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Fatima Siddiqui
Civil Hospital, Karachi

Qurat Khan
Consultant Neuropsychiatrist, Chicago, IL

Mohammad Wasay
Aga Khan University, Karachi

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CHALLENGES FOR DEMENTIA CARE AND RESEARCH IN PAKISTAN

Fatima Siddiqui¹, Qurat Khan², Mohammad Wasay³

¹Civil Hospital, Karachi

²Consultant Psychiatrist, Consultant Neuropsychiatrist, Chicago, IL

³Aga Khan University, Karachi

Corresponding author: Mohammad Wasay MD, FRCP, FAAN; Aga Khan University, Karachi Mohammad.wasay@aku.edu

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Dementia is a syndrome characterized by a decline in cognition and memory severe enough to interfere with daily life activities and is one of the major causes of disability and dependency in elderly worldwide with Alzheimer's disease being the most common cause of dementia ⁽¹⁾. 703 million individuals (9% of the world's population) are more than 65 years of age and this number will double by the end of 2050 reaching 1.5 billion (16% of the world's population) ⁽²⁾. Ageing has been the fastest in Eastern and South Eastern countries ⁽³⁾. Despite being a global health priority, with significant social and economic consequences, not much progress has been made regarding the diagnosis and management of patients with dementia especially in low and middle income countries (LMICs) like Pakistan (WHO, 2020) ⁽⁴⁾. Pakistan is a developing, heavily populated Southeast Asian country with an estimated population of 207 million, out of which 12.5 million (7% population) is above 60 years and this number is expected to reach 40 million by 2050 ⁽⁵⁾. Despite having a high ratio of elderly population, limited resources are available for their health care ⁽⁶⁾. Dementia care needs to be addressed at all levels given the rapid increase in elderly population ⁽⁷⁾. In Pakistan there are barriers to care of patients with dementia (PwD), including but not limited to lack of awareness, research, and education.

Studies done in Pakistan suggested lack of knowledge and awareness regarding dementia in the general population. Dementia is considered a normal consequence of ageing by many ⁽⁸⁾. Majority of PwD do not seek professional help until late stages of disease causing delay in diagnosis and treatment. Also there are limited resources and funds available for such patients ⁽⁹⁾. and no government health care policies are designated for PwD and other related disorders ⁽¹⁰⁾. Another obstacle to management is the lack of specialized day care centers with no nursing homes or long term care-units for PwD. Only one day care center is present in Lahore for PwD which is run by Alzheimer's Pakistan, a non-governmental organization formed in collaboration with Alzheimer's Australia. Consequently, most of the PwD are

looked after by the family members at home ⁽¹¹⁾. Additionally, there is stigma regarding attainment of external help which is considered against social and cultural norms further aggravating the burden causing caregiver distress. In Pakistani culture leaving the patients in nursing homes is a taboo and is considered as abandoning the loved ones ⁽¹²⁾ ⁽¹³⁾. Furthermore there is no formally trained and board certified dementia specialist in the country PwD are treated in polyclinics by neurologists, psychiatrists, and family practitioners. No formal dementia training programs are present in the country to train health care professionals, there is lack of facilities focusing on dementia research, and there are no brain banks ⁽¹⁴⁾.

Overcoming barriers to treatment of dementia patients, improving pathways to care, and raising awareness among general population are of utmost importance. Public awareness campaigns should be started focusing on early recognition of symptoms, appropriate care, available healthcare facilities, common myths, and ways to prevent dementia including life style changes. Additionally workshops or CMEs should be frequently arranged for capacity building of health care providers treating dementia. Behavioral neurology and geriatric psychiatry fellowship training programs would be highly beneficial. Training for formal and informal caregivers may be arranged in collaboration with organizations such as US Alzheimer's association to improve the outcome of PwD. Western literature may be translated and contextualized to fit the needs of local population. Support groups should be started for patients and/or families dealing with dementia. More day care centers should be established with activities designed for PwD ⁽¹⁵⁾. National screening programs for identification of dementia should be introduced. Healthcare institutions should have dedicated inpatient units with adequate resources and infrastructure to deal with dementia patients and for those who require hospice care. Research collaboration with neighboring countries and participation in 10/66 dementia research group projects is also required. Khan et al translated and validated the 10/66 DRG battery in Urdu in Pakistan ⁽¹⁶⁾. and the

next step would be to start dementia prevalence study. A standardized and contextualized neuropsychological battery is needed to diagnose dementia clinically. Genetic studies also need to be done. Cost effective policies and administrative regulations should be developed at national level with revamping of financial framework of healthcare to provide affordable and uniform healthcare all over the country. Strategies need to be devised for addressing caregiver burden using an interdisciplinary approach such as providing education about disease, assistance, emotional support, and training on coping strategies. ^{(17) (18)}.

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