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DEMENTIA: CHALLENGES OF PRACTICE IN PAKISTAN

Alzheimer disease (AD) is a leading cause of morbidity and mortality with an estimated 35.6 million people affected worldwide. Currently 58% people with dementia are in developing countries and this is expected to rise to 71% by 2050. By 2050, 22% of the world's population will be over 60 and most of them will be in Asian, Latin American, or African countries.¹

Pakistan is a developing country in Southeast Asia with an estimated population of 184.8 million (<http://www.census.gov.pk/>) and 5.5% of the population is 60 and above, according to 1998 census. By 2050, Pakistan will become the third most populous country in the world. However, there is lack of infrastructure to deal with this challenge and to work effectively as a clinician and researcher in the field of dementia in Pakistan.

Training and research. I am the only formally trained dementia specialist in Pakistan. I returned in July 2013 from the United States. There are no behavioral neurology, neuropsychiatry, or dementia training programs for graduating psychiatry or neurology residents. Neuroscience research is now being introduced after Pakistan gained affiliation with the International Brain Research Organization in 2007²; 2 centers of molecular research are being established, yet there are currently no neuroscience training programs at the undergraduate or graduate level in Pakistan.³ There are no active research laboratories or researchers dedicated to the genetics of dementia and genetic testing is not available for AD or other dementias. Brain banks are not yet available and autopsies are currently not performed (table). This type of procedure would be vital for research purposes. There is one local dementia registry established at a tertiary care hospital in Pakistan that has reported 60 patients.⁴ No epidemiologic studies have been done. In May 2013, a dementia research center was opened in Lahore in association with Alzheimer's Pakistan.

Dementia clinics. In 2012, 2 dementia clinics were established within academic institutions in Lahore and Islamabad. A national pharmaceutical company, Nabi Qasim, has also recruited some physicians to see dementia patients in various cities in Pakistan.

General neurologists, psychiatrists, and family practitioners see dementia patients in their practices.

Psychometrics. Cognitive psychology and psychometrics are not recognized fields and Pakistan lacks translated and validated scales in Urdu for testing cognition in dementia patients; efforts are underway to translate and validate the Mini-Mental State Examination.

Neuroimaging and biomarkers. Brain MRIs and CT scans are performed at major hospitals but most people have to pay out of pocket, which is an enormous limitation. In the last 2–3 years, FDG-PET scans and Medical Cyclotrons have been introduced at 3 different places in the country; however, they are primarily utilized for cancer imaging. Amyloid PET scans and CSF biomarker studies (amyloid, tau, p-tau, 14-3-3, NSE) are not performed in Pakistan.

Social services. Alzheimer's Pakistan is a nongovernmental, national organization that has set up a day care center in Lahore with the assistance of Alzheimer's Australia. There is no long-term care unit or nursing home for patients with dementia and almost all of these people are cared for at home by their families. These caregivers provide full assistance from the advanced stages of the disease until death without benefit of dementia counselors, social workers, case managers, or support groups. Alzheimer's Pakistan, in collaboration with Alzheimer's Disease International and the International Psychogeriatric Association, has initiated a collaborative project called Global Improvement of Dementia Care to improve the lives of patients with dementia and their families by changing health care systems through getting support from the government, health care professionals, community, and media.

Dementia and legislation. There are no laws in Pakistan pertaining to "mentally disordered" (legal term in Pakistan) people and their affairs except for the Sindh Mental Health Ordinance 2013 that was recently approved (<http://www.pamh.org.pk/Mental%20Health%20Law.php>). This law has provisions for appointing a "Guardian" and "Manager of

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Table Practicing dementia in Pakistan: Important facts and figures

Domain	Number
Trained dementia specialist	1
Dementia fellowship program	0
Neuroscience training program	0
Epidemiologic studies	0
Brain bank	0
Dementia registry	1
Dementia research center	1
Academic dementia clinics	2
Translated, validated psychometric dementia scales	0
Genetic tests for dementias	0
Brain FDG-PET for dementia	Not available
Amyloid PET	Not available
CSF biomarkers for dementia	Not available
Dementia day care center	1
Dementia nursing home	0
Dementia support group	0
Alzheimer disease clinical trials	0

Property” but these ordinances do not exist in the rest of the 3 provinces of Pakistan. Currently there is no funding available for dementia or related disorders and no topic-specific government health policy exists. Pakistan has no directives in place for living will, power of attorney, or health care proxy.⁵ Driving safety evaluations are not performed anywhere in the country for people with dementia.

Clinical trials. There are currently 1,086 AD clinical trials throughout the world, 687 (63%) of which are in the United States, North, Central, and South America; 315 (29%) in Europe; 26 (2.4%) in Africa; 31 (2.9%) in the Middle East; 116 (10.7%) in East Asia; 24 (2.2%) in North Asia; 46 (4.2%) in Japan; 47 (4.3%) in the Pacific region; 9 (0.82%) in South East Asia; 4 (0.37%) in South Asia and 4 out of 4 are being conducted in India. No trials are being conducted in Pakistan. There are no government policies for starting phase I clinical trials in Pakistan.

Recommendations. Public awareness campaigns should be started and dementia teaching programs and workshops should be arranged for neurologists, psychiatrists, and general physicians with ability to accrue Continuing Medical Education credit hours. It would also be beneficial for cognitive neurology and neuropsychiatry to be introduced as a separate entity in departments of neurology or psychiatry and as subspecialty clinics within academic institutions.

Behavioral neurology and neuropsychiatry should be incorporated into resident and clerkship curricula and residents from other specialties such as family medicine and internal medicine may rotate through dementia clinics.

Exchange Scholar/Research programs and scholarships should be promoted by academic institutions and universities in the field of neurosciences and neurogenetics.

Collaborations should be developed to share data and technology with other centers within the country as well with neighboring countries, such as India and China. These countries are more advanced but face similar cultural, economic, and management problems. Specimens could be shared for biomarkers, genetic testing, and other research studies with US and European countries. A 10/66 research center should be initiated in Pakistan.

Studies to translate and validate psychological instruments for dementia are vital and it is conceivable that if cognitive psychology were introduced to graduate and undergraduate psychology students, they could work to translate these instruments.

An inpatient unit dedicated to the needs of patients with dementia should be started and public policies and laws need to be in place. Regulatory and legal processes to initiate clinical trials should be less complex and made more expedient to attract clinical research organizations. Pakistani physicians should be open to learning new information, skills, and technology with regard to behavioral and cognitive neurology. Working together, physicians, policy-makers, and neighboring countries can help Pakistan achieve the goal of providing patients with dementia and their caregivers the assistance that is urgently needed.

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