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## Editorial

### Specialized epilepsy institutions, where we are in developing countries?

Pr. Najib Kissani, Editor in Chief of Nameej

Epilepsy high social and economic impacts, especially in developing countries. WHO reported that epilepsy accounts for 0.5% of the global burden of disease, a time-based measure that combines years of life lost due to premature mortality and time lived in states of less than full health. Epilepsy has significant economic implications in terms of health-care needs, premature death and lost work productivity. An Indian study calculated that the total cost per epilepsy case was US\$ 344 per year (or 88% of the average income per capita). The total cost for an estimated five million cases in India was equivalent to 0.5% of gross national product.

- The quality of care provided to patients with chronic non-communicable diseases: a retrospective multi-setup study in Jimma zone, southwest Ethiopia.
- Department of Health Services Management, College of Public Health and Medical Sciences, Jimma University, Jimma, Ethiopia.

- Abstract
- BACKGROUND:

- Chronic Non-Communicable Diseases are among the major causes of morbidity and mortality worldwide. However, access to and quality of health care for patients is very low in developing countries including Ethiopia. Hospitals and Health Centers are the main sources of health care for such patients in Ethiopia. In this study we assessed the quality of care patients with Chronic Non-Communicable Diseases received in hospital and health center setups.

- METHODS:

- A retrospective multi-setup study was conducted in Jimma University Specialized Hospital and four Health Centers in Jimma Zone from February to March 2010. A total of 52 process indicators of quality covering three disease conditions: Diabetes, Hypertension and Epilepsy were measured by reviewing randomly selected medical records. Quality of care was measured as a proportion of recommended components of care actually provided to patients. And also outcome and structural measures were assessed to supplement process measures of quality.
- Talk about the gap in Morocco

And arab world where =0

Although the social effects vary from country to country, the discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves. People with epilepsy can be targets of prejudice. The stigma of the disorder can discourage people from seeking treatment for symptoms and becoming identified with the disorder.

That is why WHO and its partners, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), recognize that epilepsy is a major public health concern.

In order to reduce the treatment gap and morbidity of people with epilepsy, many solutions are suggested and supported by WHO, and creating centers for people with epilepsy and their carers and relatives, what will facilitate educating and sensitizing patients and also training health professionals and by the way dispelling stigma, leading to social and professional integration of patient. In some emerging countries, such projects gave significant results, a project carried out in China, the treatment gap was reduced by 13% and there was improved access to care for people with epilepsy.

We are very concerned about such initiatives in Morocco and developing countries, that was the reason for asking Professor Johan Arends head of the Kempenhaeghe epilepsy clinic in Heeze (Netherlands), for a visit in last April 2013. I was really surprised by this huge centre, it is a leading centre of medical expertise, offering diagnosis and treatment to adults and children who suffer or are suspected to suffer from a complex form of epilepsy, a sleeping disorder and/or neurological learning disabilities. With a multidisciplinary approach runs both inpatient and outpatient epilepsy clinics in Heeze and Oosterhout for diagnostics, treatment and/or hospital admission, with ten outpatient clinics located in the south of the Netherlands. In addition to patient care, Kempenhaeghe focuses on scientific research, innovation and knowledge transfer.

There are various reasons for admission of epilepsy patients. Some people have extensive diagnostic examinations and tests, others come for observation or initiation of a therapy and/or counseling.

The duration of the hospital stay depends on what examinations and tests are needed and the treatment. The duration may be a few days, but several months as well. Before admission you will be told what ward will receive you. What we found unique and should be highlighted for our politicians and deciders is that during the hospital stay in Kempenhaeghe epilepsy centre is rather different than a stay at a general or academic hospital. The patient «is not in hospital» but is living in a different environment where life continues as normal as possible. Patients can ride horses can do agriculture exercises...etc.

We found that the old centre created for patients with epilepsy was as early as 1908, it was the Johns Hopkins Epilepsy Center specialize in providing a comprehensive care program for our patients, where physicians have been leading the way in assessment and treatment of patients with epilepsy. Where not only professionals, but also patients and their relatives can learn more about epilepsy. It is a high level centre ranked a level 4 Center accreditation by the National Association of Epilepsy Centers, the Johns Hopkins Epilepsy Center provides cutting-edge research, technology, surgical expertise, and patient care for those suffering from epilepsy or seizures.

Expert and individually tailored treatment plans are provided for all patients. These plans are designed to enable each patient to live full and productive lives.

What is more interesting, is the centre's website, where every professional and every epileptic patient can learn more about seizures and epilepsy (<http://epilepsyvoice.com/johns-hopkins-epilepsy-center/>): such 1-What are the different types of seizures?; 2-What can cause a seizure?; 3-What is epilepsy?; 4-What are the types of epilepsy?; 5-How is epilepsy treated?

Moreover, a request for an appointment for more information about epilepsy or to meet with doctors from the institution could be given by email or phone call.

About Africa, where all data highlight the high frequency of epilepsy, the big treatment gap all over the world (80%), the wide use of traditional practices, the complicate access to neurologists and the difficult economical situation. This kind of institutions is nearly inexistent; we just counted one in Cape town (South Africa). Our hope in Morocco, in Middle East, in Africa and in every developing country is to see such institutions starting, to push our politicians and deciders to put epilepsy as priority in their plans

These structures have to be a non-profit institutions and should offer services in the following fields:

- Advice and information,
- Counseling : by trained and experienced social workers or nurses for individual, group and family counseling, on living with and managing epilepsy.
- Employment and Training: advices and guidance in career options, legal implications and employee rights could be offered,
- Residential Care: either for small proportion of people with epilepsy who require specialized daily care, these institutions could help and the patients could develop life skills to get their independency and self-sufficiency,

- Education and sensitization,
- Self-help: as Epilepsy South Africa in its activities encourages self-help programs and provides guidance to existing and developing groups. Programs could be for self-help run by people with epilepsy in close association with us. Such activities are also done in Lebanon by the Association for Care of Epileptic Patients in Lebanon, in their 'ECAL Chocolate Project'; as Chocolate is a multipurpose item used in many occasions (child birth, marriage, religious as well as social events, festivals, etc.). This project after selling the products makes a good income for the patients and help in buying medications and other products to support epileptic patients who come from very poor backgrounds. The association should have provided for at least two new jobs for parents of epileptic patients. This project and the center dedicated to this project provide chances for more parents to participate in the program and gain some money on the basis of their work, whenever needed and cover for the existing financial deficiency.

So let's start in each country by highlighting the need of such centers, by stressing our politicians and deciders to act and by implicating our associations to be leaders in the start up of the initiative.

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