

## DISCRIMINATION STARTS AT HOME, SAYS STUDY

By Tessa R. Salazar  
Philippine Daily Inquirer  
September 1, 2001

### Suspicion and Misunderstanding

CONQUERORS Napoleon Bonaparte, Julius Caesar, Alexander the Great, philosophers Socrates, Pythagoras, artists Vincent van Gogh, Leonardo da Vinci, Michelangelo, writers Edward Lear, Charles Dickens, Agatha Christie, and Truman Capote were famous figures who left their indelible marks in society. Few know, however, that these people had epilepsy.

Why do people with epilepsy keep their disease hidden from the public?

Epilepsy is still often viewed with suspicion and misunderstanding. The Global Campaign Against Epilepsy said people with epilepsy are shunned by their communities and are left disadvantaged in terms of education and employment. These people, according to the Global Campaign, are "often burdened socially and economically."

Doctors Aida M. Salonga, Marissa B. Lukban and B.C. Sanchez of the University of the Philippines - Philippine General Hospital neurology and pediatrics sections conducted a survey to profile the public knowledge, attitude and practices about epilepsy. Of 153 participants (immediate family and caregivers of the patients with epilepsy), 77 percent were parents and 19 percent were health workers.

While about 40 to 70 percent of the respondents believed that their children would be able to live a normal life - finish college, get a job and have a family of their own - 59.7 percent did not want their normal children to get married to someone with epilepsy.

"These respondents have children who have epilepsy, yet majority wouldn't allow their normal children to marry somebody with epilepsy. Within the family itself, there is already discrimination. How could you expect others to accept people with epilepsy?" said Dr. Leonor Cabral-Lim, president of the Philippine League Against Epilepsy, when asked to comment on the study.

The UP-PGH study also found that 46 percent would not allow children with epilepsy to indulge in strenuous activities.

The study described the prevailing mood among relatives of patients. Their emotions ranged from anger to fear to depression. A significant number have not fully accepted the condition of their epileptic family members and 16 percent blamed themselves for their children's conditions.

The survey also asked the patients if their parents allowed them to join extra curricular activities or physical education in school - 47 percent said yes, 39.5 percent said no.

The survey also indicated that 50 percent of the respondents thought that epilepsy could be cured. Although 67 percent believe that medicines would cure the condition, a significant number said they also resorted to non-traditional means such as rituals, prayer, herbal medicine and faith healers.

### 'Primitive Practices'

More than 230 Filipinos per 100,000 population suffer from epilepsy. Of this number, 180 are children less than 5 years old, according to recent figures of the Philippine Neurological Association.

The Philippines has 150 certified neurologists, specialists who are most qualified to attend to the treatment of people with epilepsy. There are seven training institutions in neurology and about five residents are trained per program.

About 85 percent of neurologists could be found in the National Capital Region. There is at least one neurologist in every region in the country.

The survey revealed that the prevailing practices for patients undergoing active seizure "consist of primitive practices devoid of any scientific basis."

Salonga said these involved fanning the patient, forcing a spoon or any solid material inside his mouth, putting pressure on his abdomen and biting his toes. Other "remedies" included massage, pinning the body against the floor, forcing the patient to drink liquids during the seizure and pouring cold water on the patient.

Cabral-Lim said that if people with hypertension, diabetes, asthma and heart ailments are not discriminated against in the workplace, there should be no reason for people with epilepsy to be left out. Continuous medication, she said, would prevent them from having seizures.

She cited a World Health Organization report describing that compared with other chronic diseases, epilepsy carries a stigma that is a major obstacle to treatment. A Canadian study also found that people with epilepsy had "more days off at work, a lower annual income and a lower quality of life than people with chronic illnesses."