

Description of the referral centers for patients with epilepsy for the implementation of the TeleECHO project in a national institute of health

Santos-Peyret Andrea S.¹ | Crail-Meléndez Daniel² | Sebastián-Díaz Mario A.³ | Velasco-Vázquez Carmen⁴
Del Río-Quiñones Manuel Alejandro⁵ | Gómez-Figueroa Enrique⁶ | Reséndiz-Aparicio Juan Carlos⁷
Rubio-Donnadieu Francisco⁷ | Martínez-Juárez Iris E.^{1,8}✉

1*.Epilepsy Clinic

2*.Department of Neuropsychiatry

3*.Health Sciences Doctorate Program,
Anáhuac University, North Campus, State
of Mexico, Mexico

4*.External Consultation

5*.Subdirector of External Consul-
tation

6.National Institute of Neurology and
Neurosurgery Manuel Velasco Suarez,
Mexico City, Mexico

7*.Epilepsy Priority Program

8*.Cognitive and Clinical Neurophysio-
logy Laboratory.

*National Institute of Neurology and
Neurosurgery Manuel Velasco Suarez,
Mexico City, Mexico

Correspondence

Dr. Iris E Martínez-Juárez
Epilepsy Priority Program. National
Institute of Neurology and Neurosurgery
Manuel Velasco Suárez. Insurgentes
sur 3877, Col. La Fama, Tlalpan, C.P.
14269, Mexico City, Mexico.

✉ clinicadeepilepsia@innn.edu.mx

Abstract

Background: Epilepsy is defined as a neuronal predisposition to generate epileptic seizures; all diagnosed patients must follow the guidelines of the clinical record and have a reference and counter-reference system.

Objective: To describe the care centers and characteristics of patients with epilepsy referred to the Comprehensive Epilepsy Care Center 1 (CAIE 1, by its acronym in Spanish) of the National Institute of Neurology and Neurosurgery (INNN, by its acronym in Spanish), as well as evidencing the need for the decentralization of these processes through new technologies and projects such as TeleECHO.

Material and methods. An observational, descriptive and cross-sectional study was carried out. Information was obtained through outpatient referral sheets, in order to review the centers, levels of care, place of origin, and reason for the referral of patients with epilepsy to the CAIE 1, from January to December 2017. Patient information sheets without complete data were excluded.

Results. Out of 4,866 patients referred to the INNN, 627 patients had epilepsy (mean age of 33.34 ± 15.33 years, 52.8% were women). Most of the referred patients came from private physicians, and primary and tertiary care centers in the Megalopolis (Mexico City, State of Mexico, Hidalgo, Morelos, Querétaro and Tlaxcala).

Conclusions. The study allowed us to know and describe the health care centers that refer patients with epilepsy to the CAIE 1 of the INNN in one year. This knowledge will serve to implement the ECHO project, which seeks to improve the referral and counter-referral system and decentralize the care offer for patients with epilepsy. The implementation of said telemedicine program in national centers of most referral aims to reduce the epilepsy treatment gap in Mexico.

Key words: epilepsy, referral, telemedicine, information technology



Introduction

Epilepsy is a brain disease characterized by a neuronal predisposition to generate epileptic seizures.¹ In Mexico, the estimated prevalence of epilepsy is situated between 10 and 20 per 1,000 people;² all treated patients medical history must follow the guidelines regarding clinical records management⁴ and, ideally, have a referral and counter-referral system.⁵ There are multiple factors that can affect epilepsy care: the cost of antiepileptic drugs, their limited availability, the socioeconomic level of the patients, the disparity between health centers in the private and public sectors, the shortage of neurologists and epileptologists, as well as the access limitations in certain social sectors to medical care and diagnostic methods, among others.² In this regard, the Epilepsy Priority Program (PPE, by its acronym in Spanish) of the health sector in Mexico, has as its objective to regulate, coordinate and optimize strategies and actions in favor of patients with epilepsy, their families and society. The PPE focuses on two lines of work: the development of care centers and the strengthening of primary care.³ In 2020, the PPE registered 82 comprehensive care centers for epilepsy in public hospitals across the health sector. Among them was the Manuel Velasco Suárez National Institute of Neurology and Neurosurgery (INNN), a highly specialized neurological center in Mexico City, where the Comprehensive Epilepsy Care Center 1 (CAIE 1) is located.

The criteria for admission and permanence at CAIE 1 of the INNN are: to be a patient referred from a secondary care with drug-resistant and/or uncontrolled epilepsy; to be a candidate for epilepsy surgery; or to be a patient of an institution with an agreement to be treated at the INNN (Source: Official letter of criteria for admission and permanence at the INNN Epilepsy Clinic).

In 2017, the INNN provided 2,051 consultations for patients with first-time and subsequent epilepsy and, during 2018, 1,680 (Source: INNN Clinical File). These figures show the need for the decentralization of health services, as promoted by the General Health Law.⁴

Objective

To describe the source center and the characteristics of the referral of patients with epilepsy sent to the Comprehensive Epilepsy Care Center 1 (CAIE 1) of the National Institute of Neurology and Neurosurgery (INNN), in order to demonstrate the need for decentralization of care with new technologies and through projects such as TeleECHO.

Materials

The outpatient referral forms of all patients referred to epilepsy consultation to the CAIE 1 of the INNN in the period from January to December 2017 were considered, forms without complete data were excluded. A database was created expressly in the Excel program for subsequent analysis using descriptive statistics with measures of central tendency and proportions, depending on whether they were dimensional or nominal variables, respectively. To analyze the information of the referred patients, the following data was taken into account: the reasons for referral to said institution, the sex of the patients, the doctors who referred, as well as the centers and states from which the referrals came. The study was approved by the Ethics and Research Committees of the INNN (project No. 40/19).

Health centers and clinics with family or general practitioners were considered as primary care; hospitals that have basic specialties as Internal Medicine, Pediatrics, Gynecology, General Surgery and Psychiatry were included as secondary care, and, finally, highly specialized health institutions that have advanced diagnostic equipment for the treatment of complex diseases were considered as tertiary care.⁵

Methods

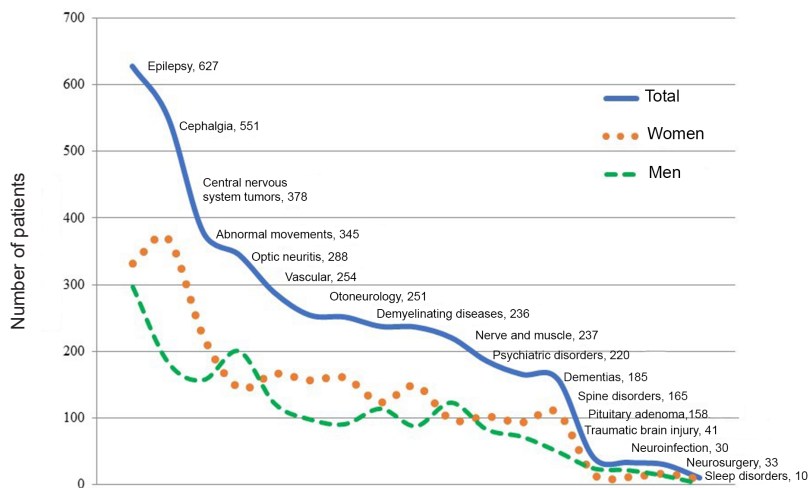
An observational, descriptive, cross-sectional and prospective study was carried out.

Results

In the period from January to December 2017, a total of 4,866 patients were referred to the INNN. Eight hundred fifty-seven patient's referral forms (17.6%) had a diagnosis of "assessment" without any specification of the neurological pathology for which they were referred. Four thousand nine patients (82.4%) were referred for various neurological pathologies. The three main reasons were: epilepsy, headache, and tumors of the central nervous system (Figure 1).

A total of 627 patients with epilepsy were referred to the CAIE 1 at the INNN. Three hundred thirty-one of them were women (52.8%) and 296 (47.2%) were men. The mean age at the time of referral was 33.34 ± 15.33 years (range 15 to 88 years). According to the distribution by age of the patients, in both sexes the age group of 15 to 20 years

Figure 1. Causes for the referral of patients to the INNN “MVS”, total and divided by sex



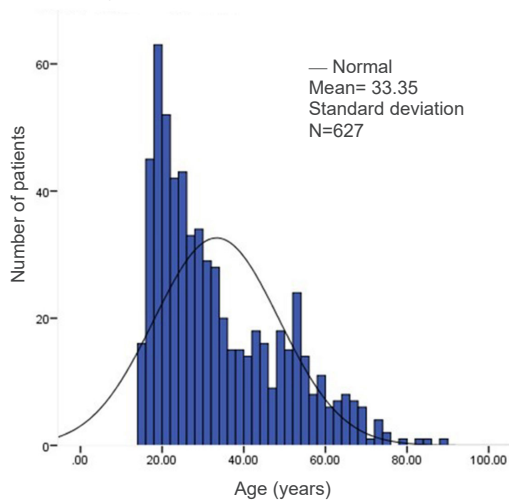
INNN “MVS”= National Institute of Neurology and Neurosurgery “Manuel Velasco Suárez”

prevailed with 146 patients, equivalent to 23% (n=146) of total referrals, with 56% of women (82 /146) (Figure 2). 29% (182/627) of patients were referred by a private physician, the rest, by public sector physicians.

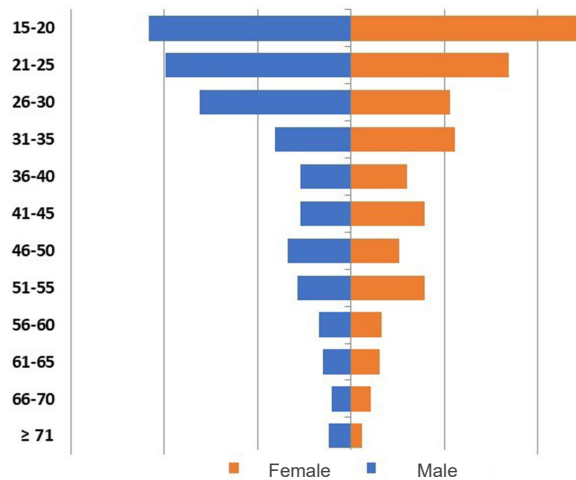
According to the level of healthcare, 32% of patients (201/627) were referred from primary care, 8.6% (54/627) from secondary and 28.3% (178/627) from tertiary; only 1.89% (12/627) were referred from other units (Table I).

Figure 2. Distribution by age and sex of epilepsy patients referred to the CAIE 1 of the INNN “MVS”

A. Distribution of patients referred to the CAIE 1 of the INNN “MVS” by age



B. Age groups of patients referred to the CAIE 1 of the INNN “MVS” by sex



CAIE 1= Comprehensive Epilepsy Care Center 1, INNN “MVS” = National Institute of Neurology and Neurosurgery “Manuel Velasco Suárez”

Table 1. Referral centers of epilepsy patients to the Comprehensive Epilepsy Care Center 1 of the National Institute of Neurology and Neurosurgery “Manuel Velasco Suárez”

Referral centers	Number of patients (%)
Primary care	201 (28%)
Secondary care	54 (9%)
Tertiary care	178 (32%)
Private physicians	182 (29%)
Others	12 (2%)
Total	627 (100%)

The states that reported the highest number of referred patients were Mexico City, with 60% (376/627), and the State of Mexico, with 27.9% (175/627), followed by other states of the Megalopolis (Table 2).

Table 2. States that referred epilepsy patients to the Comprehensive Epilepsy Care Center 1 of the National Institute of Neurology and Neurosurgery “Manuel Velasco Suárez”

States	Number of patients n (%)
Mexico City	376(60%)
Estate of Mexico	175 (27.9%)
Hidalgo	13 (2%)
Morelos	12 (1.9%)
Oaxaca	10 (1.59%)
Puebla	9 (1.43%)
Guerrero	8 (1.27%)
Michoacán	8(1.27%)
Chiapas	5 (0.79%)
Veracruz	5 (0.79%)
Guanajuato	2 (0.31%)
San Luis Potosi	1 (0.15%)
Tabasco	1 (0.15%)
Tlaxcala	1 (0.15%)
Yucatan	1 (0.15%)
Total	627 (100%)

Discussion

During the examined year, epilepsy was the main reason of referral to the INNN —only after non-specific neurological assessment—, in addition to being the principal cause for outpatient care at said institution. Most of the patients with epilepsy were referred from primary and tertiary care units, as well as physicians from the private sector.

A large part of the patients is referred from Mexico City and the State of Mexico, as well as from cities in the Megalopolis; this is probably due to the proximity and adequate access to health referral systems at the local level.

In states further away from Mexico City, we observe a limitation in terms of referral, probably caused by the scarcity of resources of the patients to travel to said institute, or because some of these states have highly specialized hospitals that provide care to these patients.

Population-based studies of epilepsy incidence report a bimodal distribution of the disease, with peaks between 5 to 9 years of age and over 64 years of age,⁶ although the prevalence of the disease can be at any age. In this investigation, referral predominated in the age group of 15 to 20 years of age, followed by the group of 21 to 30 years, who are economically active population. On the other hand, in the distribution according to sex, predominance of the referral of female patients is observed — it is well-known that the prevalence of epilepsy is also higher in females in the group of 15 to 20 years of age, and that it increases in age groups older than 64 years.⁷

Regarding this, the new Mexican healthcare model — introduced in 2015 by the Ministry of Health — establishes strategies for the implementation of health rights, whose main objective is to achieve high levels of coverage, nevertheless these efforts have not been sufficient. In the case of epilepsy patients, there is currently a high demand of tertiary care, however the majority of these patients, instead of being referred from primary and secondary care and public hospitals, are sent from tertiary care and private physicians.⁸ One of the possible reasons for the higher referral from tertiary care is that patients who were diagnosed with epilepsy in pediatric age are sent from tertiary care centers of neuropediatrics to adult neurology to the CAIE 1 of the INNN; another explanation could be that patients referred to local tertiary care centers are redirected from these institutions to the CAIE, this in addition to the fact that there are tertiary care hospitals that do not

have epilepsy surgery programs, and therefore refer patients to the CAIE 1. These, among many other reasons, seem to explain the increase in tertiary-to-tertiary care referral. It is noteworthy that this high referral of patients from tertiary care hospitals ultimately generates a failure in the referral system and produces a "boomerang" effect, in which the patient experiences an increasing gap to access timely diagnosis, treatment and follow-up.

When contrasted with those of high-income countries —where 30 to 50 per 100,000 new cases of people with epilepsy are registered per year—, it is worth mentioning that these figures can be twice as high in low-income countries. Furthermore, it has been documented that the number of neurologists in the latter is even lower:⁹ in low-income countries there are a median number of neurologists of 0.1 per 100,000 population, compared to 7.1 per 100,000 population in high-income countries. On the other hand, in the Mexican case, the frequency of drug resistance in the INNN has been reported in up to 56% of patients.¹⁰

Based on international statistics, it is observed that approximately 70% of people with epilepsy are controlled with antiepileptic drugs; and that 30% have inadequate seizure control, even with correct drug therapy.¹¹ It should be noted that 73.3% of patients with active epilepsy who reside in rural areas of low- and middle-income countries do not receive treatment or receive it inadequately; which is known as epilepsy treatment gap.¹²

According to these data, most epilepsy patients in Mexico could be treated at a primary or secondary care center. According to the CENETEC Clinical practice guide for epilepsy patient care,¹² the criteria for the referral of a patient to a tertiary care center are: having uncontrolled epilepsy after a treatment with antiepileptic drugs of approximate 2 years without achieving effective control, inadequate control despite appropriate doses within the tolerance limit, if the patient is at great risk of experiencing adverse effects from treatment, existence of structural lesion, presence of psychiatric or psychological comorbidity, existence of diagnostic doubt, and presence of cognitive or behavioral impairment, among others.

The referral and counter-referral system constitutes a medical administrative procedure —performed by the health personnel— carried out between operating units of the three levels of care, that enables the referral-receiving-returning of patients, and that has the purpose of providing timely, comprehensive and adequate medical care.¹³

The Procedure manual for the referral and counter-referral of affiliates or users offers guidelines for the process that the patient must follow to access medical examination, and establishes that this procedure must be comprehensive and involve a large group of health workers, including social workers, nurses and physicians; this in order to produce an adequate referral system for patients, which refers them to the level of care they require according to their condition for prompt diagnosis and correct treatment.¹⁴

It is therefore imperative the enhancement of the referral-counter-referral system at the tertiary care of the CAIE 1 at the INNN, following the guidelines provided in the Procedure manual and considering the data presented in this study.

A general overview of the referral and counter-referral of patients with epilepsy to the CAIE of the INNN will allow us to implement international systems, such as the ECHO Project (Extension for Community Healthcare Outcomes), which is dedicated to attend vulnerable populations by providing telementoring. TeleECHO is conformed by multidisciplinary teams, which share their knowledge with primary care physicians that are in constant contact with epilepsy patients; these strategies can help provide greater access to patient care, avoid delays, and decentralize tertiary care services.¹⁵

Conclusions

This study allowed us to identify and describe the health care centers that refer epilepsy patients to the CAIE 1 of the INNN in one year. This knowledge seeks to improve the referral-counter-referral system and decentralize healthcare for patients with epilepsy. One of the proposed actions is to reevaluate the referral to CAIE 1 of private physicians, and another to channel patients to their corresponding primary, secondary or tertiary care centers according the federal entity — as in other Latin American countries referral systems —⁶ through inter-institutional agreements, especially between tertiary care hospitals and the current 82 PPE centers.

Finally, with this study, we strive for the implementation of future telemedicine strategies¹⁶ and TeleECHO in the centers with the highest referral of patients to the CAIE 1 of the INNN, which can lead to the decrease of the epilepsy treatment gap in Mexico.

Financial support

The authors declare that the study had sources of financing.

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Article without conflict of interest

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