

Reports

Dementia in India – a call for action

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In 2016, there were 47 million people living with dementia worldwide. With ageing populations across the world, this number is estimated to rise to 131 million by 2050. Not only does it have a significant impact on the people living with dementia, their families and the wider society; but it also has a huge economic impact. Dementia was already expected to be a trillion-dollar disease by 2018, from a 2016 estimate of US\$ 818. In addition, most people with dementia remain undiagnosed and are therefore unable to access care and treatment. When dementia is diagnosed and care services exist, they often are patchy, fragmented, inaccessible, expensive and not suited to meet the needs of people suffering from dementia or their families.¹ This not only leads to increased suffering for people with dementia and their carers, as well as impacting significantly on the finances of the family through indirect costs of illness and loss of productivity, but also undermines the credibility of the health services and the practice and science of medicine itself. The care provision for people with dementia is even more inadequate in low and middle-income countries with lack of awareness in the communities, limited trained and skilled resources, inequitable allocation of available resources, unaffordability of treatment, and lack of priority given to dementia as a public health priority.

India's population in 2018 is estimated to be around 1.35 billion, the majority of which is in the working age with only around 10% of the population above 60 years. This proportion is projected to rise to 12% by 2031 and to 19% by 2050 when India is expected to have a population of 1.70 billion indicating an ageing population. With demographic ageing, comes the problem of dementia and India is expected to have one of the largest number of elders with dementia. In 2015, an estimated 4.1 million persons aged over 60 years had dementia in India.² This is estimated to rise to 6.35 million by 2025 and to 13.33 million by 2050. This indicates that the burden of dementia in India is already significant and is expected to rise rapidly over the next two to three decades. The proportion of people with dementia in age groups of 60-75 years is expected to increase steadily over time. On the other hand, a steep increase in dementia is expected in the over 75-age group after 2030. The cost of dementia care in India in 2010, was estimated to be US\$ 3.4 billion, with more than half being informal care cost (US\$ 1.9 billion), nearly one third being direct medical cost (\$1 billion) and the rest being direct social cost.³ A study in 2010 found the prevalence of dementia in Pune city to be 4.1% in those aged above 65 years. This indicates a very significant burden of the illness in the local

region. Burden of care was associated with caring for elderly with dementia with increasing severity of dementia. Social network had a protective effect on severity of dementia.⁴ Such increased numbers of people with dementia will have a marked impact on the states' healthcare systems, families (emotional and financial burden, poor quality of life) and the society at large (directly through government expenditure or indirectly through loss of productivity).

The treatment or service gap for dementia in India is thought to be nearly 90%, with only one in 10 people with dementia receiving a diagnosis, treatment or care. The reasons for this are manifold, but the main ones appear to be very poor awareness of dementia in society as well as among health care professionals, very low specialist or trained human resource capacity for the care of those with dementia, and lack of public health priority for dementia.³ This results in almost all care being delivered by the family at home and without information or financial support. The capacity of suitable care centres is very low. For instance, 4.1 million people have dementia, but full-time care capacity is estimated to be available for less than 2000 people.² Additionally, there are issues with only partial appropriation of the illness of dementia in Indian cultural settings with its financial, political and family-interpersonal relationship implications in addition to the complexities of clinical-cultural and biomedical-social encounters.⁴

The World Bank has classified India as a lower middle-income country and it is projected to be a high middle-income country by 2047.⁵ India spends just over 1% of its gross domestic product (GDP) on health and only a mere 1-2% of the health budget is spent on mental health. However, the Government of India has recently committed to spending 2.5% of its GDP on health by 2025. Also, India now has a new Mental Health Care Act, 2017, which gives every person the right to access mental health care operated or funded by the government; good quality and affordable health care; equality of treatment and protection from inhuman practices; access to legal services; and right to complain against coercion and cruelty. This commitment from the government towards spending more on health and the existence of an enabling legal framework that protects the rights of people with mental health problems and promotes inclusion are positive developments for mental health as well as for dementia. However, the benefits of this are unlikely to affect the care of people with dementia unless there is a recognition of this as a health priority. This requires advocacy by patient and carer groups as well as researchers with policy makers. However, no health problem can be addressed

without an effective, accessible, equitable, feasible and acceptable intervention. Therefore, there is an urgent need to gather evidence about such models of care delivery at primary, secondary and tertiary levels for people living with dementia. India is a country that is very diverse in region, language and culture. Hence a 'one size fits all' approach is unlikely to work. Therefore, any intervention or model of care delivery for dementia will need to be such that it can be customised to the regional, cultural and language contexts of the place where it is to be implemented.

The World Alzheimer Report, 2016, states that the models of healthcare delivery for people living with dementia need to be continuous, holistic and integrated. The current specialist model of health care delivery for dementia is neither likely to provide full coverage to meet the growing demand for services nor is it likely to be affordable. With a large service gap, lack of awareness in the community and lack of adequate specialist trained resources in low and middle-income countries like India, there is a need to involve not only primary care services in the delivery of dementia care but also community health workers trained to do specific tasks, in dementia care provision. Evidence suggests that when the responsibility of dementia care is placed with primary care physicians, care outcomes are compatible with that provided by specialists.

Indeed, memory clinics have been successfully run in primary care by primary care physicians. However post-diagnostic continuing care for dementia through primary care remains an area of research.¹

Collaborative community-based care (CCBC) models involving task shifting to lay health workers have been tried in the management of persons with Schizophrenia in India and have been found to be modestly more effective than facility-based care alone.⁶ In case of dementia care, CCBC models could include lay health workers conducting awareness sessions in the communities they work with, identification and screening of at risk people, referral to an assessment centre and following up with the family after a diagnosis has been made to provide psychoeducation, encourage concordance with medications and supporting the families in managing the illness and addressing carer stress. There is an urgent need to develop and pilot such models of service delivery for dementia, and assess their quality, effectiveness, feasibility and acceptability. Additionally, performing an economic assessment of these services and modelling the overall cost of proper vs improper management of dementia in the existing setting would be useful in establishing the cost-effectiveness of such a service. This can inform policy and enable service delivery at scale, in an equitable, affordable and sustainable manner. Such a model of care will address the problem of the large service gap in dementia, mobilise untapped resources in the local communities and most importantly equip the health systems to be prepared for the large increases in number of people with dementia anticipated over the next few decades.

Task shifted models of care, where primary care services are involved in prevention, early identification, screening, diagnosis and early treatment of dementia with support, training and supervision from specialist resources, would allow early identification, diagnosis and initiation of treatment. To enable this to happen, there is an urgent need

to develop and validate screening and diagnostic instruments to assess cognitive functioning. Such tools can be used by non-specialists through adequate training and supervision, if available in the local language. This would reduce the problem of under-detection, under-diagnosis and under-treatment in India thereby helping to reduce the large service gap.

Such primary care services of identification, screening, early diagnosis and treatment initiation, must be complemented by seamless continuing care services. These services could involve active case management by specifically trained dementia health workers to deliver specific interventions to the person with dementia and their families such as psychoeducation, adherence management, family support and advice, advocacy, enabling access to social welfare schemes and services, access to care facilities like day care and ensuring access to care for psychological and physical health problems. A clearly defined intervention package focusing on these aspects would ensure standardisation of the care being delivered, quality control and enable supervision.

Appropriate referral pathways would need to be established for complex cases where specialist input and further investigations may be required. Since dementia is a progressive illness, any model of care will need access to hospital care or specialist assessment and support for confirmation of diagnosis in complex cases, treating reversible dementias, management of physical health problems if necessary, advice on treatment of psychological and behavioural symptoms of dementia and lastly access to end of life or palliative care. Explicit guidelines regarding care delivery, risk identification and management and referral pathways would make the service integrated across primary, secondary and tertiary care. Such a model of care would be continuous, holistic and integrated as recommended in the World Alzheimer Report, 2016.¹

Additionally, any model of care for dementia will need to link with the private healthcare providers as they form the mainstay of health care provision in India. Nearly two-thirds of all health care in India, in urban as well as in rural areas, is provided by the private medical sector.⁷ Currently, dementia care too, is provided mainly by private tertiary hospitals having specialist driven care with hardly any engagement with primary care, government health services or community care services. Thus, dementia care services are largely hospital-based, expensive, fragmented and inequitable. In order to make dementia care services available and accessible to the vast numbers of people with dementia, involving private healthcare providers in the model of dementia care delivery is essential. However, the high cost of private health care which is usually met with out of pocket expenses (Catastrophic Health Expenditure-CHE) can push many families into poverty.⁸ Therefore, cost-sharing models of care need to be developed to enable the private healthcare services to be available, accessible and affordable to the wider community. In this respect, the recently launched Ayushman Bharat Scheme by the Government of India is critical. This is National Health Protection Scheme, which will cover over 100 million poor and vulnerable families (approximately 500 million beneficiaries) providing coverage up to 0.5 million Rupees (\$7150) per fam-

ily per year for secondary and tertiary care hospitalization. This could take care of the cost of hospitalisation for the most vulnerable people with dementia.

The provision of care and security for elderly, especially elderly parents, is important to Indian society. The weakening of the consanguineal family unit, especially in the urban areas, has contributed to the challenges faced by elderly, especially people with dementia. Many ended up living alone without sufficient financial, emotional, social and physical support. The Maintenance and Welfare of Parents and Senior Citizens Act, 2007 casts obligations on children to maintain their parents/grandparents and also the relative of the senior citizens to maintain such senior citizens.⁹ Hence involving families in care delivery should be an important component of any service delivery model. Lastly, for any intervention to be effective, a cultural acceptance from the community and the end-user is desirable. Study of the explanatory models of people with dementia and their carers may help in retaining what is helpful in the processes of detection and care, while identifying and addressing the cultural beliefs. This would be useful in curtailing the delay in help seeking as well as helping in better acceptance of the illness and minimization of perceived burden.

CHALLENGES AND FUTURE DIRECTIONS

There is already a significant burden of the dementia in India and with an ageing population it is only expected to grow over the coming decades. The current care services for dementia are vastly inadequate. There is an urgent need to prioritise development and piloting of tiered, integrated and holistic dementia care services accessing resources in public and private healthcare. It should be using a collaborative community-based care model to enable such a service to be universally available, accessible, equitable, effective and affordable to population at large.

India is a diverse country with a multitude of languages and dialects and vastly varying educational levels. Hence, language and education dependent screening and cognitive

assessment scales would be a challenge. The use of content-free speech analysis to predict dementia years before its onset could be a vital innovation in the prevention or early recognition of dementia.¹⁰

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COMPETING INTERESTS

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REFERENCES

1. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. *World Alzheimer Report 2016 Improving Healthcare for People Living with Dementia. Coverage, Quality and Costs Now and in the Future*. Alzheimer's Disease International (ADI); 2016. Accessed November 7, 2019. <https://www.alz.co.uk/research/world-report-2016>
2. Kishore S. Dementia in India, 2015. Published 2015. Accessed November 7, 2019. <http://dementiacarenotes.in/dementia/dementia-india-2015-info/>
3. Shaji K, Jotheeswaran ANG, Girish N, et al. *The Dementia India Report 2010*. Alzheimer's and related disorders society of India; 2010. Accessed November 7, 2019. <http://ardsi.org/downloads/ExecutiveSummary.pdf>
4. Brijnath B, Manderson L. Appropriation and dementia in India. *Cult Med Psychiatry*. 2011;35(4):501-518. doi:10.1007/s11013-011-9230-2
5. The World Bank. Data for India. Published online 2017. Accessed November 7, 2019. <https://data.worldbank.org/?locations=IN-XN>
6. Chatterjee S, Naik S, John S, et al. Effectiveness of a community-based intervention for people with schizophrenia and their caregivers in India (COPSI): a randomised controlled trial. *Lancet*. 2014;383(9926):1385-1394. doi:10.1016/s0140-6736(13)62629-x
7. International Institute for Population Sciences, Macro International. *National Family Health Survey (NFHS-3): Volume-I*. Health (San Francisco); 2007.
8. Sekher TV. Catastrophic Health Expenditure and Poor in India: Health Insurance is the Answer? In: *XXVII IUSSP International Population Conference*. ; 2013. Accessed November 7, 2019. <http://iussp.org/en/event/17/programme/paper/4043>
9. Ministry of Law and Justice. The Maintenance and Welfare Of Parents And Senior Citizens. Published 2007. Accessed October 31, 2019. <http://socialjustice.nic.in/writereaddata/UploadFile/Annexure-X635996104030434742.pdf>
10. Luz S, De Fuente S, Albert P. A Method for Analysis of Patient Speech in Dialogue for Dementia Detection. In: *Proceedings of the LREC 2018 Workshop "Resources and Processing of Linguistic, Para-Linguistic and Extra-Linguistic Data from People with Various Forms of Cognitive/Psychiatric Impairments (RaPID-2)*. ; 2018.