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Epilepsy: Stigma and Management

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ABSTRACT

People With Epilepsy (PWE) and their families often face a very common aspect of this neurological disease epilepsy, known as Epilepsy Stigma (ES). ES is considered to be one of the most important factors that have a negative influence on PWE. It is a commonly encountered global issue among PWE in all cultures. ES may have deleterious effect on the patient's life more than the disease of epilepsy itself. It is the prime duty of all health professionals to try and manage ES in order to improve the quality of life of PWE not only by controlling the seizures, but also by fighting the myths and disbelief of stigma and managing the disease with a better approach. Stigma in PWE can be encountered and dealt with by diverse specialties in health profession including physicians, surgeons, social workers, psychologists, psychiatrists and nurses. Unfortunately this important issue of ES is addressed primarily in specialized journals like Epilepsy Research, Epilepsia, Epilepsy and Behavior, Seizure and Social Science Medicine which are read by professionals interested mainly in epileptiology or social sciences, whereas the actual problem of ES and its management remains neglected and does not reach the common readers and the non-scientific communities which form a major part of the society in any culture or country. Thus, there is an obvious need that this issue should be addressed in simple language in journals targeting readers of different specialties and interests through publishing articles on ES in popular magazines and dailies of the local areas globally.

Key words: Epilepsy, stigma, management

INTRODUCTION

Epilepsy is very often a disabling condition, rendered especially disturbing because of its unpredictability and its seriousness for being a common neurological disorder worldwide. It directly affects around 50 million people, the majority of whom (80-85%) live in resource-poor countries (Radhakrishnan, 2009). Although, in recent decades scientific advances in different fields of epileptiology have witnessed modern developments such as neuroradiology, recent antiepileptic drugs and genetics, not much has been achieved in dispelling the stigma of epilepsy (Bleassel, 2005). Furthermore, despite the advances made in research and epilepsy education campaign, there remains significant misinformation in ES (Lo *et al.*, 2010). The ES is a major burden of epilepsy and by spoiling the patient's identity with its psychosocial problems, may have burden on the patient's life which is more crippling than the seizures itself. Despite the changes in public attitude, epilepsy may evoke similar response to rejection like other chronic disorders, which are deeply stigmatizing such as AIDS (Jacoby *et al.*, 2005a). Epilepsy represents a source of grief and not just a clinical condition, but also a social and psychosocial outcome (Jacoby *et al.*, 2004; Lim *et al.*, 2009). Seizures are generally benign and can be controlled in PWE. The ES still affects

the lives of PWE even among those whose epilepsy is controlled (Tekle-Haimanot *et al.*, 1991; Dawkins *et al.*, 1993; Collings, 1994; Gambhir *et al.*, 1995; Kleinman *et al.*, 1995; Placencia *et al.*, 1995; Nyame and Biritwum, 1997; Bener *et al.*, 1998; Baker *et al.*, 2000, 2005; Al-Adawi *et al.*, 2001; Baker, 2002; Austin *et al.*, 2002; Reis and Meinardi, 2002; Morrell, 2002; Kamgno *et al.*, 2003; Dilorio *et al.*, 2003; Ndoye *et al.*, 2005; Baskind and Birbeck, 2005; Diamantopoulos *et al.*, 2006; Theodore *et al.*, 2006; Lim *et al.*, 2009; McCagh *et al.*, 2009; Rafael *et al.*, 2010). From the available literature it appears that there is a surmounting need to promote epilepsy awareness programs for increasing public knowledge about epilepsy with the aim of reducing negative attitude towards ES. Furthermore, it is important for all health professionals to know about the different issues of ES and help in its reduction. By reviewing stigma in epilepsy and its management, it is hoped that this article will help the health professionals to participate in designing comprehensive epilepsy care models for achieving reduction in heavy burden that ES casts on the lives of PWE.

Background of ES: The most pathetic aspect of epilepsy is that unlike many other diseases such as hypertension, diabetes or cardiac disorders, the symptoms and signs of epilepsy are curiously unhidden. Furthermore, epilepsy is unpredictable and not easy to understand by the terrified watchers, as to why and what seemed to be the reason for a normal person to behave in a very strange manner, which makes the seizures look like chaos against the cultural norms. The PWE are perceived as creating ambiguity in their social interactions and so threaten the social order, by being unpredictable and out of control. By losing control on themselves, PWE are seen as reverting to primitive acts and hence represent 'anomic' terror to those without epilepsy (Bagley, 1972) and they are seen as uniquely dangerous. It is a common phenomenon in many accident and emergency departments to see that a patient brought in for management of generalized tonic clonic seizures, seems to the general watchers including physicians and nurses like a crisis and peace is not restored until the seizures are suppressed, even though they might be a psychogenic non-epileptic seizures. Even now till to date, PWE are often perceived as violent (Kate Collins *et al.*, 2007).

The history of epilepsy goes back to more than three to four thousand years of ignorance, superstition and misconceptions even before Babylonian Era (Temkin, 1971). The word epilepsy comes from another Greek word epilambanein which means to seize, attack, possess or 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 (Obeid, 2008). For years many religions have regarded PWE as being possessed and epilepsy is considered as contagious even in the 18th century (Temkin, 1971). 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 neurologic condition; in spite of the fact that in his writing on falling sickness, Hippocrates (400B.C.) stated that epilepsy is not a sacred disease, but a disorder in the brain (Temkin, 1971).

Extensive studies worldwide showed that enough knowledge about epilepsy is lacking especially in poor income countries (Dawkins *et al.*, 1993; Collings, 1994; Kleinman *et al.*, 1995; Bener *et al.*, 1998; Baskind and Berbeck, 2005; Birbeck *et al.*, 2007). In many African countries, still epilepsy is considered as contagious and supernatural power is quoted as its cause (Tekle-Haimanot *et al.*, 1991; Rwiza *et al.*, 1993; Nyame and Biritwium, 1997; Reis and Meinardi, 2002; Kamgno *et al.*, 2003; Baskind and Birbeck, 2005). In some regions in India, epilepsy is confused with a mental

illness and the law equates epilepsy with temporary insanity till recently (Mani, 1997). It is surprising that misconceptions about epilepsy are still present in developed countries. In a recent study in USA, out of 19,441 high school adolescent, 22% of them were not sure whether epilepsy was contagious in nature (Austin *et al.*, 2002). Minorities in USA still believe in the supernatural etiology of epilepsy (Theodore *et al.*, 2006). Even in the 21st century in UK a substantial number of the public regards epilepsy as a mental rather than physical disease (Jacoby *et al.*, 2004). The lack of accurate knowledge about epilepsy is found not only in the public, patients and their families but at times even among health professionals (Al-Adawi *et al.*, 2001; Baskind and Birbeck, 2005; Chomba *et al.*, 2007; Obeid, 2008). Misconceptions about epilepsy have a major role in ES production whether perceived, enacted or courtesy ES. Though, the scientific explanation of epilepsy is gaining ground in developed countries, but still it is not the case in poor-income countries. There are differences in the level of knowledge about epilepsy among different countries, but this level varies within the same country depending on the culture, whether it is a rural or urban area and also on the socio-economic factors (Baker *et al.*, 2000, 2005; Doughty *et al.*, 2003; Jacoby *et al.*, 2005b; Theodore *et al.*, 2006; Wang *et al.*, 2008; Onwuekwe *et al.*, 2009; Rafael *et al.*, 2010).

The different media still give misinformation about epilepsy which influences the public perception (Krauss *et al.*, 2000; Baxendale, 2003; Kerson and Kerson, 2006; Caspermeyer *et al.*, 2006). Stigmatizing language is used in printed materials which is reflected in a recent study in which 30% of the stories about epilepsy embrace this language which contains either exaggeration or inaccuracies (Krauss *et al.*, 2000; Caspermeyer *et al.*, 2006). The movies also portray epilepsy in a way that highlights myth, misconception and misunderstanding (Baxendale, 2003; Kerson and Kerson, 2006). In the era of internet many sites are also spreading misconceptions and misunderstanding regarding etiology and treatment of epilepsy. Some Arabic language sites display misinformation incriminating supernatural power of Jinn as a cause for epilepsy and also advice to use funny treatment like garlic (Obeid, 2008). Also, the websites in western world are not providing the standard medical information about epilepsy (Burneo, 2006).

TYPES OF EPILEPSY STIGMA (ES)

Epilepsy associated stigma has long been recognized as a significant cause of psychosocial morbidity for PWE. The most amazing aspect of ES is its wide range of definitions (Doughty *et al.*, 2003). The origin of the word Stigma comes from Latin word Stigmat which means mark or brand and from a Greek word stizein, that means to tattoo (Morrell, 2002). The concept of stigma was introduced by Hoffmann in 1963 who 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. It includes disapproval and rejection from others and it is an attribute that is deeply discrediting and hence leads to spoiling of the individual's identity that ultimately disqualifies him/her from social acceptance. Another widely accepted definition defines Stigma as a social process or related personal experience characterized by exclusions, rejection, blame and devaluation (Weiss and Ramakrishna, 2006). Based on these definitions, ES has been divided into three kinds of ES.

Perceived ES: It refers to the feeling of shame of being epileptic with its associated oppressive fear of encountering enacted stigma (Morrell, 2002; Doughty *et al.*, 2003; Rafael *et al.*, 2010). It is commonly associated with illness and medical conditions that have visible signs or arouse feeling

of dread and fear (Goffman, 1963). The PWE assume that from their prevailing illness they will be devaluated and discriminated. Thus, such misleading notion compels them to adopt strategies like social withdrawal and secrecy that inflicts negative impact on their Quality of Life (QoL) and hence reinforces in them the feeling of perceived ES.

Enacted ES: Refers to actual episodes of discrimination against PWE only on the pretext that they suffer from epilepsy (Morrell, 2002; Doughty *et al.*, 2003). The legacy of the idea that epilepsy is a product of sin and evil possessions means that the cause of epilepsy is ambiguous and the seizures present far greater danger to those with epilepsy than the non-epileptics. People believe in the idea of epilepsy being a contagious and this idea is still prevailing in poor and developing countries (Rwiza *et al.*, 1993; Jacoby, 1994; Baskind and Birbeck, 2005a, b; Ndoye *et al.*, 2005; Nubukpo *et al.*, 2006).

Courtesy ES: It is a kind of stigma that affects the whole family members and even those who have an association with the patient (Kleinman *et al.*, 1995). West reported that parents with children with epilepsy often experienced a sense of shame and their child was seen as conferring shame on the whole family by virtue of being odd (West, 1979). Kleinman described that in the Chinese culture, the moral weight attached to epilepsy, threatened familial aspiration and life chances and because of family disgrace, PWE are kept at home and their diagnosis is kept secret (Kleinman *et al.*, 1995).

These three kinds of ES act dynamically and synergistically with each other and lay a major hurdle in the path of managing epilepsy treatment.

PREVALENCE OF ES

Developed and developing countries have geographic, economic and social differences and these variations incur a major influence upon the prevalence and incidence of ES worldwide. Measuring the prevalence of ES by direct questionnaires or with instruments is a difficult target to achieve. ES is a complex phenomenon which prevails worldwide, with regional, inter-and-intra-regional and cultural variations (Jacoby *et al.*, 2005a; Baskind and Birbeck, 2005; Ndoye *et al.*, 2005; Theodore *et al.*, 2006; Tran *et al.*, 2007; McLaughlin *et al.*, 2008; Onwuekwe *et al.*, 2009; Rafael *et al.*, 2010; Whatley *et al.*, 2010). Most researches were done in North America and Europe with few from low-income countries. The published works from Northern areas place greater emphasis on perceived ES, whereas studies in the Southern hemisphere e.g., Africa emphasize on enacted ES (Reis and Meinardi, 2002; Rafael *et al.*, 2010). To have accurate knowledge about the prevalence of stigma, a cross-cultural research may benefit from a multi-disciplinary team from various cultures, to develop a common frame and shared research tools, which may allow for contextual and cross-cultural adaptations (Reis and Meinardi, 2002). In USA and Europe, some studies found that about 18% of PWE felt severely stigmatized with some variations among countries studied (Baker *et al.*, 2000; Morrell, 2002; Doughty *et al.*, 2003; Theodore *et al.*, 2006; Varley *et al.*, 2010). In developing countries, ES is not yet fully explored, but from the published work, it seems that at least more than a 1/3 of PWE may face stigma, but it may also be as high as 60% (Kamgno *et al.*, 2003; Baker *et al.*, 2005; Birbeck *et al.*, 2007; Youssef *et al.*, 2009; Radhakrishnan, 2009).

A complex controversy exists in the published literature for the prevalence of ES in general. Most of the current work quote young age as the onset of epilepsy and furthermore, duration and

frequency of seizures, lower level of education, presence of seizure related injuries; encountering acts of discrimination and generalized tonic clonic seizures, are the main factors that play a significant role in the magnitude of ES (Chaplin *et al.*, 1992; Jacoby *et al.*, 1996; Moran *et al.*, 2004; Whatley *et al.*, 2010). A recent data revealed that experience of actual discrimination, introverted personality, problem solving capabilities, controllability and emotional state were independently correlated with feeling of ES beside psychologic dysfunction (Lee *et al.*, 2005). There is an association between ES and employment as unemployed people tend to report higher level of ES (Dilorio *et al.*, 2003; Parfene *et al.*, 2009). Injuries associated with epilepsy were significantly related to ES scale (Baker *et al.*, 2005). 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 (Baskind and Birbeck, 2005a, b). All these controversies play a significant obstructive role in compiling the real data of epilepsy and ES and need to be addressed in a more organized manner with a global consensus on the issue.

IMPACT OF ES ON PWE

Quality of Life (QoL): Although, QoL and psychosocial functions have been extensively investigated, there is a lack of standardized approach towards such investigations (McLaughlin *et al.*, 2008). Therefore, it makes it extremely difficult to summarize and indicate what measures should be used for improving QoL of PWE. Variations in the sociocultural attitudes in the country of residence of PWE and the patients themselves, make it difficult to determine the magnitude of the impact of psychosocial problems that the PWE encounter (Levin *et al.*, 1988; Jilek Aall *et al.*, 1997; Collings, 1994; Kleinman *et al.*, 1995; Nyame and Biritwum, 1997; Djibuti and Shakarishvili, 2003; Baker *et al.*, 2000, 2005; Jacoby *et al.*, 2005a; Tran *et al.*, 2007; Reisinger and Dilorio, 2009; Smith *et al.*, 2009; Rafael *et al.*, 2010). The psychosocial impact affect PWE in self-esteem, family dysfunction; social capital and impairment of QoL (Collings, 1990; Chaplin *et al.*, 1992; Wagner and Vickrey, 1995; Jacoby *et al.*, 1996; Baker *et al.*, 1997; Buck *et al.*, 1999; Suurmeijer *et al.*, 2001; Jacoby, 2002; Bishop and Allen, 2003; Moram *et al.*, 2004; Lee *et al.*, 2005; Tracy *et al.*, 2006; Sherman, 2009; Smith *et al.*, 2009; Rafael *et al.*, 2010). The ES in PWE expose them to health hazards and reduce their access to treatments (Buck *et al.*, 1997; Aylward, 2008; Varley *et al.*, 2010).

Marital status: The rate of marriage is comparatively lower in PWE than the general populations which has been demonstrated in many studies with highest rate being reported as 58.9% from Cameroon (Nyame and Biritwum, 1997; Shackleton *et al.*, 2003; Wada *et al.*, 2004; Baskind and Birbeck, 2005; Agarwal *et al.*, 2006; Santosh *et al.*, 2007). The lower marriage rate is related mainly to unemployment, but also the attitude of the public towards PWE plays a significant role also. The divorce rate is higher in PWE compared to control and the main cause is the fact that some couples do not disclose their disease to their future partners prior to marriage (Santosh *et al.*, 2007).

Employment status: The rate of employment is also very low among PWE and several factors have been implicated as the cause of high unemployment rate in PWE which includes patient personality, education, intelligence, age, psychosocial and neuropsychiatric functions (Smeets *et al.*, 2007). In spite of the availability of literature on this issue, it has not been fully investigated and the rate of unemployment ranges between 12-60% (Smeets *et al.*, 2007). However, many studies have confirmed that unemployment and underemployment rates are generally higher

in PWE than in the general population (Smeets *et al.*, 2007; Parfene *et al.*, 2009). In a recent study from the United States, it was found that a high self-perceived importance of work and decreased fear of workplace discrimination, are significantly associated with better employment rate in PWE (Bautista and Wludyka, 2007; Parfene *et al.*, 2009). To date many employers and even workmates are unhappy to work with PWE and hence a significant number of PWE conceal their disease (Harden *et al.*, 2004; Parfene *et al.*, 2009). Although, there is some improvement in employer's attitude in the West, a study in UK indicates that employers still have a high concern regarding occurrence of work-related accidents in employing PWE (Jacoby *et al.*, 2005b).

There is a need for specific rehabilitation programs to help PWE to find and maintain employment which should focus on increasing self-efficacy and coping skills of PWE (Smeets *et al.*, 2007). 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 (Smeets *et al.*, 2007).

Education level: The level of education in PWE is also generally low and this is true universally, but it may show variations between countries and also among communities. Even in Europe and America, the academic achievement of PWE is at a lower level (Fisher, 2000; Birbeck and Kalichi, 2003; Morrell, 2002; Baskind and Birbeck, 2005). The situation is alarmingly 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 home (Morrell, 2002; Wagner *et al.*, 2009). The school drop out rates of children with epilepsy is higher in low income countries (Gamage, 2005). A seizure occurring at school results in poor self perception and reduced social interaction beside its fueling ES courtesy in the family. Teachers and parents may also have dismal opinions about capabilities and behavior in children with epilepsy (Pala and Vankar, 1997; Sanya *et al.*, 2005; Fernandes *et al.*, 2007). Learning disabilities occur in a significant portion of children with epilepsy and the cognitive impairment related to antiepileptic drugs may adversely affect the academic achievement in PWE (Besag, 2006). Experimentally induced epilepsy in laboratory models have also established the fact that epilepsy causes learning disabilities and cognitive impairment due to neurodegenerative changes in the hippocampus areas of the brain (Tariq *et al.*, 2008).

Depression level: Depression is the major psychiatric problem in PWE. It is a mood disorder characterized by loss of energy, interest, feeling of guilt, difficulty in concentration and thoughts of death, hopelessness or even suicide (Jackson and Turkington, 2005; Reisinger and Dilorio, 2009). The prevalence of depression is variable with figure quoted between 20-55% which is higher in hospital based studies than the community studies (Jackson and Turkington, 2005; Baker, 2006). Depression can be of reactive nature due to the many social ills of epilepsy particularly social ES, underemployment and education problems in PWE. Many studies have indicated that death by suicide is higher in PWE than in general population with variable incidence in different countries and the higher being reported from Denmark as compared to UK (Baker, 2006; Bell and Sander, 2007). Depression has a significant impact on QoL in PWE, more than the burden of seizures itself (Bishop and Allen, 2003; Sherman, 2009; Whatley *et al.*, 2010).

Psychiatric level: The increased incidence of neuropsychiatric features of epilepsy can be due to seizures, their underlying etiology and the associated psychosocial effects, which may lead to

functional limitations (Smith *et al.*, 2009; Whatley *et al.*, 2010). The effects of ES in addition to the adverse effects of antiepileptic drugs also contribute to the psychiatric disorders in PWE (Besag, 2006; Varley *et al.*, 2010).

Anxiety level: 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 perceived ES (Jackson and Turkington, 2005). Physicians treating PWE should not only focus on seizure control, but it is of vital importance for them to recognize and look for any symptoms of anxiety or depression as well and treat them (Reisinger and Dilorio, 2009).

MANAGEMENT OF ES

The two major aspects of managing and fighting ES are:

- Firstly, prevention of epilepsy should be the prime aim and its reduction also if it already exists
- Secondly, dissemination of accurate knowledge about epilepsy is the most important way to fight ES. This should be addressed to all individuals including the patients, health caretakers, families and friends of PWE, educators, the public at large, potential employers, health insurance, the policymakers and the media of all kinds. The factors that can markedly reduce the burden of ES and the disease itself should be given priority in the following preferential order for its management:

The early control of epilepsy: Majority of PWE (70-80%) can live a normal life since an effective control of seizures leads to reduction of ES especially the perceived ES which is significantly related to the seizure frequency (Jacoby, 1992; Baker *et al.*, 1997; Moran *et al.*, 2004; Sherman, 2009; Whatley *et al.*, 2010). Control of epilepsy is still a real problem in poor-income countries as around 90% are not receiving treatment (Scott *et al.*, 2001; Radhakrishnan, 2009). The treatment gap as defined by a workshop of ILAE 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 of time, expressed as a percentage (Meinardi *et al.*, 2001; Theodore *et al.*, 2006). 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, since some communities do not realize the existence of medical treatment for epilepsy disorder (Radhakrishnan, 2009). The evidence shows that treatment and good control over seizures can allow the epilepsy patients to participate in both contact and non-contact sports without harmfully affecting seizure frequency (Arida *et al.*, 2008). Furthermore, experimental research in animal models should be encouraged by all government agencies for developing new drugs for epilepsy in addition to the available drugs. Recently, pentoxifylline has been reported to have neuroprotective effect in ameliorating status epilepticus (Tariq *et al.*, 2008). Such studies will be of immense value in managing epilepsy.

Education: Education is the most important tool to fight ES. For stigmatization to be consistently effective, the stigmatized person must hold the same beliefs as the society that devaluates him. It is known that most adults with epilepsy often have insufficient knowledge about their disease and its treatment, despite large amount of available knowledge (Dawkins *et al.*, 1993; May and Pfafflin, 2002; Smith *et al.*, 2009). Physicians usually do not have the time in the clinic to discuss all aspects of epilepsy with their patients, a large section of who are unsatisfied with such attitude

(Prinjha *et al.*, 2005; Sherman, 2009). Improving the knowledge about epilepsy has resulted in improvement of attitude towards PWE (Gutteling *et al.*, 1986; Mirnics *et al.*, 2001; Kim *et al.*, 2003; Aylward, 2008; Wang *et al.*, 2008; Youssef *et al.*, 2009). The public education can be delivered through all media venues, by lectures in schools, churches, mosques and social gatherings. This can be done by health professional organizations or any health professional with adequate knowledge about epilepsy. Mothers with offspring with epilepsy should be given the necessary knowledge about different aspects of epilepsy and should be encouraged to help their children to have a normal life as the child self-esteem and confidence are affected by felt ES which is linked to mother's attitude that 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 with eyes of their parents. Parents can be ES coaches by fostering ES 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 (May and Pfafflin, 2002; Wang *et al.*, 2008). By aggressively educating the youth, there is a hope to change the society's perception of epilepsy within the next generation (Coelho, 2006; Youssef *et al.*, 2009).

Self advocacy: Physicians, health professionals and epilepsy organizations should help PWE to be self-advocate so as to gain self-esteem (Aylward, 2008). Health providers can be an important advocate for their patients. As the essence of discrimination is forming opinions about others based not on individual merits but on membership of a group with certain characteristic, a successful career patient with epilepsy can be an effective advocate to dispel this myth (Rafael *et al.*, 2010). The formation of stigmalogy as a new science is needed as suggested in the conference held in USA (Keusch *et al.*, 2006). 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 North America, China, Argentina, Senegal and Zimbabwe are an example of this useful and effective method which will help in promoting positive attitude towards PWE which eventually will lead to minimize ES (Theodore *et al.*, 2006; Aylward, 2008; Wang *et al.*, 2008).

Prioritization of epilepsy campaign: 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 (Scott *et al.*, 2001; Radhakrishnan, 2009). 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 (Meinardi *et al.*, 2001; Theodore *et al.*, 2006; Radhakrishnan, 2009). 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 ES (Dua *et al.*, 2006). The collaborative research on ES started by a panel of experts from UK, China, Vietnam, Amsterdam, US, GCAE, WHO is launching a research which aims at developing a culturally appropriate approaches to reduce ES and discrimination associated with epilepsy in developing world which entails finding a cross-culturally relevant theoretical model of ES (Caprio and Hauser, 2009).

Legalizing the rights of PWE: 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 (Kobau and Price, 2003; Harden *et al.*, 2004; Smeets *et al.*, 2007; Bautista and Wludyka, 2007; Parfene *et al.*, 2009). The past history of epilepsy had witnessed many legal restrictions across the world which has shown a significant improvement (Mani, 1997; Jacoby, 2002). In spite of this improvement, still restrictions are currently present like 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 (Jacoby, 2002, 2008). The same notion applies to driving license which is not uniformly and scientifically addressed (Jacoby, 2002, 2008).

In conclusion, it can be summarized that myths, misconceptions and misunderstandings about epilepsy continue even to date. Programs aimed at increasing knowledge and reducing negative public attitudes should be enhanced. This aspect of fighting and managing ES is important to promote better de-stigmatization campaigns. Various media campaigns, especially video-sharing websites like You Tube, have the potential to remediate the significant misinformation and persistent ES surrounding epilepsy (Lo *et al.*, 2010). Developing a comprehensive epilepsy care model with combined efforts and consensus of all global agencies along with vigorous campaigning and advertisements, could play a very vital and significant beneficial role in educating the common public about positive features of life with epilepsy. Furthermore, this will help in informing primary and secondary physicians also, about the current trends in the management of epilepsies and scaling up routine availability of low-cost antiepileptic drugs globally.

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