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Psychosocial and Cultural Aspects of Epilepsy

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1. Introduction

Epileptic activity within the brain has an effect on the behavior, mood, and cognitive functions of the epileptic patient. Additionally, his/her behavior and mood may be affected by the attitude of others to his/her disability. Furthermore, the patient's social and psychological adaptations may modify his/her epileptic experiences. As a consequence of the interaction between these aspects patients with epilepsy face many cultural and psychosocial problems (Betts et al., 1976). The definition of the term psycho-social in dictionaries is "pertaining to or concerning the mental factors or activities which determine the social relations of an individual" (Webster, 2011). Meanwhile, the definition of culture is all the knowledge and values shared by a society (Webster, 2011). As many as possible previously published studies on the psychosocial and cultural aspects of epilepsy were identified from various parts of the world by using multiple search strategies. Published literatures cover varieties of areas, including: psychiatric problems (e.g. mood disorders, anxiety, psychotic disorders); feeling of shame, fear, and worry; low self-esteem; problems related to education, employment, dating, marriage, child-bearing, poor quality of life, and stigma (Lai, 2007). Publications on the link between culture and epilepsy show the believed etiology of epilepsy, public awareness, understanding and attitude toward epilepsy (Fong & Hung, 2002). Although some of these aspects have been considered in earlier chapters, at the risk of some repetition, we aim in this chapter to introduce an overview of different psychosocial areas related to epilepsy and examining the public awareness, understanding and attitudes of different cultures to epilepsy.

2. Psychological effects of being epileptic

To be epileptic is to be stressed and stress can influence the incidence of fits. Under stress many people develop anxiety symptoms which may be seen as a fight or flight reaction, some become depressed, and others show obsessive ritualistic behavior. There are those who develop temporary psychotic states or acute conversion (hysterical) reactions which effectively isolate them from the stressful situation (Betts et al., 1976). Beside the significance of the stress to the epileptic, the reaction of individual depends on several factors. Firstly, the support which a person has from family and friends affects his ability to cope. Secondly, the genetic constitution of the individual and the responsiveness of his autonomic nervous system to stress may play an important part (Slater & Shields, 1969, as cited in Betts et al., 1976). Thirdly, stress responses are influenced by educational and cultural background. Finally, reactions are

acquired and learnt as a part of growing up. Children are influenced greatly by the social mores of their family and the example of their parents (Betts et al., 1976).

Diagnosis of epilepsy can result in many psychological difficulties. Grief at the realization of being disabled goes through stages of shock, anxiety, bargaining and denial, mourning and depression, internalized anger, externalized anger, acknowledgement and finally acceptance and adjustment (Buchanan, 2002). Such grieves can occur either at onset or on realization of difference. Guilt can result in affective disorder. Anxiety combined with guilt can grow to become depression (Mendez, 1996). Depression appears to be the most common psychiatric comorbidity (Gilliam et al., 2003). The literature published has identified general mood disturbance, depression, and pathological distress, which are independent of seizure control, as significant predictors of quality of life impairment among people with epilepsy (Gilliam et al., 2003). Anxiety related emotions, which are very common in the epilepsy population, are amongst the most pathogenic secondary consequences (Mitan, 1983). However, anxiety disorders have not been extensively investigated. Many patients are afraid of dying during an epileptic attack, or seriously hurting themselves. These are feelings that are difficult to cope with both for the patient and the relatives. Also the experience of losing control is difficult to handle, rendering feelings of helplessness and being "reigned over" by the epilepsy (Siegler, 1981).

With regard to the more severe psychopathologies, the schizophrenia-like psychoses appear to be recorded and represented in India, Africa, and Japan. Interestingly, the rather characteristic features that Slater and Beard in 1963 described, namely that preponderance of positive over negative symptoms, and the high prevalence of first-rank symptoms, seem to be reported in the series that have examined these cases (Trimble & Krishnamoorthy, 2003). In Africa, Gureje, 1991, examined an unselected sample of 204 patients with epilepsy and noted that 37% were classified as having a psychiatric illness, and in almost a third, this was psychosis. Matsuura & Trimble, 2000, reviewed the Japanese studies that related to psychoses. Prevalence rates of psychosis varied with different institutions, from 0.9 to 9.1%. Finally there is a need for well-designed epidemiological studies of the psychological consequences and the comorbid psychiatric disorders in epilepsy. Coordinated protocols that attempt to explore these issues across cultures are desirable to understand the interface between behavior and the brain.

3. The social effects of being epileptic

To be epileptic means being exposed to the fear of having attacks, being at a disadvantage in terms of work and personal relationships, being open to prejudice, this exists both in the lay public and in the medical and nursing professionals. Unpredictability in connection with epilepsy is a source of fear and insecurity, giving the patient a constant feeling of being under threat. Fear of social exposure of fits and feelings of disgrace often lead to social isolation. Mitan, 1983, reports that between 50 to 75 per cent of the patients participating in an epilepsy research project in Los Angeles spent almost all their time at home. Many epileptic patients develop an extreme dependence upon their relatives, and this dependence interferes with the development of social skills. Public ignorance and fear of the unknown is another important source for the epileptic patients' problems. It is frightening to see a person having an epileptic attack, losing control of himself, and the simplest way to prevent such fear is to avoid the person with epilepsy. The consequence is even more social isolation and difficulty with employment for the patient as well. In Norway the employment rate was

21 per cent below the general population (Sletmo, 1982). Unemployment is higher among people with epilepsy, by up to 50% in developed countries if seizures are not fully controlled and up to 100% in developing countries. This can be caused by employer prejudice resulting from stigma and a lack of information, a belief that machinery should be avoided by the people with epilepsy, inability to drive, or poorer academic achievement. Disclosure to an employer is therefore a difficult decision. Unemployment commonly results in a lower self-esteem, lessened well-being and a lower quality of life (Bishop & Hermann, 2000; Gummit, 1997). In addition to feelings of loneliness, as a consequence of Social isolation, about 20 % of the patients reported that they lacked close friends (Hills, 2007). Dansky & Andermann, found that the marriage rate for women with epilepsy was 86% of that in the normal population, and for men with epilepsy it was 59%. Emotional problems are the most common hindrances to marriage (Dansky & Andermann, 1980).

Across the world and throughout history, epilepsy has been a culturally devalued condition. Such devaluing often leads to people with epilepsy being stigmatized and bearing psychosocial burden (de Boer et al., 2008). Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many sphere of life, over many centuries and in many cultures (Pahl & de Boer, 2005). The experience of stigma occurs when individuals possess a socially relevant and significant difference that others in the general population use as a reason to set them apart, resulting in the individuals' experience of status loss and discrimination (Link & Phelan, 2006). The original Colony for epilepsy was founded at Chalfont in 1893 in a quite part of what was then rural England, in order to provide employment for people with epilepsy. People with epilepsy were all too often an outcast and epilepsy carried the stigma of insanity. As time went on, conditions in the open community improved for those with epilepsy. Anticonvulsants were affecting much better control of fits. Epilepsy was no longer considered as a form of insanity (Laidlaw & Laidlaw, 1976). Finally, epilepsy is not just a clinical disorder but a social label; and a wealth of research supports the view that the social prognosis of epilepsy may be less optimistic than the clinical one, particularly for the four-fifths of affected people who live in the world's resource poor countries (WHO, 2011), and for those with intractable seizures (Jacoby & Baker, 2000). Although progress continues to be made in relation to medical management of epilepsy, including the development of new antiepileptic drugs, attention to the social adjustment of individuals with the condition is still limited. Traditionally, the outcome of health conditions has been measured in terms of mortality. More recently, new indexes have been developed. These attempts to define better the need for health services and related interventions, to define health outcomes in terms of body, person, and social functioning, and to provide a common framework for research, clinical work, and social policy (de Boer et al., 2008).

4. Culture aspects of epilepsy

One of the leading brain disorders in developing countries is represented by epilepsy. It is estimated that 80% of people suffering from epilepsy around the world, reside in developing world such as Africa (WHO, 2004). In developed countries, the lifetime prevalence rate for epilepsy ranges from 3.5 to 10.7 per 1,000 person-years (Forsgren et al., 2005; Theodore et al., 2006). In the other hand, the lifetime prevalence rates for active epilepsy varied from 1.5 to 14 per 1,000 person-years in Asia (Mac et al., 2007), from 5.1 to 57.0 per 1,000 person-years in Latin America (Burneo et al., 2005), and from 5.2 to 74.4 per 1,000

person-years in sub-Saharan Africa (Preux & Druet-Cabanac, 2005). It is uncertain whether these broad variations between environmental regions are attributable to varying definitions of epilepsy or whether they are related to geographically relevant risk factors such as poverty, illiteracy, poor sanitation, inaccessibility of medical care, birth-related trauma or cerebral cysticercosis (de Bittencourt et al., 1996). Cultural interpretation contributes to exclude epileptic patients from the educational and productive fields, aggravating the burden they face and favoring a treatment gap estimated to 80% (WHO, 2004). Treatment gap is the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage (Meinardi et al., 2001).

4.1 Epilepsy in Africa

The reaction to epilepsy in Africa is shaped by traditional indigenous beliefs which are surprisingly similar, in some way or other, throughout most of the African continent and result in severe psychological hardship. The African epilepsy sufferers have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest (Jilek et al., 1997). In 1970 Osuntokun & Odeku, reviewed 522 Nigerian epilepsy sufferers and observed that the patients suffered psychosocial handicaps including suicidal tendency because they themselves considered epilepsy a social disgrace. Modern treatment for epilepsy is often unavailable in Africa. The reason might be lack of treatment facilities, but also the general belief that epilepsy is of supernatural causation and therefore not treatable by Western medicine (Osuntokun & Odeku, 1970). Behavior often of sudden impulsive onset and discharge of bursting seizures make the victim become visible as if in the hold of an eccentric power. This provokes powerful panic in those present and has most likely done much to be responsible for the belief that epilepsy is caused by evil spirits or other supernatural forces.

Although Africa is a diverse continent, and represents people of different cultural background, a widely held notion is that epilepsy may be caused by evil spirits (Carod-Artal & Vazquez-Cabrera, 2007). Other beliefs include witchcraft and contagious fears from bodily secretions (saliva, stool, or urine) that could potentially transmit seizures to bystanders (Carod-Artal & Vazquez-Cabrera, 2007). An added cause cited by Mauritania Moorish populations is the diet; the term "iguindi" refers to all clinical manifestations including seizures attributed to excessive eating (Traore et al., 1998). In Nigeria, Africa's most populous country, epilepsy is thought to be contagious, and that belief is even popular among medical school students (Awaritefe, 1989). A belief of the Bini of Nigeria is that epilepsy is a disease where the heart gets blocked by foam, restricting circulation and resulting in a seizure. In Uganda epilepsy is thought to be a result of a lizard spinning around in circles in the head disturbing the brain causing dizziness, usually followed by a seizure. In Malawi epilepsy is thought to be due to an insect moving inside the stomach. In Swaziland epilepsy is thought to be caused by sorcery, which sends evil animals or spirits into the body, causing convulsion (Andermann, 2011). A connection between the phases of the moon and convulsive attacks has been made since ancient times. It was, and still, is believed that either the new or the full moon is directly influencing and provoking seizure activity (Jilek, 1979).

Sub-Saharan Africa- and the continent of Africa as a whole- attach a huge social stigma to epilepsy (Jilek et al., 1997). Prejudice against the disease is common, persons with epilepsy are usually stigmatized and even pronunciation of the word 'epilepsy' is a taboo (Carod-

Artal & Vazquez-Cabrera, 2007). To suffer from epilepsy in Africa often means to also suffer from a very specific psychological and social trauma (Jilek-Aall & Jilk, 1989). It will drastically change the way a person perceives life and his or her position within the family unit. Additionally, because of the belief that epilepsy may be contagious or caused by supernatural forces, epilepsy sufferers are shunned and feared by their fellow men, and they themselves are ashamed and frightened (Jilek et al., 1997).

The traditional indigenous beliefs and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation (Diop et al., 2003). In Africa preventable causes of epilepsy are more frequent than elsewhere, including infectious disease, head trauma, insufficient perinatal care and consanguinity (WHO, 2004). In 1997 the Global Campaign against epilepsy was launched to bring epilepsy 'out of shadows' to reduce treatment gap and social and physical burden, educate health personnel, dispel stigma, and support prevention (Diop et al., 2003). The Global Campaign against epilepsy consists of providing a platform for general awareness and assist departments of health in developing national epilepsy programs (Diop et al., 2003). The aim of reducing the treatment gap needs to take into consideration the cultural environment. Information and education of the public in general is important in order to enable and empower people to make informed choices. Cultural aspects should be studied with regard to patients' perceptions, attitudes and practices in relation to epilepsy, as well as their socio-familial relations. They provide the background for appropriate information, education and treatment programmes to be adapted in a holistic way to cultural specificities with a great chance of success. Furthermore research should be done to find out how apparent conflicts between cultural and scientific concepts can be resolved (WHO, 2004).

4.2 Epilepsy in Asia

Although substantial economic development and improvement of health services have occurred, Asia is a heterogeneous and resource-constrained continent. Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia (Mac et al., 2007). There are some biological differences in epilepsy between Asia and the West, mainly related to the young average age and smaller physique among Asians. This probably partly explains the smaller doses of antiepileptic drugs found effective in some trials involving Asians (Yang et al., 2007). The climate differences partly account for the higher prevalence of Japanese encephalitis and malaria, which remains important causes of acute symptomatic seizures in parts of Asia (Tan, 2007). Numerous studies on knowledge and attitudes towards epilepsy have been done in Asia, particularly in Chinese communities within and outside china. Many communities remain negative towards people with epilepsy, with a third to half thought that a person with epilepsy cannot work like other people (Mac et al., 2007).

Some studies in Asia have looked into some specific research topics. The gender issue has been studied in Pakistan, showing that there are many more difficulties for female patients with epilepsy in coping with pressure from society and family, and female epileptic patients tend to internalize the prejudice and discrimination (Aziz et al., 1997). In Sri Lanka, marriage is most often arranged between the parties. Most men are unwilling to accept proposal from a girl who has epilepsy. A history of epilepsy often results in breaking proposals. Thus, women with epilepsy often remain single. When epilepsy is concealed and subsequently exposed after marriage, the wife is either ill-treated or sent back to her parent's home. Women with epilepsy are often beaten and divorced by their husbands.

Epilepsy is legally a valid reason for divorce in Sri Lanka (Gamage, 2004). In addition, there is misbelieving that women with epilepsy cannot bear children. Finally many women with epilepsy come from lower socioeconomic background and had very little formal education. They are often unskilled and have great difficulty in finding suitable employment (Gamage, 2004). In Korea actual discriminatory practices in the employment of patients with epilepsy are prevalent, and there are 24.5% who have been treated unfairly at work. More than half of those who disclosed their disease to employers report that they have been refused a job because of epilepsy (Lee, 2005).

In conclusion, what discriminate epilepsy in Asia from other regions is probably not so much genetic or biological differences of Asians or environmental factors that control the causes of acute symptomatic seizures and epilepsy, but the psychosocial, cultural, economic, political and organizational factors that influence epilepsy causation, management and outcome.

4.3 Epilepsy in native tribes from central and South America

American beliefs about epilepsy differ from those observed in African or Asian cultures. Epilepsy was a well-recognized disease in pre-Columbian cultures, as Spanish chroniclers of the sixteenth century reported (Carod-Artal & Vazquez-Cabrera, 2007). Several native societies persist in Central and South America with a traditional medical system, empiricism, rites and initiations, whose knowledge is orally transmitted (Carod & Domenech, 1995). Epilepsy is caused by an attack suffered by an animal spirit who accompanies the person, after a fight between the spirits who serve the forces of good and evil (Carod-Artal & Vazquez-Cabrera, 2007). People with chronic epilepsy are considered witches. Epilepsy is called "teawarup" by Kamayura, and is caused by the revenge of the spirit (mama'e) of the armadillo killed by a huntsman. It is treated with two roots. Epilepsy is called "tukuri" by Chipaya people, and is originated by a witchcraft that enters into the nose and the head, as a wind. Tukuri is treated with a ritual animal sacrifice called willancha, and by taking several dried insect infusions and bird's blood (Carod-Artal & Vazquez-Cabrera, 2007). For the hunter-fisher-gatherer tribe of Amerindians, epilepsy may be caused by an accident, the rupture of an animal-hunting taboo, familial violence, or due to witchcraft. Epilepsy cannot be dissociated from religious beliefs. Malefic powers can be originated either from the direct action of a harmful shaman or by interactions with the Devil. "Nahualism", the disruption of the accompanying animal spirit of the person, is an explanation for epilepsy in many Meso-American cultures (Carod-Artal & Vazquez-Cabrera, 2007).

4.4 Spirituality and religion in epilepsy

Convulsions had an historical association with spirits and religion, primarily through the concept of spirit possession (Reis, 1994). Epileptic seizures initially attributed to voodoo spirit possession (Carrazana et al., 1999). The religious aspects of epilepsy have been observed in traditional African cultures (Baskind & Birbeck, 2005) as occurred in South American cultures (Carod-Artal & Vazquez-Cabrera, 2007). Even in deeply different and distant cultures such as the Greco-Roman, Judeo-Christian, Islamic, Hindu, and Voodoo traditions, epilepsy has consistently been seen as an infliction or possession by a supernatural power, be it a god or a demon (Magiorkinis et al., 2010). The Greeks referred to epilepsy as the Sacred Disease, and over the millennia, the disorder has been associated with

prophets, mystics, diviners, and the like (Temkin, 1971). Hippocrates began his discourse on the "sacred disease" by refuting the connection between epilepsy and the divine; he argued against the widespread beliefs of prophetic and mystical powers attributed persons with epilepsy and the disorder's divine causation. However, Hippocrates attempt to dissociate epilepsy and religion was unsuccessful. Subsequent religious figures were asked to heal people with epilepsy. The New Testament gospels of Matthew (17: 14-20), Mark (9: 14-29), and Luke (9:37-43), who was a physician; recount how Jesus cast out the evil spirit from a boy with epilepsy who just had a seizure, thereby curing him (DeToledo & Lowe, 2003). Throughout the Middle-Ages and the Renaissance, religious and magical treatments of epilepsy predominated (Temkin, 1971), and in the nineteenth century the religiosity of persons with epilepsy was stressed by physicians such as Esquirol, Morel, and Maudsley (Davinsky & Lai, 2008). Hyperreligiosity has been described in people with epilepsy by many early writers, including Echeverria, Clouston, Howden, and Kraepelin (Trimble & Freeman, 2006). One of the more influential investigators of recent times was Slater, who noted that mystical delusions were common in his series of patients with epilepsy and psychosis (Slater & Beard, 1963). Additionally, Dewhurst and Beard, 1970, reported on a series of patients with epilepsy who underwent religious conversions. All six had temporal lobe epilepsy, and none had been particularly religious before their conversion. More recently an investigation of religiosity in patients with temporal lobe epilepsy was done by Trimble and Freeman, 2006. They examined the religious experiences of 28 patients with epilepsy and religiosity, 22 patients with epilepsy and no expressed interest in religion, and 30 volunteer regular churchgoers. Members of the epileptic religious group were significantly more likely to have had past episodes of postictal psychosis and to have bilateral cerebral dysfunction. Finally, literature surveys have revealed that between 0.4% and 3.1% of partial epilepsy patients had ictal religious experiences; higher frequencies are found in systematic questionnaires versus spontaneous patients reports. Among patients with ictal religious experiences, there is a predominance of patients with right temporal lobe epilepsy. Postictal and interictal religious experiences occur most often in temporal lobe epilepsy patients with bilateral seizure foci (Davinsky & Lai, 2008). Although psychological and social factors such as stigma may contribute to religious experiences with epilepsy, a neurological mechanism most likely plays a large role. The limbic system is also often suggested as the critical site of religious experience due to the association with temporal lobe epilepsy and the emotional nature of the experiences. Neocortical areas also may be involved, suggested by the presence of visual and auditory hallucinations, complex ideation during many religious experiences, and the large expanse of temporal neocortex. In contrast to the role of the temporal lobe in evoking religious experiences, alteration in frontal functions may contribute to increased religious interests as personality trait (Davinsky & Lai, 2008).

5. Conclusion

Epileptic activity within the brain has an effect on the behavior, mood, and cognitive function of the patients. Problems related to areas such as overprotection, education, employment, marriage, child bearing, and psychiatric disturbances will vary according to the stage of epilepsy and the level of understanding in the society. There is widespread prejudice against epilepsy in almost all cultures. Among some cultures in Africa and Asia people with epilepsy are regarded with hostility and denied access to what medical and

social care may be available. Epileptic patient may become an exile from his society, exposed to social and religious taboo, isolated, sometimes denied the right to have children except with other epileptics. This reaction to epilepsy is essentially one of rejection.

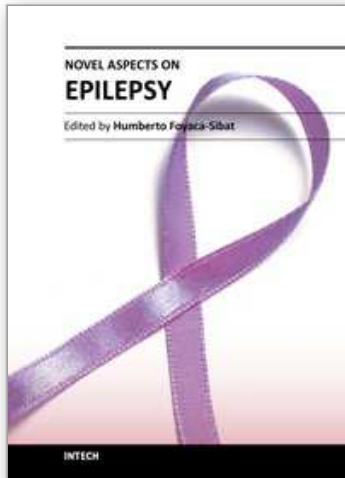
People with epilepsy, sometimes along with their family members, are often stigmatized. This stigmatization generates a hidden burden, which discourages patients from seeking the diagnosis and care they need and deserve. Additional fallout of stigmatization is the discrimination, as people who experience seizures but are able to work are unemployed; and many who are able to find employment are underemployed. It is often said that social attitude towards the disorder often causes more distress to the person with epilepsy and the near ones than the disease itself.

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This book covers novel aspects of epilepsy without ignoring its foundation and therefore, apart from the classic issues that cannot be missing in any book about epilepsy, we introduced novel aspects related with epilepsy and neurocysticercosis as a leading cause of epilepsy in developing countries. We are looking forward with confidence and pride in the vital role that this book has to play for a new vision and mission. Therefore, we introduce novel aspects of epilepsy related to its impact on reproductive functions, oral health and epilepsy secondary to tuberous sclerosis, mitochondrial disorders and lisosomal storage disorders.

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