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# EPILEPSY: THE PAKISTAN PERSPECTIVE SOME SUGGESTIONS

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Epilepsy is a disease that affects more than 65 million people around the world. In Pakistan prevalence of epilepsy is 9.99/1000 people, thus around 2million people in Pakistan suffering from epilepsy<sup>1,2</sup>.The prevalence in children is much higher 14.6/1000<sup>3,4,5</sup>.Prof. Charles Newton in the lancet quotes 50,000 deaths from epilepsy annually in the US<sup>6</sup>. The death rate in the developing countries is much higher. The exact figures are difficult to assess due to lack of epidemiological surveys and incomplete data collection. However it is thought that the number will be greater and considered at least twice to three times the estimated figures<sup>7</sup>. This is disturbing considering the fact that this is a controllable disorder. Sadly adequate facilities for diagnosis, treatment and ongoing management specifically for epilepsy are virtually nonexistent. Though some epidemiological studies have been done the variation in methodology and population sample shows the need for appropriatedata collection<sup>4</sup>.

The manifestations of epilepsy are diverse varying from brief "staring spells" in children often overlooked, to repeated seizures of such seriousness as status epilepticus requiring hospitalizations, resulting in death or permanent morbidity. These are consequences of the disease that we all see as physical ailments; however there is a much more serious human problem here that is the influence of epilepsy on the emotional health of the affected individual and their families, which is the fear of repulsion and ridicule on the part of society. This causes secrecy and a sense of shame leading to social isolation and constant emotional pressure on all concerned. Jobs are lost, families disintegrated and increased dependency. In children overprotection by parents result in decreased self esteem and antisocialism, school dropouts. Another major fallout of this scenario is not coming for early treatment and denial of illness seeking alternate routes resulting in increased risk of sudden death (SUDEP), status epilepticus and other complications increasing treatment costs and hospitalizations with more mental disability.

Most of this suffering and economic loss is unwarranted. Up to twenty years ago only 4-5 medicines were available for treatment. Now over 25 different medicines are in the market. With the use of drugs appropriate to the specific case and type of epilepsy complete control can be achieved in 50% and reasonable adjustment to normal living with few sparse seizures in another 35%<sup>10,11</sup>. These ~80% will be mentally normal or nearly so with a personality that is acceptable and they can be good productive members of society. About 25-30% will remain refractory to oral medications and other options like epilepsy surgery should be offered to them. A survey conducted by Prof. Hasan Azizshowed only 27.5% of epileptic persons in urban areas and 1.9% in the rural areas were treated with antiepileptic medications<sup>1,2</sup>.

It is estimated that >80% of individuals with epilepsy living in developing countries remain untreated<sup>8,9</sup>.Many people with epilepsy or the families do not even know that they have a disorder that can be controlled by medications. This is a very serious scenario we are facing with over a million people and as many families devastated with a condition that can so easily be managed.

The obstacles to this are twofold. In the first place there is only one epilepsy specific center in Pakistan, and only 2-3 neurologists specializing and dedicating practice to epilepsy. General practitioners and even pediatriciansare often not familiar with latest treatment possibilities.

Secondly the stigma associated with epilepsy, the feeling that it is uncontrollable and the shame leads to concealment rather than quest to seek help.

This is our challenge has physicians. This is becoming a serious public health issue and the government, ministry of health should take this seriously before millions of treatable patients productive members of society end up on the streets.Comprehensive epilepsy centers and Epilepsy Health care teams need to be formulated.

Below are four simple suggestions that may help alleviate some of the suffering of millions of our patients

1. Epilepsy has a stigma attached to it as it is also clouded in myths: the urgent need is to create mass awareness programs, media and public advocacy work with traditional healers regarding bewitchment, curses spirits etc, and health care workers to improve understanding of the condition.

2. Epilepsy is socially very expensive from loss of jobs low self esteem etc: The need for Epilepsy support groups help patients cope and rehabilitate back to society.

3. Epilepsy diagnosis is clinical and established by simple tests: Physician training workshops to help understand and recognize the condition, facilitate effective management and counseling strategies

4. Epilepsy is amenable to simple drug therapy in an outpatient department: Medications are available but there are problems distributing them to remote areas. Some medications are far too expensive for the average person to afford thus the need for Comprehensive Epilepsy Centers linked to small centers in the remote areas providing diagnosis, treatment guidelines and subsidized medications.

Given the prevalence of epilepsy the government should include this as a priority on their public health agenda and access to treatment made freely available. It's time to take epilepsy seriously.

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