

Epilepsy: Stigma and Impact on Quality of Life

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Abstract

Stigma is the biggest problem for people who develop epilepsy, it is argued that for many people with epilepsy, the stigma itself is more disturbing than managing the clinical effects of the disease.

The more evident the stigma, the more discriminatory, concrete and tangible it is and frequently pushes the people who are recipients of it and their families to live the disease with discomfort, shame and often isolating themselves.

This review aims to deepen knowledge about the disease deepen knowledge about the stigma present toward patients with epilepsy, in family and social settings, by proposing interventions approved by the scientific literature, aimed at preventing and/or reducing stigma and consequently helping to improve quality of life.

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Introduction

Epilepsy, a neurological disorder is characterized by seizures resulting from abnormal electrical discharges in the brain. According to WHO around 50 million people worldwide suffering from epilepsy, in developing countries, almost 80% of people live with epilepsy. The global prevalence of epilepsy is generally taken as between 5 and 10 cases per 1000 persons by WHO in 2019 [1].

Researchers have made progress in gaining a better understanding of the neurobiological basis, diagnosis, and treatment of epilepsy. Psychological problems persist and have a detrimental effect on recovery from this condition and prognosis. There is a need to resolve psychological issues, particularly the stigma associated with illnesses. Psychologists and psychiatrists need to focus on the psychological as well as social issues of people with epilepsy. According to World Health Organization (WHO), people with epilepsy can live a normal life medically, but the stigma related to the disease affects their lives makes their life more hard [2].

Correlation between stigma and epilepsy

When we talk about stigma, we mean an "attribution of unfounded prejudice that results in the isolation of the patient" [3].

Stigma is the biggest problem for people who develop epilepsy, it is argued that for many people with epilepsy, the stigma itself is more disturbing than managing the clinical effects of the disease.

This is due to false theories that have contributed, over the years until today, to negatively increase the social stigma of this disease.

To understand the level of misinformation, just think that for some people it turns out to be a contagious disease, for others a mental illness.

It is important and necessary to remember that these negative connotations of epilepsy do not only come from people in general, but also from health professionals and people involved in health education [4].

Epilepsy has been defined as the "ultimate stigmatizing condition," and people with epilepsy report having feelings of stigmatization and/or discrimination based solely on the label of epilepsy.

In 2000, Baker et al. published the results of a study that collected clinical data on patients' perceptions of stigma through a 3-item questionnaire, Jacob's Stigma Scale. It was administered to 5211 patients with epilepsy residing in 15 European countries and based on the data collected, 55% of Italian patients reported feelings of stigma [5].

The more evident the stigma, the more discriminatory, concrete and tangible it is and frequently pushes the people who are recipients of it and their families to live the disease with discomfort, shame and often isolating themselves.

This occurs, therefore, as a consequence of the most obvious manifestation of the condition: the epileptic seizure. It is therefore understandable how, due to the lack of adequate information, over time a distrust of people with epilepsy has consolidated with a consequent increase in prejudices. In addition to the deep discomfort caused by stigma, in the experience of people with epilepsy, there is a strongly negative effect on self-esteem [5].

Stigma and disinformation

In 2005, ILAE conceptually described epilepsy as "a brain disorder characterized by a persistent predisposition to develop epileptic seizures and the neurobiological, cognitive, psychological, and social consequences of this condition" [6].

This definition highlights the psychological and social impact linked to this disease, which has always been a source of stigma due to cultural stereotypes attributed to its etiology [7].

Epilepsy is one of those diseases whose main impulse to discrimination against affected people and consequent social marginalization is fear. This in turn is fueled by the lack of familiarity and knowledge of the disease and the management of its manifestations, which are often unpredictable and destabilizing.

Even today in the workplace, working alongside a colleague with known epilepsy causes anxiety and discomfort, feelings closely related to the worry of not knowing how to manage a possible seizure [8].

Despite the advancement over the years of knowledge on epilepsy and associated seizures, in Italy, according to a 2010 study, 56.1% of Italian adults consider epilepsy a psychological/psychiatric disease, 36.5% a form of madness and 4.1% a possession of an evil spirit.

A high percentage of people suggest restrictions on regular work and recreational activities for those affected, as well as restrictions on marriage and procreation [9].

Based on this data, it is easy to understand why people with epilepsy claim that they do not feel safe when they are alone in public, without their caregiver by their side.

This concern stems both from the fear that bystanders will overreact to the possible crisis, and from the uncertainty that the people around them will be able to provide them with appropriate treatment.

In an interview with people with epilepsy, participants responded that they had the unwanted experience of a bystander calling EMS while they were having a seizure, when it was not necessary [10].

However, not everyone feels comfortable disclosing their health condition to colleagues or peers to avoid facing possible discrimination.

In addition to this, a person is still more likely to have epileptic seizures outside of these "comfort" places, given the recurrent and sudden nature of these manifestations.

This distress hinders their daily lives by affecting their mental health and well-being, and eventually ends up affecting their seizure episodes as well as anxiety is recognized as one of the exacerbating factors of epilepsy [11].

Sharing information about your health status with bystanders in advance and finding accountable people can be challenging. However, if the general public knew how to deal with the situation when a person has a seizure, they could receive immediate and appropriate first aid even in the absence of their caregivers.

Influence of stigma on quality of life

The prevalence of epilepsy in developed countries is 4-8 per thousand and almost half of patients report feeling stigmatized. The psychosocial impact of epilepsy is well recognized, and people with epilepsy complain of the significant impact of this condition in terms of family dysfunction, and, more generally, impairment of quality of life with increased levels of anxiety and depression.

The effects of stigma are debilitating and affect many areas of life for people with epilepsy, including difficulties accessing

education, finding and maintaining stable employment, and/or developing intimate relationships.

It is important to make a distinction between "acted" stigma and "felt" stigma. Acted stigma implies real episodes of discrimination, felt stigma includes the fear of potential discrimination and the shame associated with it. In addition to factors related to epilepsy, psychosocial factors also have a significant impact on health-related quality of life.

Perceived stigma appeared as one of the most significant determinants. In fact, it was found that perceived stigma contributed to the quality of life in people with epilepsy to twice the extent of clinical variables [5].

Legislation and Reference Organizations

Draft Law no. 763 presented on 12 January 2023: Provisions for the protection of the rights of people with epilepsy:(...)"

It is therefore essential to ensure that the care of the person with epilepsy, in developmental age, adulthood or the elderly, takes place through an individual life project, which guarantees in a multidisciplinary way, both for the health and social aspects, highly specialized personnel and paths of scholastic, work and, in any case, social inclusion that avoid possible forms of discrimination and submersion of the phenomenon".

In art. 4, dedicated to the rights of people suffering from drug-resistant forms of epilepsy, anti-discrimination measures are envisaged, especially for those who, despite adequate therapy, manifest crises with loss of contact with reality or the ability to act. In art. 6 provides for the establishment of the National Permanent Observatory for Epilepsy, a body participated by institutional representatives, professional associations in the world of epilepsy, in charge of preparing and proposing actions to improve the diagnosis, therapies and inclusion of people with epilepsy and their families, as well as the consolidation of the structure and operators dedicated to their care and support for scientific research [12].

The Resolution on Epilepsy approved on 26 May 2015 by the 68th World Health Assembly, the decision-making body of the World Health Organization, underlines the need for governments to formulate, strengthen and implement policies in order to promote and protect the rights of persons with epilepsy.

The priorities, which have emerged and are recognized worldwide, concern three fundamental thematic areas:

1. improving the quality of care in the epilepsy field;
2. increase information on epilepsy in the population to reduce prejudice and discrimination;
3. Promote research in epilepsy to improve the life prospects of people with epilepsy.

At international and national level, various Associations and Scientific Societies are committed to ensuring that the WHO Resolution can be implemented.

The International League Against Epilepsy (ILAE) is the international association that brings together all doctors, health professionals and researchers involved in the fight against epilepsy, with the aim of ensuring essential resources to understand, diagnose and treat people with epilepsy.

The International Bureau for Epilepsy (IBE) is an international organization, whose main purpose is to improve the social condition and quality of life of people with epilepsy and those who care for them.

Finally, the Epilepsy Alliance Europe (EAE) was created under the protection of ILAE and IBE in order to highlight the need to increase funds for the development of new therapies for epilepsy and the improvement of services for patients suffering from this disease.

Also at the Italian level, companies and associations have been born that have as their objective the social promotion and improvement of the quality of life.

The Italian League Against Epilepsy (LICE) is a non-profit scientific society that pursues the purpose of contributing to the improvement of diagnosis, therapy, assistance, research, training and scientific information in the field of epilepsy, as well as to the overcoming of the related social stigma, promoting and implementing initiatives to achieve these goals.

In each region, it is responsible for recognizing diagnosis and treatment centers of various levels that can be the point of reference for people with epilepsy.

In addition, one of the fundamental tasks is education, which is carried out through the organization of both national and regional congresses and courses, with the aim of training increasingly qualified and up-to-date health personnel.

The Italian Association Against Epilepsies (AICE) brings together people with epilepsy and their families, promoting relations between institutions and industrial, secular and professional associations in the world of epilepsy, with the aim of offering the best quality of life to people with epilepsy and their families.

One of the objectives it seeks to pursue is the removal of discriminatory factors, the recognition of cases of recovery after 10 years in the absence of crises and in the absence of therapy, school integration and the administration of drugs during school hours.

The Italian Epilepsy Federation (FIE) is a social promotion association that brings together the main associations of people with epilepsy active on the national territory.

It coordinates and directs the statutory activity common to all member associations, supports treatment-oriented research, disseminates correct information on epilepsy, is actively engaged in the fight against prejudice and acts as an interlocutor of institutions, in the world of work and in schools to represent the problems related to the disease and promote the adoption of laws aimed at improving the condition of people with epilepsy and their caregivers.

FIE's mission is to bring out the issue of epilepsy in every social and institutional area, in which individual and collective freedom is expressed, to ensure that people with epilepsy can benefit from educational and professional opportunities not associated with stigma and discrimination and demand respect for their civil rights [13].

Family impact of epilepsy

Epilepsy does not only affect the individual who has this disorder, but has consequences on all family members, so much so that frequently parents of children with epilepsy, in order to follow the life of their children in all the different aspects, face penalizing economic and work consequences.

The diagnosis of epilepsy is often experienced as an all-encompassing, engaging tragedy, capable of altering the normal rhythms of existence and shaking the stability of a family. It is not uncommon for parents of children with epilepsy to be overprotective, limiting, sometimes even in a not entirely unjustified way, the autonomy of their children.

These behaviors, assumed by mothers and fathers of children with epilepsy, testify to the lack of awareness of the condition even by the families who are directly affected. In addition.

They are the tangible testimony of the misinformation and stigma that society assigns to epilepsy and from which arise the isolation behaviors, relational difficulties and depressive or aggressive reactions that children with epilepsy can manifest [14]. Many times caregivers may experience an affiliate stigma, in which they perceive and internalize the negative view of society and present a psychological response [15].

Stigma is the biggest problem for people who develop epilepsy; it is argued that for many people with epilepsy, the stigma itself is more disturbing than managing the clinical effects of the disease.

The more evident the stigma, the more discriminatory, concrete and tangible it is and frequently pushes the people who are recipients of it and their families to live the disease with discomfort, shame and often isolating themselves. The effects of stigma are debilitating and affect many areas of life for people with epilepsy, including difficulties accessing education, finding and maintaining stable employment, and/or developing intimate relationships.

Il Journal of Clinical Nursing reported: "Determining the role and responsibilities of the community epilepsy nurse in the management of epilepsy" (2022) that through specialized nurses it is possible to start a training program on crisis care in an emergency aimed at school groups, care facilities for and jobs. As far as the working environment is concerned, 60% of people with epilepsy are unemployed either because he gives up looking for a job or because he loses it after declaring his pathology. That is precisely why training must also be extended to include employers of so that people with epilepsy can also have or maintain a position without fear of dismissal and prejudice.

Legislation as a form of protection of rights

In many countries, laws that affect the lives of people with epilepsy do not protect their human rights and, in some cases, violate them.

L' "Epilepsy priorities in Europe: A report of the ILAE-IBE Epilepsy Advocacy Europe Task Force" (2015) states that there is a need to develop well-designed legislation to improving equity in access to health services and community integration for women people with epilepsy.

The goal we set ourselves was to deepen knowledge on the stigma present towards patients with epilepsy, and to propose interventions aimed at preventing and/or reducing stigma and consequently contributing to improving the quality of life.

According to the study "Educational interventions improving knowledge about epilepsy in preschool children" (2020), it has been shown that the roots of prejudice are formed during the preschool age and, for this reason, it is necessary to provide

information to children that is correct and that prevents the stigmatization process from being implemented. Through the use of a questionnaire, it was seen that the use of videos and educational games for children was an effective method to give them basic knowledge about the disease and, in doing so, prevent prejudices from developing.

For years now, interventions have been implemented on both young people and adults to try to break down stigma. As described in the table in the article "Epilepsy-related stigma and attitudes: Systematic review of screening instruments and interventions report by the International League Against Epilepsy Task Force on Stigma in Epilepsy" (2021) videos, readings of comic books, distribution of flyers, lessons and awareness campaigns for people without epilepsy were proposed. In fact, this study states that the majority of interventions to be implemented to eliminate stigma are educational in nature.

Social network channels could be used as a means of information for everyone, children and adults, as stated in the article "Stigma reduction interventions for epilepsy: A systematized literature review" (2020). Despite the few sources cited above, all those used for the drafting of the study have the same common theory, that is, that at the basis of any intervention to reduce prejudice there must be a knowledge of the pathology. Without knowledge, any kind of intervention will be in vain.

The importance of training "People tend to be afraid of epilepsy because they don't know what to do if a child has a seizure. Conscious training for teachers and the whole school can help eliminate fears and create an environment of acceptance for all children with disabilities epilepsy". This is what the International Bureau for Epilepsy says in its "advocacy toolkit" (2017).

For this to happen, however, there is a need for training for both all staff and students. The training course should include simple and accessible information about epilepsy, explanations of the different types of seizures and what to do in the event of a prolonged seizure, information on individual care plans that clearly describe what the individual child needs in terms of medical attention and care.

Conclusion

The review reveals some essential points that need to be paid attention to with respect to the stigma that people with epilepsy suffer.

The effects of stigma are debilitating and affect many areas of life for people with epilepsy, including difficulties accessing education, finding and maintaining stable employment, and/or developing intimate relationships.

Evidence states that there is often a lack of awareness and knowledge of epilepsy in schools, and for this reason children are placed at risk of discrimination and social exclusion.

Furthermore, all the knowledge and attitudes of teachers, also seen as educators of young people, can be transferred voluntarily or involuntarily to children and it is for this reason that their training is essential, because their prejudice or judgment negative can then be reflected in the child.

In addition to teachers, another important category to which a periodic training are nurses. Moreover, to the practical skills they must be able to bring front, have the task of educating

patients, but also caregivers. For this reason, in hospitals it is necessary that there are specialized figures, able to give answers and cope with problems. Having specialized health personnel means increasing the understanding of the people, reduce the prejudice that often starts from the hospital environment and reduce the impact of epilepsy on the person and in the family.

Information is the first point at the base of the process and these must come from authoritative sources.

Staff training is essential to give ordinary people and healthcare personnel the adequate knowledge to manage the disease and cope with a possible critical event.

Last but not least, the commitment to strengthen and implement policies in order to promote and protect the rights of people with epilepsy.

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