Psycho-social Impact of Epilepsy and Issues of Stigma

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Introduction

Epilepsy itself is a very common medical condition that may occur among people of all ages, sex and races. Despite seizures may only last for a few seconds or a few minutes, it has much psychosocial repercussions to the patients and their family members. As people with epilepsy is a highly diversified and complex group due to different aetiologies, the author will only focus the discussion on those patients without other co-morbidities like physical disability, cerebral palsy and mental retardation. The impact to individuals is also very unique.

Impact on Children and Adolescents

Education is the most important domain to children and adolescents. Generalised tonic-clonic seizure (Grandmal) is the most noticeable, but threatening form of epilepsy to the classmates and teachers. After the seizure, though the patient will recover soon, he or she will feel very embarrassed due to the ‘horrible’ gesture during the fit and the disturbance caused to the class.

As some forms of epilepsy are less visible like petit mal, but appear to be rather ‘strange’ and ‘abnormal’ such as complex partial seizures, classmates and teachers may interpret the patients as ‘not attentive’, ‘rebellious’, ‘crazy’ as well as having ‘emotional and conduct problems’. Some playful classmates may even negatively portray or mock at the patients, resulting in much psychological sufferings of the patients like lowered self-esteem and emotional and behavioural disturbance. Moreover, some patients have under-achievement at schools. It may be due to the impairment of cognitive functions, side effects of medications like drowsiness, frequent absence to schools, poor concentration, and restricted social lives. The disadvantaged academic performance and difficulties in peer relationship limit better education opportunities and career. It is not surprising that depressive symptoms and even suicidal attempts are common among the adolescents.

Impact on the Parents

The impact of epilepsy also extends to the whole family. It will be extremely difficult for parents to fully admit and accept that their children are diagnosed as having epilepsy. They are overwhelmed by enormous worries and concern about the child’s prognosis, unpredictable nature of epilepsy, the side effects of anti-convulsants and the impairment to the brain functions as well as their future career and marriage.

Among all, one of the difficult things for the parents to accept is the label of epilepsy. In the Chinese literature, epilepsy is written as ‘癲癇症’. The first character ‘癲’ carries a negative connotation, similar to ‘insane’ and ‘crazy’. And, in the traditional folks, epilepsy is attributed to pregnant mothers’ consumption of mutton or blame for one’s wrong-doing. These myths exert much guilt and shame to the parents.

Hence, the stigma attached to epilepsy is more debilitating to the parents and the family. These ‘differentness’, ‘discreditable’ and ‘spoiled identity’ cause further stress and burden to the family.

Impact on Adult Patients

One of the most significant impact on adult patients is employment opportunities. The severity of seizure activities, educational attainment and social skills will largely determine their vocational opportunities. Generally speaking, they need to avoid employment with potential risk to their own lives and the public such as driving buses. Certain job natures may trigger seizure activities like night shift work.

For those who are working, patients are inclined to conceal their illness lest they will not be employed or even lose their jobs. Keeping this ‘spoiled identity’ and ‘hidden disability’ from colleagues and employers is a very stressful and prolonged process. On top of coping with the normal work stress, they are also suffering from the stress of managing their epilepsy identity.

For those who have seizures at the workplace, feeling of embarrassment and guilt would be very strong.
They will feel more helpless, rejected and frustrated in the midst of misunderstanding and gossips. Some patients may even lose their jobs directly or indirectly after seizures.

Another major impact on adults is the interpersonal relationship embracing friendship, courtship and marriage. Withdrawal from social lives, fear of rejection and worry over inheritance and pregnancy limit their social support network and establishment of new family support system in the long run.

In addition, both anxiety and depressive symptoms are prevailing among adult patients in both local and overseas studies. The chronicity of epilepsy, the unavailability of stable jobs, restricted social lives, lowered self-concept and family conflicts will further affect their quality of life.

**Issues of Stigma (Felt Stigma and Enacted Stigma)**

Both the patients and their family members tend to conceal their epilepsy due to their fear of being stigmatised and discriminated. This ‘felt stigma’ will further exert stress and restrict normal participation in society. As released on the International Epilepsy Care Day 2008 held in Hong Kong, more than 70% patients and family members opined that the Chinese name of epilepsy misled people to regard epilepsy as mental illness. More than 40% respondents are concealing their/their family member’s epilepsy.

There is inadequate understanding and misconception of epilepsy among the public too. In 2002, 1,128 subjects were interviewed in Hong Kong for their knowledge and attitude towards epilepsy. About 58.2% subjects had heard about epilepsy before. Of these, 52.7% would wrongly put an object into a patient's mouth during an epileptic seizure to prevent injury of the tongue. 32.2% would not allow their children to marry persons with epilepsy. The lack of understanding among the public will foster a sense of fear, misunderstanding and even discrimination in the community. There are some actual cases of discrimination/enacted stigma resulting in termination of employment after epileptic fits in the workplace. Therefore, stigma (both felt and enacted) among the patients, family members as well as the public needs to be stamped out.

**Interventions**

In response to the needs of patients with epilepsy and their family members, Community Rehabilitation Network (CRN) started epilepsy services in 1994. It has been under the subvention of the Social Welfare Department since 1997. Three intervention strategies are important and effective in helping the patients in the community, namely self-management, mutual support and social awareness.

**Promoting Self-management**

It is of paramount importance to enhance the sense of self-efficacy among the patients and their family members through enhancement of self-management skills of epilepsy. Educational talks, first aid workshops and Epilepsy Self-help courses are conducted to enhance the sense of mastery, better compliance and coping capacity towards epilepsy.

**Enhancing Self-help Groups/Mutual Support**

Self-help groups can provide information, support and facilitate growth and change among the patients and their family members through enhancement of self-management skills of epilepsy. Educational talks, first aid workshops and Epilepsy Self-help courses are conducted to enhance the sense of mastery, better compliance and coping capacity towards epilepsy.

**Arousing Social Awareness**

Arousing the awareness of the public about epilepsy, combating stigma and fostering a positive environment for the patients are of parallel importance. It will be both important to the patients and the public.
Community education programmes include school education, awareness campaign, Epilepsy Care Day, and production of educational materials like the ‘Demystifying Epilepsy’ Educational Kit. A more informed public and positive attitude will also help the under-diagnosed patients to seek treatment.

References

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Conclusion

Epilepsy exerts a lot of psychosocial impact to the patients of epilepsy of all ages and their family members. Epilepsy is not only a medical and personal condition, but also a social and public health issue which requires multi-disciplinary and multi-level intervention. Together with the individual treatment by medical professionals, self-management, self-help and social awareness among the patients and the public will also be critical to enhance the quality of lives of patients and to promote a more inclusive society.