Epilepsy Diagnosis Delay in a Tertiary Hospital Center: What Facts, for What Reasons?

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Abstract

Objectives   Epilepsy remains a public health problem in developing countries, especially in Morocco. This prospective study was performed to expose new data about the time required to diagnose epilepsy in a tertiary hospital center and the main reasons behind its delay.

Methods   From January 2018 to December 2019, time from first seizure to diagnosis was acquired from 300 patients using face-to-face interview with pre-established sheet at the neurology department in tertiary hospital center (Marrakech, Morocco).

Results   Of the 300 patients, the mean epilepsy diagnosis delay was about 5 years, ranging from 1 month to over 40 years, with an 18 months difference between urban and rural habitation. About 36.4% had a delayed diagnosis of 1 year, 34% delayed by more than 5 years, and 26% delayed above 10 years. The main type of seizures was focal, mainly affecting young male patients. Rural habitation and seizure type impact significantly the delay of diagnosis.

Conclusion   This study revealed considerable epilepsy diagnosis delay with a statistically significant impact of rural habitation and seizure type. New and efficient strategies are needed to be developed to reduce the delay in epilepsy diagnosis and improve epilepsy care.

Keywords
► epilepsy
► diagnosis delay
► reasons
► tertiary hospital center

Introduction

Epilepsy is a chronic neurological disorder with various etiologies and prognosis, characterized by the repetition of spontaneous epileptic seizures within the same person. The incidence of epilepsy is generally taken between 30 and 100/100,000 people per year in industrialized countries, and between 109 and 232/100,000 people per year in developing countries.[1] The prevalence of epilepsy ranges between 4.04/1000 population and 12 or more per 1000 population.[1] In Morocco, an overall estimate revealed that nearly 700,000 people suffer from epilepsy,[2] while the prevalence is over than 1%, based on an epidemiological study of childhood epilepsy performed in Casablanca.[3]

The problem of a late epilepsy diagnosis has been highlighted in developing countries.[4] Medical care remains very basic, with low accessibility to electroencephalogram (EEG) and magnetic resonance imaging (MRI).[5] Very little is known about the extent and reasons behind the delay between first seizure and diagnosis,[6] compared with its consequences on patient's quality of life and the risk of injury related to uncontrolled seizures.[5]

Understanding the reasons behind diagnosis delay is critical, not only for our country but also for all developing countries. In our study, we tried to quantify the epilepsy diagnosis delay in a tertiary hospital center and investigate reasons that contribute to this significant delay.

Methods

Our prospective study covered the period between January 2018 and December 2019. It took place at the Neurology Department of University Hospital of Marrakech. The survey counts 300 patients of both sexes coming directly to our center or after being referred from general hospitals and emergency departments. Patients were included if they had an epilepsy diagnosis delay ≥ 1 month, and had generalized or focal epilepsies defined clinically according to the International League Against Epilepsy "two unprovoked seizures >24 hour apart" with EEG and imaging results (MRI or—if not doable—computed tomography). Exclusion criteria were <1 month of epilepsy diagnosis delay, treatment with an anti-seizure drugs in the past, or any ongoing disease that could influence the measures.

After detailed explanation of the objectives of the study and agreement of the consultants, they were interviewed face-to-face, in dialectal Arabic and/or French according to the choice of patients. We performed a pre-established sheet piloted by the authors. The sheet consisted of two parts containing closed and open questions. The first part concerned demographic details (age, sex) with socioeconomic characteristics, while the second part included information about age at diagnosis, age of onset of seizures, seizures type, frequency of seizures, and treatment received. Diagnosis delay was calculated as the difference between age at diagnosis and age of seizure onset.

The data was collected and processed by SPSS (Statistical Package for the Social Sciences) version 22 in French. The statistical treatments are based on descriptive analyses (frequency means, standard deviation...) and analytical as well (Tests of association between the variables) with significance set at $p < 0.05$.

Results

The demographic characteristics of the 300 patients with epilepsy are summarized in ►**Table 1**; the mean age was 23 years, ranging from 1 to 82 years. Only one-third of the patients were noted as married.

Regarding the seizure type, most had focal seizures (187 cases; 62.3%), followed by generalized seizures (113; 37.7%). The median age at first seizure was 15 years (range: 1–75 years) (►**Table 2**).

A delay in diagnosis was recorded for 300 patients, with a raw mean of 5.4 years (range: 1 month–43 years). About 70% of patients had a delay of 1 year to 10 years between the first seizures and medical diagnosis (►**Table 2**).

The impact of habitation on the time from first seizure to medical consultation was more significant; in rural areas the average time to diagnosis was around 5.5 years, while in

Table 1 Demographic characteristics of patients at the time of attendance at the neurology department ($n = 300$)

Variables	Number of patients	Percentage (%)
Gender		
–Male	173	57
–Female	127	43
Civil status		
–Married	107	35.5
–Single	193	64.5
Socioeconomic level[a]		
–Lower class	193	64.3
–Middle class	104	34.6
–Higher class	3	1.1
Residence		
–Rural	190	63.3
–Urban	110	36.7
Age		
<5 y	30	10
5–10 y	68	22.7
11–20 y	107	35.7
21–30 y	54	18
>30 y	41	13.6

[a]The three classes have been defined according to this Moroccan report "La stratification sociale marocaine: Note de Synthèse".[7]

urban areas, the average was 4 years, with a difference of 18 months (►**Fig. 1**). We also found that focal seizures were associated with a longer delay compared with patients with generalized seizures (►**Table 2**); the difference was around 1 year.

There was no significant association between epilepsy diagnosis delay and marital status, gender, or socioeconomic level ($p > 0.05$) (►**Fig. 2**).

Discussion

Through this study we found a delay in epilepsy diagnosis: 36.4% had a delay in diagnosis of 1 year, 34% more than 5 years, and 26% above 10 years, with an average of 5.4 years. Compared with other studies in developed countries, the difference seems clearer. An Australian study revealed delay in diagnosis of more than 2 years in only 14% of the cases; other researchers also noted comparable results.[6] Unfortunately, few studies from developing countries on this subject have been published. In the light of our data, we tried to evaluate the role of some factors on delay in seeking medical assessment.

Misdiagnosis of epilepsy could be a factor responsible for diagnostic delay particularly in focal seizures. While we did not investigate this aspect in the current study, probable reasons for misdiagnosis include confusion with other

Table 2 Summary of first/type seizure and diagnosis delay ($n = 300$)

| Variables	Number of patients	Percentage (%)	
Age at first seizure			
<5 y	90	30	
5–10 y	70	23.4	
11–20 y	85	28.4	
21–30 y	35	11.6	
>30 y	20	6.6	
Diagnosis delay[a]			
<1 y	11	3.6	
1–5 y	109	36.4	
5–10 y	102	34	
>10 y	78	26	
Seizure type	Number of patients	Percentage (%)	Average of diagnosis delay (y)
Focal seizures	187	62.3	5
Generalized seizures	113	37.7	4

[a]Diagnosis delay is the time from first seizure to first medical consultation calculated by the difference between age at diagnosis and age at first seizure.
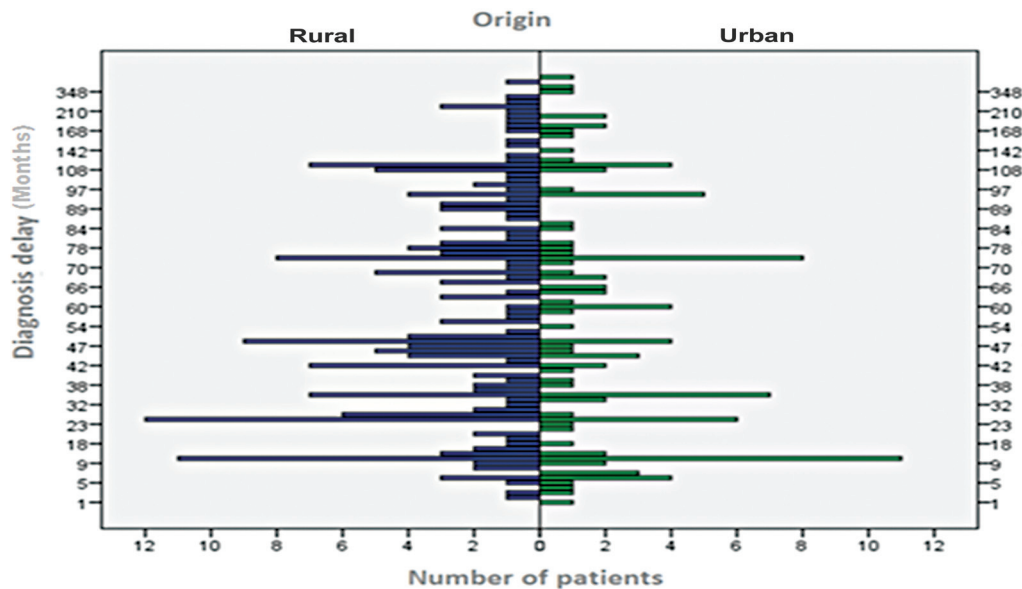
Fig. 1 Diagnostic delay (in months) correlated to origin and number of patients ($n = 300$). We found that patients from rural areas had more epilepsy cases and a higher diagnosis delay than patients from urban areas.

cardiovascular, digestive, or psychiatric pathologies. The excessive focus placed on tonic–clonic seizures for recognizing epilepsies by general practitioners is also a possible reason. In Morocco, no accurate statistics on diagnostic errors are available. Misdiagnosis in epilepsy has been highlighted recently in many papers; it ranges between 2 and 71%.[8] Many general practitioners charged with diagnosing epilepsy do not have sufficient knowledge of the clinical features of epileptic and nonepileptic seizures and most of them do not have easy access to the full range of appropriate investigations.[9]

Our results did not find a significant association between socioeconomic disadvantages and delay to first medical consultation. High cost of antiepileptic drugs, medical investigations, lack of social insurance, and stigma seem to be important factors responsible for diagnostic delays. Unfortunately, this was not evaluated in our study. Recent studies investigating the knowledge, beliefs, and attitudes of public toward epilepsy have revealed that the lack of information and illiteracy has a bearing on the time from first seizure to first attendance at a medical facility.[10–12]
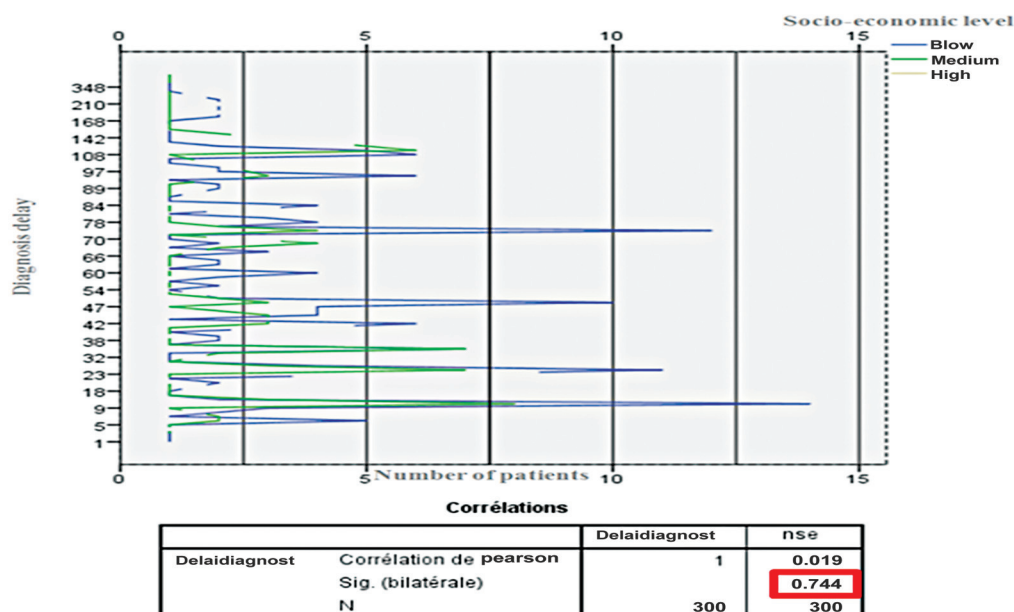
Fig. 2 Diagnostic delay (in months) correlated to socioeconomic level and number of patients ($n = 300$). The blue line refers to the lower class; the green line refers to a middle class, while the white line refers to the higher class. We did not find a statistically significant association between epilepsy diagnosis delay and socioeconomic level ($p > 0.05$).

The findings from this study indicate a considerable delay in diagnosing epilepsy with a statistically significant impact of rural habitation and seizure type, while insignificant association with marital status, gender, and socioeconomic level. We discussed the main factors that might be involved in this delay in recognition of the epilepsy onset. To provide rapid and high-quality epilepsy care, new strategies in sensitization and management were adopted. We diffuse educational programs through many applications (WhatsApp, Facebook, and Zoom). Our Web site (neuromarrakech.com) provides information about epilepsy in two languages (Arabic/French). We frequently employ teleconsultation between medical centers in Morocco and Africa, because it overcomes the shortage of human resources challenges posed by long distances and geographic factors.[13]

Limitations of This Study
Our study has certain limitations. At first, the duration of the study was limited to 2 years in a single medical center, with a total number of 300 patients with delayed diagnosis of epilepsy. An additional limitation was the possibility of bias in the acceptance of cooperation and the clarity of responses from all patients, especially patients with intellectual disabilities and young children, where parents/caregivers may give false or overstated answers.

Conclusion

The findings from this study revealed considerable epilepsy diagnosis delay with a statistically significant impact of rural habitation and seizure type, while insignificant involvement of marital status, gender, or socioeconomic level was noticed on the delay of epilepsy diagnosis. A global approach, defined by the economic and medicosocial status of the country, is essential to develop new efficient strategies with clear guidelines to make the ways of current care better not only in our country but also in all developing countries.

Conflict of Interest
None declared.

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