

REVIEW ARTICLE

Comprehensive epilepsy care: Contributions from para-medical professionals

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Abstract

Comprehensive epilepsy care is synonymous with treatment conducted by multi-disciplinary team including medical specialists as well as non-medical professionals. A comparative study between epilepsy centers in Europe and Asia showed that in Asia, the medical specialists saw more patients per day in the ambulatory clinic, and there were more personal contact with patients per year than in Europe. However, it was uncommon for non-medical professionals to participate in the treatment of epilepsy in Asia. The difference in clinical practice in the latter between Europe and Asia should be addressed. This review paper illustrates some examples of work done by nurses, occupational therapists, and educators of children in the National Epilepsy Center in Shizuoka, Japan, where comprehensive epilepsy care is being practiced. There are ample possibilities for treatment of epilepsy other than medicinal and surgical interventions. Comprehensively organized treatment teams including medical and para-medical professionals can best explore these possibilities. Reducing epileptic seizures by prescribing anti-epileptic drugs or by brain surgery is not the sole goal of treatment of epilepsy.

INTRODUCTION

Although a comprehensive epilepsy treatment program is often accepted as a key concept in management of epilepsy, the term has not been clearly defined. In the recommended guidelines by the National Association of Epilepsy Centers, it is described as: "In the best sense of the term, a comprehensive epilepsy program is one in which a multi-specialty team (physicians, psychologists, nurses, social workers, and specialized technical help) is brought together to provide an organized approach to the management of people with complex problems related to epilepsy".¹ Thus, comprehensive care is synonymous with an epilepsy care conducted by a multi-disciplinary team. This is contrary to the clinical practice particularly common in many general hospitals, where specialists in various disciplines are treating epilepsy patients independently. Epileptology as a clinical discipline should not merely be a sub-specialty of neurology, psychiatry, pediatrics, or neurosurgery, but an independent specialty concerned with people with epilepsy of all ages. Medical professionals should keep a close working relationship with non-medical professionals related to epilepsy care. Interactions between medical and non-medical professionals can give rise to new possibilities

in treatment of epilepsy which is difficult to achieve with the medical professionals working on their own.

COMPARISON OF STRUCTURES OF EPILEPSY SERVICES BETWEEN THE EAST AND WEST

The results of a questionnaire on structures of comprehensive services for epilepsy were reported at the International Bethel-Cleveland Clinic Epilepsy Symposium in 1999.² The questionnaire consisted of 36 questions involving all aspects of epilepsy services. This included outpatients as well as in-patients, children as well as adult services in 11 institutions from Europe and USA.

The same questionnaire was distributed to 10 representative institutions in Asia and Oceania. They were from Australia, India, Indonesia, Japan, Korea, Malaysia, Singapore, Sri Lanka, Taiwan and Thailand. The responses were compared with those of Europe and USA. In summary, it was found that: 1) The number of out-patients seen in the institutions per year was much greater in Asia than in Europe and USA, with some Centres seeing more than 5,000 patients per year. However, the numbers of in-patients seen in the institutions were smaller, with most Centres seeing less than 100 patients

per year. 2) The physicians saw their outpatients more frequently in Asia than in Europe and USA. 3) The cost per outpatient visit was lower in Asia, most being less than US\$200. The cost of in-patient was also lower in Asia, being less than US \$200 per day. In Europe, the cost for most Centres was more than US \$200 per outpatient visit and per in-patient day. 4) The proportion of patients with difficult to treat epilepsies were similar in Asia as compared to Europe. The medical facilities for diagnosis and treatment of epilepsy, such as EEG, CT, MRI, serum anti-epileptic drug measurement, and epilepsy surgery were also available in majority of the Centers in Asia. 5) The Centres in Europe on the other hand, saw more patients with co-existent learning disabilities, neuropsychological deficits and employment difficulties. 6) On the other hand, services such as assessments in neuro-psychology, education, occupational ability, and quality of life were seldom conducted in Asia. Programs for vocational training, training for every-day living and social competence, social work counseling, patient and family education were not a regular feature of the care given. They were provided on request or not at all. The lack of these comprehensive epilepsy services in Asia was mainly economic, this included the lack of funding to educate and employ para- or co-medical professionals related to epilepsy program.

CONTRIBUTION OF PARA-MEDICAL PROFESSIONALS TO THE THERAPEUTIC OUTCOME

The National Epilepsy Center in Shizuoka, Japan was founded on 1975 as a special center for epilepsy under the patronage of the Ministry of Health. It now has 170 beds, 80 for children and 90 for adults. In addition to Medical Doctors including Neurologists, Psychiatrists, Pediatricians, and Neurosurgeons, non-medical professionals including Nurses, Social Workers, Occupational Therapists, Psychologists, Play Therapists and School Teachers participates in the care of the patients with epilepsy. It is obvious that the non-medical professionals contribute directly or indirectly to the improved epilepsy care. The followings are some of the examples.

1. Risk of death by drowning associated with seizures in bathtub

It is well known that epilepsy patients have

increased mortality when compared to general population. The standardized mortality ratios for accident and trauma are higher, suggesting that accident and trauma are frequent causes of death in epilepsy patients as compared to the general population. Among the accidents, it has been reported that patients with seizures were twice as likely to drown as compared to those without seizures, and many of the drowning occurred in bathtubs.³

A study was carried out by a team of Nurses on causes of death among the in-patients and out-patients in the National Epilepsy Centre, Shizuoka.⁴ A total of 171 deaths was recorded among the 20,000 out-patients, which were not necessarily sudden but unexpected. These deaths were anecdotally reported and were not result from exhaustive investigations. Among the 171 deaths, drowning accounted for the largest group (56 patients), followed by complications from other diseases (38 patients), accidents (27 patients), suicide (10 patients), status epilepticus (7 patients) and unidentified causes (33 patients). Among the 56 deaths from drowning, in 44 patients, the drowning occurred in bathtubs, the other 12 patients drowned in other locations.

Drowning is the most common cause of fatal accidents among epilepsy patients. It may occur as a result of submersion when the patients develop seizures when swimming. This is particularly common when swimming in the seas and rivers, but it may also occur in the swimming pools. As reported above, death by drowning in bathtubs was the common cause of death in our study. In spite of this, with over 3,400 in-patients during the last 25 years in the National Epilepsy Centre, Shizuoka, there was not a single case of death by drowning in bathtubs. Our patients take baths 2 to 3 times a week in the Japanese style deep bathtub. One or 2 Nurses usually would watch over the patients while they are bathing. Whenever the nurses see a patient having a seizure, they would immediately extend their hands and rescue the patient. In the study period, there were 174 submersion episodes associated with seizures. Seventy-three episodes were associated with complex partial seizures, 54 episodes with absences, 21 episodes with tonic seizures, 6 episodes with tonic-clonic seizures, and 20 episodes with unclassified seizures. The impairment of consciousness resulted in submersion during bathing. The attendant nurses were able to prevent the accidental death from drowning.

Thus, if a patient's seizures are under good control, just like driving, he may be allowed to take bath unsupervised. Otherwise, he should only be allowed to take bath under supervision. The Nurses in the National Epilepsy Centre, Shizuoka were not only able to prevent many accidental deaths from drowning in bathtubs, but also to study and report this important finding.

2. Contributions from occupational therapy^{5,6}

The purpose of occupational therapy is to rehabilitate the patients to work; to evaluate the patients' working ability, to improve the interpersonal relations in the working situation, to help develop motor skills, and to introduce patients to prevocational training wherever possible. In the National Epilepsy Center, Shizuoka, occupational therapy workshops are conducted 5 days a week, 4 hours a day, and supervised by 4 Therapists. Carpentry, handicrafts, pottery, printing, horticulture, calligraphy, flower arrangement, painting, cooking, laundry, shopping, excursion and group meeting are the activities offered. The patients are able to choose these activities in combination depending on interests and disabilities.

A survey on functional impairment and disabilities in patients with difficult-to-treat epilepsy was conducted by Occupational Therapists from the National Epilepsy Center, Shizuoka. Sixty patients who attended the occupational therapy for more than 3 months were examined using WHO classification of functional impairment and disabilities.⁷ The mean age of the patients was 27.3 years. There were 34 males and 26 females. Their Wechsler Adult Intelligent Scale (WAIS) IQs were below 70 in 26 patients. The classification of the epilepsies was: partial epilepsy (39 patients), generalized epilepsy (14 patients) and others (7 patients). Of the 60 patients, the impairments were: psychological (60 patients), skeletal (52 patients), intellectual (48 patients), language (44 patients), ocular (10 patients), aural (10 patients), visceral (2 patients) and disfiguring (1 patient). They have disabilities in: situational (56 patients), behaviour (55 patients), dexterity (44 patients), communication (43 patients), personal care (37 patients), locomotor (27 patients), and body disposition (26 patients).

Of 37 patients who visited out-patient occupational therapy, 19 patients were later integrated into social life and 18 patients failed in the rehabilitation. Age, IQ level, psychiatric symptoms, physical and neurological disability

did not appear to affect the success in social integration and rehabilitation. However, of the patients having seizure associated with falling, more than twice the number of patients were not successful in social integration and rehabilitation. Of those patients who benefited in the rehabilitation, many aspects of work habits (volition, patience, spontaneity, concentration), and work abilities (comprehension, selection, adaptation) showed remarkable improvement. On the other hand, of those who failed in the rehabilitation, all aspects of behaviour showed little or no improvement. The character traits showing improvements were: aggressive, negativistic, suspicious, authoritative, over-confident, under-confident, anxious, dependent, indifferent, discontent, interfering, and competitive attitudes, as well as inability to judge appropriate social distance. These were reflected in the improvement in interpersonal relationship.

In 50 patients who completed more than 50 sessions of in-patient occupational therapy, the influence of seizures on work performances was studied. The mean age of the patients (29 males and 21 females) was 27.5 years (range: 18-59 years). Their IQs were below 70 in 39 patients, and 12 patients had neurological disabilities. Thirty-five patients had weekly or daily seizures. The classification of the seizures was: complex partial seizures (35 patients), tonic-clonic seizures (17 patients), simple partial seizures (3 patients), tonic seizures (3 patients), and absence seizures (3 patients). The seizure frequency of 50 patients while participating in the therapy sessions was compared with that occurring in the ward for comparable period and time. Thirty-six patients had seizures while participating in occupational therapy, whereas 41 patients developed seizures in the ward. Thus, participation in occupational therapy appeared to have a protective effect in seizure occurrence.

As for whether seizure occurrence hamper work activities, a total of 116 seizures were witnessed among 36 patients. In 18 patients, the work was not hampered, and the patients could continue their activities. The work was interrupted in 32 patients, with the patients resuming their work after a short interruption. Their work was slowed down in 4 patients, and had to be discontinued in 12 patients. The seizures that interrupted and discontinued the work were those associated with protracted postictal recovery, falling, or severe symptoms such as convulsive seizure, violent automatisms or prominent postictal confusion. Seizure frequency

made no difference.

As for the need of the attending Occupational Therapists to exercise precaution to prevent patients from injuries during seizures, of the 50 patients, 28 patients did not need any special precaution. The Therapists had to always attend beside the patients in 20 patients, 17 patients were recommended to sit on a chair, 12 patients to wear protective helmets, 12 patients to avoid use of cutlery, and 9 patients to use armchairs. As long as these precautions were taken, seizure-associated injuries did not occur.

The Occupational Therapists concluded that seizures could hamper work activities, but the work could be resumed in the majority of patients. Work was likely to be discontinued especially when the postictal recovery was prolonged. The attending persons should have good knowledge of the seizure behaviors in the individual patients, so as to take appropriate countermeasures to prevent injury. Work has a protective effect in seizures occurrence. Success in occupational therapy was associated with improvement in social integration, behaviors and attitudes, as well as interpersonal relationship.

3. Social development in preschool children with epilepsy and group therapy⁸

A long-term observational study was carried out by a group of Play Therapists to assess the levels of social development in preschool children with epilepsy and to examine the effectiveness of group therapy. The patients consisted of 22 boys and 7 girls. Their ages were from 3 to 6 years. Their IQs were greater than 70. Their ages of onset of epilepsy ranged from birth to 5 years. The types of epilepsy were: symptomatic localization-related epilepsy (16 patients), symptomatic generalized epilepsy (12 patients), and idiopathic localization-related epilepsy (1 patient). The children's behavioral development was assessed using the Tsumori Mental Development Scale for Infants and Young Children⁹ and expressed in developmental quotients (DQs) in 5 different components. The components were motor function, exploration behavior and dexterity, social behavior, activities of daily living (meal-taking, toilet control), and language. Group therapy consisted of role-play sessions utilizing linguistic ability. After modeling the leaders in role-plays, the children were encouraged to engage in role-playing among themselves in play shopping, and playhouse. The group therapy session was

conducted once weekly for about 90 minutes in each session. The children were observed to assess the "level of play behavior"¹⁰ and the 6 aspects of "role of play in development".⁸

It was found that the DQs of the children for exploration and social behavior were significantly lower than those for motor function, activities of daily living, and language. This was true among both groups of children with IQ higher and lower than 100. The items in the exploration behavior consisted of, for example, "play in a sandbox for over an hour", "making a railroad or train with blocks", "making a tunnel in a sand pile", and "hammering in a nail". The items in the social behavior consisted of, for example, "play house for 30 minutes", "make a shop among children only", "play shopping", "shed tears when listening to a sad story", "play in friend's house". After 14 or more group therapy sessions, the task performance improved in 10 out of 12 children. These children became capable of acting out the behavior specific for a role, understand various rules for shopkeepers and customers, and were able to share emotions with other children. The DQs in the exploration behavior also improved. Thus, 10 of the 12 children who had undergone group therapy showed improvements in task performance, level of play behaviors, and DQ scores in the Tsumori scale, indicating a beneficial effect of group therapy. This social-developmental improvement was associated with decrease in seizure frequency in 7 out of the 10 children.

In summary, management of children with epilepsy should include early assessment of intellectual ability and social developmental. Group therapy centered on role playing activities is able to promote the development of social skills.

The three examples of work done by non-medical professionals demonstrated that there exist ample possibilities in treatment of epilepsy other than pharmacological or surgical interventions. Management teams comprehensively organized to include medical as well as pare-medical professionals can best explore these possibilities.

REFERENCES

1. The National Association of Epilepsy Centers. Recommended guidelines for diagnosis and treatment in specialized epilepsy centers. *Epilepsia* 1990; 31: S1-12.
2. Pfaefflin M, Seino M, Specht U, and the ILAE Commission on Asian and Oceanian Affairs. Structure of comprehensive care for people with

- epilepsy. In: Pfaefflin M, Fraser RT, Thorbecke R, Specht U, Wolf P, eds: *Comprehensive care for people with epilepsy: Current problems in epilepsy*: London: John Libbey, 2001: 359-65.
3. Hauser WA, Hesdorffer DC. *Epilepsy: frequency, causes and consequences*. Epilepsy Foundation of America, Demos, 1990: 297-326.
 4. Rachi K et al. Difficulties in providing nursing care for in-patients with refractory epilepsy. Presented at the Second Asian and Oceanian Epilepsy Congress, Taipei, 1998.
 5. Harada N, Kuroda M, Kawamura T, Inoue Y. Direct and indirect influence of seizures on occupational therapy. Presented at the Second Asian and Oceanian Epilepsy Congress, Taipei, 1998.
 6. Harada N. Experiences in occupational therapy. Presented at Bethel-Shizuoka Workshop on Comprehensive Epilepsy Services, 2001.
 7. WHO. *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*. 1980.
 8. Sugiyama O, Matsunaga M, Suzuki K, Ishii M. Group therapy by means of role-playing in preschool children with epilepsy. The 32nd Congress of the Japanese Association of Special Education. *Abstract*, 1998: 518-21 (in Japanese).
 9. Tsumori M, Isobe K. *Mental development scale for infants and young children*. Tshoshuppan, Tokyo, 1991 (in Japanese).
 10. Parten MB. Leadership among preschool children. *J Abnormal Social Psychology* 1933;27:430-40.