NEUROLOGIC DISABILITY: A HIDDEN EPIDEMIC FOR INDIA

India, the world’s second most populous country, is facing the emergence of a hitherto “hidden” epidemic: neurologic disability. The rapid economic, demographic, and social transformation of India in recent decades has already resulted in the double burden of unresolved epidemics of infectious diseases (e.g., malaria, tuberculosis) coupled with rising rates of chronic diseases (e.g., cardiovascular diseases). Neurologic disability is likely to join these public health concerns as a third epidemic, largely due to 3 emerging health trends: 1) an increase in traumatic brain injuries (TBI) from road traffic accidents (RTA); 2) an increase in the incidence of age-related dementia; and 3) an increase in the stroke incidence. Without adequate preparation, the treatment and long-term care for an increasing population of neurologically disabled people will strain India’s health care system and economy in the coming years in unprecedented ways.

THE TRENDS Traumatic brain injury. Presently, comprehensive epidemiologic studies of TBI in India are lacking. Based upon studies done in the 1990s, it was estimated that nearly 1 million persons are disabled due to TBI in India annually, a likely underestimation of the current scenario.1,2 In India, 60%–70% of TBI results from RTA1,2 and RTA in India has increased dramatically in recent years due to widespread motor vehicle access and inadequate safety protocols.3 It has been reported that India has the highest mortality rates from RTA in the world, with 161,736 RTA deaths in 2010 (National Crime Records Bureau, India).3 For each RTA-related death, at least 20 serious injuries occur in India.4 By this estimate, approximately 3.2 million serious RTA-related injuries occurred in 2010. Again, there is lack of population-based data on how many RTAs result in TBI. However, from the few hospital-based studies conducted in metropolitan cities, we can surmise that TBI is seen in the majority (approximately 70%) of RTA-related injuries in India. By this estimation, in 2010, 2.2 million people had TBI due to RTA alone. As RTAs contribute to 60%–70% of all TBIs (http://indianheadinjuryfoundation.org/affect-tbi.html), this would lead to 3.3–3.5 million TBI (from all causes) in 2010 in India. However, due to lack of recent population-based data on the other causes of TBI, such as falls or violence, this will be a rough estimate (e.g., with the increase in the aging population, fall-related TBI is likely to increase). Given the long-term disability rate of approximately 50% after brain injury,1,2 India is generating approximately 1.5–1.7 million neurologically disabled people every year due to TBI alone.

Dementia. The second contributor to the emerging epidemic is dementia. The Indian population is aging rapidly due to a combination of increasing life expectancy and declining fertility rates. The proportion of older adults in India is predicted to increase dramatically from 76 million in 2001 to 301 million by 2051 (from 7.1% to 17% of the population).4 As the risk for dementia increases with age, roughly doubling every 5 years after age 65, the number of people with dementia is expected to triple in India by 2050, adding at least 1.6 million neurologically disabled persons due to dementia annually.5

Stroke. Stroke is the third major contributor to the emerging epidemic. While stroke incidence has declined by over 40% in the past 4 decades in developed countries, the incidence rate in India has doubled. The incidence rate of stroke in India is currently estimated to be 145 per 100,000 people with approximately 1.5 million new cases reported in 2010.6 Stroke results in long-term disability, including paralysis, language problems, and other cognitive deficits, in 30%–40% of cases, and therefore 0.45–0.6 million people with disability will be added to the population annually.

Taken together, the rising rates of TBI, dementia, and stroke will potentially add over 3.5 million people to the disabled population annually, almost equal to the population of a metropolitan city like Nagpur or Lucknow. This is a staggering number: every minute, 7 people will acquire a neurologic disability, amounting to nearly 11,000 every day.

THE BURDEN This emerging epidemic of neurologic disability will place an immense burden on Indian society as a whole. Neurologic impairment is among the...
leading causes of disability-adjusted life years (DALY), an indicator of overall disease burden expressed as the number of years lost due to ill health, disability, or early death. In other words, while the overall life expectancy in India is increasing, the overall quality of life will be diminished by the increasing prevalence and duration of neurologic disability.

There will also be immense direct and indirect economic costs. Currently, the annual cost of dementia-related care in India is INR 160 billion ($3.2 billion USD). Although similar estimates of the cost of TBI-related disability are not available, the economic loss due to RTA was estimated at nearly INR 550 billion every year or nearly 3% of India’s GDP in 2000. India had 3,28,466 RTAs with 80,118 deaths in 2000. The reported death due to RTA has doubled in a decade, with 161,736 deaths from 4,61,757 RTAs in 2010. As a significant amount of this cost will be due to TBI-related societal costs, we expect it to be doubled over the last decade, when counting in increase in RTA from 2000 to 2010. Currently there are no available data on cost of stroke-related disability in India. Although it is difficult to accurately estimate the overall economic cost of neurologic disabilities in India, neurologic disabilities are known causes of economic burden the world over. Globally, the annual cost of dementia alone has been estimated to be $604 billion USD for 2010 (1.01% of world GDP). Therefore, the total cost for all neurologic disabilities is likely to cause a significant dent in Indian GDP.

In India, family members provide most of the care of disabled persons. A disproportionate amount of this economic burden, therefore, will be borne directly by individuals and their families. Studies have shown that almost two-thirds of low income families in India resort to the sale of family assets or incur loans to support the care of a neurologically disabled family member, and over 90% reported ceasing involvement in paid work or education to provide care. Therefore, the burden of neurologic disability in India is likely to be disproportionately experienced by the poor.

THE RESPONSE The public health importance of this rising epidemic of neurologic disability remains hidden from legal records and official statistics. For instance, by some estimates only a fraction of the 1.4 million annual RTA in India is recorded (http://www.irtc.com/crash-investigation.html). In addition, there is deep-seated social stigma associated with disability in India, which results in the exclusion and underreporting of individuals with disabilities. This lack of recognition for neurologic disabilities has created a huge lacuna in health care policy and the health care system of India that will likely lead to a lack of preparedness in India for this epidemic. India, with a population over 1 billion and very limited numbers of neurologic and mental health facilities (1 bed per 40,000) and a dearth of mental health professionals (fewer than 3 psychiatrists/neurologists per million), is already struggling to provide neurologic and mental health care to its entire population. Moreover, the primary health workers are not trained for managing neurologic disabilities and institutional care for neurologic disability is confined to a few metropolitan cities. Adding to this problem, awareness about neurologic disability as a medical disorder is inadequate among the general population and health care professionals.

The required steps. To counter this epidemic, the scientific and medical communities need to act on multiple levels. First, India needs to reduce the RTA rate drastically by enforcing traffic laws and raising public awareness of the importance of responsible driving. Second, there is an urgent need for the development and implementation of standardized data collection tools for assessing neurologic disability in primary care in order to improve both diagnosis and documentation for accurate health statistics. Third, there is a need to develop trained professionals with expertise in neurorehabilitation to cope with the problem. Undergraduate medical and nursing curricula should emphasize neurologic disability issues. Availability of specialty courses and research funding in neurorehabilitation needs to be expanded. Fourth, this epidemic calls for Indian scientists and health care professionals to engage in more research aimed at neurorehabilitation. Overall, given the alarming scale of potential public health and economic threat, this epidemic calls for making neurologic disability a public health priority in India and mandates urgent changes in national health policy.

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