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The 30-Year Odyssey of Epilepsy Rural Camps: The Exotic Paradigmatic Journey of Change

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"Epilepsy Care and Research Foundation Jaipur" was constituted with an aim to serve people with epilepsy (PWE) to address the unmet needs of society and rural population suffering from epilepsy especially in rural Rajasthan. I want to share this association of three decades as Founder and Chief Neurophysician and I have chosen this topic because of the treatment gap that still exists for epilepsy in rural setups, especially in developing countries including India. The core theme highlights epilepsy care in rural areas via camps.

There is a dramatic global disparity in the care for epilepsy between high- and low-income countries as well as rural and urban setup in these countries. At this point of time, nearly 12 million PWE are expected to be residing in India. This contributes nearly to one-sixth of the global burden of the disease. The rural prevalence of epilepsy is higher of 1.9% as compared to the urban where it is 0.6%. It might be higher due to underreporting by PWE, the reason being social stigma. Indian data on epilepsy prevalence is quite variable owing to the varying and differential reporting in male population, low socioeconomic status, and rural setup. Many people with active epilepsy do not receive appropriate treatment for their condition, leading to a large treatment gap. The lack of knowledge of antiepileptic drugs (AEDs), poverty, cultural beliefs, stigma, poor health infrastructure, and shortage of trained professionals contribute to the treatment gap.[1–3]

Rural areas being resource-limited areas, these areas are hard to reach and potentially are the hub of major diseases. The major reasons for poor compliance with treatment include failure to understand the principles of drug treatment, the cost factor, and erratic drug supplies. Other factors that interfere with effective treatment are the attitudes of the patients and their family members toward the disease, the influence of faith healers and quacks, concomitant traditional treatment, and the fear of the side effects of drugs. The journey started with the first camp which was organized in the year 1994. This first camp was organized at Primary Health Centre, Ratan Nagar, Churu district of Rajasthan on the first Saturday in the month of April 1994. At first, a total of 25 PWE got registered in the camp and started on treatment mainly. These PWE were from nearby villages of Churu district. The number increased exponentially every month and there was no looking back. Currently, a total of 8,534 PWE are registered in the camp and are on regular follow-up.

In the year 1996 to 1997, the first clinicodemographic profile of these PWE was laid out. This clinicodemographic study was carried out with an aim to analyze the clinical characteristics of PWE, assess the efficacy and side effects of AEDs, and simultaneously health educating them. Two hundred and eighty-four PWE were studied over a period of 1 year. Seizures were classified according to the International League Against Epilepsy Classification (1981).[4] It was found that the most common semiology was generalized tonic-clonic seizures (GTCS) and males were affected more as compared to females.

A door-to-door survey was conducted in the year 2005 in part of rural Rajasthan, with an aim to study the prevalence rate of active epilepsy and clinical profile including attitudes and beliefs of people about epilepsy in Churu Tehsil (Rajasthan). The study results showed male-to-female ratio of 1.1:1. Overall prevalence was found to be 3/1,000 population. The treatment gap recorded at that time was 80%. Seventy-eight percent PWE had GTCS. Phenytoin sodium, levetiracetam, phenobarbitone, sodium valproate, carbamazepine, and clobazam were the common drugs prescribed. The medicines are provided free of cost to them for better compliance and to eradicate economic barriers in procurement of the medicines by PWE. It was observed that when the free medicines were

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discontinued 52% of people stopped the treatment and only 19% decided to buy medicines bearing the cost in 2000. In 2004, people became more aware and we saw only 9% of people stopped treatment in 2004. The discontinuation rate for medicines decreased. The frequency of follow-up visits of PWE increased monthly. Compliance with medication also increased in the year 2004 with 46% taking the medications even on the days of fasting compared to the year 2000 when only 27% took the medication.[5]

To understand the perception and beliefs of population a knowledge, attitude, and practice (KAP) study was conducted in the year 2007. Generalized seizures were the most common (84%) type of seizure, followed by partial seizures (9.4%). The most common drugs used were phenytoin sodium, followed by phenobarbitone. When enquired regarding alternative therapy preferred or practiced by PWE, ayurvedic treatment was the most common alternative therapy used. Regular health education played a major role in shaping beliefs and eradicating myths and misconceptions of PWE. Evil spirits were believed to be the cause of the disease by 26.4% of the patients in 2000, but only in 11.2% in 2004. Faith in the curative power of drugs increased from 18% in 2000 to 59% in the year 2004. Polytherapy was being resorted to by 60% of patients in 2000; this was reduced to 45.6% in 2004.[6]

From the year 2018 to 2023 studies were carried out targeting other aspects of epilepsy in rural India. Studies on adverse effects of epilepsy and its medications in male population, female population, and pregnancy, and fear among PWE in coronavirus disease 2019 (COVID-19) era and impact of COVID pandemic on PWE were carried out. The COVID-19 pandemic negatively affected patients with epilepsy and increased seizure frequency, depression, anxiety, unemployment, and financial difficulty in obtaining medication. In camps during the COVID era compliance and follow-up difficulties were a challenge. Increase in seizures was seen during COVID infection. There was difficulty in interviewing and examination. Availability of medicines and economic burden was also a challenge. Note that 30.3% of patients had increased seizure frequency during the COVID-19 pandemic. The percentage of patients who forgot to take regular AEDs was 22.7%. Also, 12.1% faced difficulty in obtaining medicine due to the lockdown.[7]

Epilepsy in women affects their sexual and reproductive functions and children born to such women are potentially at an added risk of epilepsy per se along with teratogenicity of AEDs. Women with epilepsy in the reproductive age group on AEDs are at an increased chance of acquiring obstetric complications and pose an added risk of teratogenicity for their offspring. In this context, it is proposed to individualize monotherapy AEDs along with folic acid supplementation (to mitigate the antinuclear effects of AEDs) balancing the efficacy-safety profile of AEDs in the process. Congenital malformations were seen maximum with sodium valproate. Major congenital malformation (neural tube defects, hypospadias) were found in 8% and minor (club foot, ventricular septal defect) in 5.32% of cases. Increased risk of intrauterine deaths, stillbirths, low birth weights, and preterm births in women with epilepsy (13.33%).[8]

Male sexual health is often ignored or goes unaddressed especially in countries like India where the stigma of disease and taboo of infertility or sexual dysfunction both adds on synergistically. In a study conducted on male population with epilepsy, a significant impairment of sexual functions was observed in male epileptics with GTCS. Looking at the high magnitude of implicit sexual dysfunction in epileptic patients (not being reported), a high index of suspicion should be kept in mind by the practicing neurologist/physician.[9] Another study from the region focusing on effects of antiseizure medications on semen parameters inferred that the mean sperm count was significantly lower in focal as compared to GTCS. Prolonged therapy beyond 2 years affects semen liquefication time, sperm motility, morphology, and ejaculate volume. Sodium valproate was found to be most notorious and levetiracetam being the least toxic.[10]

The magnitude of the epilepsy treatment gap in India ranges from 90 (rural) to 22% (urban). Various gadgets and mobile applications can be taken into consideration to bridge the knowledge gap and access to health services. MIRGI SAMJHO mobile application as a source of epilepsy was designed for diagnosis and treatment monitoring in PWE, achieved the highest aesthetic score with the highest graphics quality and visual appeal. The MIRGI SAMJHO program was conducted to guide for first aid to seizures as well as disease management and control. The information in the app and MIRGI SAMJHO program was exactly relevant to the purpose of the program.

Epilepsy Care and Research Foundation was started to achieve holistic goals of providing best treatment, removal of various stigmas, and social rehabilitation for the patients with special emphasis in rural areas. Epilepsy Care and Research Foundation also aims to provide free medical care including drugs to the poor, free consultations, and counseling for PWE. The Web site for Epilepsy Care and Research Foundation is http://epilepsycareandresearchfoundation.com and the helpline number 9610114345 is running for guidance of the patients and caregivers.

Future recommendations: In my opinion "Rural Epilepsy Care Model" must be established by the governmental bodies for better management of PWE and smooth conduct of health services in remote areas of the country. At primary health center (PHC) medical officers should provide emergency treatment, diagnose and identify suspected patients of epilepsy, start initial treatment and provide free AEDs, and provide follow-up for epilepsy patients. Optimal referral to the District Medical Officer when required, maintain simple records, train peripheral health workers like auxiliary nurse midwife and others by providing them symptomatology, identify persons who may be suffering from epilepsy, and to guide them to PHC for confirmation and treatment, and follow-up of epilepsy patients. The pyramid with PHCs need to be strengthen for epilepsy services unlike current pattern where the pyramid has a narrow base and is unstable with maximum services provided at the tertiary level. With this

rural model we can make the base of health care pyramid stronger.

In conclusion, the clinicodemographic profile of patients, resources available, and KAP toward epilepsy and challenges encountered in remote and rural areas are different from the urban areas which need a special attention and work needs to be done at the basic level so that the treatment gap can be narrowed improving quality of lives of a greater proportion of PWE residing in these areas.

Conflict of Interest

None declared.

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