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Qamar Zaman

*Shifa International Hospital, Islamabad, Pakistan*

Maimoona Siddiqui

*Shifa International Hospital, Islamabad, Pakistan.*

Zaha Iqbal Malik

*Shifa International Hospital, Islamabad*

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# DEMENTIA IN PAKISTAN; AN UNPRECEDENTED CHALLENGE AND LOCAL CULTURAL BELIEFS, PROBLEMS AND ACTIONS REQUIRED.

Qamar Zaman<sup>1</sup>, Maimoona Siddiqui<sup>2</sup>, Zaha Iqbal Malik<sup>3</sup>

<sup>1,2</sup>CPS (Neurology), SCE Neurology (UK). Neurologist, Shifa International Hospital, Islamabad, Pakistan.

<sup>2</sup>FCCP (Medicine), FCPS (Neurology). Associate professor, Head of the department. Division of Neurology,

<sup>3</sup>MBBS Research Associate. Department of Neurology, Shifa International Hospital, Islamabad

**Correspondence to:** Qamar Zaman, Shifa International Hospital, Islamabad, Pakistan. Email: qamar\_zaman1400@yahoo.com

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## ABSTRACT

Changing cultural and social dynamics has brought a major shift in lifestyles and associated risk factors for various disorders that were previously uncommon in Pakistan. Dementia is among the one of these emerging problems that is going to affect the elderly population worldwide but more so in the developing world. To adequately deal with the problems faced by patients with dementia and their caregivers, several important measures are needed that can help to reduce the morbidity and burden on the families and overall society. Increasing the awareness regarding the risk factors may help to reduce the dementia burden similarly knowledge about its symptoms will help early recognition and proper referral. Several modifications in the health system like focus on the palliative care, specialized dementia trained personnel and separate care units for dementia are the need of the time. Moreover, research regarding the various complementary therapies and enrolment into international research trials should be encouraged.

**Key words:** Dementia, Memory, Cognitive domains, Skills, Speech, Awareness.

## Background:

Dementia refers to the progressive decline in cognitive abilities to such an extent that an individual is unable to carry on his routine activities efficiently<sup>1</sup>. Although memory decline or forgetfulness is considered as a hallmark of dementia, in some cases the effected person might not have any memory issues at all and impaired cognitive performance is due to the inadequacies related to the other cognitive domains like speech, planning, and loss of learned skills, abstract thinking, decision making, and changes in personality. In many cases, behavioral issues like depression, anxiety and psychosis are the earliest manifestation of dementia<sup>2</sup>.

The golden words "A talent for following the ways of yesterday is not sufficient to improve the world of today"<sup>3</sup> have proven unexceptionally true historically. As it has been observed through the course of time that human societies have always been the agent of change due to the changing human behavior and responses to the upcoming challenges and demands. The societies

and nations that were able to learn from experiences of the past and open to the new ideas efficiently survived the adversaries and flourished while those that were not ready to change only succeeded to become the part of the history<sup>4</sup>. A similar shift in the several life aspects has transpired Pakistani society during the last two decades<sup>5</sup>. A large population moved from rural to the urban areas and adapted the sedentary lifestyles. This increased the cardiovascular and several other risks making them predisposed to various co morbid conditions which were uncommon in the past<sup>6</sup>. Dementia is one of these emerging problems that are going to pose a great threat in the coming days<sup>7</sup>.

The reason so much emphasis is given to the dementia issue in the developing world is due to the fact that it is a terrible condition both for the patients and their families. It robs the person of his ability to act as a person and also his interaction with all those close to him become meaningless and inappropriate. These patients are unable to convey their physical and psychological needs and develop various behavioral problems which put not only their own dignity at stakes

but also rob the family of their enjoyment and hope. Providing care for dementia patients is quite extensive, demanding and exhausting both psychologically and physically. It has been observed that their level of burden may be quite higher compared to the burden faced in other high morbid conditions<sup>8</sup> as shown in the figure below (Figure 1)<sup>9</sup>.

According to an estimate, about 46.8 million people are living with dementia worldwide and among them, 58% belong to low and middle-income economy region. Pakistan is a lower-middle-income country that is located in South East Asia and currently the sixth most populous nation of the world<sup>10</sup>. The available data from Pakistan revealed the prevalence of dementia to be 172 per 10,000 individuals<sup>11</sup>. Although literacy rate and awareness regarding health-related issues are improving but still there is no organized structure and framework to tackle the dementia related health issues in our country<sup>12</sup>. We want to suggest several important measures and strategies required not only in Pakistan but also the other developing nations that may help in tackling this new challenge of dementia. Moreover we also need to join hands in hands with the various countries and regions and open the doors to the mutual experience sharing among them as they may be different culturally and socially but alike regarding issues related to dementia. Here are some suggestions in this regards.

#### **Public Awareness:**

Awareness in the general public about the symptoms, causes, complications and outcome of dementia is very important so that lifestyle modifications and primary prevention measures can be carried out timely. It is well known that with the advancing age, there may be a slight decline in cognition causing impairment of problem-solving and reasoning, cognitive speed, working memory and encoding skills. In age related cognitive changes, delayed recall and recognition is usually preserved and it is never severe enough to cause impairment of daily activities. It should be conveyed to public that any impaired cognitive functions to such an extent that a person is unable to carry out daily activities should be referred for evaluation<sup>20</sup>.

Various lifestyle factors that may affect future dementia risk include cardiovascular risk factors like midlife hypertension, obesity, physical inactivity, diabetes, old-age, and smoking, hearing loss, depression, social isolation and sleep disorders<sup>13, 14, 15</sup>. There is also moderate evidence implicating exposure to air pollution, aluminium, silicon, selenium, pesticides; vitamin D deficiency and electric and magnetic fields as a risk factor for dementia as well<sup>16</sup>. Lifestyle modifications like exercise, fasting, dietary modifications encouraging the use of Mediterranean diet and the diets comprising of whole grains, green leafy vegetables, nuts, fish, berries, olive oil, cheese, beans and chocolates<sup>17</sup>. Living close to nature and away from the major roads has also shown to decrease the dementia risk<sup>18</sup>. Similarly starting education at an earlier age and mind stimulating activities like the use of video games, mental exercises and intellectually demanding therapies might also play the protective role in dementia<sup>19</sup>.

Also clarification of a common myth about dementia that it is an untreatable condition should be made So that people might not be reluctant in visiting the doctors<sup>12</sup>. This problem can be further aggravated by the fact that there may be restricted access available to many patients due to the non-uniform distribution of diagnostic and treatment facilities in the country. Role of media, newspaper and seminars is vital and compulsory in this regard.

#### **Training and expertise at primary care level:**

As already mentioned above, neurology facilities are not uniformly available everywhere in the country. Most of the well-equipped setups and trained neurologist are present only in the capital cities and easy access to these setups may not be possible for many patients from remote areas. The general practitioners, paramedics and other primary care level staff are not mostly well aware and trained to rule out the mimics of dementia, the initial assessment of dementia patients like doing mini-mental state examination (MMSE) and Montreal cognitive assessment (MOCA) test<sup>21</sup>, establishing the diagnosis and treatment of dementia<sup>22</sup>. Also due to unavailability of the proper referral system, referring the dementia patients to the concerned specialty is often delayed or carried out quite late not only delaying the identification of treatable causes, but also the appropriate timely measures for those with degenerative causes<sup>22</sup>.

GPs and primary care personnel should be trained to identify dementia, able to perform MMSE or MOCA and ruling out the "mimics". Patients should primarily be referred to the neurologist/dementia experts so a comprehensive plan of management is made and discussed with the patient and the caregivers.

### **Improvement in diagnostic facilities:**

Purpose of Investigation in dementia patients is to identify the treatable causes and rule out mimics. In cases of degenerative dementias, investigations help in early diagnosis, differentiation between the various types, prognosis and planning future care. Some pertinent investigations include brain imaging, CSF B amyloid testing, and genetic testing. Workup for treatable causes includes endocrine, nutritional, chronic infections, autoimmune, metabolic and toxic workup. Types of brain imaging techniques used for the clinical assessment of dementia are grouped into three categories: structural imaging (which includes CT and MRI). Functional imaging (99mTc-HMPAO, HMPAO-SPECT, 18F-FD, FDG-PET, DaT scan) and molecular imaging (Amyloid PET PiB)<sup>23</sup>.

CSF β amyloid testing is used in early identification and differentiation from other dementias. Genetic testing is usually carried out after a causal mutation has been found in the family. It is usually carried out in Alzheimer's disease (AD), Fronto-Temporal Dementia (FTD) and other degenerative dementias. Currently, we have only structural imaging available in the country. CSF β amyloid and genetic testing are rarely used due to unavailability and the reason behind this is the cost and the lack of technical expertise<sup>24</sup>.

Emphasis on the need for these investigations and their role in the diagnosis of the disease may help to open up new opportunities and interests of the health authorities along with several organizations promoting this expertise.

### **Advance directives and legal matters:**

Dementia is considered as an illness where patients mostly lose their capacity for consent. In developed countries in such cases where a person could not make his own decisions then by the law, the treatment options and end of the life issues are mostly decided by taking into account the advance directives, legal attorney, or by the treating physicians in the best interest of the patient<sup>25</sup>. There are no well documented guidelines for this and the concept of an advance directive or legal attorney is rarely practiced in Pakistan. Such decisions in most cases are taken by the family or the doctors that may lead to the confusion and compromise the care as well as the autonomy of the patient<sup>26</sup>. Another issue related to this aspect of dementia care is whether the diagnosis should be disclosed to the patient or not. Many of the patient relatives and caregivers feel that disclosing such dire diagnosis would be a source of stress and would cause loss of happiness left in the residual days for him<sup>26</sup>. According to a study, most (57%-83%) relatives of dementia sufferers didn't want the patient to be informed about the diagnosis while more than 70% of the relatives were in the favor of diagnosis being disclosed to the patients<sup>27</sup>.

Autonomy is an important principle of medical ethics and in cases where patient still has the capacity; his participation should be encouraged in decision making giving him a chance and choice to decide for himself. A clear cut guideline on DNR and other end-of-life-care decisions should be established. Moreover concept of advance directives and selecting a legal attorney should also be encouraged.

### **Palliative care options:**

Palliative care can be defined as: "an approach to care that improves the quality-of-life of patients and their families facing problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual needs"<sup>28</sup>. It has been observed that the palliative needs of these people are equal to those of cancer patients. As it is common during the terminal phases of dementia, patients are totally unaware of their needs and they are mostly bed bound. They may be unaware of the dietary needs and there are swallowing issues; similarly, there may be problems with bowel and bladder controls, recurrent hospital admission due to infections, electrolyte imbalance, dietary deficiencies, bed sores, constipation, pain etc. Their care needs are different from other patients and dealing them in hospitals like other patients may increase the sufferings of the patients and affect their dignity. It will also lead to an unnecessary financial burden on the family and health care system. Palliative care is undeveloped and unutilized in Pakistan<sup>26</sup>.

It is very important to improve the palliative care facilities in the country including the provision of a multi-disciplinary team that has expertise in feeding strategies, physiotherapies, pain management and other issues encountered

dementia patients.

## **7. Dementia groups for experience sharing:**

Dementia groups are quite important in providing an opportunity for the caregivers of dementia patients to come into contact with other people who are passing through similar situations and also with the medical team where they can discuss the issues they encounter in providing care for their beloved as well as share experiences and techniques for coping up with the challenges faced by them on a daily basis. It also helps to increase their morale as they get to realize that they are not alone and there are other people with the likewise issues<sup>29</sup>. The concept of dementia groups in Pakistan is sadly quite confined and very few caregivers have access to it<sup>26</sup>.

Neurology society, public health services and health authorities should actively participate to frequently organize such groups including fundraising and incentives for the interested individuals and also campaign to encourage the caregivers for participating in such groups and its benefits.

## **Research opportunities:**

Various studies have shown that conventional therapy with Chinese herbal medicine may bring symptomatic benefit for patients with mild-to-moderate Alzheimer's disease. Other therapies like laughter, happiness, music, hydrotherapy and herbal products have also shown some positive effects in dementia<sup>30</sup>. Moreover, aromatherapy, multisensory stimulation, massage, animal therapy and music therapy, have also been recommended by the (NICE) guidelines as alternative first-line treatments<sup>31</sup>. There are a number of Islamic medicinal therapies that have been claimed to be useful in many disorders. Some of these include kalonji (black seeds), Hajama (cupping therapy) and cucurmin<sup>32</sup>. Similarly, intermittent fasting has been shown to improve the cognition in some studies<sup>33</sup>. Many countries are conducting trials for newer therapies for dementia including pharmacological and natural therapies. However, there is less focus on research in this context and also only a negligible get the chance to participate in international trials to find any hope.

We need to conduct trials to find benefit and provide recommendations including various Islamic medicinal therapies. A liaison with international trials and enrollment of those who wish to participate will also prove to be beneficial.

## **Dementia nurses, caring homes, specialized care facilities:**

Due to the increase in education level, a large number of females have entered the working class compared to the previous trends where females usually handled the domestic duties including the care giving for the sick at home. Due to this cultural shift, less support system is available nowadays<sup>26</sup>. Nursing homes and specialized dementia care facilities are becoming a fundamental requirement where patients can be better looked after. Also, dementia patients need specialized care and skilled personnel who are trained and have adequate abilities to handle and manage the important issues encountered by such patients<sup>34</sup>.

The expertise that might prove useful includes dementia nurses, dementia care managers, physiotherapists, occupational and speech therapists<sup>35</sup>. Their role might extend from providing the guidance and training to the caregivers regarding dressing, feeding, mobility, emotional support and various other matters at home to the provision of inpatient services<sup>36</sup>. These setups may act as a point of the first contact in case of any health issues faced by dementia patients, thus reducing the burden on routine Accident and emergency departments but also an easily accessible source for relatives and caregivers.

## **Conclusion:**

There is a desperate need for an organized and comprehensive campaign regarding Dementia and its care, considering its growing emergence in society and the limited preparations that have been made in this regard. Growing need to create awareness in the general public that dementia can be prevented and/or is treatable while in other cases there may be many pharmacological and non-pharmacological options that can help in improving the patient's quality of life. Focus on the setting a solid infrastructure at the primary health level and training the personnel about timely recognition

and appropriate referral is the backbone in this regard. Also developing strategies to establish the dementia nursing homes, trained personals, caregiver support groups and also promoting the research are no doubt vital factors.

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**Qamar Zaman;** concept, data collection, data analysis, manuscript writing, manuscript review

**Maimoona Siddiqi;** data collection, data analysis, manuscript writing, manuscript review

**Zafar Iqbal Malik;** data analysis, manuscript writing, manuscript review