

## EPILEPSY - BEYOND THE 'PURLE RIBBON': AN OVERVIEW OF PSYCHOSOCIAL ASPECTS

**NIGHAT HAIDER<sup>1</sup>, IMTIAZ AHMAD DOGAR<sup>2</sup>, MOWADAT HUSSAIN RANA<sup>3</sup>**

<sup>1</sup>Ph. D. Clinical Psychologist, Department of Psychiatry & Behavioral Sciences, Allied/DHQ hospitals, PMC, Faisalabad.

<sup>2</sup>Professor & Head, Department of Psychiatry & Behavioral Sciences, Allied/DHQ hospitals, PMC, Faisalabad.

<sup>3</sup>Professor & Chief Editor, Journal of Pakistan Psychiatric Society (Sitara e Imtiaz).

26<sup>th</sup> March is a day celebrating the purple ribbon i.e. World Epilepsy Awareness Day. Epilepsy is a well known neurological condition that still poses a challenge to physicians. Among a population of 50 million that suffers from this disease around the world, 80% of sufferers are from developing countries<sup>1</sup>. The risk of depression is raised up to 77 %<sup>2</sup> in patients with epilepsy with suicide rates five times higher in patients with epilepsy<sup>4</sup> especially in temporal lobe epilepsy where the risk is 25 times higher<sup>2</sup>. Deliberate self harm is 5-7 times higher in patients suffering from epilepsy than the normal population<sup>5</sup>. Two third of patients who report the precipitating factors involved in an epileptic fit report going through a stressful event.

Although epilepsy is a neurological condition, psychiatrists play a pivotal role in its treatment<sup>2</sup>:

- In the differential diagnosis of episodic disturbances of behavior
- In the treatment of psychiatric and social complications of epilepsy
- In the management of seizures caused by psychotropic medication
- In the management of psychological side effects of anticonvulsants

Since the majority of patients of epilepsy live in LAMI (low and middle income) countries,<sup>1</sup> public health resources for treatment are scarce and neurological consults are only available at tertiary care district hospitals or in private medical settings. These factors contribute to the overwhelming numbers of sought consultations by patients of epilepsy from general physicians and psychiatrists rather than neuro physicians. The role of psychiatrists, therefore, goes far beyond just the basic prescription of drugs.

The burden of informational care lies with psychiatrists. This includes guiding the patient and his family through the triggers of the fits, ways of controlling fits by minimizing the occurrence of these triggers, communicating psychosocial risks and complications, and communicating to them, the various ways to deal with the complications of epilepsy.

The physician's role appears can be reduced down to three basic tasks<sup>8</sup>. The first is the appraisal of the experience of illness as a threat or demand. The components of this threat may include immediacy, ambiguity, uncontrollability, or undesirability. It also incorporates the health belief model of the patient which may include identity of illness in form of a label and associated symptoms, causal ideas, consequences, time line and curability / controllability<sup>9</sup>. On the other

hand, the role of friends and family contributes to the appraisal of illness as a threat. The way family reacts to the condition and lends their role in management or withdrawing from the responsibility, mark the boundaries of social impairments the patient may face<sup>6</sup>.

The second appraisal is related to identifying the resources at hand at an individual and public level. Hardiness, restlessness are traits that are attributed to personal resources. While public resources are founded on the basis of the following 4 components being provided to the patient<sup>10</sup>.

- Emotional support; providing a sense of being cared
- Esteem support; Providing an air of being respected
- Instrumental support; helping the access to management or providing management.
- Informational support; the array of information that is helpful in managing the illness.

The third task is contributing to the magnitude of stress generated by illness by way of coping with the illness. The aim of coping may be problem focused or emotion focused<sup>11</sup>. The technique for coping may be cognitive, behavioral or social in which the patient may change their views, life styles and ways of borrowing help from professional agencies. The effective results may be produced by benefit finding and downward comparison in reappraising the chronic medical condition epilepsy has produced<sup>8</sup>. Style of coping (active or passive) may also be worked upon for an over all better outcome<sup>12</sup>.

Then there is the part of communicating the mechanic role that medication plays in the recovery from the disease. Making the patients understand the mechanism through which the drug will either be worse than the disease itself or help with its treatment.

Epilepsy is still grossly misunderstood and much like psychiatric illnesses, carries a stigma with it<sup>13-15</sup>. This highlights the need to focus upon the pathway of care. By raising awareness at all concerned levels; among colleagues including mental health professionals, general physicians, medical specialists, neuro physicians and neuro surgeons, among professional organizations like PPS, PMA, ECT, among patients and lay men, we can increase awareness and decrease stigma to help correct the pathway to care and shift it to a medical paradigm rather than a super natural one. Providing informational care, constitutes the major part of the treatment<sup>16</sup>;

- Nature, aetiology and prognosis of epilepsy.
- Drug treatments available including efficacy, side effects,

- interactions, and compliance.
- Likely duration of treatment
- Aggravating factors
- Risks including first aid, accidental injury and sudden death
- Information on driving, education and employment
- Addressing special issues for women

This information may include clarifying the cultural myths about epileptic fits, re assurance to the patient and family regarding the relative preservation of cognitive and intellectual abilities, particularly after the management of epilepsy, importance of treatment adherence, and the non-contagious nature of epilepsy. The mental health professionals must also work with the patient and the family on issues like education, marriage, change of home, job, driving, swimming, types of sports and leisure best suited. We must also play our role in reducing stigma, marginalization and discrimination experienced by patients of epilepsy. There is also a need for a greater awareness and use of concepts highlighted by WHO on subjects of treatment gap, mental health gap, standard guidelines of management, prevention of misuse of polytherapy, and separating psychogenic / dissociative fits from epileptic fits amongst GPs, PHCPs, psychiatric trainees, medical specialists and health care providers in general<sup>17</sup>. The crux of the treatment does not lie in the medical prescription but is obtained by imparting proper informational care to the patient and family, a difficult feat as perceived by the clinicians in light of the number of patients they have to attend to. Keeping printed material in local languages that explains the basic informational care regarding epilepsy is a practical solution. Such leaflets may be presented to the patient with prescriptions and conveyed to be read over by the patients themselves or by a relative or friend. The social responsibility of the patients to spread the awareness to their social circle must be emphasized.

The purple ribbon calls to our attention the need to open the knots in the mind of the patients, families, and the community as regards their understanding of epilepsy. The mental health professionals must play their role in this pursuit. Epilepsy is as much a mental issue as it is a neurological disease.

## REFERENCES

1. World Health Organization. <http://www.who.int/mediacentre/factsheets/fs999/en/>
2. Cowen P, Harrison P, Burns T. Shorter Oxford Textbook of Psychiatry. (6th. ed.). Oxford, UK: Oxford University Press. 2012.
3. Jaloby A, Baker GA, Steen N, Potts P, Chadwick DW. 1996. The clinical course of epilepsy and its psychosocial correlates; findings from a UK Community Study. *Epilepsia*. 37:148-181.
4. Barraclough B. Suicide and epilepsy. In *epilepsy and Psychiatry* (eds. E.H. Reynolds and M.R. Trimble), PP. 72-6. Churchill Livingstone, Edinburgh. 1981.
5. Hawton K, Fagg J, Marsack P. Association between epilepsy and attempted suicide. *Journal of Neurology, Neuro Surgery and Psychiatry*. 1980;43:168-70.
6. Spatt J, Langbauer G, Mamoli B. Subjective perception of seizure precipitants: results of a questionnaire study. *Seizure*. 7:391-5.
7. Frucht MM, Quigg M, Schwaner C, Fountain NB. Distribution of seizure participants among epilepsy syndromes. *Epilepsia*. 41: 1534-9.
8. Gelder MG, Andreason NC, Lopez-Ibor Jr JJ, Geddes JR (Eds). *New Oxford Text Book of Psychiatry* (2nd ed). Oxford University & Press Inc. New York. 2009.
9. Kleinman A. *The illness narratives; suffering, healing and the human condition*. Basic Books. New York. 1988.
10. Cohen S, Wills TA. Stress, social support and the buffering hypothesis. *Psychological Bulletin*. 1985. 98:310-57.
11. Lazarus RS, Foldman S. *Stress appraisal and coping*. Springer. New York. 1984.
12. Carver CS, Weintraub JK, Scheiev MF. Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*. 1989;56:269-83.
13. Caveness WF, Gallup GH Jr. A survey of public attitudes toward epilepsy in 1979 with an indication of trends over the past thirty years. *Epilepsia*. 1980;21:509-518.
14. Jacoby A, Gorry J, Gamble J, Baker GA. Public knowledge, private grief: A study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia*. 45:1405-15.
15. Diamantopoulos N, Kaleyias J, Tzoufi M, Kotsalis C. 2006 A Survey of public awareness, understanding and attitudes toward epilepsy in Greece. *Epilepsia* 47:2154-2164.
16. David AS, Fleminger S, Kopelman MD, Lovestone S, Mellers JDC. *Lishman's organic psychiatry: A text book of neuropsychiatry* (4th ed.). Oxford, UK: Wiley-Blackwell. 2009.
17. World Health Organization. *mhGAP intervention guidelines for mental, neurological and substance use disorders in non specialized health settings*. version 2.0. Geneva, Switzerland: WHO. 2016.