

Overcoming Misunderstandings and Stigma About Epilepsy, a Common Disease

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Epilepsy is a common disease affecting about 1% of the population, i.e., one million individuals in Japan. More than 70% of these patients could become seizure-free if they receive suitable treatment including modern medication and surgery after correct diagnosis by specialist epileptologists. However, there is a common misperception, even among physicians, that epilepsy is untreatable. Moreover, epilepsy has been associated with strong negativity and prejudices throughout human history from ancient to modern societies. Professor Nakasato has made vigorous efforts both in the development of new diagnostic strategy and better treatment of epilepsy, and in trying to dispel such mistaken views of epilepsy and to broaden accurate understanding of this disease. For example, Professor Nakasato and his colleagues were deeply involved in the making of short educational videos demonstrating various types of epileptic seizures as portrayed by professional actors, and a DVD of these videos in Japanese, English, Taiwanese and Indonesian has already been distributed free of charge to more than 30,000 medical staff worldwide. We spoke with Professor Nakasato about his research and awareness activities including the production of the epilepsy videos.

Epilepsy, a Common Disease

The primary and consequently the biggest problem for the treatment of epilepsy is the fact that many people, including physicians and medical staff, think that “epilepsy consists only of grand mal (generalized clonic-tonic, in other words full body) seizures.” Epilepsy cannot be diagnosed based only on the medical record of full body seizures. It is important to find ways to ask the patient or their family about the presence of seizures other than full-body seizures, ranging from small seizures that only the patient recognizes to seizures that only close people can observe. Previously, I would mimic epileptic seizures at medical or public lectures, but such illustrations were not good enough. Seizure video clips recorded from actual patients normally cannot be shown beyond a limited group of medical-attendants because of patient confidentiality. Seizure descriptions often do not make much sense to listeners based only on verbal explanations. Faced with this challenge, I decided to produce a collection of videos demonstrating the various types of epileptic seizures. Reading descriptions of patients from other physicians, I usually see a medical history of grand mal seizures, but with little or no comments on the other seizure types. Therefore, my first step in seeing new patients is to ask about subtle and repetitive symptoms suggesting possible smaller seizure events. The most common type of epileptic seizure is “complex partial seizure (CPS),” in which the patient presents with unresponsiveness and motion arrest with or without automatism, such as abnormal manual, facial, or tongue movements. Unfortunately, patients are not aware that CPS has occurred. Consequently, interviewing witnesses of the event is the key for correct diagnosis. You may find this statement an exaggeration, but I believe that CPS is something that everyone should learn about in elementary school. Even many physicians are

unaware of CPS. Consequently, my colleagues and I were very serious about the details of seizure presentation in producing our videos of seizures. Professional actors were shown video clips of patients during seizures, then received extensive performance guidance. Some clips required more than 10 retakes. We believe that our final product has achieved a genuine reproduction of seizure. Upon seeing the video, some overseas epileptologists even asked me how I got patients to consent to video disclosure. The original plan was just to have a Japanese version. However, we created an English version and showed at the Asian and Oceanian Epilepsy Congress 2016 in Hong Kong. The video elicited a very favorable reaction and many requests from specialist doctors in various countries to translate the content.

Importance of Listening to Patients

Diagnosis of epilepsy depends more on history taking from patients and family members than on laboratory examinations, electroencephalography (EEG) or neuroimaging such as magnetic resonance imaging. Methods of asking detailed questions are very important to develop in order to get the patient to describe small seizures or family members to explain unusual behavior that the patient does not acknowledge. Some seizures occur as sudden queasiness or feelings, or panic or concern that freezes the spine. Better history taking depends on how much experience the physician has had to observe real seizures in an epilepsy monitoring unit (EMU) including long-term video and EEG recordings.

Epilepsy is often difficult to diagnose on an outpatient basis, so approximately one-third of the epilepsy patients are expected to undergo long-term video-EEG monitoring in inpatient unit for several days. In our EMU at Tohoku University Hospital, patients undergo seizure monitoring, neuroimaging, neuropsychology tests, and psychosocial evaluation including family, school, and work environments. A medical approach alone cannot achieve the goal of epilepsy treatment. Our assessment also considers the psychological and mental aspects. A 2-week inpatient stay in the EMU can definitely change a patient's life.

Do Diagnosis Guidelines Exist for Epilepsy?

Epilepsy is a chronic brain disease manifesting as various types of seizures and symptoms. Despite such presentational diversity, most people and even physicians prefer to discuss epilepsy based on stereotypical views. In extreme terms, such misunderstanding leads to misperception of epilepsy as “a dangerous disease that prevents people from working or leading a normal life because of repeated seizures that involve falling down.” Let me emphasize again that this misunderstanding is the primary and the biggest problem of epilepsy. Everybody knows the name but nobody knows the truth.

I served as a committee member to establish treatment guidelines for epilepsy at the International League Against Epilepsy. Guidelines are now available for treating epilepsy, but the vital guidelines for diagnosis have not yet been prepared. Diagnosis cannot be easily covered with a single-page flow chart because of

the wide variety of manifestations. Even specialist epileptologists cannot perfectly classify epilepsy types and might just begin treatment before establishing the final diagnosis. Therefore, I recommend that both general practitioners or neurologists as well as epileptologists based at outpatient clinics should refer patients for admission into an epilepsy center for extensive study in EMU. The treatment team will then extensively discuss the diagnosis and treatment strategy for each patient for more than half an hour. The team normally reaches a mutual diagnosis in about 70–80% of cases (although not 100%) at such case conferences. This procedure differs greatly from a single physician establishing a diagnosis in an outpatient clinic.

The specialty of “epileptologist” is strictly controlled in developed countries in the US and Europe, requiring experience with several hundred cases of inpatient examinations. About 600 board-certified epileptologists are currently practicing in Japan. The actual number of epileptologists might be even smaller using the standards applied in the US and European countries. Nevertheless, the diagnosis and treatment of the approximately one million patients with epilepsy in Japan is completely impossible with only 600 epileptologists. Obviously, all physicians involved in neurology, such as pediatric and adult neurologists, neurosurgeons, and psychiatrists will see and care for patients with epilepsy. However, I would like to emphasize that initial treatment by nonspecialists should be limited to one year if the patients continue to be affected by residual seizures and/or other symptoms. All these patients should be referred to specialist epileptologists and ideally to epilepsy centers equipped with a long-term video-EEG monitoring unit.

Education! Education! Education!

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I am always thinking about my mission as an administrative head of the Department of Epilepsy as well as the Epilepsy Center, both at Tohoku University Hospital. Our department cannot treat all patients in Miyagi Prefecture, let alone Japan, even if I work hard at my outpatient clinic from morning to night every day. This target becomes even more impossible in the case of inpatient examinations. In other words, my primary mission is not increasing the number of patients that I see, but instead putting emphasis on raising the quality of diagnosis at the university hospital and training as many medical personnel as possible. Therefore, the most important mission of the Department of Epileptology at Tohoku University Hospital is training people. Education of 100 physicians who can correctly diagnose 100 patients a year would be far better than me treating 1,000 patients a year. I am not talking about education of specialist epileptologists, but rather general neurologists, neurosurgeons, and psychiatrists who do not consider epilepsy as their primary consideration. The impact of education might be even higher for general practitioners. Our goal is helping these physicians to gain additional understanding of epilepsy and to provide the foundation to understand that “I can make a diagnosis up to this point by myself but after that the patient should be referred to a specialist epileptologist.”

Something I say at the final seminar series before graduation to sixth year students at the Medical School of Tohoku University each year is that physicians should try to make patients who come to them happy as a minimum requirement, but this alone is not

enough. Consideration should be also given to the happiness of patients who are not directly seen later in a career.

In terms of comprehensive patient care, employment support is an important area where epilepsy awareness should be effectively promoted with high priority. Patients with epilepsy can obviously continue in meaningful employment if the correct diagnosis results in complete resolution of seizures after adequate treatment. But many people continue working while still having seizures after accurately communicating the seizure characteristics and suitable accommodation from managers and colleagues. People working at “Hello-Work” and other employment assistance agencies must support epilepsy patients in finding jobs and maintaining jobs. Currently, the lack of basic knowledge among vocational counselors often results in people with epilepsy being told to “give up work because of your epilepsy.” Efforts to educate vocational counselors at these agencies can help patients find employment based on their ability to work. This is a vital step in improving the quality of life of patients. Employment actually has a favorable impact on the treatment.

Leveraging the Power of Social Networks

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I hope to develop a system for efficiently diagnosing epilepsy on a team basis. This requires improvement in the level of epilepsy centers, as the core facility, as well as boosting knowledge of epilepsy among general physicians and promoting greater awareness in the general public to abolish misunderstanding about epilepsy. A common misperception is that epileptic seizures are a severe illness that prevents patients from working or makes them unsuitable as a marriage partner. Activities to promote appropriate understanding that regardless of having epilepsy, everybody has the right to have a meaningful life and an opportunity to achieve their life goals based on their strength. We are enlisting many tools to send this message, including Twitter and other social media, newspapers, local FM radio, and television. People working in the public relations office at Tohoku University Hospital and Tohoku University School of Medicine are also helping. As an example of the effectiveness of this approach, a patient living in a distant place, who I have never actually met, saw my Twitter comments and decided to see a specialist epileptologist at an epilepsy center in Sapporo. Within a few months, the patient informed me that she had undergone EMU examination and subsequent surgical treatment. Now she is completely seizure-free.

Our Tohoku University Epilepsy Case Conferences now takes place online using a high definition television-based remote conference system. This case conference has been connected to more than 10 facilities across Japan. But we are extending our remote conferencing system to Indonesia, Taiwan, and other East Asian countries with negligible time differences. We plan to utilize seizure videos translated to foreign languages to provide basic knowledge on epilepsy to physicians, and to medical students, nurses, public health personnel, and school teachers. We will continue to promote awareness of epilepsy utilizing various networks. I should like to conclude by emphasizing the mission of the International League Against Epilepsy: A world where no person's life is limited by epilepsy.



Profile:

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