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Review

Epilepsy stigma: Moving from a global problem to global solutions

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ABSTRACT

Stigma and exclusion are common features of epilepsy in both the developed and developing countries and a major contributor to the burden associated with the condition. Reducing the stigma of epilepsy is key to reducing its impact and so improving quality of life. The social consequences of having epilepsy can be enormous, be it that they vary from country to country, based on cultural differences and economic circumstances. The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from concepts of epilepsy held by the general public.

In this paper, I review the history of epilepsy and consider how different historical and cultural understandings of epilepsy have determined the experience of stigma for those affected by it. I consider how this history of stigma impacts on the position of people with epilepsy today, many of whom may still experience serious limitations to their enjoyment of economic, social and cultural rights and have many unmet needs in the areas of civil rights, education, employment, residential and community services, and access to appropriate health care. Finally, I will discuss some current initiatives aimed at addressing the issue of epilepsy stigma worldwide, which offer hope of an end to the social exclusion and prejudice which people with epilepsy have endured for so long.

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1. Introduction

“Around fifty million people suffer from epilepsy. Many of them suffer silently. Many of them suffer alone. Beyond the suffering and beyond the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death”.
Dr. Gro Harlem Brundtland, Director General WHO, 1998–2003, on the occasion of the 2nd launch of the ILAE/IBE/WHO Global Campaign Against Epilepsy in 2001

There is general agreement that stigma and exclusion are common features of epilepsy in both the developed and developing countries and a major contributor to the burden associated with the condition. Reducing the stigma of epilepsy is therefore key to reducing its impact and so improving quality of life. Epilepsy is a universal condition and knows no racial, national or geographical boundaries. Epilepsy often has profound physical, psychological and social consequences; seizures can cause misunderstanding, fear, secrecy, stigmatisation and social isolation. The social consequences of having epilepsy can be enormous, be it that they

vary from country to country, based on cultural differences and economic circumstances. The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from concepts of epilepsy as held by the general public.

“Unfortunately, pre-occupation with the control of seizures, both on the part of the physician and the patient, often seems to overshadow an adequate concern for the other factors. Yet in term of disability, for many patients it is these other factors, which determine whether they will or will not make a satisfactory life adjustment”
Richard Masland, former Secretary General, International Bureau for Epilepsy.

People have been writing and speaking about epilepsy for some 4000 years. Through the centuries, many misconceptions about the condition were conveyed, based on the culture of a particular era or in a particular part of the world. These concepts and prevailing prejudice may lead to rejection, denial of education and isolation – especially but not solely – in the developing world. Attitudes towards people with epilepsy are influenced, in part, by the extent of knowledge about the condition.

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“The history of epilepsy can be summarised as 4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma”.

Rajendra Kale, India (Bringing Epilepsy Out of the Shadows – BMJ 1997;315:2–3)

However, times are changing in the area of epilepsy and stigma. We can see light at the end of the tunnel, hope is glimmering from a distance. When checking the internet on initiatives and information on improving understanding epilepsy, Google showed 4,840,000 results for understanding epilepsy and 72,900 for combating stigma in epilepsy, demonstrating that there is rapidly increasing interest in this issue and many initiatives are under way to decrease the stigma and discrimination of people with epilepsy. On a global level, the number of epilepsy associations such as Epilepsy Action is growing steadily, sharing similar aims and objectives. Research shows that all these efforts made are beginning to make a difference, but also that much more needs to be done. Epilepsy Action and its fellow organisations are much needed to “bring epilepsy out of the shadows” and allow people with epilepsy to live ‘in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction’ (www.epilepsy.org.uk/about/objectives).

2. The concept of epilepsy

The concept of epilepsy has varied profoundly during the past 2–3000 years. Epilepsy has been considered sacred as well as diabolical. People with epilepsy have been looked upon as “being chosen” or as “being possessed” depending on the popular belief of that moment or place, and with clear consequences for the treatment of and attitudes towards people with epilepsy. It is not difficult to understand why people were mystified by epilepsy, given that its symptoms are sudden and often dramatic.

“Epilepsy has been given many names, such as burning disease, drowning disease, shameful disease, or simply “it”. But everywhere in the world it is a hidden disease”.

Hanneke M. de Boer (Netherlands)

In his book “The Falling Sickness”,¹ Temkin reported that as early as in Mesopotamian civilisation seizures were described and related to “the hand of sin”, the god of the moon. In Greek and Latin astrology it was considered that under certain conditions and when the moon was in an evil position, it caused people to convulse or become ‘lunatic’ or liable to falling fits. Epilepsy and the moon were linked for many reasons, among them the pagan belief that epilepsy was the vengeance of the goddess of the moon. Further, physicians believed that the waxing moon heated the atmosphere surrounding the earth, consequently melting the brain and so provoking a seizure. These two views were linked by a third philosophical theory based on the sympathetic relation between macrocosm and microcosm – the moon had supposedly the same cold temperament as the brain and was therefore able to inflict headache and epilepsy.²

In the Christian world, the biblical story of Jesus healing a boy showing symptoms of an epileptic seizure had important consequences and led to the opinion, shared by many Greek and Latin priests, that, “epileptics were demoniacs” and that epilepsy was brought about by an unclean dumb and deaf spirit”. In marked contrast, in the book “On the Sacred Disease” written by a physician follower of Hippocrates (400 BC), it was noted that the alleged divine

character of epilepsy was only ‘a shelter for ignorance and fraudulent practices ...for the gods do not make men’s bodies unclean as the magicians would have them believe.’ This writer concluded that epilepsy, ‘is no more divine than other diseases, it is hereditary, its cause lies in the brain, the releasing factors of the seizures are cold, sun and winds which change the consistency of the brain. Therefore epilepsy can and must be treated not by magic but by diet and drugs”.

“Teacher, I brought you my son, who is possessed by a spirit that has robbed him of speech. Whenever it seizes him, it throws him to the ground. He foams at the mouth, gnashes his teeth, and becomes rigid. I asked your disciples to drive the spirit out, but they could not.”

Gospel According to Mark (9:14-29), 70 A.D.

In Arab-Persian manuscripts direct reference to epilepsy is rather scarce. One of the first references probably dates from the 6th century A.C., according to which “a god tells Zoroaster that epileptic persons are prohibited from offering sacrifices in his honour”. During the post Mohammed period there is, however, no mention at all in any of the scientific texts of epilepsy as a sickness caused by demons. The writings of two major medieval Islamic practitioners who dealt with epilepsy (Avicenna and Mohammed ibn Zakariya al-Razi) had profound influences on the Western world and as late as 1700 this material was still fundamental for students in Eastern and Western universities.³

The handbook on witch-hunting, *Malleus Maleficarum* (The Hammer of Witches), written by two Dominican friars, Heinrich Kramer and Jacob Sprenger, under papal authority and first published in 1487, brought a wave of persecution and torture, leading to the deaths of more than 20,000 women. The book’s main purpose was to challenge all arguments against the existence of witchcraft and to instruct magistrates on how to identify, interrogate and convict witches. The presence of seizures was identified as a characteristic of witches (Epilepsy.com. Information, Community, Empowerment. Topic Editor: Steven C. Schachter, M.D. Last Reviewed: 11/30/04. Last Update 21-10-2007).

In the Western world the fight against the supernatural and occult really only started at the time of the Enlightenment, in the late 17th and 18th century, with the final step in the progress of enlightened medicine being the denial of demoniac influence. Only then did the Hippocratic concept of epilepsy as a brain disorder begin to take root in Europe. Under the leadership of three English neurologists, John Hughlings Jackson, Russell Reynolds and Sir William Richard Gowers, the modern medical era of epilepsy began. Jackson defined a seizure as “an occasional, an excessive and a disorderly discharge of nerve tissue on muscles” and recognized that seizures can alter consciousness, sensation and behaviour.⁴

“A seizure is “an occasional, an excessive, and a disorderly discharge of nerve tissue on muscles. Seizures can alter consciousness, sensation, and behaviour”.



John Hughlings Jackson, 1835–1911

By the beginning of the 20th century, epilepsy was associated with a variety of psychological disorders and a high rate of inheritability; and many theories as to its causes had been advanced. During the last century the development of new diagnostic techniques has led to rapid changes in reasoning⁵ – but societal concepts of epilepsy have lagged behind medical concepts, leading to the often unnecessary detainment of people with epilepsy for extended periods of time. It was the common belief that witnessing even one seizure might make a physically healthy person epileptic⁶; and separating people with epilepsy from the other inmates in asylums was done not because people were concerned about the influence of the insane on the people with epilepsy, but quite the reverse.

“Epilepsy is an ancient disease that has been “explained” for as long as it has been perceived. Its manifestations invite arcane theories of its causes and its meanings. Seizures are dramatic, public and frightening. They occur with unpredictable frequency in unexpected places. The forced cry, the loss of consciousness, the fall, the twitching and the foaming at the mouth, they all suggest possession by the spirit”.

Leon Eisenberg (1922–2009), from Eisenberg L. (1998), *Epilepsy*, a comprehensive textbook, eds. Engel J, Pedly TA, p. 2205.

Even in the twenty-first century, in African Cameroon,⁷ people still believe that people with epilepsy are inhabited by the devil; in Liberia⁸ the cause of epilepsy is related to witchcraft or evil spirits; and most traditional healers in Swaziland⁹ mention sorcery as the cause of epilepsy. The fact that in Senegal those who suffer from epilepsy are held in high esteem stands in stark contrast to the situation in its surrounding countries. In Asia, the situation is not so different. In Indonesia for instance, epilepsy is either considered as ‘karma’ or as a punishment from unknown dark forces. In India, especially in the rural areas, epilepsy is often considered to be due to an evil spirit, which needs to be exorcised – by tying the person to a tree, beating him, cutting a portion from his hair from the scalp, squeezing lemon and other juices on his head or starving him, to mention just a few methods. In Nepal, epilepsy is associated with weakness, possession by an evil spirit or a reflex reaction to the colour red.¹⁰

“Having petit mal epilepsy from age 11, with occasional grand mal seizures, it was instilled in me that nobody should know of this illness of mine. As a result, I thought I had a dreadful illness. One that I could not share, even with my closest friends”.

Carol d’Souza – from *Conquering Epilepsy: Personal stories of people living with epilepsy: finding the rainbow after the storm*. Indian Epilepsy Association, Bombay chapter.

In the so-called developed world, misconceptions may be different, but there too they can lead to problems for people with epilepsy. In Kentucky, USA,¹¹ a survey of public awareness and understanding of and attitudes towards epilepsy revealed that 54% of parents could not list a cause for epilepsy. A similar survey carried out in Germany in 1996 showed that 20% of the respondents believed epilepsy to be a form of mental disease. And attitudes toward people with epilepsy are, at least in part,

influenced by the degree of knowledge of the condition. For example, a trans-national survey conducted in the Netherlands, the United Kingdom and Ireland among a group of professionals including psychologists, occupational physicians, vocational therapists and social workers, revealed that 15% of respondents believed in the existence of an epileptic personality and 32% believed that epilepsy affected intellectual performance. After these people had been educated about epilepsy, these figures changed for the better.¹²

3. The concept of stigma

As a feature of many chronic health problems, stigma contributes to the hidden burden of illness. Health-related stigma is typically characterized by social disqualification of individuals and populations who are identified with particular health problems.¹³

Since the 1960s, the concept of stigma has been well described by Goffman, Jones, Scambler, Stangor and Crandall, and many others. Goffman, for example, defined stigma as “the situation of the individual who is disqualified from full social acceptance”.¹⁴ The following definitions of stigma were accessed from an Internet search:

Free-on line dictionary Encarta	A symbol of disgrace or infamy Sign of social unacceptability: the shame or disgrace attached to something regarded as socially unacceptable
Dictionary.com	A mark of disgrace or infamy; a stain or reproach, as on one’s reputation

Stigma can be seen as an attitude, located at the individual level, based on ignorance, prejudice and fear of a particular group. The UK Institute of Psychiatry initiative, Mental Health Care, states that stigma is best defined in three words:

- * Ignorance
- * Prejudice
- * Discrimination

The link between these three nouns is obvious: ignorance has been defined as lack of knowledge, information, or education; prejudice as a baseless and usually negative attitude toward members of a group, common features of which include negative feelings, stereotyped beliefs, and a tendency to discriminate; and discrimination has been defined by the United Nations as “less favourable treatment of persons”, and in the English Oxford Dictionary as “the making of a distinction, to give unfair treatment, especially because of prejudice”. Discrimination against individuals and groups thrives when left unchecked and unchallenged. It is a societal issue and resolution lies with the population at large, rather than those individuals experiencing symptoms of distress.

Dell et al.¹⁵ defined stigma as the relation “between the differentness of an individual and the devaluation society places on that particular differentness”. However for stigmatisation to be consistently effective, the stigmatised person must acquiesce in society’s devaluation.

Common to theories of stigma is the emphasis on a social group process. Furthermore, stigma theorists have highlighted the previously neglected role of power relations in the social construction of stigma.¹⁶ The labelling, stereotyping, separation from others and consequent status loss that are key elements of stigma are relevant only “in a power situation that allows them to unfold”.¹⁷

Components of stigma

- Distinguishing and labelling differences
- Linking human differences with negative attributes
- Separating “Us” from “Them”
- Status loss and discrimination
- Dependence of stigma on power

B.G. Link, J.C. Phelan¹⁷

It has been shown that people with epilepsy themselves often internalise societal devaluations of them and as a consequence they do not feel empowered to change the situation (see box below). Indeed, negative stereotypes of persons with epilepsy are so ingrained in the collective belief that they have become an accepted part of many people’s concept of the disorder.¹⁸ In 1987, the United States Supreme Court wrote that “a review of the history of epilepsy provides a salient example that fear, rather than the handicap itself, is the major impetus for discrimination against people with handicaps”. The Court’s ruling was an important affirmation of federal law that prohibited discrimination on the basis of a perception of a handicapping condition rather than the actual condition itself.¹⁹

Question: “Why don’t you have a job?”

Answer: “When you have epilepsy, nobody wants to know you”!
Introduction at job interview: “I am William, and oh, before I forget to tell you, I have epilepsy, but that is not dangerous. And what you read in the paper about people with epilepsy being aggressive is not true. Of course in a minor seizure I may accidentally hit someone, but I would never do so on purpose.”

(Both are real life examples.)

4. Epilepsy and stigma in the 19th and 20th century

Until the second half of the 19th century there were no special institutions for people with epilepsy in Europe. If it was not possible for people with epilepsy to be cared for in their families, either because their seizures were too serious or too frequent or because they had some additional mental or physical handicap, they were put in prisons, ‘lunatic asylums’ or the former leprosy ‘colonies’. From the 1860s onwards, special epilepsy institutions were established, for instance in Germany, the Netherlands, the UK and France, where people with epilepsy could be cared for. Such institutions were usually geographically isolated, in order not to confront “society” with their inhabitants – a fate not even members of royalty could escape, as illustrated by the story of Prince John, the youngest child of George V and Queen Mary of England. In the annals of 20th century royal history, Prince John has always been a shadowy figure, hardly rating more than a passing mention. The logical, if brutal, reason for this was that John was the unfortunate royal child who was not ‘quite right’ and so had to be hidden from public view. There was nothing unusual about John’s isolated life – in the early part of the 20th century, an abnormal child did not elicit sympathy. An ‘epileptic’ like John was regarded as mentally unbalanced and a shame on his family – all

the more so because his was the Royal Family. At that time, epilepsy was seen as untreatable, there were certainly no drugs to control it. John’s parents therefore faced the danger that their youngest son might have an epileptic fit in public where dozens, maybe scores, of people could see his plight – and theirs – and the newspapers, however reverentially, might report it. To the world of today, shutting John away appears cruel and unfeeling, but was, in fact, the only recourse open to his parents, given the social mores of the time²⁰.

The Lost Prince – Prince John 1905–1919, a BBC television series, brought Prince John’s shamefully sad story into the light



Picture reproduced by kind permission of the BBC

Mounting psychiatric interest in epilepsy in the late 19th and early 20th centuries meant the behaviour of people with epilepsy in between their seizures was increasingly studied and the development of the concept of the ‘epileptic character’ entered the literature. In this literature, there was no consensus as to what actually constituted the epileptic character. Nonetheless, the idea evolved and in the 21st century, The Dictionary of Psychology²¹ defines it thus: ‘a personality pattern observed in a minority of individuals with epilepsy, possibly due to a reaction to the frustrations and anxieties this disease engenders, rather than to constitutional tendencies. These individuals are described as irritable, stubborn, egocentric, uncooperative and aggressive.’

“Sensitiveness and egocentricity are usually described as the salient features of the epileptic character and certainly in many cases these character traits are well marked. The person with epilepsy has an acute awareness of the shortcomings of others, but is blind to the faults in his own character.”

Macniven: Psychosis and criminal responsibility. In Freedom and Responsibility: readings in philosophy and law. Ed. H. Morris. Stanford University Press. Stanford, California, 1961

5. Epilepsy and stigma: the challenges and possible solutions

The past century has seen spectacular changes in the way we live and think. Human brilliance and technology have come together to propose solutions we dared not imagine sixty years ago, when Epilepsy Action was founded. We have conquered diseases that once seemed insurmountable. We have saved millions of people from premature death and disability. And our search for better solutions to the problems of ill-health is, as it should be, ceaseless. So, where has that brought us, what is the

situation concerning epilepsy-related stigma now? The following eye-witness account makes it clear that even though the situation for people with epilepsy is nowhere near as grim as in the past, misunderstandings and prejudice persist.

“It’s surprising in 21st century Britain to come across a disease which, for many people, is still associated with fear and stigma. Not long ago, I was driving home from my regular outpatient clinic in a residential centre for people with severe epilepsy. As I turned a corner I saw a man lying in the road, and a group of people huddled on the pavement some distance away. I stopped to administer first aid, asking the onlookers to tell me what had happened. “He’s an epileptic from the colony up the road,” said one. “He fell down and had a fit. “We thought we shouldn’t touch him”.

So they left him unconscious in the middle of a busy road, in the rain. I can only imagine that fear and ignorance prevented them from helping”.

VIEWPOINT

By Mark Richardson

Professor of Epilepsy, Institute of Psychiatry

From: ‘Time to face up to feared disease’

BBC News: Wednesday, 10 June 2009

People with epilepsy may still experience serious limitations to their enjoyment of economic, social and cultural rights. They have many unmet needs in the areas of civil rights, education, employment, residential and community services, and access to appropriate health care. Discrimination in access to education is not unusual for people affected by the condition.

Research into the vocational interests of people with epilepsy shows that people with epilepsy are often advised not to undertake their training of choice, because of the suspected consequences of having epilepsy. In many parts of the world people with epilepsy still do not have good prospects of holding a job and building a future for themselves. Several studies in European countries, for instance in Germany and Italy, indicate that of the persons of working age, only 40–60% are employed, 15–20% are unemployed and 20% retire early from employment. The restrictions on full participation in community life can marginalize people with epilepsy from society.

So how can we best address these problems and challenges? Well-crafted legislation based on internationally accepted human rights standards is undoubtedly an important means of preventing violations and discrimination, promoting and protecting human rights, enhancing the autonomy and liberty of people with epilepsy and improving equity in access to health care services and community integration. Legislation can serve to legally enforce the goals and objectives of policies and programmes related to epilepsy²². The good news is that though legislation based on centuries of stigmatisation existed until recently or still does in many countries (for instance, a law prohibiting people with epilepsy to marry in the UK was repealed in 1970⁴!), ancient laws are being replaced by modern ones, such as the recent marriage legislation and driving legislation in India and the anti-discrimination legislation in Colombia. This has undoubtedly happened because of the tireless efforts of people with epilepsy themselves and their national IBE and ILAE members/chapters!

The International League Against Epilepsy (ILAE) was founded 100 years ago, Epilepsy Action 60 years ago and the International Bureau for Epilepsy (IBE) 50 years ago; and all three organisations have grown enormously, especially during recent decades. Their stated goals/visions are reproduced below.

The goal of the International Bureau for Epilepsy:

To improve the quality of life of all persons with epilepsy and those who care for them.

The vision of ILAE:

A world in which no person’s life is limited by epilepsy.

The vision of Epilepsy Action:

To live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction

The objective of the World Health Organization:

The attainment by all people of the highest possible level of health

Despite their best efforts to date, we are still faced, according to the European Declaration on Epilepsy²², with the following challenges to reach to above goals and objectives and make the visions come true:

- Improving public understanding of epilepsy and thereby reducing its stigma
- Removing discrimination against people with epilepsy in the workplace
- Helping people with epilepsy to understand their condition and empowering them to seek appropriate treatment and lead fulfilled lives
- Improving the knowledge of health care professionals and other professionals about epilepsy
- Ensuring the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment
- Stimulating research on epilepsy and its management
- Encouraging close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE
- Providing practical assistance for countries with underdeveloped epilepsy services.

“So we are facing the two challenges of reducing stigma and of building up capacity to correctly diagnose and treat epilepsy patients world-wide. It can be done.”

Dr. G. Harlem Brundtland

Current evidence suggests that if all parties and individuals working in the field of epilepsy worldwide, or having a personal interest in the disease, or having epilepsy, join forces to deal with the challenges, turning them into actions, we should then be able to bring about global solutions.

In 1997, the three leading organisations in area of epilepsy and general health, ILAE, IBE and WHO, decided to join forces in an attempt to, in partnership, raise epilepsy to a level of awareness that had not been achieved ever before, despite all efforts by each of the separate organisations and their affiliates. This

partnership is the ILAE/IBE/WHO Global Campaign Against Epilepsy, which has as its mission statement: *To improve the acceptability, treatment, services and prevention of epilepsy worldwide*. To date over 90 countries have developed activities under the Campaign and collaboration between IBE, ILAE and WHO has given the Campaign the opportunity to build a framework for concerted action on a global, regional and national level to raise awareness and diminish the treatment gap. Activities under the Campaign, organised by the local members and chapters of IBE/ILAE, have been developed in over 100 countries. To date, these activities encompass:

- The organisation of Regional Conferences with the aim to raise awareness for epilepsy and develop and adopt Regional Declarations on Epilepsy which can serve as an instrument for dialogue with governments, healthcare providers, and other key stakeholders.
- Conferences have taken place in all six WHO Regions, resulting in Regional Declarations for all.
- The development of Regional Reports on Epilepsy, describing the present situation in each Region, outlining initiatives taken under the auspices of the Campaign to address the problems, defining current challenges and offering appropriate recommendations. With the recent publication of the Eastern Mediterranean and the European Reports, all WHO Regions now have their own.
- The implementation of ‘Demonstration’ projects with the objectives to:
 - reduce the treatment gap and social and physical burden
 - educate health personnel
 - dispel stigma
 - prevent discrimination

Projects have now been completed in Brazil, China, Senegal and Zimbabwe, are ongoing in Georgia, and are currently proposed for Cameroon, Ghana, Honduras and India.

- A project on legislation, aimed at collecting information on existing legislation and regulations related to epilepsy in the areas of civil rights, education, employment, residential and community services, and provision of appropriate health care, from countries all over the world, in order to review the comprehensiveness and adequacy of these legal measures in promoting and protecting the civil and human rights of people with epilepsy. A publication including basic principles for epilepsy legislation and guidance for developing, adopting and implementing legislation has been developed and will be available shortly.

Concurrently, WHO has developed its mental health Gap Action Programme (mhGAP), aimed at scaling up services for those with mental health problems especially in low- and middle-income countries. Working together with its partners amongst whom are ILAE and IBE, this includes a focus on epilepsy. The programme asserts that with proper care, psychosocial assistance and medication, many people could be treated for epilepsy, and begin to lead normal lives – even where resources are scarce.

One person’s story can help to clarify how steps such as these can provide solutions to the problems routinely faced by people with epilepsy worldwide: Zhaoming lives in a rapidly expanding township on the outskirts of Yinchuan, in north central China. Life, however, was not always so perfect for him. Like millions living with epilepsy, Zhaoming spent almost 30 years living ‘in the shadows’; suffering from low self-esteem, and stigma from his fellow villagers – none of whom were prepared to give him a job. “No one really

understood what was wrong with me,” Zhaoming explains, “people thought I was mad or possessed by the devil.” “Finally one doctor diagnosed it as epilepsy and told me to get some medicine. But as I had no income I couldn’t afford to buy it. I used to have almost two seizures a week in those days. . . it was a terrible time.” Zhaoming began taking phenobarbital in 2001, which he was given free as part of a Global Campaign Demonstration Project. Since then he has been ‘seizure free’ (WHO 2010).

‘I am a very lucky man’ Zhaoming says, ‘I have a good business, a nice home and I have three beautiful grand-daughters. . .very lucky!’



WHO 2010

Zhaoming’s story shows what can be done if we all join forces to improve the quality of life of all persons with epilepsy and to meet the challenge of creating a world in which no person’s life is limited by epilepsy, where everyone understands the disorder, where attitudes towards the condition are based on fact not fiction, and all will attain the highest possible level of health!

“The collaboration between the International Bureau for Epilepsy, the International League Against Epilepsy and WHO has shown that when people with different backgrounds and roles come together with a shared purpose, creativity is released and expertise is used in innovative and constructive ways”.

Dr. G. Harlem Brundtland

6. Conclusion

Through this historical account, I have tried to offer the thoughts of professionals and lay people concerning the falling sickness in ancient and modern times in developed and less developed countries. Early studies indicated that the situation for people with epilepsy was rather grim. In order to remove the stigma and thus improve the quality of life of people with epilepsy all over the world, knowledge concerning the condition as well as the understanding of the various cultural concepts held both by wider society and by people with epilepsy themselves, must be addressed. I am convinced that through continuing to take action over the next 60 years, the situation with regard to epilepsy stigma will look very different by 2070.

Conflict of interest statement

None declared.

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