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Increased non-attendance at epilepsy clinic in patients with neuropsychiatric comorbidities: A prospective study

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ABSTRACT

Background: In patients with epilepsy, regular follow-up is vital for adequate seizure control, antiseizure drugs' (ASDs) side effects, psychiatric comorbidities, and planning for epilepsy surgery. Non-attendance creates barriers to adequate patient care, inefficient allocation of resources, loss of income, and unnecessary emergency department visits due to lack of seizure control. This study aimed to determine the causes and sociodemographic characteristics of the non-attendant population at the Epilepsy Clinic.
Methods: A prospective and observational study was carried out on patients treated at the Epilepsy Clinic of the National Institute of Neurology and Neurosurgery (NINN) in Mexico from August 2015 to June 2016. A phone interview was made with all those patients who did not attend the epilepsy consultation. This call incorporated ad hoc questions to meet the objectives of this study.
Results: During the study period, 1299 patients had an appointment at the epilepsy clinic, where 233 (17.9%) patients missed their consultation, 123 (52.8%) were male, mean age was 35.9 ± 14.42 years. The most frequent cause of non-attendance was forgetfulness of the appointment in 62 patients (26.6%). Two patients died; no patient was reported to have experienced SUDEP. Non-attendant patients showed statistically significant overall prevalence of psychiatric comorbidities (41.6%), particularly depression, anxiety, and interictal psychosis.
Conclusion: Information on non-attendance at various specialist consultations is scarce, and to our knowledge, this is the first study to address non-attendance in patients with epilepsy in Latin America. Improving hospital protocols to reduce non-attendance can increase patient adherence to follow-up, ultimately improving the quality of care in the epilepsy clinic.

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1. Introduction

Medical care provided by specialists is a scarce resource in the public health system. It is expensive and difficult to access for the general population, especially in developing countries [1]. Access to medical care and active patient participation is essential to achieve optimal clinical results and improve quality of life, especially in chronic diseases such as epilepsy.

The World Health Organization reports 50 million people with epilepsy (PWE) worldwide, making it the most common neurological disease, nearly 80% PWE live in low- and middle-income countries [2].

The burden of epilepsy extends beyond the effects of seizures themselves; medical and psychiatric comorbidity have a strong negative impact on quality of life [3]. Where epilepsy is heavily stigmatized, the social and economic morbidity of this condition influences every aspect of a person's life, thus limiting opportunities for education, employment, and self-sufficiency [4]. Recent estimates suggest that epilepsy contributed 0.7% of the global burden of disease in 2010, of which

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Latin America contributed 0.024% [5]. Population studies in Mexico reported a prevalence of 6.8–38.8 lifetime prevalence rates per 1000 inhabitants, which affects more than one million Mexicans [6].

Non-attendance at specialist healthcare appointments remains a major problem worldwide, is considered an indicator of ineffective healthcare services, results in wasted resources and significant healthcare costs; in the UK it is estimated that £600 million a year is lost due to non-attendance at appointments [7]. In patients with epilepsy, a regular follow-up is vital for adequate seizure control, antiseizure drugs' (ASDs) side effects, psychiatric comorbidities, epilepsy surgery planning, or risk of Sudden unexpected death in epilepsy (SUDEP) [8].

The collection and data analysis on epilepsy are essential for planning resources for the growing health needs of patients with this chronic illness. Epidemiological data on PWE are useful not only for academic purposes but also for guiding and evaluating programs to optimize the treatment and quality of life of these patients. Most of the data on patients with epilepsy come from developed countries, where the rates of the disease are different compared to developing regions [9].

The epilepsy clinic at the National Institute of Neurology and Neurosurgery (NINN) collects the sociodemographic and clinical characteristics of PWE regularly in a standardized electronic registry. All patients attending the epilepsy clinic have at least one initial evaluation by the psychiatry department. The appointment is scheduled in an electronic system and in written form on an appointment card. The general objective of this study was to determine the causes of non-attendance at the Epilepsy Clinic. The specific objectives were to estimate the percentage of non-attendance at the epilepsy clinic, to determine clinical characteristics, socio-economic factors, seizure control, and whether the non-attending patients had suffered SUDEP.

2. Material and methods

A prospective and observational study was carried out on patients treated at the Epilepsy Clinic of the NINN in Mexico from August 2015 to June 2016. The study protocol was approved by the bioethics and research committee of the NINN (#122/14). Informed consent was obtained from all participants after the procedure had been fully explained. Study inclusion criteria consisted of patients > 15 years, seen at Epilepsy Clinic with diagnosis of epilepsy according to the ILAE and who agreed to answer a phone interview. Patients who did not agree to participate or were unreachable through phone call were excluded.

A phone call interview was made to all patients who did not attend the epilepsy consultation. This call incorporated *ad hoc* questions to meet the objectives of this study; including causes of nonattendance and rescheduling, economic income, monthly cost of care, seizure frequency, admissions to the emergency department (ER), and mortality. The study questionnaire can be seen as a supplementary material.

The rest of the demographic variables, clinical characteristics, type of epilepsy, pharmacological treatment, and comorbidities were analyzed from the clinical record. Patient data were collected in data sheets and subsequently captured in a data base in SPSS V. 21 program for analysis. Descriptive analysis of nominal variables was performed using percentages and proportions, for numeric variables mean and standard deviation were used. Bivariate analysis was performed for nominal variables using chi-square or fisher's exact test and for numeric variables using *t* Student test or Mann–Whitney *U*.

3. Results

During the year of study 1299 patients had an appointment at the epilepsy clinic, where 233 (17.9%) patients did not attend their consultation and twenty-eight patients (2%) were unreachable by phone call and excluded.

3.1. Clinical and sociodemographic data in non-attendant patients

From the 233 nonattendant population analyzed, 123 (52.8%) were male and 110 (47.2%) were female, patients' mean age was 35.9 ± 14.42 years, 158 (68%) were single, 58% unemployed, and 1.7% had intellectual disability. Most patients depend economically on their spouse or legal guardian (88%), only 22 (9.4%) were economically independent. Average household monthly income was 210 ± 180 USD, with an average monthly expense in epilepsy care of 67 ± 57 USD. One hundred and five (45%) patients had at least one visit to the ER due to uncontrolled seizures during the studied

Table 1
General characteristics of the attendant and non-attendant population.

Population of the Epilepsy Clinic (*n* = 1299) Excluded *n* = 28 (2.2%)	Non-attendant patients *n* = 233 (17%)	Attendant patients *n* = 1038 (79%)	*p*-value (Confidence interval)
Gender	Male 123 (52.8%)	Male 509 (49%)	0.298 (CI 0.87–1.545)
	Female 110 (47.2%)	Female 529 (51%)	
Age	36 ± 14	33 ± 12	0.048 (CI 0.82–4.50)
Years since diagnosis	19 ± 14	17 ± 13	0.215 (CI.,0.44–3.44)
Intellectual disability	*n* = 4 (1.7%)	*n* = 41 (3.9%)	0 0.141 (CI 0.67–1.45)
Marital status	Single 158 (68%)	Single 761 (73.3%)	0.829 (CI 0.692–1.343)
	Married 57 (24%)	Married 247 (23.7%)	
	Divorced 14 (6%) Widowed 4 (2%)	Divorced 24 (2.3%) Widowed 6 (0.6%)	
Residency	Mexico City and metropolitan area 177 (76%)	Mexico City and metropolitan area 741 (71.3%)	0.159 (CI 0.911–1.761)
	Other areas 56 (24%)	Other areas 297 (28.6%)	
Employment status	Unemployed *n* = 134 (57.5%)	Unemployed 581 (55.9%)	0.669 (CI 0.705–1.252)
	Employed *n* = 54 (23.2%)	Employed 280 (26.9%)	
	Student *n* = 45 (19.3%)	Student 177 (17%)	
Type of epilepsy	Structural epilepsy *n* = 141(60%)	Structural epilepsy *n* = 598 (57.6%)	0.082 (CI 0.80–0.91)
	Genetic epilepsy *n* = 52 (22%)	Genetic epilepsy *n* = 205 (19.7%)	
	Cryptogenic epilepsy *n* = 40 (17.2%)	Cryptogenic epilepsy *n* = 235 (22.6%)	
Seizure control	Seizure free > 1 year: 66 (28%)	Seizure free > 1 year: 227 (21.9%)	**0.034 (CI 1.025–1.946)**
	Not seizure free: 167 (71%)	Not seizure free: 811 (78%)	
Antiseizure drugs	Polytherapy *n* = 160 (69%)	Polytherapy *n* = 708 (68.2%)	0.891 (CI 0.752–1.387)
	Monotherapy *n* = 73 (31%)	Monotherapy *n* = 330 (31.7%)	

period. Overall clinical and demographic characteristics of non-attendant patients are described in Table 1.

The identified causes of non-attendance in this population are shown in Fig. 1. The most frequent cause of non-attendance was forgetfulness of the appointment in 62 patients (26.6%). The second most common cause of non-attendance was "personal reasons" referred by the patient or the family as missing the appointment due to interference with work or family issues. Only 6% of patients had already rescheduled their appointment by the time of the interview.

Psychiatric comorbidities presented in 26.3% of attendant patients and in 41.6% of nonattendant patients, of which forty-five (19.3%) had depression, 20 patients had anxiety (8.6%) and 17 had interictal psychosis (7.3%). Two patients died (0.8%), both deaths were related to epilepsy, one had a head trauma during a seizure, and the second one died from complications of *status epilepticus*. No patient was reported to have experienced SUDEP.

3.2. Comparison between non-attendant versus attendant patients

A bivariate analysis was performed comparing the clinical and sociodemographic characteristics of nonattendant versus attendant patients. Twenty eight percent of non-attendant patients were seizure free, in contrast to with 21.9% of attendant patients ($p = 0.034$ (CI 1.025–1.946). Non-attendant patients showed statistically significant overall prevalence of psychiatric comorbidities, particularly depression, anxiety, and interictal psychosis ($p < 0.001$, CI 0.374–0.675) (Fig. 2). Age, years since diagnosis, marital status, employment status, residency location, type of epilepsy, or number ASDs between both populations were not statistically significant, as described in Table 1.

4. Discussion

Epilepsy represents an important economic burden for health systems, individuals and their families, patients' nonattendance leads to poor follow-up, delay in diagnosis, and inadequate control of epileptic seizures, as well as to an inefficient allocation of resources and an increase in hospital expenses.

Most population seen at the NINN are low-income households, with no access to social security, the majority of the non-attendant population is unemployed and financially dependent on their family, where the cost of general medical care, such as transportation, consults and ASDs, can represent up to 30% of the family's monthly income. Missing consecutive visits has shown to worsen epilepsy treatment outcomes and has been identified as an indirect measure of adherence to treatment [10].

The percentage of non-attendance found in our series was 17.9%, similar to other international series of non-attendance in neurology and epilepsy care, as seen in Table 2. Lower non-attendance rates were seen in high-income countries like the UK (9%) [8] and Spain (14–19%) [10,11] where there is overall better healthcare culture and greater financial resources. Low-income countries and rural areas, such as Zimbabwe and Ethiopia, presented much higher rates of non-attendance (>40%) [12,13]. In Kenya, several risk factors have been associated with not seeking medical treatment (traditional religious beliefs, negative attitudes about medical treatment, distance healthcare facilities, paying for ASDs, learning difficulties, focal epilepsy) [14]. Mexico is classified as a middle-income country and although our non-attendance rates were not as high, the reasons why patients do not attend their appointments are similar to those of low-income.

The main cause of nonattendance was forgetfulness of the programmed appointment, previous studies have described similar findings [15,16]. The second cause was "personal problems", mainly referred as unable to have a leave of absence from their work or family issues, also formerly reported [15,17]. Seizure freedom was the third most important cause of non-attendance, we found a significant difference in the rate of seizure freedom between the non-attendant and attendant population, as previous studies have shown that higher control rates result in less adherence to follow-up [8,10]. Other studies have reported transportation difficulties, distance to health services [10,12,13,16], and patients reporting lack of improvement or preferring alternative treatment [13,17,18], as the main reasons for nonattendance, which are summarized in Table 2.

Regarding psychiatric comorbidities, it has been previously reported that PWE have higher rates of psychiatric and somatic disorders compared to the general population [19]. A Canadian study reported a 17.4% prevalence of depression [20], and a meta-analysis indicated 21.3% of depression and 10.2% of anxiety in PWE [21]. In our study, non-attendant patients had a significantly higher incidence of psychiatric comorbidity, reported in 41.6% compared to 22% in attendant patients. The most frequent comorbidity was depression, followed by anxiety, and interictal psychosis, observing a possible bi-modal relationship with non-attendance, whereby people with more comorbidities are less likely to engage and attend their follow-up [22].

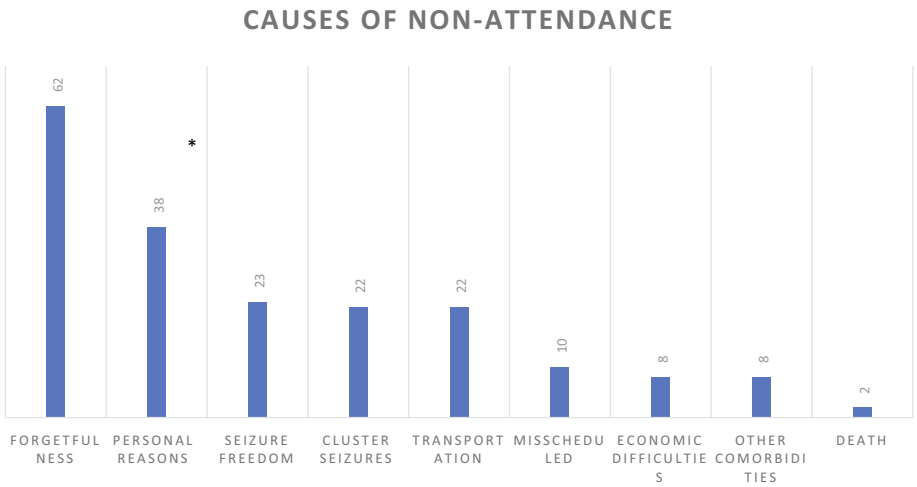

Fig. 1. Causes of non-attendance at the Epilepsy Clinic.

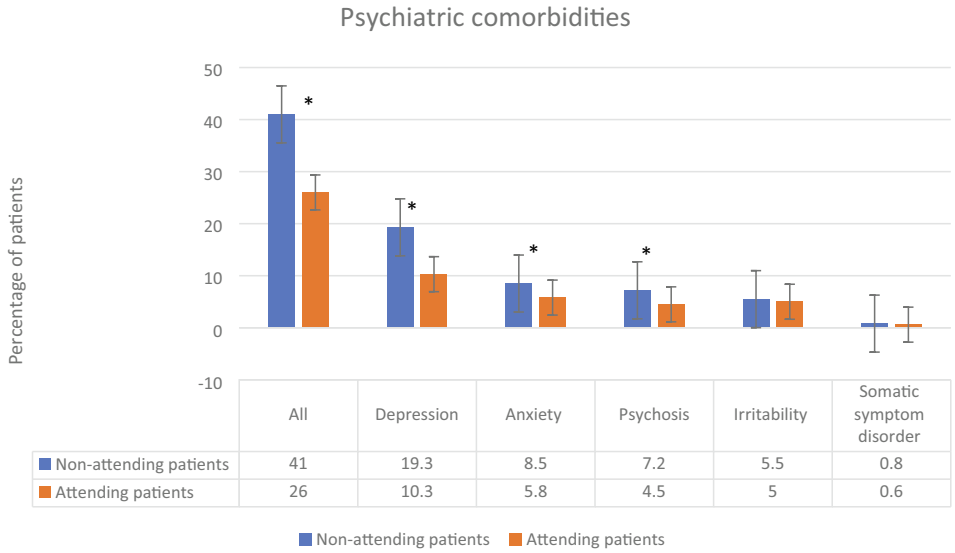

Fig. 2. Psychiatric comorbidities in attendant and non-attendant patients to the Epilepsy Clinic, statistically significant differences are shown with a bold asterisk (*) * = *p-value* = <0.05.

Table 2
Publications of non-attendance in neurology/epilepsy consultation across the world.

Clinic	Author	Year	Country	Population	Percentage of Non-attendance	Causes of Non-Attendance
Epilepsy	Zertuche-Ortuño, et.al.	2021	Mexico	Adult	17.9%	-Forgetfulness 26.6%, -Personal reasons 16.3% -Seizure freedom 9.8%
	Haque, et.al.	2017	Ireland	Adult	18.9% general population 20.2% residential care 24% social housing	-Failure of outpatient appointment notification -Transportation difficulties
	Minshall, et.al.	2017	United Kingdom	Adult	9%	-Not mentioned
	Ibekwe, et. al.	2016	Nigeria	Pediatric	23%	-Financial constraint 42.3% -Interference with school period 30.7% -Alternative treatment 11.5%
	Dewa, et.al.	2014	Zimbabwe	Adult	46.4%	- Shortage of ASDs - Transportation difficulties
	Berhanu, et.al.	2009	Ethiopia	Adult	40%	- Transportation difficulties - Alternative treatment
	Tsai, et. al.	1992	Taiwan	Adult	44%	- No improvement or deterioration
Neurology	Rebolledo, et.al.	2014	Chile	Adult	16%	-Not mentioned
	Al-Faris, et.al.	2012	Saudi Arabia	Pediatric	29.5%	- Wrongly registered Appointments 27.5% - Forgetfulness 22.5% - Busy parents 20%
	Alcolea, et.al.	2008	Spain	Adult	14.4%	–Not mentioned
	Íñiguez-Martínez, et.al.	2003	Spain	Adult	22.9%	–Not mentioned
	Morera-Guitart, et.al.	2002	Spain	Adult	19%	- Transportation difficulties

Identifying the predisposing factors and causes for non-attendance allows cost-effective measures to be carried out to improve compliance at the epilepsy clinic. The loss of appointments hinders adequate treatment and follow-up, it is therefore associated with lack of seizure control, ER visits, and death. Given the high financial implications of nonattendance in our country, there is a need to consider effective strategies to reduce this burden [23].

Limitations of this study include that it was conducted in a single tertiary epilepsy center, so the results may not be generalizable to primary care or even other epilepsy clinics. Not all non-attendant patients were localized through the phone calls and therefore excluded. Timing of appointments at NINN is established by the physician, usually every 4–6 months in patients with controlled seizures or more frequently in difficult cases. The appointment is scheduled in an electronic system and in written form on an appointment card given to the patient; however, there is no appointment reminder system, these could represent a bias in our findings.

Determining the demographic characteristics of non-attendant patients at the NINN Epilepsy clinic will help provide the necessary information to create effective programs to prevent dropouts, thus optimizing services, adherence to treatment, and eventually reduce the treatment gap in our hospital and other epilepsy centers. Past studies have suggested outreach programs, as well as incentivizing appointment attendance with transport vouchers or personalized SMS reminder messages to improve outpatient attendance rates [24–26].

5. Conclusions

To our knowledge this is the first study to address nonattendance in patients with epilepsy in Latin America, reporting a

nonattendance rate of 17.9% at the Epilepsy Clinic, similar to worldwide statistics. Higher rates of psychiatric comorbidities were reported in the non-attendant patients, thus stressing the need of psychiatric consults in PWE. Improving hospital measures such as appointment reminders through what's app messages, email, phone call, or SMS, have shown to help maximize patient's attendance; performing these actions at NINN's Epilepsy clinic and other epilepsy clinics will ultimately enhance the quality of care for PWE. Further research could be the implementation of a system to reduce non-attendance rates and evaluate their effectiveness.

Declaration of interests

The authors have no competing interests to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2021.108202.

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