

## Stigma

*An aspect of epilepsy not to be ignored*

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## ABSTRACT

إن الشعور بأن المرض وصمة شخصية معيبة أو وصمة عار هو أحد أهم العناصر ذات التأثير السلبي علي حياة مرضى الصرع وعائلاتهم. وهذه مسألة عامة عادة ما نقابلها لدي مرضى الصرع في مختلف الثقافات. وهذا الشعور بوصمة العار ربما يكون له تأثير أكثر ضررا من المرض نفسه علي حياة المريض. إن من واجب العاملين المهنيين في مجال الرعاية الصحية محاولة تحسين أسلوب حياة مرضى الصرع فيما هو أكثر من محاولة السيطرة علي النوبات الصرعية، واحد الوسائل للقيام بذلك هو مكافحة الشعور بوصمة العار أو الوصمة الشخصية المعيبة بسبب المرض. ويتعامل مرضى الصرع مع مختلف العاملين المهنيين في المجال الصحي بما في ذلك الأطباء والجراحين والأخصائيين الاجتماعيين والأخصائيين النفسيين والأطباء النفسيين وطاقم التمريض، ومن ثم فإن الشعور بوصمة العار أو الخجل من المرض يمكن مجابهته والتعامل معه بواسطة تخصصات مختلفة. وللأسف فإن هذه المسألة يتم تناولها بصورة أساسية بالمجلات الطبية المتخصصة مثل مجلة مرض الصرع ومجلة الصرع والسلوك والنوبات الصرعية وطب العلوم الاجتماعية وهذه المجلات الطبية يقرأها المتخصصون المهتمون أساسا بمرض الصرع أو العلوم الاجتماعية. لذلك نشعر بأن هذه الموضوع يجب تناوله أو التعامل معه من خلال مجلات طبية تتوجه أساسا إلى القراء من ذوي الاهتمامات والتخصصات المختلفة.

Stigma is considered to be one of the most important factors that have a negative influence on people with epilepsy (PWE) and their families. It is a global issue commonly encountered in PWE in all cultures. Stigma may have deleterious effects on the patient's life, more than epilepsy itself. It is the duty of all health professionals to try and improve the quality of life of PWE beyond seizures control, and one of the important ways to do so is by fighting stigma. Many different health professionals including physicians, surgeons, social workers, psychologists, psychiatrists, and nurses deal with PWE, and hence stigma in PWE can be encountered and dealt with by many diverse specialties. Unfortunately, this issue is addressed primarily in specialized journals like *Epilepsia*, *Epilepsy and Behavior*, *Seizure*, and *Social Science Medicine*.

Professionals interested mainly in epileptology or social sciences read such journals, and we feel that this issue should be addressed in a journal targeting readers of different specialties and interests.

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Epilepsy is the most common serious neurological disease worldwide. It affects around 50 million people, most of whom (85%) live in developing countries.<sup>1</sup> Although recent decades have witnessed scientific advances in the different fields of epileptology such as neuroradiology, recent antiepileptic drugs and genetics, but not much so in dispelling stigma.<sup>2</sup> Stigma by spoiling the patient's identity with its psychosocial problems, may have a burden on the patient's life that is more crippling than seizures.<sup>3</sup> Despite the changes in public attitude, epilepsy may evoke a similar response to rejection like other chronic disorders, which are deeply stigmatizing such as acquired immune deficiency syndrome (AIDS).<sup>4</sup> Epilepsy represents a private source of grief and not just a clinical condition, but a social label.<sup>5,6</sup> Seizures are generally benign and can be controlled in 70-80% of patients.<sup>7</sup> Stigma can still affect the lives of 30-50% of PWE even among those who are controlled.<sup>8-49</sup> Therefore, it is of paramount importance for all health professionals to know of the different issues of stigma and help in its reduction. By reviewing stigma in epilepsy, we hope that this article will help the health professionals to participate in achieving the reduction of the heavy burden that stigma casts on the lives of people with epilepsy (PWE).

**Definition of stigma.** A curious aspect of stigma is its wide range of definitions.<sup>50</sup> The origin of the word stigma comes from Latin “Stigmat” which means “mark” or “brand” and from the Greek “stizein” to tattoo.<sup>31</sup> The concept of stigma was introduced by Goffman in 1963. He defined stigma as “loss of status and power resulting from separation of those stigmatized from the general population because of a characteristic that has been culturally defined as different and undesired.”<sup>51</sup> It includes disapproval and rejection from others. It is an attribute that is deeply discrediting leading to spoiling of the individual identity, which will be disqualified from social acceptance.<sup>51</sup> Another widely accepted definition by Weiss defines stigma as a social process or related personal experience characterized by exclusions, rejection, blame, and devaluation.<sup>52</sup>

**Types of stigma.** There are 3 main types of stigma: **Perceived ‘self’ stigma.** It refers to the feeling of shame of being epileptic with its associated oppressive fear of encountering enacted stigma.<sup>5,31,32,48,53,54</sup> It is commonly associated with illnesses and medical conditions that have visible signs, or arouses feeling of dread and fear.<sup>51</sup> People with epilepsy assume from prevailing illness stereotypes and lay people theories that they will be devaluated and discriminated against, which causes them to adopt coping strategies to address these assumptions typically through social withdrawal and secrecy. These will cause a negative impact on quality of life, and hence reinforces the feeling of stigma.<sup>54</sup>

**Enacted stigma.** Actual episodes of discrimination against PWE only on the grounds that they suffer from epilepsy.<sup>5,31,48,53-55</sup> The legacy of the idea that epilepsy is a product of sin and possession means that the cause of epilepsy is ambiguous, and although the seizures present far greater danger to those with epilepsy than the non-epileptics, the issue of peril is echoed in the idea of epilepsy being contagious. This idea is still dominant in poor resource countries.<sup>14,17,19,24,36-38,40</sup>

**Courtesy stigma.** This type of stigma goes beyond the patient to affect the whole family members, and even extends to affect those who have an association with the patient.<sup>8,9,20</sup> West<sup>9</sup> found that parents with children who suffer from epilepsy often experience a sense of shame and their children are seen as conferring shame on the whole family by virtue of being odd.<sup>9</sup> Kleinman<sup>20</sup> described in the Chinese culture that the moral weight attached to epilepsy threatened familial aspiration and life chances.<sup>20</sup> Because of family disgrace PWE are kept at home and their diagnosis was kept secret.<sup>20</sup> The different types of stigma are a complex network of forces, which act dynamically and synergistically with each other.

**Why epilepsy is one of the common stigmatizing diseases?** Epilepsy is unhidden unlike many other

diseases such as hypertension or diabetes. It is unpredictable and not easy to understand by “the terrified watchers” why what seemed to be a normal person behaves in a very strange manner. This makes the seizures look like chaos against the cultural norm.<sup>56</sup> People with epilepsy are perceived as creating ambiguity in their social interactions and so threatening the social order, by being unpredictable and out of control.<sup>57</sup> By losing control PWE are seen as ‘reverting’ to ‘primitive’ and hence represents ‘anomic’ terror to those without epilepsy.<sup>58</sup> By representing human weakness unpredictably, they are seen as uniquely dangerous.<sup>59</sup> It is a common phenomenon in many accidents and emergencies departments to see that a patient brought for management of generalized tonic clonic seizures, are considered by watchers including physicians and nurses like a crisis, and peace is not restored till seizures are suppressed even though they might be psychogenic non-epileptic seizures. Still, people with epilepsy are often perceived as violent.<sup>43</sup>

**Roots of stigma in PWE.** The label ‘epilepsy’ and its history: The history of epilepsy goes back to more than 4000 years of ignorance, superstition, and misconceptions even before the Babylonian era.<sup>60</sup> The word epilepsy comes from the Greek word ‘epilambanein’ which means to ‘seize’, attack or ‘possess’, ‘overwhelmed’ by surprise implying supernatural power as a cause of epilepsy. It is interesting to know that ‘sara’ the synonymous word for epilepsy in Arabic, Persian, and also Turkish means ‘falling as if struck’ carrying the same implication of an outside force.<sup>61</sup> For years many religions have regarded persons with epilepsy as being possessed.<sup>60</sup> Epilepsy is considered as contagious even in the 18th Century.<sup>60</sup> The medical understanding of epilepsy was recognized at the end of the 19th Century when epilepsy was finally confirmed at least in developed world as a neurologic condition.<sup>60</sup> There is evidence that PWE always passively accept being labeled as epileptics and may tend to negotiate less intimidating diagnosis than epilepsy, or alternatively focus on clinical uncertainties and deny the diagnosis altogether.<sup>61</sup> In a cohort of 70 patients with epilepsy studied by the author in Saudi Arabia, 62 patients (88.6%) disliked the label ‘Sara’ as they believed that it is stigmatizing by itself, and preferred to be diagnosed as suffering from vague terms like ‘dizzy spells’.<sup>61</sup> It is unfortunate that neither epilepsy nor ‘sara’ tell us that seizures have something to do with the brain. It is not feasible to change these deeply rooted words, but at least an addendum following epilepsy or Sara should be added like ‘electro-cerebral disturbances’.<sup>61</sup>

**Not enough knowledge of epilepsy.** Extensive studies worldwide showed that enough knowledge of epilepsy is lacking especially in poor income countries.<sup>14-16,18-20,24,26,36,40,46</sup> In many African countries, still epilepsy

is considered as contagious, and supernatural power is quoted as its cause.<sup>8,12,14,17,24,32,34,36-38</sup> In Arab countries, mystical beliefs on epilepsy prevail, and epilepsy in many Arab Communities is considered as a mental or psychiatric disease.<sup>25,26,28,47,62-64</sup> Possession by evil is considered as one of the major causes of epilepsy.<sup>25,26,28,47,62-64</sup> It is surprising that misconceptions of epilepsy are still present in developed countries. In a recent study of 19,441 high school adolescents in the United States (US), 22% of them were not sure if epilepsy is contagious.<sup>30</sup> Minorities in the US still believe in the supernatural etiology of epilepsy.<sup>41</sup> Even in the 21st Century in the United Kingdom (UK), a substantial minority of the public regard epilepsy as a mental rather than a physical disease.<sup>6</sup> The lack of accurate knowledge of epilepsy is found not only in the public, patients and their families, but at times even among health professionals.<sup>28,38,45,47</sup> Misconceptions of epilepsy have a major role in stigma production whether perceived, enacted, or courtesy stigma. The scientific explanation of epilepsy is gaining ground in developed countries, but this is still not the case in poor-income countries. There are differences in the level of knowledge of epilepsy among different countries. This level is variable even in the same country depending on the culture, whether it is a rural or urban area, and also on the socio-economic factors.<sup>4,18,25,27,36,38,39,41,48,49</sup>

**Misinformation by the media.** The different media venues whether written, radio, television, the web, and the movies still give misinformation on epilepsy, which influences the public perception.<sup>65-69</sup> Epilepsy is commonly considered as the dramatic grand mal giving the impression that all PWE have chronic and incapacitating disease.<sup>4</sup> Stigmatizing language is used in printed materials, which is reflected in a recent study in which 30% of the stories on epilepsy embrace this language that contains either exaggeration or inaccuracies.<sup>65,68,69</sup> The movies also portray epilepsy in a way that highlights myth, misconception, and misunderstanding.<sup>66,67</sup> In the era of the web, many sites are spreading misconceptions and misunderstanding regarding etiology and treatment of epilepsy. Some Arabic language sites as an example, give misinformation that incriminates supernatural power of devil "Jinn" as a cause for epilepsy, and one of these sites advises the use of funny treatments, such as garlic.<sup>70-72</sup> Even in the West, the websites may not provide the standard medical information on epilepsy.<sup>73</sup>

**The prevalence of stigma.** It is very difficult to measure the prevalence of stigma by direct questionnaires and instruments. Stigma is a complex phenomenon, which is worldwide, with regional, inter-and-intra-regional and cultural variations.<sup>4,12,18,27,36,37,39,41,48,49</sup> Most research was carried out in North America and Europe with a few from low-income countries. The research projects

from the North place greater emphasis on perceived stigma, whereas studies in the Southern hemisphere, for example, African countries South of the Sahara emphasize on enacted stigma.<sup>32</sup> To have accurate knowledge on the prevalence of stigma, a cross-cultural research may benefit from a multi-disciplinary team from various cultures, to develop a frame and shared research tools, which allow for contextual and cross-cultural adaptation.<sup>32</sup> In the US and Europe, some studies found that approximately half of PWE feel the stigma; 18% of them feel severely stigmatized and there is some variation among the countries studied.<sup>27,31,48,74</sup> In developing countries, stigma is not yet fully explored, but in what has been published, it seems that at least more than a one third of PWE may face stigma, but it may be as high as 60%.<sup>34,39,46</sup> The lack of adequate treatment in developing countries with the chance of PWE having frequent witnessed seizures may increase the chance for PWE to be vulnerable to enacted stigma, which will eventually make the patients live in fear and this will subsequently augment the perceived stigma as well. The published data on stigma may show some bias, as these studies are carried out by people with different specialization and interests.

**Factors contributing to the size of stigma.** These are very complex resulting in some controversies in the published literature. Most of the current data quote young age of onset, duration and frequency of seizures, lower level of education, presence of seizure related injuries, encountering acts of discrimination, and generalized tonic clonic seizures, as the main factors that play a significant role in the magnitude of stigma.<sup>74-78</sup> Frequency of seizures is considered to be a factor strongly related to felt stigma.<sup>74,75</sup> This issue contradicts the finding in a study in which 14% of those who were seizure-free for >2 years still reported the feeling of stigma.<sup>53</sup> In the study by Baker,<sup>55</sup> multivariate analysis showed that impact of epilepsy, age of onset, country of origin, feeling on life, and injuries associated with epilepsy were significantly related to stigma score, but seizure frequency was not.<sup>55</sup> More recent data revealed that experience of actual discrimination, introverted personality, problem solving capabilities, controllability, and emotional state were independently correlated with feelings of stigma, beside psychologic dysfunction.<sup>79</sup> There is an association between stigma and employment as unemployed people tend to report higher levels of stigma.<sup>35,80</sup> Injuries associated with epilepsy were significantly related to stigma scale.<sup>27</sup> Burns are marks, which in some African countries are very stigmatizing, and some traditional healers link the burns with the patient having a sealed fate.<sup>38</sup>

**The impact of stigma on PWE.** Quality of life and psychosocial function have been extensively investigated, nevertheless, there is a lack of standardized approach,

which makes it extremely difficult to summarize and indicate what measures should be used, and in which patients and in which sub population.<sup>3-5,11,12,18,20,24,27,35,39,41</sup> This difficulty is complicated by the fact that there is lack of information on quantitative measure of the level of stigma. The studies on stigma have approached this issue from a different perspective.<sup>6,20,78,82,83</sup> Most of the studies were based on questionnaires with (yes or no answers).<sup>6,20,81-83</sup> Comparison between groups use the difference between proportions and the quantitative values, which are expressed as percentage. This approach lacks comparative powers for the variable of interest within the extreme (yes or no). Very recently, stigma scale of epilepsy (SSE) was used to investigate people's perception and attitude towards epilepsy providing a measure of stigma perception that varies between zero (minimal stigma perception) to (100 maximal perception).<sup>84,85</sup> Variations in the sociocultural attitudes in the country of residence, and patients themselves make it difficult to determine the magnitude of the impact of the psychosocial problems PWE encounter. The psychosocial impact affects self-esteem, reduced employment opportunities, family function, social capital, quality of life, and increased levels of anxiety and depression.<sup>5,12,20,25,35,39,74-92</sup> This negative impact of stigma may be stronger in late life as epilepsy is associated with serious complications.<sup>93</sup> It is interesting to know that stigma in PWE exposes them to health risks that reduce their access to treatment.<sup>94</sup> In the Arab countries, psychiatric/mental diseases are very stigmatizing and patients are commonly rejected by the Society.<sup>95,96</sup> Epilepsy is considered as a mental disease by a large population of Arab societies, and this belief will increase the negative impact on the life of PWE in these regions.

#### ***Increased rate of underemployment or unemployment.***

Employment, besides its economic reward is important for personal status, identity, and self-worth. It is a very important part of public health, and having a job improves the quality of life. Several studies have confirmed that unemployment and underemployment rates are generally higher in PWE than in the general population, which was recently reviewed extensively by Smeets.<sup>92</sup> Despite the abundant literature on this issue it has not been fully investigated, and the rate of unemployment ranges between 12-60%.<sup>92</sup> There is little agreement in the employment rate as there are variations between different countries and communities.<sup>92</sup> Many psychosocial factors have been implicated in causing high unemployment rate in PWE, that includes patient personality, education, intelligence, age, psychosocial, and neuropsychiatric functions.<sup>92</sup> A recent study from the US found that a high self-perceived importance of work and decreased fear of workplace discrimination, are significantly associated with better employment

rates in PWE.<sup>97</sup> To date, many employers and even work mates are unhappy to work with PWE, causing a significant number of PWE to conceal their disease.<sup>98</sup> Despite the fact that there is some improvement in employers attitude in the West, a study in UK indicates that employers have a high concern regarding the occurrence of work-related accidents in PWE.<sup>99</sup> There is a need for specific rehabilitation programs to help PWE to find and maintain employment and these should focus on increasing self-efficacy and coping skills of PWE.<sup>99</sup> In low-income countries such programs may not be feasible, and it is of prime importance to focus first on seizures control as many studies indicate that unemployment is higher among patients with more frequent seizures.<sup>92</sup>

***Lower rate of marital status in PWE.*** The marriage rate is lower in PWE than the general populations, which were demonstrated in many studies with varying rates, with the highest unmarried rate of 58.9% (control of 16.7%) being reported from Cameroon.<sup>24,34,36,100-103</sup> The lower marriage rate is related mainly to unemployment, but attitude of the public towards PWE plays a significant role. The divorce rate is probably higher in PWE compared to control, and the main cause of divorce is a result of the fact that some couples do not disclose their disease to their future partners prior to marriage.<sup>103</sup>

***Lower level of education.*** There is a universal lower level of education in PWE than in the general population. It shows differences between countries and also among communities, but even in Europe and America the academic achievement of PWE is lower than control.<sup>31,36,104-105</sup> The situation is dismal in low-income countries as in some communities of these countries children are barred from going to school as they may be considered mentally feeble, or the parents are under the fear that their child with epilepsy may sustain injury or even die outside the home during a seizure.<sup>31</sup> The school drop out rates of children with epilepsy is higher in low income countries.<sup>106</sup> Seizures occurring at school result in poor self perception and reduced social interaction beside its fueling effect on stigma courtesy in the family. Teachers and parents may also have dismal opinions of capabilities and behavior in children with epilepsy.<sup>107,108</sup> Learning disabilities occur in a significant portion of children with epilepsy. The cognitive impairment related to antiepileptic drugs may adversely affect the academic achievement in PWE as well.<sup>109</sup>

***Increased rate of psychiatric disorders.*** The increased incidence of neuropsychiatric features of epilepsy can be due to seizures, their underlying etiology, and the associated psychosocial effects. These may all lead to functional limitations. The effects of stigma in addition to the adverse effects of antiepileptic drugs also contribute to the psychiatric disorders in PWE.<sup>109</sup>

**Depression.** This is the major psychiatric problem in PWE. It is a mood disorder characterized by loss of energy, interest, feelings of guilt, difficulty in concentration, and thoughts of death, hopelessness, or even suicide.<sup>110</sup> The prevalence of depression is variable with figures quoted between 20-55% being higher in hospital based studies than the community studies.<sup>110,111</sup> Depression can be of a reactive nature due to the many social ills of epilepsy particularly social stigma, unemployment, and education problems. It is a very serious condition, often an ignored aspect in PWE. Many studies have indicated that death by suicide is higher in PWE than in the general population with variable incidence in different countries being higher in Denmark than the UK.<sup>111,112</sup> Depression has a significant impact in quality of life in PWE more than the burden of seizures.<sup>90</sup> It affects compliance of PWE to antiepileptic drugs, increases the risk of unprovoked seizures, and also leads to isolation.<sup>110,111</sup> Treatment of depression depends on opinions rather than evidence. It includes antidepressants, non-pharmacologic treatment such as vagus nerve stimulation, psychological therapies including cognitive behavior therapy, patient support group, family therapy, and counseling.<sup>113</sup> Anxiety. Anxiety occurs in 10-25% of PWE, and it may be due to the unpredictable nature of seizures and perceived loss of control, both of which are related to the felt stigma.<sup>110</sup> Physicians treating PWE should not only focus on seizure control, but it is of vital importance to recognize and look for any symptoms of anxiety or depression and treat them.

**How to fight stigma.** There are 2 aspects of fighting stigma: Primary prevention should be the golden aim, and its reduction if already present. Efforts to reduce stigma need to focus on contributing to and those perceiving stigma on epilepsy.<sup>4</sup> Dissemination of accurate knowledge of epilepsy is the most important way to fight stigma. This should be addressed to all individuals including the patients, their families and friends, the public at large, educators, potential employers, health insurance, the media, and the policy makers.

**Education.** Education is the most important tool to fight stigma. For stigmatization to be consistently effective, the stigmatized person must hold the same beliefs as the society that devalues him. It is known that most adults with epilepsy often have insufficient knowledge of their disease and its treatment, despite large amounts of available knowledge.<sup>16</sup> Physicians usually do not have the time in the clinic to discuss all aspects of epilepsy with their patients, a large section of whom are unsatisfied with such an attitude.<sup>114</sup> Improving the knowledge of epilepsy has resulted in improvement of attitude towards PWE.<sup>115-119</sup> The public education can be delivered through all media venues, by lectures in schools, churches, mosques, and social gatherings. In a

community-based study in which 34% of PWE suffer from perceived stigma, the majority of them felt their stigma could be ameliorated by education intervention, which targets the public.<sup>120</sup> This can be carried out by health professional organizations or any health professional with adequate knowledge of epilepsy. Mothers with offspring with epilepsy should be given the necessary knowledge of the different aspects of epilepsy and should be encouraged to help their children to have a normal life as the child's self-esteem and confidence are affected by felt stigma, which is linked to mother's attitude. The mother's attitude can be of great help in fostering self-acceptance, self-confidence, and self-worth, which helps to prepare the child in dealing with his feelings and attitudes of others. Diseases of children are always viewed through the eyes of their parents. Parents can be stigma coaches by fostering stigma in their children. Educational programs have been shown to improve patient's knowledge and understanding of their epilepsy, its treatment, and psychosocial consequences of having epilepsy.<sup>121</sup> By aggressively educating the youth, there is hope to change the society's perception of epilepsy within the next generation.<sup>122</sup> Providing correct information and appropriate education will definitely help the campaign of destigmatization.<sup>123</sup>

**The importance of early control of epilepsy.** The majority of PWE (70-80%) can live a normal life as control of seizures leads to reduction of stigma, especially the perceived stigma, which is significantly related to the seizure frequency.<sup>76,77,82</sup> Control of epilepsy is still a real problem in poor-income countries, as around 90% of PWE are not receiving treatment.<sup>124</sup> The treatment gap as defined by a workshop of the International League Against Epilepsy, 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.<sup>125</sup> The treatment gap in poor income countries is due to financial inaccessibility to anti-epileptic drugs, limited human and technical resources for PWE, illiteracy in addition to cultural background, as some communities do not even realize the existence of medical treatment for epilepsy.

**Lack of prioritization.** In poor income countries, epilepsy is not recognized generally as a public health priority, as the low budget for health is directed to conditions like infections, which are perceived to be of a higher priority than epilepsy.<sup>124</sup> The recent data of ILAE/IBE/WHO global campaign against epilepsy survey reinforces the need for urgent substantial and systematic action to enhance resources for epilepsy care especially in low-income countries.<sup>125</sup> The campaign of ILAE/IBE/WHO launched in 1997 to take 'epilepsy out of shadow' through its different branches and organizations is the important leader in fighting

stigma. The collaborative research on epilepsy stigma (CREST) started in 2004 by a panel of experts from the UK, China, Vietnam, Amsterdam, US, GCAE, and WHO is launching research that aims at developing a culturally appropriate approach to reduce stigma and discrimination associated with epilepsy in developing world, which entails finding a cross-culturally relevant theoretical model of stigma.<sup>127</sup>

**Legal and regulatory action.** Laws should be made to protect the rights of PWE against any form of discrimination. This is of paramount importance in employment, as PWE still encounter difficulties in finding a job.<sup>33,92,97-99</sup> The history of epilepsy had witnessed many legal restrictions across the world, which has shown a significant improvement.<sup>60,128,129</sup> Despite this improvement, still restrictions are currently present such as employment in certain jobs such as teaching, police force, fire-brigade and prison services on the ground that PWE may be a risk to the health and safety of other persons, and these restrictions are not evidence based.<sup>27,88</sup> The same notion applies to a driving license, which is not uniformly and scientifically addressed.<sup>88,129</sup>

**Self-advocacy.** Physicians, health professionals, and epilepsy organizations should help PWE to be self-advocates to gain self-esteem. Health providers can be an important advocate for their patients. As the essence of discrimination is forming opinions of others based not on individual merits but on membership of a group with certain characteristics, a successful career patient with epilepsy can be an effective advocate to dispel this myth.<sup>59</sup> The formation of stigmalogy as a new science is needed as suggested in the conference held in Bethesda (USA).<sup>130</sup> The role of ILAE\IBE\WHO as forefront leaders to 'take epilepsy out of shadow' needs the support of governments to achieve this golden goal. The demonstration projects supported by these organizations in China, Argentina, Senegal, and Zimbabwe are an example of this useful and effective method, which will help in promoting positive attitudes towards PWE, which eventually will lead to minimize stigma. The fight against stigma should be a patient centered approach, which starts with intervention targeting the intrapersonal level, to empower affected persons to assist in the development and implementation of stigma reduction programs at other levels. Stigma reduction strategies should be at different levels like intrapersonal, interpersonal, organizational, institutional, community, and governmental levels. A combination of such levels may yield results in fighting and reducing the stigmatized concept of epilepsy.<sup>131</sup>

As stated by Trostle, "to have epilepsy is to open oneself to the full force of the past and the contemporary social prejudice and misunderstanding."<sup>59</sup>

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