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PRIORITY EPILEPSY PROGRAM 39 YEARS AFTER ITS CREATION ACTIONS THAT GIVE RESULTS

Reséndiz-Aparicio Juan Carlos[1,2]✉

1. Priority Epilepsy Program, Manuel Velasco Suárez National Institute of Neurology and Neurosurgery. Programa Prioritario de Epilepsia, Instituto Nacional de Neurología y Neurocirugía Manuel Velasco Suárez
2. Department of Pediatric Neurology, Hospital Psiquiátrico Infantil Dr. Juan N. Navarro, Mexico City

Correspondence

Juan Carlos Reséndiz Aparicio. Instituto Nacional de Neurología y Neurocirugía Manuel Velasco Suárez, Av. Insurgentes Sur 3877, La Fama, Tlalpan, 14269, Ciudad de México, México.

✉ ppepilepsia@innn.edu.mx

Abstract

Introduction: The Priority Epilepsy Program (EPP) of the health sector in Mexico has been working for 39 years to train and update physicians of the first level of care throughout the country (pediatricians, general practitioners, family members, internists and other health system professionals), who usually attend to the patient, child or adult, who presents a first epileptic crisis. **Methods**: An article summarizing evidence, written as a narrative review showing the work and results of the EPP over the past five years, following the work ethic of a group of neurologists and pediatric neurologists working in public institutions of the health sector of our country. **Results**: the PPE has 93 Comprehensive Epilepsy Care Centers (CAIE) in public institutions, spread throughout the country. More than a thousand doctors have been trained annually in different cities, measuring the degree of learning with pre- and post-training examinations. Eighteen scientific articles have been published on epilepsy management and treatment issues in the clinical guide format, prepared by the coordinators of the CAIE. The first training was conducted through the NeuroECHO platform of the National Institute of Neurology and Neurosurgery, taught by PPE coordinators and epilepsy experts of the same institute. The National Registry of Epilepsy Patients was established, with data of more than ten thousand patients, which will allow a situational diagnosis of epilepsy in Mexico.

Keywords: *epilepsy; epilepsy program; training*

Background

The high prevalence of epilepsy in Mexico[1,2] fostered the creation of the Priority Epilepsy Program (PPE, as abreviated in Spanish)[3,4] as a highly important health program. Prior to its creation, the prevalence of this condition was studied in 1983 through a protocol endorsed by the Pan American Health Organization (PAHO) and the International League Against Epilepsy (ILAE), reporting a prevalence of 15.6 per 1000 inhabitants.[1]

The beginning of the activities of the Mexican Health Sector MPE was stipulated in the decree of the Official Gazette of the Federation of October 24, 1984, in the section of the Ministry of Health and Assistance.[3,4] The Secretary of this institution, Guillermo Soberón Acevedo, published the agreement that established the coordination of priority health projects, which is based on the right to health protection granted by Article 4 of the Constitution and which regulates the General Health Law. This agreement consists of seven articles and one transitory article.[3,4] Article 3 states that the coordinators will be responsible for promoting actions aimed at unifying the criteria, procedures and techniques used in the participating entities, as well as evaluating their results and proposing any necessary adjustments. The PPE's mission is to update and train the first level of care (first contact), which is made up of pediatricians, general practitioners, family physicians, internists and health system workers, where the child or adult patient who presents a first crisis is generally attended;[2,5] this has been and continues to be the work carried out by the EPP

Its founder, and national coordinator until 2016, was Dr. Francisco Rubio Donnadieu. As of 2017, the responsibility of coordination passed to Dr. Juan Carlos Reséndiz Aparicio. Since its foundation, the PPE has worked uninterruptedly according to its mission, that is, to standardize, coordinate,

systematize and optimize strategies in favor of the patient with epilepsy, their families and society.[2] The headquarters of the national coordination of this program is located at the facilities of the Instituto Nacional de Neurología y Neurocirugía Dr. Manuel Velasco Suárez[6,7]

The PPE is a program that has included public institutions from the entire health sector, including hospitals of the Mexican Social Security Institute (IMSS), the Institute of Security and Social Services for State Workers (ISSSSTE), the Ministry of Health, the Ministry of National Defense (SEDENA), the National System for Integral Family Development (DIF), Petróleos Mexicanos (PEMEX), the Institute of Social Security of the State of Mexico and Municipalities (ISSEMyM), Centers of Social Security of the State of Mexico and Municipalities (ISSEMyM), and the Ministry of Health, the National System for the Integral Development of the Family (DIF), Petróleos Mexicanos (PEMEX), the Social Security Institute of the State of Mexico and Municipalities (ISSEMyM), Teletón Children's Rehabilitation and Inclusion Centers (CRIT), as well as national health institutes, high specialty hospitals and university hospitals[2,5,7]

In all these institutions, Comprehensive Epilepsy Care Centers Centros de Atención Integral para Epilepsia, CAIE, as in Spanish abreviated) have been established, a term coined by Dr. Francisco Rubio.[2,5] This term, according to the PPE guidelines in Mexico, is used to indicate that within the hospitals incorporated into the program there is an area for the care of patients suffering from epilepsy - who will be attended by a neurologist or pediatric neurologist, certified by the Mexican Council of Neurology (Consejo Mexicano de Neurología).[2,5]— that has the necessary resources to perform an electroencephalography. This also implies that the patient is approached in a comprehensive manner, i.e., not only with the indication of a drug, but also through an assessment that considers the patient's comorbidity and addresses the needs of his or her family, school or work area and incorporation into society. The physician in charge of the CAIE has as an amendment the training of the personnel of his unit and of his community[2,5,7]on the subject, as well as the referral (sending) of the patient to a unit that has greater resources for their care, which includes the counter-referral of patients,[2,5] that is, the return to their primary care units. On the other hand, given the differences in the implementation of resources throughout the country, it was established as a minimum requirement that the units have an EEG, although many centers in the program have a more extensive resource of technology.[2,3,5,7]The concept of CAIEs, specific to the EPP, is different from the implementation of epilepsy centers in other countries.[8]

The neurologist or pediatric neurologist who wishes to be part of the PPE, in addition to meeting the basic requirements, must receive written authorization from the director of that institution. To this end, the director sends a letter to the national coordination of the PPE requesting admission, designating the neurologist who will be responsible for that CAIE. Once the case is evaluated, the PPE issues a letter of acceptance of admission. From that moment on, a new active center is integrated, as well as a new collaborator in the work in favor of the patient with epilepsy. The core of the work of the EPP lies in the training of the first contact physician, who has the initial approach with the patient, and who is often the primary care physician, a health professional who practices general, family, pediatrician or internist medicine, without being a specialist in neurosciences.[2,5]

Although this article analyzes what has been done in the EPP in the last five years, it cannot ignore what has been done during the 39 years that the program has been in operation, work that has served as the basis for the report of the last five years. Over the years, several publications have been produced, such as guidelines, brochures and books, which have helped in epilepsy training. The last book, produced with the help of some colleagues in the area, was published by Alfil publishing house in 2016.[2]

Among the key objectives of the PPE was to continue training a broad group of physicians and paramedical personnel throughout the country under the tutelage of the neurologists and pediatric neurologists who serve as coordinators in each of the CAIEs. To achieve this, it was necessary for the knowledge of this group to be homogeneous, especially considering that, in 2014, the definition of epilepsy had been modified,[9] and that in 2017 two very relevant articles were published, which raised the new classifications of epilepsy, the international classification of seizure type[10,11] and the classification of epilepsies,[12] both with terminology that needed to be thoroughly understood, updated, and incorporated into the program's vocabulary. To this end, the decision was made to invite all the coordinators of the institutions to elaborate the Clinical Guidelines of the Priority Epilepsy Program.[7] In order to have a frame of reference, the concepts of the Andalusian Epilepsy Society (SAdE, as abbreviated in Spanish) Guidelines were taken up again.[13,14] These works that have had a high global impact. Likewise, two meetings of PPE coordinators were held, one in the city of León, Guanajuato, in March 2018, and another in the city of Cuernavaca, in October 2019, in which the need for such clinical guidelines was presented. The meetings were attended by the president of the SAdE, who

shared his experience, and a training on the development of guidelines was conducted. Based on this, the topics to be addressed in each of the guidelines were collectively chosen. On the other hand, it was pointed out that there are often no country-specific statistics available, which makes it necessary to extrapolate data from other regions, adjusted to a possible national scenario. For this reason, once the group of specialists with homogeneous and updated knowledge on epilepsy was established, a new project was launched, the elaboration of a national registry of patients with epilepsy, which would have to be carried out based on the new concepts of definition and classification determined by the ILAE in 2017. The National Epilepsy Registry was established with the purpose of having a situational diagnosis of epilepsy in the country, and constitutes an observational and multicenter study, which has registration in ClinicalTrials.gov (ID: NCT04383522). Informed consent and assent were obtained in the case of minors. Likewise, the project was submitted to the evaluation of the research committees of the different institutions, being the research ethics committee of the National Institute of Neurology and Neurosurgery the first to give the go-ahead for its realization, this in research protocol No. 68/21, submitted by Dr. Iris Enriqueta Martínez Juárez on October 4, 2021

Objective

The purpose of this article is to inform the medical community about the activities of the last five years of the Priority Epilepsy Program, so that it can serve as an example for the implementation of similar national programs in other countries.

Methods and results

This article constitutes a synthesis of evidence and is presented as a narrative review. In narrative reviews[15,16] the evidence to be synthesized is selected in a non-reproducible way and without an exhaustive search; they represent a type of review carried out by experts in a topic, and in general the methods used to obtain and select the information are not stated, for these reasons, they are considered subjective and without specific methodology. These reviews are ideal to be able to answer basic questions, in this case, these questions correspond to how the Priority Epilepsy Program of the Health Sector in Mexico works and what are the results.

Narrative reviews are a frequent type of article in the medical literature, however, there are not many instruments to measure their quality. This article adheres to the Narrative Review Article Rating Scale,[17] (SANRA, as abbreviated in English), and follows the guidelines set out in the instrument, such as providing a justification for the article considering the interest for the reader, indicating the objectives in a concrete manner, carrying out a bibliographic search, citing references, according to scientific reasoning and an adequate presentation of the data.

Comprehensive Epilepsy Care Centres (CAIEs)

In 2017, active CAIE centres were registered through updated letters from the directors of each institution. At that time there were 45 centres, so the next step was to request new letters and invite physicians to continue to actively participate. The number of CAIEs in the country continued to increase, and by the beginning of 2023, 93 institutions across the health sector were integrated into the EPP. The following is an abbreviated list of centres by health sector institution: 40 in Ministry of Health hospitals, [15] in IMSS, 11 in ISSSTE, 10 in university hospitals, 8 in CRIT Teletón, 4 in national health institutes, 2 in Pemex, 1 in DIF, 1 in ISSEMyM, and 1 in SEDENA. The full list of institutions is shown in Figure 1, which is subdivided into: 1A, which shows the centres throughout the country, 1B, which presents the CAIEs in the central region of the country and 1C, which shows the centres in Mexico City. A detailed list of the centres can be found on the PPE website.[18]

Face-to-face training

The most important activity to be developed in the EPP is the national training of first contact physicians, with the aim of ensuring that they know, recognise and treat patients with epilepsy correctly. Prior to 2007, the National Epilepsy Week was held, in which doctors from a region were invited for training and PPE collaborators who were available to act as teachers were called upon. However, since an average of 300 physicians were trained annually, the costs were high, as the physician-teachers had to travel from remote locations. In order to make the necessary adjustments for the proper functioning and based on the powers granted by the decree creating the priority programmes in Mexico.[3,4]

The training provided to physicians in their cities through face-to-face events are called Regional Meetings. The intention is to hold one such meeting per year in each of the seven regions, however, at times this has not been possible due to security concerns and restrictions due to the COVID-19 pandemic. Table 1 shows the regional meetings that have been held from 2017 to 2019, i.e. in a pre-pandemic period, recording the number of physicians attending.

At the end of 2021, face-to-face training resumed and two meetings were convened, one in the city of Tepic and the other

Figure 1. Map of the distribution of the Comprehensive Epilepsy Care Centers (CAIE) of the EPP. 1A) General map of CAIEs in the Mexican Republic. 1B) Map of CAIEs in the Central Region of the country. 1C) Map of CAIEs in Mexico City.

Figure 1A

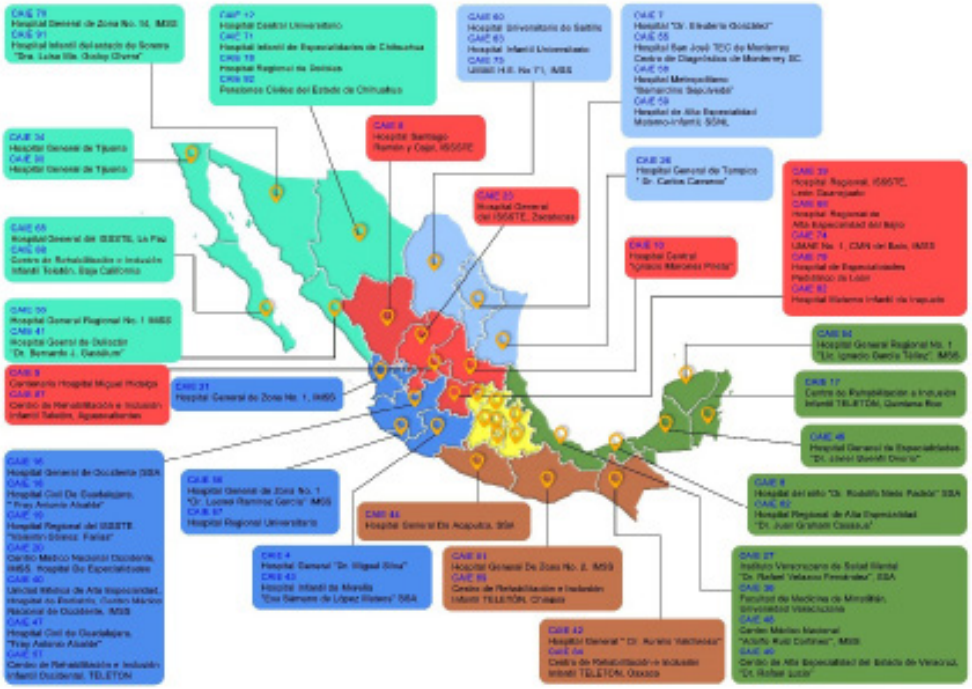


Figure 1B

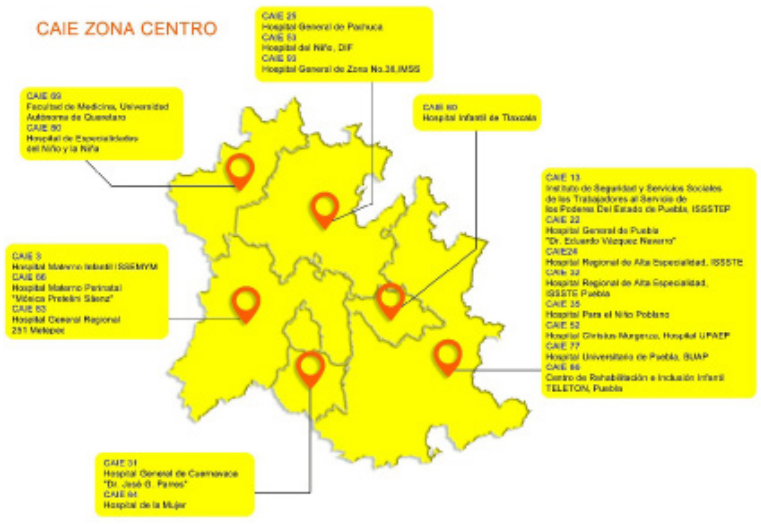
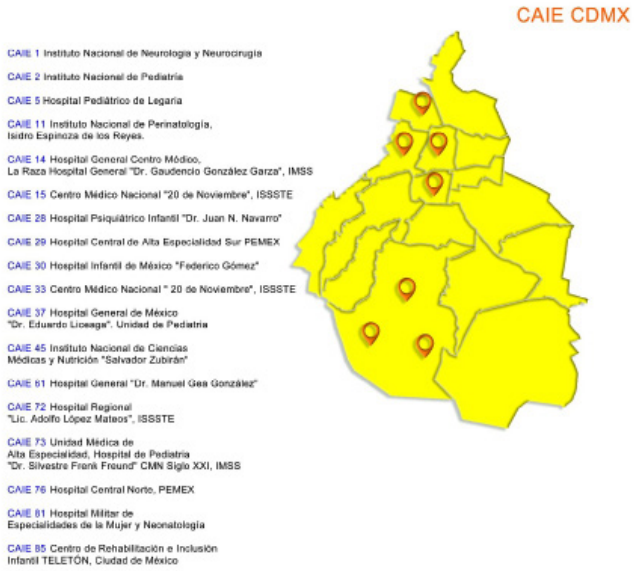


Figure 1C



in Morelia, as shown in Table 2. In 2022, the regular activities of the MPE were re-established following COVID-19 related indications from the state authorities of the city hosting the trainings, e.g. on the percentage of attendees according to the different auditoriums. Table 2 shows these activities and the number of first contact physicians trained in 2021 and 2022. During the meetings, pre- and post-training evaluations are conducted to assess the level of epilepsy knowledge acquired by the participants. In general, participants move from an average score of four to an average score of eight. As an example, Table 3 shows the results of the pre- and post-training tests conducted at the 2022 meetings.

EPP Clinical Guidelines

The PPE Clinical Guidelines were developed in 2018, working with the CAIE coordinators, who were assigned into ten groups, one per topic.[7] It was decided that the best forum for the guidelines was the official publication body of the Mexican Academy of Neurology, which would allow easy access to the country's neurologists. The first ten clinical guidelines were published in English in the Revista Mexicana de Neurociencias, followed by a Spanish version, which was considered important as they were Mexican guidelines. The topics of the guidelines were:

- Definition and classification of epilepsy[19]
- Management of seizures in the emergency department[20]
- Management of the first unprovoked seizure in adults and children[21]
- Antiepileptic drugs of choice for focal and generalised seizures in adults[22]
- Antiepileptic drugs of choice for epileptic syndromes and epilepsy in paediatric patients[23]
- Diagnosis and treatment of febrile seizures[24]
- Epilepsy in pregnant women and women of childbearing age[25]
- Status epilepticus in children and adults[26]
- Pre-surgical evaluation in refractory epilepsy[27]
- Discontinuation of chronic antiepileptic treatment[28]

To conclude the project, it was decided to produce eight additional clinical guidelines with the most important topics in terms of approach, diagnosis and management of patients with epilepsy. The same methodology of working groups was followed, convening all the coordinators for an initial meeting in the city of Cuernavaca in 2020. In the same year, the eight guidelines were published in the Revista Mexicana de Neurociencias, both in Spanish and English. On this occasion the topics were:

- Neonatal seizures[29]

Table 1. Training activities in Regional Meetings from 2017 to 2019.

Region	2017		2018		2019	
	Place	Attendees	Place	Attendees	Place	Attendees
Central	Pachuca, Hidalgo	87	Tlaxcala, Tlaxcala	300	Toluca, Estado de México	150
Central-West	Aguascalientes, Aguascalientes	314	León, Guanajuato	400	Durango, Durango	404
Northwest	Tijuana, Baja California Norte	334	Delicias, Chihuahua	308	Mazatlán, Sinaloa	305
Northwest			Tampico, Tamaulipas	Canceled	Torreón, Coahuila	320
West	Morelia, Michoacán	101	Guadalajara, Jalisco	360	Colima, Colima	159
Southeast and Southwest	Mérida, Yucatán	214	Campeche, Campeche	80	Villahermosa, Tabasco	207
Total		1050		1448		1545

Table 2. Training activities at Regional Meetings in 2021 and 2022

Region	2021		Región	2022	
	Place	Attendees		Place	Attendees
Central	Puebla, Puebla	Canceled due to pandemic-COVID-19	Central	Cuernavaca, Morelos	184
Central-West	Veracruz, Veracruz		Central-West	Zacatecas, Zacatecas	294
Northwest	La Paz, Baja California Sur		Northwest	La Paz, Baja California Sur	113
Northwest	Monterrey, Nuevo León		Northwest	Monterrey, Nuevo León	138
West	Tepic, Nayarit	130	Southeast and Southwest	Veracruz, Veracruz	127
West	Morelia, Michoacán	121	Southeast and Southwest	Mérida, Yucatán	260
Total		251			1116

Table 3. Average number of evaluations at 2022 Regional Meetings.

Average number of evaluations (2022)			
Region	**Place**	**Initial**	**Final**
Central	Cuernavaca, Morelos	4.11	7.6
Central-West	Zacatecas, Zacatecas	4.11	7.45
Northwest	La Paz, Baja California Sur	5.21	7.43
Northwest	Monterrey, Nuevo León	4.89	7.31
Southeast and Southwest	Veracruz, Veracruz	5.38	8.12
Southeast and Southwest	Mérida, Yucatán	4.46	7.43
General		4.69	7.55

- Pharmacological management of epilepsy in the elderly[30]
- Use of non-invasive EEG and video EEG in epilepsy[31]
- Differential diagnosis of epilepsy[32]
- Epilepsy and psychiatric comorbidities[33]
- Non-psychiatric comorbidities in the adult patient with epilepsy[34]
- Social aspects of epilepsy in Mexico[35]
- Epilepsy and neurodevelopment[36]

These 18 Epilepsy Clinical Guidelines constitute a thematic basis for the management of epilepsy in Mexico, and are intended to homogenise the knowledge of the EPP coordinators on this condition. This will allow for further training of first contact physicians through the Regional Meetings, and will encourage the adoption of these criteria in the daily medical practice of neurologists and paediatric neurologists working in the different public sector institutions in our country.

National Register of Epilepsy Patients

This database, which would provide sufficient data on the characteristics of epilepsy in Mexico, was developed over five months of work, with the help of an engineer for the technical part. The database was preloaded into the system, registering the possible responses that would facilitate the capture of the information and the homogeneity of the data. A small pilot test was carried out with patients from the Children's Psychiatric Hospital in Mexico City and, when it was assessed that the system was working optimally, a meeting of coordinators was convened at the end of 2020 to publicise the project and to start capturing patients in the database in 2021.

The registry has a possibility of up to 490 variables. The information was captured through six enabled master buttons, which integrate general data; the complete diagnosis, including type of seizure, type of epilepsy, epileptic syndrome, aetiology and comorbidities; previous and current treatments; special data in the case of newborns, pregnant women, status epilepticus, among others, and a care button, through which the type of doctor attending the patient and other professionals involved in their management were recorded. The data capture was completed in December 2022, however, in September 2021 a first cut-off was carried out, achieving the registration of 5,855 patients in almost the entire country. Data analysis is currently underway, which to date includes more than 10,000 patients nationwide.

NeuroECHO Epilepsy Online Course

In 2020, face-to-face trainings were suspended due to the COVID-19 pandemic. However, in order to continue the trainings, and as a result of the initiative of Dr. Angel Antonio Arauz, Director of INNN, we worked on the joint preparation of the first online course of the ECHO platform. Project ECHO (Extension for Community Health Outcomes) is a program of monthly teleconferences through which mentoring is provided by means of technology, using case studies as a fundamental basis for learning. The NeuroECHO Epilepsy online course was held from March to November 2021, and 170 physicians, both students and faculty, participated. The course had the endorsement of the Universidad Panamericana and the ECHO group, based in the United States, as well as the endorsement and score of the Mexican Council of Neurology. The online course consisted of nine sessions; in each tele-mentoring session, cases presented by the students were analyzed and two brief topics from the 18 clinical guidelines were taught. EPP coordinators from all over the country served as teachers, together with experts from the INNN. The results of this online training are shown in abbreviated form in Table 4.

Social networks

During the reporting period, the incursion into social networks was achieved; profiles were created on Facebook and Instagram with the aim of increasing the dissemination of knowledge of epilepsy in these media; however, it should be noted that the number of followers is still low. Likewise, the program has had an active web page for more than 15 years,[18] which is constantly updated. For each of the regional meetings, a promotional video is produced and disseminated in the state where the training will take place. In addition, videos have been produced to raise awareness among the population of the importance of knowing about epilepsy.

Finally, it is worth mentioning the development of the free Epilepsia Mexico application, which is used to monitor a patient's epilepsy and enables the recording of relevant information regarding his or her disease. The application allows to keep a calendar of seizures with a very detailed breakdown, store videos of the seizures, and set reminder alarms for taking medication, medical appointments or performing studies, and includes an alarm button with geolocation, which when activated sends a message previously prepared by the patient to the recipient assigned by the patient.

Discussion

The management of various diseases requires constant updating and epilepsy is no exception. This disease has a high prevalence in our country,[1,2] so its knowledge is basic for any health professional. The main objective of the PPE is

to make known what epilepsy is and how to approach and treat it. Being the neurological pathology par excellence, epilepsy represents the health problem most frequently faced by the neurology services of any hospital in the country.[37] The development of the CAIEs makes it possible for each institution to have a physician or group of physicians who are committed not only to providing care, but also to training physicians from their community and other neighboring states,[2,5] which, in turn, implies training and updating of the entire medical community. In 2011, the Pan American Health Oa particular project for

Table 4. Abbreviated report of the results of the NeuroECHO Epilepsy online course.

NeuroECHO Epilepsy (2021 March-November)			
Sessions	9	Students with all the requested requiremnts	134
Themen	18	Certificates with endorsements	134 attendees
Tenured lecturers	2		34 guest lecturers
Guest lecturers	34		2 tenured lecturers

Latin America that aims to improve the quality of care for patients with epilepsy. One of the most important objectives of this project is to have national epilepsy care programs with activities at the regional level, which, as has been shown in this article, has been carried out in Mexico since 1984.rganization (PAHO) developed the Epilepsy Strategy and Plan of Action.[3,4]

Currently having a presence in 93 health sector institutions, the EPP is representative at a national level. However, considering that in many parts of Mexico it is difficult for a patient to be seen by a neurology specialist, the training of first contact physicians and paramedical personnel is of great importance, either to treat or correctly refer a patient with suspected epilepsy. As established by PAHO, it is advisable to monitor the progress of national epilepsy programs and to implement them with particular attention to vulnerable groups,[38] This is why the EPP emphasizes training first contact physicians, who are the professionals who receive most patients from vulnerable groups when they have their first epileptic seizure. In this sense, if this type of physician can recognize and treat the seizure or refer the patient to a CAIE in his or her region, this will result in better care for the patient with epilepsy.

In the trainings, videos of patients with epilepsy are used, with prior authorization, so that physicians learn to recognize the different types of seizures. Since the general community may think that epilepsies are only generalized tonic-clonic seizures - which, as we know, do not represent the most frequent type of seizures -, it is important to understand that epilepsy is not the most common type of seizure.[2,5,7,19]— It is essential to identify the different types of manifestations that a patient may have. Likewise, one of the objectives of the trainings is to recognize those conditions that can be mistaken for epilepsy,[39] which also requires the use of patient videos, with prior authorization. On the other hand, the elaboration of clinical guidelines through the coordination of such a large group of specialist physicians, in addition to involving a great effort,[7] which generated a sense of belonging, since they are considered to belong to the EPP. This encourages those involved to recommend them and present them in the different forums dedicated to epilepsy, both in the regional meetings, the most important forum for national training of the EPP, and in the institutional meetings of each of the health care centers.

Knowing the characteristics of the behavior of a disease in a region makes it possible to create specific care strategies, which is why it is so important to complete the National Register of Epilepsy Patients, which will provide a clear situational diagnosis of the management of patients with epilepsy in Mexico and the behavior of the disease. In turn, social networks are a tool that cannot be ignored in the dissemination of knowledge about epilepsy in the medical population and the general population. Finally, this article contributes to OPS[38] in terms of technical cooperation with other countries to design and strengthen national epilepsy care programs, as the study shows the efforts made in Mexico that can be replicated in other countries.

Conclusions

In a country where neuroscience physicians are not enough to care for a population of more than two million patients with epilepsy, it is essential to train first contact physicians. The work of the coordinators of each of the institutions that belong to the EPP to care for their patients and train other professionals represents a valuable work ethic and friendship. In this sense, epilepsy has the power to unite physicians from different health sector institutions under the same objective. The PPE will continue to work on the training of first contact physicians from all over the country, both in face-to-face and remote mode, the latter through online courses such as NeuroECHO epilepsy. Likewise, it can be proudly stated that the EPP is a program that has published 18 clinical guidelines for the approach and treatment of epilepsy.

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This article has no conflicts of interest.

Authors' contribution

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