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# STROKE MANIFESTO- WHAT MUST BE DONE FOR STROKE CARE IN PAKISTAN

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Pakistan is the sixth most populous country in the world, with an estimated population of 190 million. Non communicable diseases including stroke now account for 41% of the total disease burden of Pakistan. An estimated 4.8% of Pakistan's population is living with stroke; this translates to 9.1 million individuals. Until recently, stroke was mostly believed to be a disease for which little or nothing could be done. We now know that strokes are among the most preventable and treatable of all diseases. Thousands of people are dying each year due to stroke when their lives could be saved. Hundreds of thousands more are living with permanent disability for the want of vital service improvements.

## **What are the effects of inadequate services?**

Stroke-specific fatality has been reported between 7% and 20% in various studies from Pakistan. Up to 63% of all stroke patients develop complications and up to 89% are dependent, partly or completely for activities of daily living. Stroke units have proven to decrease mortality and morbidity in acute stroke. Even in major cities of Pakistan, stroke unit care is missing. There are fewer than 10 dedicated stroke units in the entire country. If all acute care hospitals have a stroke unit, significant number of lives could be saved. Due to lack of required number of trained neurologists and stroke specialists, a large percentage of strokes are misdiagnosed or mistreated. Less than 0.01% of stroke patients receive the life-saving clot buster/thrombolysis treatment in Pakistan. The standard of care medication, alteplase (tissue plasminogen activator-rtPA) is not even a registered drug in Pakistan. Only one or two of our acute care hospitals are currently providing this treatment at all. It is estimated that less than 10 % patients of stroke receive acute rehabilitation services. A vast majority of our patients are not aware of the role of rehabilitation services in stroke care. Unfortunately, a large number of treating physicians do not emphasized on getting rehabilitation services. All the above facts imply that the place, time and day of a particularly stroke largely determine whether the stroke patient recovers, dies, or lives the rest of his/her life with disability. Where patients live also dictate whether they receive the rehabilitation and support they need after leaving hospital. For many who survive with disabilities after being unable to receive prompt treatment, there is a double injustice. The lack of availability of acute rehabilitation means that many people must live with avoidable or unduly severe disabilities.

## **Do stroke services cost too much?**

The economic burden related to cost of stroke care and loss of life years related to stroke related disability in Pakistan is not known. However, international data strongly suggests that the death and disability prevented by appropriate and timely stroke intervention not only saves healthcare related costs, but also outweighs the overall economic burden on the society incurred by these facilities.

## **How can change be secured?**

We are asking people in general – regardless of whether their lives have yet been touched by stroke or not – to join our campaign urging the government to implement the measures that will eliminate avoidable death and disability from stroke. We are calling on the government & institutes to implement the following 12 recommendations:

## **1. Public Education on Stroke and Cardiovascular Diseases**

Need to establish a program to educate the public about symptoms and signs, as well as risk factors of stroke and cardiovascular diseases. The program should aim about the recognition of conditions/illnesses that can result in stroke and heart attack, and how to reduce their risk of having a heart attack, stroke or the warning sign of stroke, a Transient Ischemic Attack (TIA).

## **2. Declaring Stroke as a Medical Emergency**

Government shall support a national campaign to increase public awareness of the warning signs of stroke, and early recognition of stroke. The campaign should aim at ensuring that stroke is not only recognized early but is treated as a medical emergency.

## **3. Stroke Unit Care**

The provision of stroke units in acute hospitals could reduce death and dependency rates by 20% - saving hundreds of lives and sparing thousands more from disabilities requiring long term care due to disabilities either at home or in institutions like nursing homes and long term health care facilities. The tertiary care public sector & private hospitals should ensure that every admitting patient with acute stroke has a properly staffed and fully resourced stroke unit.

## **4. Stroke Unit Standards**

We call on the health sector to comply with Pakistan Stroke Society Guidelines in the delivery of a national network of stroke units and to continually monitor compliance with these standards. The clot busting treatment medication needs to be registered by the drug regulatory authority (DRA) with its availability in the public sector institutes. Necessary staffing and equipment supply should be ensured at all levels of care including government and non-government teaching institutions as well as public and private sector hospitals.

## **5. Clot-busting Treatment (Thrombolysis)**

Treatment with clot-busting drugs or thrombolysis dissolved blood clot that causes stroke by blocking the supply of blood to the brain. Thrombolysis with tissue plasminogen activator (TPA) or alteplase has shown to prevent death and disability from stroke, but must be delivered to eligible patients within 4.5 hours. It is estimated that less than 100 people in the whole country currently get this treatment annually, only in the premium private hospitals. In the teaching/tertiary care institutes there shall be 24/7 availability of thrombolysis to all suitable stroke patients. This should be made an urgent priority.

## **6. Emergency Response Services**

Health ministries of all provinces shall make to guarantee that emergency services are equipped and empowered to deal with acute strokes. Telemedicine which is rapidly evolving field in acute medicine should be targeted as the main fortress of delivery of acute stroke care.

## **7. Consultant Stroke Physicians**

There are less than 10 trained stroke specialists in the whole country, with less than 150 available trained neurologists in Pakistan's acute care hospitals. This shortage of specialists is exacerbated by the fact that stroke can be difficult to identify. At least 35% of strokes and more than half of TIAs are currently misdiagnosed in Pakistan. The failure to provide the correct diagnosis in a large number of cases carries devastating consequences for patients. We call on the government to ensure at least one year Stroke Fellowship training for most physicians who have PMDC accredited postgraduate neurology degree. Specialized stroke training should be designed for internal medicine physicians interested in providing stroke care. The government should on an urgent basis recruit and train more consultant stroke

physicians in all public sector hospitals to provide greater expertise in the diagnosis and treatment of stroke.

## **8. Training of Ambulance Personnel and First Contact Emergency Care Providers**

We call on the government to have formal ambulance drivers training program so they are aware of the basic emergency measures. They should be trained how and where to take the patient for emergency treatment on the basis of the signs and symptoms of patient. There are several ambulance services in the country, which all need to have a unified structured training program for ambulance drivers and emergency ambulance staff.

## **9. Post stroke rehabilitation, discharge and after care**

Need to give every patient privilege to appropriate levels of short and long term rehabilitation in hospital and in the community. Additionally, there should be access to long term nursing and home-health care.

## **10. Ban on avoidable stroke risk factors**

Stroke does not happen in one day. Several modifiable and non-modifiable risk factors bring changes in the blood vessel over a period of several years before the stroke strikes. It is important that all modifiable risk factors be appropriately treated. However, some of the risk factors are not medical conditions, but are potential addicting substances including smoked (cigarette, huqqa, biri, shisha, etc.) and chewed tobacco (naswar, pan, mishri, ghutka, bazaar, ghundi etc.) and need to be immediately eliminated from the society. Government should have formal legislation and its strict implementation to ban the import, manufacture, sale and consumption of these potentially lethal substances including smoked and chewed tobacco.

## **11. Monitoring and maintenance of stroke care**

We call on the government to appoint provincial stroke coordinators with responsibility for ensuring that stroke services are meeting the needs of people who have had a stroke in every community in Pakistan and to eliminate age, gender, and other discrimination from stroke services.

## **12. National Stroke Registry**

We call on the government should form on urgent basis a National Task Force for Stroke Care with involvement and participation of all stake holders including government, physicians, professional organization, Non Governmental Organizations (NGO), patient support groups and media. This task force should ensure that all the above recommendations are appropriately evaluated and carried out. This task force should also be given the task of organizing and maintaining a National Stroke Registry.

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**Dr. Abdul Malik:** Study concept and design, protocol writing, data collection, data analysis, manuscript writing, manuscript review

**Dr. Ismail Khatri:** Data collection, data analysis, manuscript writing, manuscript review

**Dr. Mohammad Wasay:** Data collection, data analysis, manuscript writing, manuscript review