, compared to the past. From 1947 to 1967 there were only six institutes in India offering postgraduate degrees and only 14 qualified as (Doctor of Medicine) MDs from these institutes. There are a number of doctors from India trained in the UK and USA and figures from the Institute of Psychiatry, London indicate that from India alone 101 received training in psychiatry between 1949 and 1966; they formed about 10 percent of the total number of trainees during those years. \(^{[20]}\)

Conclusion
There is a need on all fronts including government, NGOs, professionals, policy makers and people to create awareness and understanding of dementia and its impact in India. Though there are a number of steps governments and policy makers have suggested but there must be systems in place to check them and support them appropriately. The growing elderly population in India is a combination of number of factors like improvement of healthcare access, conquering some of the communicable / infectious diseases, awareness of medical conditions and betterment of life style. These advancements in medicine lead people to live longer raising question of increasing number of dementia patients that has been projected to rise more than ever. The carer burden has been an issue widely discussed in the current day research in psychiatry, as a whole and dementia cannot be excluded. Better opportunities of training for those who provide informal care, economical support and allowance, education and awareness of families supporting their loved ones. These informal caregivers do save the government a huge amount of revenue, though this review has not focused on the topic of economic savings. It must be the responsibility of all involved in the service development and policy making to help and support these caregivers and that will in turn is huge economic investment which will yield results.

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References


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