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VIEWS AND REVIEWS

Approach to epilepsy stigma: From reducing stigma to enhancing dignity

[1]Chong-Tin Tan, [1]Kheng Seang Lim, [1]Stephanie Lim, [2]Gus A Baker, [3]Shi Chuo Li

[1]Division of Neurology, Department of Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia; [2]University Department of Neurosciences, Walton Centre for Neurology and Neurosurgery, Liverpool, UK; [3]China Association Against Epilepsy, Beijng, China.

Abstract

Psychosocial burden of epilepsy is crucial in the care of epilepsy. Traditionally the effort to overcome the psychosocial burden of people with epilepsy has been by reducing social stigma but less on self-perceived stigma. Self-perceived stigma is an aspect of self-esteem and dignity. Maslow has divided the self-esteem and dignity into the "lower" and "higher" version. The "lower" version is the respect from others. The "higher" version is from self-evaluation. Thus, the approach to reduce stigma works toward "lower" version of esteem. A comprehensive approach to increasing esteem and dignity should thus also include efforts toward the "higher" version, to improve self-evaluation. In fact, enhancing self-esteem by reducing stigma also exert its effect through self-evaluation. As self-evaluation is dependent on cultural values, dialogue with the traditional culture, to draw out the relevant elements in the culture is a neglected aspect of comprehensive epilepsy care.

Keywords: Epilepsy stigma, self-esteem, dignity, culture

INTRODUCTION

There are 60 million people with epilepsy worldwide and 80% of those live in resource poor countries. While there have been significant advances in the medical management of epilepsy there has been limited progress in improving the quality to life of those with the condition. The recently launched World Health Organisation Intersectoral Global Action Plan [IGAP] by the WHO Brain Health Unit identified as one of its goals was to improve the quality of life of people with neurological disorders, their carers and families and reduce the stigma, impact and burden.[1] The IGAP also identified as a guiding principle as the importance of empowering people with epilepsy and as a strategic objective the strength the public health approach. In order to achieve the objectives of the IGAP there is a clear need to address the stigma of epilepsy. However any initiatives to reduce the stigma of epilepsy will have to appreciate its complex nature and its variability across continents. This paper considers a greater understanding of stigma in Asian populations and the role that individuals with epilepsy contribute to ameliorating it.

REDUCING STIMGMA BY CHANGING THE PUBLIC ATTITUDE

Epilepsy stigma is important in its impact on the life of people with epilepsy (PWE). Among adults with epilepsy, Jacoby et al. has mentioned that stigma was associated with impaired self-esteem, self-efficiency, and sense of mastery; with greater perceived helplessness, rates of anxiety and depression, somatic symptomatology and reduced life satisfaction.[2]

Traditionally, the approach to stigma has been to change the attitude of the community towards epilepsy, thus reducing the social stigma. The basic belief is that we form our self-image by seeing ourselves through the eyes of other people. Thus, if we can change the way the community perceive epilepsy, we will then be able to reduce the self-perceived stigma of epilepsy. Thus, the KAP studies are all about measurements of the general public and the important people such as

Address correspondence to: Prof Dr. Kheng-Seang Lim, University Malaya Medical Centre, 50603 Kuala Lumpur, Malaysia. Email: kslimum@gmail.com

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the teachers' knowledge, attitude and perception towards epilepsy.[3] It is believed that negative stereotypes were often internalized by persons with epilepsy, who saw themselves as having an "undesirable difference" and so anticipated being treated differently.[4] The effort of the patient-based society has been concentrated around changing the public attitude towards epilepsy.

THE TWO VERSIONS OF SELF-ESTEEM

The understanding of human needs is best known as depicted by the American psychologist Abraham Maslow, who proposed the hierarchy of human needs in 1943.[5] According to this theory, our most basic needs are physiological, followed by safety; social belonging and love; self-esteem, self-actualization and transcendence. Self-esteem represents the human desire to be accepted and valued by others. Maslow noted two versions of esteem needs: a "lower" version and a "higher" version. The "lower" version of esteem is the need for respect from others. The "higher" version is based on one's self evaluation, the need for respect from one's own self, or self-respect.[6] Based on Maslow's lower version of self-esteem, it is common for people to enhance their externals to improve their attractiveness to others and enhance their own self-esteem, for example, wearing expensive brands, living in exclusive addresses, seeking honorifics and titles.

The traditional approach to reducing epilepsy stigma is thus about the "lower" version of dignity or self-esteem, by improving the perception of epilepsy from others to reduce the social stigma. It would appear that enhancing the "higher" version of dignity and self-esteem, that is based on self-evaluation, should be an equally important strategy that has been thus far neglected. As even changing the attitude from others (the "lower" version) ultimately work through the "higher" version of self-evaluation.

THE "HIGHER" VERSION OF SELF-ESTEEM

As for Maslow's higher version of self-esteem, according to psychologist Em Griffin, self-esteem can be simply stated as: "Do I like myself?" It is based on four building blocks. Firstly, a sense of moral worth, I am basically OK. Secondly, a sense of competence, it is based on the ability affected by the height of self-expectation; and past achievements. Thirdly, it is a sense of self-determination, "I am the master of my fate/ Captain of my soul" instead of feeling powerless to change our lives. Fourthly, a sense of unity, "my behaviour is consistent over time"; "I have lived as declared", a sense of integration; "I have satisfied my own internal yardstick".[7]

High self-esteem is important, it is related to confidence leading to willingness to take risk and venture into unknown and thus also self-motivation. It affects socialization and is related to happiness. The world looks good to those with high self-esteem, whilst low self-esteem is prone to depression.[7] It is thus consistent with the result of the study that identified self-determined motivation and higher self-esteem to higher employment.[8] It would also explain the phenomenon of people like the great Russian novelist Fyodor Dostoyevsky, who described his epilepsy illness as: "Every ten days a fit, and it took me five days to recover from it… my fits incapacitate me completely, and after every attack I cannot collect my thoughts for four days…" Despite the frequent and disabling seizures, Dostoyevsky was a most productive writer, and has been acclaimed to be one of the greatest novelist in history.[9]

The five-stage model of self-esteem by Michele Borba, is built on five building blocks: security, selfhood, affiliation, mission and competence.[10,11] This model has a wide acceptance and citation. It can perhaps be adopted by the epilepsy community to enhance the 'higher' version of self-esteem. These 5 senses can be scored positively or negatively (high and low self-esteem). This is also a model for self-empowerment, whereby a higher self-esteem can be achieved using this model by setting realistic and achievable goals, being aware of own strengths, and accepting own weaknesses. Although it was first described in childhood education, it has been applied in many other fields including entrepreneurship.

Although Borba's five-stage model of self-esteem is based on the developmental model of a child, it can also be applied to adult, where the emphasis of selfhood includes the relationship with community.

The sense of security, selfhood and affiliation would be strongly dependent on the environment ('lower version') for the self-esteem; whereas the sense of mission and competence would reflect the 'higher' version of self-esteem.

IDENTIFYING CULTURAL VALUES THT UNDERLIE THE SELF-EVALUATION

The social stigma as well as self-evaluation process in self-esteem for PWE would be dependent on the

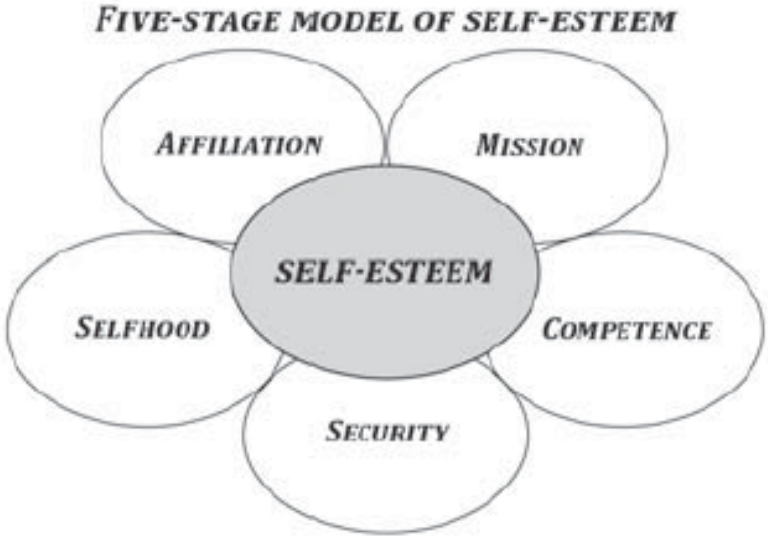

Figure 1. Five-stage model of self-esteem

*Sense of **security** means that a person (in this case a child) has a feeling of strong assuredness; he or she feels comfortable and safe. Sense of **selfhood** is a feeling of individuality, which means that a person is acquiring self-knowledge that includes an accurate and realistic self-description in terms of roles, attributes and physical characteristics. Sense of **affiliation** is a feeling of belonging, acceptance or relatedness. It is also a feeling of being approved of, appreciated and respected by others. Sense of **mission** is a feeling of purpose and motivation. It can be seen also as self-empowerment through setting realistic and achievable goals. It means that a person is willing to take responsibility for the consequences of one's decisions. (This is similar to self-motivation or self-determination.) Sense of **competence** is a feeling of success and accomplishment in things that are regarded as important or valuable. A person is aware of one's strengths and he or she is also able to accept one's weaknesses.*

cultural values that the PWE lives. An example is the understanding of the relationship between Borba's 'selfhood' and 'affiliation' model of self-esteem. This is the divergent concepts of the link between individuals and community in different cultures. The strong emphasis on individuality and trend towards 'individualism' is very much a phenomenon of the Western culture, although such a concept between self and community is also gradually being adopted by the other cultures as part of the process of globalization.[12] Another example of the different cultural understanding between 'selfhood' and 'affiliation' is the concept of family 'honour' and 'disgrace' in the traditional Chinese and some Islamic cultures.[13] Thus, the social stigma is not just confined to individuals, but the whole family, which may aggravate the social stigma perceived by the individuals. In the context of two versions of self-esteem, 'individualism' would be highly relevant in the 'higher' version of self-evaluation, while the family 'honour' and 'disgrace' can aggravate social stigma in the 'lower' version of self-esteem.

It is thus the responsibility of the epilepsy investigators to identify the concepts and attitude towards epilepsy in the particular culture. It also involves understanding what the community, family and patient meant by success. For majority of the modern world in the globalized age where life revolves around work, it would include education, ability and past achievements. As competence is nurtured by solving problems and overcoming difficulties, attitudes to difficulties in life; attitudes to illness (epilepsy), life overall ('Life is difficult'), independence and self-development are all important ingredients of self-evaluation. Of course, moral integrity, independence, harmony, attitude to leisure, family values and religiosity are also valued in most cultures.

As the development of personality and abilities are mainly during the childhood and youth, the upbringing style would thus be crucial. This explains why onset of epilepsy in childhood is a risk factor for unemployment and stigma.[14,15]

THE NEED FOR DIALOGUE WITH THE TRADITIONAL CULTURE

As the values of the family and PWE are a reflection of the values of the culture of the community, dialogue with traditional culture to capture the positive relevant values is thus a part of the comprehensive management of epilepsy. For example, in Chinese (Confucius) tradition, the main purpose of life is to be a 'gentleman' 君子, to fully express the true human nature. The essence of being a gentleman is "benevolence" and "virtue". The ability to resist feeling inappropriate shame – 'not feeling ashamed' 不耻 is a trait of 'gentleman'. This implies a sturdiness of character. Chinese (Confucius) culture emphasizes the importance of exerting vitality in the presence of adversity. Traditional Chinese culture also takes a positive attitude towards hardship and adversity, that it is essential for developing character and skills. Allowing freedom and nurturing independence and avoid overprotection is thus consistent with traditional Chinese attitude to upbringing.[16] Similar dialogue with Islam, Hindu, Buddhism and others are necessary.

CONCLUSION

The approach to overcoming the low self-esteem in PWE should go beyond changing public perception and attitude to reduce stigma. It should also entail enhancing the PWE's self-esteem from positive self-evaluation. This is commonly by nurturing the PWE's inner strength and ability to thrive through difficulties. Attention to upbringing style is thus important. As values are culture bound, it is also important to have dialogue with various traditional cultures to draw out the aspects that may be particularly important to enhance the PWE's self-evaluation.

According to Austin et al 2022[17] The success of reducing stigma will be dependent upon accelerating the development of effective epilepsy stigma-reduction interventions, based upon unified theories of stigma transcending individual conditions will be needed. Integral to a multistranded and multidimensional approach to stigma reduction will be the need to understand and address the role of the individual with epilepsy, in the context of their culture and environment. Perhaps the objective of any such programme should be to make each individual confident enough to be, where possible, an ambassador for their epilepsy!

This article is consistent with previous research on stigma[18] that discussed the stigma of epilepsy, in a particular social and cultural context, can be demonstrated at the internalized, interpersonal and institutional levels. Further that depending on the specific circumstances of PWE, a personalized approach to eliminate factors that cause internalized and interpersonal stigma needs to be adopted. Only by addressing impacting factors at each of these three levels can the stigma of PWE be alleviated or even eliminated.

DISCLOSURE

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REFERENCES

1. World Health Organization. Draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031. Geneva; 2022.
2. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurol* 2005;4:171-8. doi: 10.1016/S1474-4422(05)01014-8.
3. Lim KS, Lim CH, Tan CT. Attitudes toward epilepsy, a systemic review. *Neurol Asia* 2011;16(4):269-80.
4. Kwon CS, Jacoby A, Ali A, *et al*. Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy-Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. *Epilepsia* 2022;63(3):573-97. doi: 10.1111/epi.17135.
5. Maslow AH. A theory of human motivation. Psychological Review 1943; 50(4): 370-96.
6. Deckers L. Motivation: Biological, psychological, and environmental. Routledge Press. 2018.
7. Griffin E. Making friends and making them count. IVP. 1987: 36.
8. Baumeister RR, Campbell JD, Krueger JI, Vohs KE. Does high self-esteem cause better performance, internpersonal success, happiness, or healthier lifestyles? *Psychol Sci Public Interest* 2003;4:1-44. doi: 10.1111/1529-1006.01431.
9. Dostoyevsky F. The Idiot. Translated with an introduction by Magarshack D. Penguin Classic. 1955: 8.
10. Borba, M. Esteem builders: A K-8 self-esteem curriculum for improving student achievement, behavior and school climate. Carson, CA: BL Winch & Assoc./Jalmar Press. 1989.
11. Borba M. Home esteem builders. Torrance. CA: Jalmar Press. 1994.
12. Bellah RN, Madsen R, Sullivan WM, Swidler A, Tipton SM. Habits of the heart. University of California Press. 1985, 1996.
13. Kleiman A, Wang WZ, Li SC, et al. The social course of epilepsy: chronic illness as social experience in interior China. Soc Sc Med 1995;40(10):1319-30. doi: 10.1016/0277-9536(94)00254-q.
14. Lim KS, Wo SW, Choo WY, Tan CT. Impact of

epilepsy on employment in Malaysia. *Epilepsy Behav* 2013;27:130-134. doi: 10.1016/j.yebeh.2012.12.034.
15. Wo MCM, Lim KS, Choo WY, Tan CT. Factors affecting employability in people with epilepsy. *Epilepsy Res* 2016;128:6-11. doi: 10.1016/j.eplepsyres.2016.10.003.
16. Tan CT, Lim CK. Epilepsy care: Work, upbringing, leisure, and Chinese culture. *Neurol Asia* 2019; 24(3):197-202
17. Austin JK, Birbeck G, Parko K, *et al*. Epilepsy-related stigma and attitudes: Systematic review of screening instruments and interventions - Report by the International League Against Epilepsy Task Force on Stigma in Epilepsy. Epilepsia 2022 Mar;63(3):598-628. doi: 10.1111/epi.17133.
18. Guo W, Wu J, Wang W, *et al*. The stigma of people with epilepsy is demonstrated at the internalized, interpersonal and institutional levels in a specific sociocultural context: findings from an ethnographic study in rural China. *Epilepsy Behav* 2012; 25(2): 282-8. doi: 10.1016/j.yebeh.2012.08.013.