The Wife of a Bicycle Mechanic

Jewati is her name. She is a person with epilepsy. This waif-like young woman lives in India but her story could have happened in any developing country because epilepsy is everywhere and so are the problems that go with it.

I met Jewati and her mother at a district hospital some 30 miles outside New Delhi. She is the youngest in the family of seven children. None of her brothers and sisters suffer from epilepsy. In any event, they live their own lives and she doesn’t hear from them.

On paper, Jewati is married. In reality, her elderly mother is her one and only life support and companion. Jewati had one child that died a few years ago from diarrhoea. She is barely literate and doesn’t have any occupational training. On top of that she suffers from epilepsy. So much in the minus column and very little to show in the plus column.

The stigma experienced by persons with epilepsy all over the world can shut them from their community, isolate them from their family, drive them from school and prohibit them from holding down a job.

A year ago, Jewati’s husband, a bicycle mechanic, upon witnessing an epileptic fit of his wife, beat her up with a stick and threw her out of the house saying he didn’t want to see her ever again. Since then she’s been living with her mother. Why didn’t she complain about domestic violence? She thought the police would ask for money and she had none.

She started suffering from epilepsy some 12 years ago. Her mother took her to see the local traditional healer. He diagnosed evil spirit possession that no medication can possibly cure. And it is so powerful, said he, that even he wouldn’t be able to exorcise it. At least he didn’t charge them anything.

“Our biggest challenge is to de-mystify epilepsy, to make people understand that there is nothing supernatural about it,” explains Dr Derek Yach, World Health Organization (WHO) Executive Director in charge of Mental Health and Neurological Disorders. “Age-old superstitions die hard, be it in Cairo, Calcutta or Caracas. Indeed, a law in the United Kingdom forbidding persons with epilepsy to marry was repealed only in 1970. That is why we have launched the Global Campaign Against Epilepsy (GCAE) – to bring it out of the shadows.”
Six years ago Jewati went to the district hospital for the first time. She was given three different types of medication free of charge but the results were very poor. She took the medicine for a couple of years, experimenting with her medication depending on the frequency of seizures, but eventually decided to stop when she saw no improvement. That might have been because, instead of taking three different pills a day, she was taking just one, thinking that by spacing it out she could save two trips to the hospital. It takes 32 rupees for she and her mother to get to the hospital and back to the village. For them, this is serious money. The hospital is 16 kilometres away. Part of the distance they walk on foot and for the rest of the journey they take a bus operated by a private transport company.

Jewati’s father died nine years ago. The mother has a buffalo and she sells buffalo milk. The Haryana State Government pays her a pension as an elderly person of about 300 rupees a month (US$1=46 rupees). These are the only sources of income for both women. There is no vegetable plot, no land, no nothing. The buffalo is parked right in front of the door and neighbours allow the buffalo to graze on their land. Mother and daughter prefer not to think about the time when the buffalo won’t be there anymore.

In 1999, the Indian Government passed a law stipulating that epilepsy is not a mental illness and therefore does not provide grounds for divorce. Good law but some people simply don’t want to hear about it, especially if it concerns women.

Epilepsy is a brain disorder caused by a violent electricity discharge in the brain. In the overwhelming majority of cases epilepsy can be successfully controlled by anti-epileptic drugs and surgery. Plugging the so-called treatment gap, the number of persons with epilepsy who are not covered by public health services, is the biggest challenge for the GCAE, a joint programme of WHO, the International League against Epilepsy and the International Bureau for Epilepsy to control epilepsy in developing countries.

Among men, epilepsy is less of a burden. Rajiv is 20 years old. About five years ago he started suffering from epilepsy. Seizures were very rare - once or twice a year - but lately the frequency increased and he decided to go to the hospital. He visits the hospital every 15 days takes his medicine as prescribed and now he believes his epilepsy is controlled.

Rajiv doesn’t have any fixed occupation. He lives in town and feels quite relaxed about work. In his town which is just two kilometres away from the hospital there is always some kind of work to be found. His parents have died and he lives with his grandmother. He is single and in no hurry to get married. “I live in town. It’s village folks who get married early. It is a big undertaking and I can’t afford it as yet.” He feels much better now and he can move around looking for a day’s job without thinking too much about epilepsy. The origin of this medical condition? “It is not a brain illness,” he says. “It is gas in the abdomen. That is what my grandmother told me, she knows best.”

Epilepsy is often referred to as a hidden disease, its origins, causes and treatment shrouded in mystery and solutions reserved for traditional healers.

More often than not, traditional healers are the first port of call for epilepsy patients especially in rural areas. Villagers feel so much more comfortable describing the symptoms to someone they can readily relate to. They are not exactly on the same wave
length with hospital personnel. Often enough, it takes two or three visits before hospital doctors get the real story from their patients.

The second phase of the Global Campaign Against Epilepsy programme, “Out of the Shadows”, was launched in February 2001 as “demonstration projects” got under way in Argentina, China Senegal and Zimbabwe. These projects will highlight means of drastically reducing the treatment gap which currently exists in all developing countries. In China alone, the project will reach five districts with a total population of two and a half million people.

In India, the knowledge about the real causes and treatments for epilepsy is also spreading. There is still hope for Jewati.

Epilepsy is the most common serious brain disorder. It affects at least 50 million people world-wide, 85% of them living in developing countries. Up to 80% of persons with epilepsy can lead normal lives if properly treated. At the present time, over 50 countries joined the Global Campaign against Epilepsy spearheaded by the World Health Organization, the International League against Epilepsy and the International Bureau for Epilepsy.

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