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**REVIEW ARTICLE**

# Psychosocial impact of scientific and technological development on the study of epilepsy

## Impacto psicosocial del desarrollo científico-técnico en el estudio de la epilepsia

## Impacto psicossocial do desenvolvimento científico-técnico no estudo da epilepsia

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## ABSTRACT

**Introduction:** views has been expressed that there is no disease more linked with social problems than epilepsy. **Objective:** to describe the social impact of scientific and technological development on the study of epilepsy. **Method:** a narrative review was carried out supported on the documentary research of several bibliographic sources found in electronic databases. The main search criteria were as follow: articles published in the last 10 years, which had relation with aspects concerning the psychosocial impact of scientific and technological development on the study of epilepsy. **Development:** the supernatural effect attributes to epilepsy, including its social repercussions, is the result of centuries of speculative theories and false beliefs about this disease. Epilepsy has negative impact on social well-being, causing serious economic problems, isolation, social exclusion and discrimination. Epilepsy is described as a disease with a great influence on all levels of quality of life. The abnormalities detected using novel neuroimaging techniques referred to the presence of cognitive impairment, refractory period and other aspects which may be indirectly related to psychosocial alterations in patients. **Final considerations:** epilepsy, in addition to its traumatic effects, has negative psychosocial consequences that affect the healthy performance of patients. In recent years, the scientific and technological advancements have partially limited the negative social effects causes by this disease with the use of new technologies for its study and treatment.

**Keywords:** epilepsy; epilepsy surgery; neurosciences; neuroimaging; social health protection

## RESUMEN

**Introducción**: se ha planteado que no existe otra enfermedad asociada a tantos problemas sociales como lo es la epilepsia. **Objetivo**: describir el impacto social del desarrollo científico-técnico en el estudio de la epilepsia. **Método:** se realizó una revisión narrativa a partir del estudio documental de varias fuentes bibliográficas encontradas en base de datos electrónicas. Los principales criterios de búsqueda fueron: artículos publicados en los últimos 10 años sobre impacto psicosocial del desarrollo científico-técnico en el estudio de la epilepsia. **Desarrollo**: el efecto sobrenatural atribuido a la epilepsia, con su consecuente repercusión social, es resultado de especulaciones provocadas por siglos de falsas creencias sobre esta enfermedad. El impacto social de la enfermedad es negativo, genera problemas financieros, de aislamiento, de exclusión social y discriminación. Se plantea que la epilepsia tiene gran influencia en todos los niveles de calidad de vida. Las anomalías detectadas por las novedosas técnicas de estudio por neuroimagen en la epilepsia se han relacionado con el deterioro cognitivo, refractariedad de la enfermedad y otros hallazgos que pueden estar relacionados indirectamente con las alteraciones psicosociales de los pacientes. **Consideraciones finales:** la epilepsia, además del daño orgánico, genera consecuencias psicosociales negativas que limitan el desempeño saludable de los enfermos. En los últimos años los adelantos científico-técnicos han limitado de forma parcial los efectos sociales negativos de la enfermedad con la incorporación de novedosas tecnologías para su estudio y tratamiento.

**Palabras clave:** epilepsia; cirugía de la epilepsia; neurociencias; neuroimagen; protección social en salud

## RESUMO

**Introdução:**tem sido sugerido que nãoháoutradoençaassociada a tantos problemas sociaisquanto a epilepsia. **Objetivo:**descrever o impacto social do desenvolvimento científico-técnico no estudo da epilepsia. **Método:**realizou-se revisão narrativa a partir do estudo documental de diversas fontes bibliográficas encontradas em bases de dados eletrônicas. Os principaiscritérios de busca foram: artigos publicados nos últimos 10 anos sobre o impacto psicossocial do desenvolvimento científico-técnico no estudo da epilepsia. **Desenvolvimento:** o efeito sobrenatural atribuído à epilepsia, comsuaconsequenterepercussão social, é fruto de especulações causadas por séculos de falsas crenças sobre essadoença. O impacto social da doença é negativo, gera problemas financeiros, isolamento, exclusão social e discriminação. Sugere-se que a epilepsia tenha grande influência em todos os níveis da qualidade de vida. As anormalidades detectadas pelas novas técnicas de estudo de neuroimagemna epilepsia têm sido relacionadas à deterioração cognitiva, refratariedade da doença e outrosachados que podem estar indiretamente relacionados àsalteraçõespsicossociais dos pacientes. **Consideraçõesfinais:** a epilepsia, além dos danos orgânicos, geraconsequênciaspsicossociais negativas que limitam o desempenhosaudável dos pacientes. Nos últimos anos, os avanços técnico-científicos limitaram parcialmente os efeitossociais negativos da doençacom a incorporação de novas tecnologias para seuestudo e tratamento.

**Palavras-chave:** epilepsia; cirurgia de epilepsia; neurociências; neuroimagem; proteção social nasaúde

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## INTRODUCTION

The International League Against Epilepsy (ILAE) defines epilepsy as a disease of the brain characterized by any of the following conditions: at least 2 spontaneous (or reflex) seizures occurring more than 24 hours apart; a spontaneous (or reflex) seizure and the probability of subsequent seizures similar to the overall recurrence risk (at least 60%) after 2 spontaneous seizures, occurring over the next 10 years; diagnosis of an epileptic syndrome.(1,2,3)

This disease, considered to be one of the most frequent diseases affecting the central nervous system, is the result of a wide range of underlying causes.(1,2,4)

Epilepsy is estimated to affect more than 50 million people worldwide. The proportion of the general population with active epilepsy (patients with ongoing seizures or in need of treatment) is estimated to be between 4-10 persons per 1000 population. About 5 million patients are diagnosed annually and the incidence of sudden death is known to be 3 to 4 times higher in patients compared to people without epilepsy.(4,5)

In Cuba, and in contrast to the reality that existed before 1959, well-articulated capacities to society have been created, for example: health research, derived from the state of health of the population.(6,7) As a result of the application of this policy, health indicators in the population have been improved in a sustained manner. That is why, at present, non-transmissible diseases, such as epilepsy, predominate over infectious diseases.(8,9)

On the other hand, it is known that despite the increase in the number of antiepileptic drugs in recent decades, 40% of people with epilepsy are considered medically untreatable or drug-resistant.(4)

According to the ILAE, drug-resistant epilepsy (DRE) is considered as the failure to control seizures with two pharmacological treatments that have been: well tolerated, adequately selected, appropriately dosed and given in monotherapy or polytherapy. Of the total number of patients with RRF, 5-10% may be candidates for surgery.(2,4,10,11)

The prevalence of these disorders justifies the development of surgical techniques for their treatment; consequently, the understanding of the underlying pathophysiology and the technological capacity to evaluate and treat these epileptic disorders has progressed to levels that allow safe and effective intervention.(4,12))

The knowledge currently achieved in the fields of informatics, neuroanatomy, neurophysiology and neuroimaging has allowed the development of tools for the study of patients, such as magnetic resonance imaging (MR), which has also allowed the detection of new biomarkers of postsurgical clinical evolution.(13)

Based on this knowledge, MR image processing techniques have been developed, which have allowed the identification of cerebral white matter tracts involved in the pathophysiological mechanisms of epilepsy. Current scientific evidence has demonstrated the negative relationship between white matter abnormalities and the health of epileptic patients; examples include: the refractoriness of seizures, the appearance of cognitive impairment, and the persistence of seizures after epilepsy control surgery.(14,15,16,17,18)

All of the above reinforces the theory that epilepsy is a disease of neural networks.(19) Furthermore, it helps to understand why some patients with drug-resistant focal epilepsies do not have a favorable postsurgical clinical evolution despite having been evaluated as ideal candidates for the surgical procedure.

In addition to these findings, there is no other disease associated with as many social problems as epilepsy. The negative impact of this disease on all social aspects of the patients results in economic difficulties, limitation of their daily performance, problems of social inclusion and discrimination.(20)

At present, although solid steps have been taken towards the study of structural brain alterations in epileptic patients through novel neuroimaging techniques, the links between the data provided by these tools and the social impact on the population of epileptic patients have not yet been clarified. For this reason, the following question is posed as the problem of this research: What is the social impact of scientific-technical development in the study of epilepsy?

The data provided by the present study may contribute to improving and perfecting the biopsychosocial approach that should be taken into account in the care of patients with epilepsy. Thus, the strategic principle of using science to solve the problems affecting the population is fulfilled. The authors aim to describe the social impact of scientific-technical development in the study of epilepsy.

## METHOD

A narrative review was carried out based on the documentary study of systematic reviews, meta-analyses, clinical practice guidelines, original articles, doctoral theses, conferences and audiovisual materials found in electronic databases and websites, such as: Medline, ClinicalKey, PubMed, Scopus and SciELO.

The search was conducted between May-December 2022, with the criteria of the combination of keywords: epilepsy, neurosciences, social protection of health. Limits for the search were established: idiomatic (Spanish, English) and temporal: (published in the last 10 years).

Of the 1875 documents found, 124 were reviewed, selected with the strategy that their objective was related to the psychosocial impact of scientific-technical development in the study of epilepsy. A review of the subject matter in question was also carried out in texts of specialized classical literature, in addition to historical political literature of Cuba.

## DEVELOPMENT

### Historical notes

The initial descriptions of epilepsy appear in the Edwin Smith papyrus, 3000 B.C.E., which speaks of patients possessed by spirits and trepanations for religious purposes, in order to make the evil being leave the patient through that "window". Imhotep (approximately 2690-2610 B.C.) used the word "brain" and spoke of convulsions. In the code of Hammurabi (1750 B.C.) a disease called "bennu" appears the name of the demon that the Babylonians held responsible for causing epilepsy. The Sakikku, one of the oldest medical texts (1067-1046 B.C.) uses the terms "antasubba" and "miqtu" to refer to epilepsy.(21,22)

Hippocrates (5th century BC) calls it a "sacred disease" and refers to its cerebral origin. Galen (129-201 AC) was the first to assert that the condition was a disease and not a divine phenomenon; he advocated that trepanations should be performed contra-lateral to the side of the seizure. Avicenna (980-1037 AC) introduced the term epilepsy.(21,22)

From this background it can be deduced that the supernatural effect attributed to epilepsy, with its consequent social repercussions, is the result of mere speculation provoked by so many centuries of false beliefs. This fact contributed to increase the terror towards this disease.(23)

Scientific development began to overshadow obscurantism; thus, Bravais, in 1827, related the presence of seizures to lesions in the cerebral cortex; H. Jackson in 1888 described focal seizures. In 1886 Victor Horsley operated on the first patient with epilepsy and resected the temporal lobe in a patient with a brain tumor. In 1935, Foerster and Altenburger made the first electrocorticographic recording.(12,22)

Among the most relevant scientific-technical advances in the study and treatment of epilepsy described since the 70's of the 20th century are microsurgery, video electroencephalogram, computerized axial tomography (CAT) and MR.(21)

In Cuba, since 1960, President Fidel Castro Ruz, quoted by Díaz-Canel Bermúdez, came to project the future of the country as a "future of men of science, of men of thought". (6) As a result of this policy, tertiary care medical centers were created, such as the Institute of Neurology in 1962 (which became the Institute of Neurology and Neurosurgery in 1966) and the Ibero-Latin American Center for Transplantation and Regeneration of the Nervous System on February 26, 1989 (which later became the International Center for Neurological Restoration).(24,25) Over the years, these institutions became references for the diagnosis, treatment and rehabilitation of diseases of the nervous system such as epilepsy.

Precisely, with the creation of the National Epilepsy Surgery Program, it has been possible to systematize a work system that has had a remarkable positive impact on the quality of life of epileptic patients in Cuba and other countries, and that has achieved in many cases their social integration.(26)

In Cuba, the coincidence of the development of science and technology with a well-articulated, universal, accessible and free health system has made it possible to raise the care of patients with epilepsy to higher levels. In poor nations, unfortunately, this reality is diametrically opposed.

## Epidemiological aspects

Approximately 50 million people worldwide have epilepsy, making it one of the most common neurological diseases worldwide. Five million of them live in the Region of the Americas.(27)

In Latin America and the Caribbean, 62% of the countries reported having at least one anticonvulsant, but most of the time these are only available at the secondary and tertiary levels of care, which makes it very difficult for people to access primary care. It is also known that in this region, two-thirds of the countries do not have a program for epilepsy care and 80% do not have adequate legislation on epilepsy.(27)

Mortality due to epilepsy in Latin America and the Caribbean is 1.04 per 100,000 inhabitants, higher than that of the United States and Canada, where it is 0.50 per 100,000 inhabitants.(27)

It is also known that, in the area referred to, more than half of the people with epilepsy do not receive any type of medical care from the health services. This may be influenced by the fact that the region has a rate of 0.7 neurologists per 100,000 inhabitants (higher than the 2010 average of 0.3). Globally, that indicator is also lower than in the Region of the Americas (0.4).(27) In 2016 in Cuba, the prevalence of epilepsy was estimated to be between 280-330 sufferers per 100 000 inhabitants.(28)

## Social impact of epilepsy

Throughout history, the patient with epilepsy has suffered a constant stigmatization that has led to social marginalization, precisely because of the spectacular nature of the seizures. In fact, Marilyn Zaldívar (Centro Internacional de Restauración Neurológica, Cuba, unpublished observations, 2018) states in a research in this regard, that there is no other disease associated with as many social problems as epilepsy.

This disease has been associated for centuries with fear, misunderstanding, discrimination and social stigma. Even today in many countries, the quality of life of people living with epilepsy and their families is still affected by the stigma associated with the disease. For example, in the United States it is known that since 1978 about three quarters of epileptics have at least one psychosocial problem, about half suffer from a mental health problem in addition to cognitive disorders, and the unemployment rate is twice that of the general population.(27,29)

In this sense, not being considered fit in all their conditions, being discriminated against, badly treated or stigmatized, generates constant anguish, stress or pressure for the patient at the time of involvement in society and limits their intellectual, emotional and global potential.(30)

Stigma produces fear of exposing their disease to people in general, pressure generated by society to draw inappropriate conclusions due to being misinformed, such as: considering that it is a communicable disease, that they are incapable of working, or that they should not marry, among others.(30)

The negative impact of this disease on all social aspects, (work, driving, interpersonal relationships, and education) results in financial problems, isolation, problems of social inclusion and discrimination. That is why it is suggested that epilepsy has a great influence on the three levels of quality of life (physical, mental and social).(10)

At the end of the 1970s, at the request of the United States Congress, the Commission for the Control of Epilepsy and its Consequences was formed. The panel of experts that formed it conducted a national survey of the state of care and treatment of people with epilepsy in that country, in addition to investigating the hitherto unknown needs of patients. Among the impressions of the investigation was that: "Possibly the least understood and most neglected aspects of epilepsy were the social, psychological, and behavioral disorders, which are very common."(29)

In recent years there has been growing interest in quantifying the impact of epilepsy on the quality of life of affected patients and in understanding its main determinants. Traditionally, attention has focused on the type of epilepsy, its etiology, age of onset, type of seizures, frequency, long-term course and the drugs used in its treatment.(31)

Currently, there is greater interest in the study of the global impact of comorbidities and the psychosocial dimension in the clinical course of the disease. Therefore, it is suggested that the evaluation of epilepsy control by simply considering the frequency and severity of seizures, in addition to monitoring the adverse effects of antiepileptic drugs, is inadequate for the evaluation of the overall health of epileptic patients.(31,32)

It is possible to eliminate the negative connotations of the word epilepsy if the social skills are available to support the project and accompany the change. All those involved, sick and healthy, are an active part of this process of change and this change begins with the acceptance of difference, intimately related to social equality.(33)

Despite the achievements made, there is still a long way to go in the social vision of patients with epilepsy, leading to the improvement of the quality of their comprehensive care. That is why the authors of this study believe that psychosocial factors should be considered as an essential element in the comprehensive management of people with epilepsy.

## Principles of scientific and technical development of health in Cuba

Knowledge, science, technology and innovation are essential inputs to advance in the process of both economic and social development.(6)

The attention to man and his health as a broad concept have benefited enormously from the development of science and technology, and the examples are endless.(34)

Technological advances constitute an element of vital importance for human life and health, since they condition the increase in the quality and standard of living of men, and these factors are fundamental indicators of human health. Nevertheless, the global distribution of cognitive, scientific and technological capabilities is highly asymmetric and highly concentrated in a small group of countries.(6,34)

As a result, developing countries have fewer scientific and technological capabilities, which are often divorced from the productive sectors and social policies of their nations.(6)

In reference to the cost of technological development, there are four different classes to consider in relation to healthcare: cost-effectiveness, cost-utility, cost-minimization and cost-benefit. This means, in short, that the technology used for healthcare may be appropriate for those places where there is real technological maturity, but it is too expensive and inadequate in many cases if the same technology is to be used in countries without sufficient technological development in general. This problem cannot be ignored and its solution is not an easy one.(35)

To this fact must be added, also, the availability of qualified human resources capable of effectively using the technologies to enhance the favorable impact that they generate in the study of epilepsy.

A possible solution to this dilemma could be the creation of a group made up of different experts, not only physicians but also sociologists, epidemiologists, biomedical engineers and patients, so that a consensus can be reached from their discussions.(35) The authors of this study consider that epilepsy should be approached from an interprofessional perspective, taking into account the active participation of patients and their families.

Consequently, a condition for moving towards a sustainable development model is the value of equality as an ethical principle, which provides policies with a rights-based foundation, a humanist vocation, with the closing of structural gaps and technological convergence, towards higher levels of productivity for future generations.(6)

Cuba has worked systematically in this direction. The Science and Technological Innovation System for Health (SCITS) is unique and integral; as principles, it conceives the interdependence between teaching, services and research, and the incorporation of scientific advances into social practice. This approach makes it possible to study health problems and needs at the three levels of care (primary, secondary and tertiary), with alternative solutions in accordance with a sectoral, intersectoral and multidisciplinary perspective, and in keeping with local culture.(7)

The current development of SCITS is due to the will and priority attention given by the State to research, innovation and the development of products and services to meet the health needs of the population. This principle is based on capacity building to absorb technologies, adapt them, and learn to use them efficiently and effectively. In all this, learning as well as research is the key. Therefore, the resources, conditions and training of human capital are guaranteed, so that its programs and projects develop actions that contribute to the welfare of the population, equity and efficiency.(6,7)

For the development of scientific activity, it is essential to have highly qualified personnel committed to health problems and their solution. Research training begins in undergraduate studies, is strengthened in the performance of the work activity and reaches its highest degree of updating and specialization in postgraduate education (in Cuba or abroad), which reaches the doctoral level.(7)

Since the triumph of the Cuban Revolution, a stable growth in the training of qualified human resources has been maintained. As a result, the morbidity and mortality indicators of the Cuban population have reached favorable levels, similar or even better in relation to some developed countries.

## Scientific and technical advances for the care of patients with epilepsy

Studying the brain is essential in order to understand diseases such as epilepsy.(30) One aspect that must be considered in relation to the etiology of employment, educational, social and other psychosocial problems is the degree of brain alteration that may be present in some patients suffering from this condition. This consideration has rarely been discussed in relation to psychosocial problems in epilepsy.(29)

The authors of the present study are of the consideration that the high prevalence of epilepsy has demanded investments in the technical scientific field, which have allowed perfecting its study and treatment. Thanks to this, the quality of life of epileptic patients has been improved.

Fortunately, since the beginning of the 21st century, interest in the study of structural brain alterations in patients with epilepsy has been growing. Consequently, diagnostic tools have been developed and perfected, such as: monitoring-electroencephalogram, advances in structural and functional neuroimaging, MR imaging, single photon emission tomography, positron emission tomography, magnetoencephalography, functional magnetic resonance imaging, and other technical advances such as the stereotactic placement of invasive electrodes for the treatment of drug-resistant epilepsy.(4,36)

These advances have also brought with them the creation of tools for post-processing of the images obtained by these neuroimaging studies, such as automatic fiber quantification, voxel-based morphometry, connectometry, path for the analysis of brain diffusion images, among others.(14-18)

The data obtained in the investigations that have used the methodologies referred to above have made it possible to demonstrate structural alterations in the cerebral white matter of epileptic patients with a level of precision that was not evident decades ago. These findings have been related to the refractoriness of the disease, sudden death and the appearance of cognitive deterioration in patients, in addition to the persistence of seizures even after surgery for the control of epilepsy.(14-18)

Although great strides have been made in the study of structural disorders of epilepsy, it is still not clear how they are related to psychosocial alterations in patients.(29) These abnormalities may underlie the reduction of psychosocial well-being of epileptics, with attention to the impact on them, their family and society, the fact of presenting drug resistance, risk of sudden death, cognitive impairment, and so on.

This gap in knowledge constitutes a source of stimulus to try to clarify, from the scientific-technical advances of neurosciences, the factors related to the psychosocial problems of epilepsy. In this way, we can contribute to improve the therapeutic approach to this disease.

## FINAL CONSIDERATIONS

Epilepsy, in addition to organic damage, generates negative psychosocial consequences that restrict the healthy performance of patients. In recent years, scientific and technical advances have partially limited the negative social effects of the disease with the incorporation of new technologies for its study and treatment, and the quality of life of epileptic patients has improved.

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