



Epilepsy-associated levels of perceived stigma, their associations with treatment, and related factors: A cross-sectional study in urban and rural areas in Ecuador



Jaime Luna^{a,b,c}, Mandy Nizard^{b,c}, Danielle Becker^d, Daniel Gerard^e, Alejandro Cruz^f,
Voia Ratsimbazafy^{b,c,g}, Michel Dumas^{b,c}, Marcelo Cruz^h, Pierre-Marie Preux^{b,c,i,*}

^aEcuadorian Academy of Neuroscience, Quito, Ecuador

^bINSERM, U1094, Tropical Neuroepidemiology, Limoges, France

^cUniv. Limoges, UMR-S 1094, Tropical Neuroepidemiology, Institute of Neuroepidemiology and Tropical Neurology, CNRS FR 3503 GEIST, F-87000 Limoges, France

^dHospital of the University of Pennsylvania Medical Center, Penn Epilepsy Center, University of Pennsylvania Medical Center, USA

^eDepartment of Access to Medicine, Sanofi, France

^fNeuroLogic International, Quito, Ecuador

^gCHU Limoges, Department of Pharmacy, Limoges F-87000, France

^hFundacin Tierra Nueva, Quito, Ecuador

ⁱCHU Limoges, CEBIMER, Limoges F-87000, France

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ABSTRACT

Background: Epilepsy is felt to be a stigmatizing condition. Stigma has been considered one of the major factors contributing to the burden of epilepsy and to the treatment gap. Stigma has a negative effect on the management of people with epilepsy (PWE). Furthermore, lack of information and inappropriate beliefs are still the factors that most contribute to stigma and discrimination. In this study, we assessed the level of perceived stigma in urban and rural areas and we report their association with in antiepileptic drug (AED) use, effects on seeking medical care, and stigma-associated factors.

Methods: A cross-sectional study in urban and rural areas in Ecuador from January 2015 until May 2016. People with a confirmed diagnosis of epilepsy were included using three sources of information. The survey was implemented through a questionnaire to determine perceived stigma and evaluate the factors associated. The perceived stigma was measured using the revised Jacoby's stigma scale to detect differences in levels of stigmatization. Access to treatment was evaluated through self-report of AED use, and attainment of medical care and stigma-associated factors were assessed. Furthermore, a multivariate analysis adjusted for possible confounders was performed using stigma as the outcome variable.

Results: A total of 243 PWE were interviewed, 65.8% reported feeling stigmatized and 39.1% reported a high stigmatized level. We found a significant difference in high stigma perception in the urban area compared to the rural area. However, the lack of use of AEDs was significantly higher in the rural areas. No significant correlation was found between use of AEDs and the levels of perceived stigma. PWE who did not talk about their condition and those who did not feel well informed about their epilepsy had significantly higher perceived stigma levels. Additionally, the multivariate analysis demonstrated that area, educational level, type of seizure, talk about epilepsy, and information were associated with perceived stigma.

Conclusion: The stigma perception was relevant in all PWE. We found a higher stigma level perception in the urban compared to rural area. Moreover, the lack of treatment was a serious problem mainly in rural areas. Even though we did not find that perceived stigma was associated with AED use, our study pointed out the influence of educational level and information related to stigmatization. Consequently, a coordinated effort to reduce stigma should include strategies focused on PWE education and information about their condition.

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* Corresponding author at: Institut de Neurologie Tropicale, Inserm U1094, Faculté de Médecine, 87025 Limoges Cedex, France.

E-mail addresses: jaimeandreslunam@gmail.com (J. Luna), pierre-marie.preux@unilim.fr (P.-M. Preux).

1. Introduction

Epilepsy is the most common chronic neurological disorder worldwide with a global estimate of about 70 million cases of lifetime epilepsy. Nearly 80% of persons with epilepsy are found in developing countries [1]. It is a major public health problem, especially in Latin America, where the median lifetime epilepsy (LTE) prevalence is 17.8/1000 and the median prevalence of active epilepsy (AE) is 12.4/1000 [2].

AEDs are the simplest and safest means of controlling epilepsy [3]. Early and appropriate care in more developed countries achieves seizure control in 70–80% of cases; allowing people to live near-normal lives [4]. Unfortunately, a substantial treatment gap is evident in developing countries. About 60% of patients with epilepsy receive no antiepileptic drugs [5]. When left untreated, epilepsy can result in multiple health problems [6] and can have serious physical and psychological consequences. It is also associated with social consequences, including human rights violations and discrimination [7].

Stigma related to epilepsy often causes suffering independent of the physical manifestations of the disorder and affects how people respond to the disease burden [8]. People with epilepsy (PWE) are still viewed with fear, suspicion, and misunderstanding and are subject to horrendous stigma [9] that appears to be influenced by psychosocial and cultural factors [10]. Furthermore, lack of information and inappropriate beliefs are still the factors that most contribute to stigma and discrimination [11]. Lack of information regarding epilepsy is common in resource-poor countries [12]. Additionally, the concern for stigma leads to several consequences including the lack of access to treatment [13].

In this study, we measured perceived stigma in urban and rural areas developing country through a revised and validated scale which was designed to detect more subtle differences in levels of perceived stigma. Also we report the associations between the levels of perceived stigma and treatment, specifically, AED use and the seeking of medical care and correlation between stigma-associated factors.

2. Methods

A descriptive cross-sectional study was performed in urban and rural areas in Ecuador from January 2015 until May 2016.

2.1. Study area and population

Ecuador is a South American country located on the west coast of the continent. It has a total population of 14,483,499 inhabitants. Catholicism is the most common religion and Spanish is the most spoken language, followed by Quechua, the language originally spoken by the Indigenous.

The study took place in the urban metropolitan area of Quito and the rural area of Napo province, an Amazonian region. Furthermore, a door-to-door (DTD) survey was performed in both study areas.

Quito, capital city of the Republic, is the second most populous city in Ecuador. It is located in the Andes Mountains, nearby by high volcanoes, with an elevation of 2850 m above sea level. The urban area of Quito has an area of 320 km² and a population of 1,609,418 inhabitants. It has a majority ethnicity of Mestizo, whose people are of mixed ethnic ancestry (American Indian and European descent). It is divided into 32 districts. The DTD survey in this area was performed in one district: Turubamba. It is a southern district in the urban area of Quito with a population of 56,169 inhabitants. Turubamba has a district area of 17.19 km², consisting of 18 zones.

Napo is a province in the Amazonian jungle which is less developed and is without much industrial presence. It has an area of 12,542 km² and a population of 103,697 inhabitants. The population is mainly native Indigenous who speak both Spanish and/or Quechua.

The province of Napo has 5 districts. The DTD survey was performed in one district population: Archidona. It is a rural population in the Amazonian region with 5748 inhabitants and has only one zone.

All the data correspond to the census of 2010 developed by the National Institute of Statistics and Census in Ecuador (INEC).

2.2. Sources of information and case-finding

The study sample consisted of a group of PWE obtained through 3 sources of information in both study areas: medical records, key informants, and a DTD survey in each community. The same sources of information and case-finding methodology procedures were used in the urban and the rural areas to identify PWE.

The medical records were obtained from health care centers in the study areas, using the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) code G40 established for Epilepsy, which is the standard diagnostic tool for epidemiology, health management, and clinical purposes recommended by the World Health Organization (WHO), to identify the patient registry in the health care facilities. The main local public and private health care centers were surveyed in the urban area and we decided to survey exhaustively the health care facilities in the rural area because of their small number. The key informants were health community stakeholders. We included PWE without an age restriction and if the participant was younger than 15 years of age, their parents answered the survey.

The DTD survey was developed in urban and rural districts using a two-phase design. In the first phase, approximately 1500 people were screened in each DTD survey district. A probabilistic sampling using a probability proportion to size was performed. Furthermore, participants had to meet the following inclusion criteria: people who had lived for more than 6 months in the study area and were aged greater than or equal to 15 years old. Interviewers, who were health care workers of the primary health care system, received training about epilepsy and the interview technique in order to collect the surveys. They delivered the epilepsy research survey in tropical and subtropical countries developed by the Institute of Epidemiology and Tropical Neurology, Limoges (France) to determine epilepsy suspect cases. The second phase consisted of evaluation and confirmation of the suspect cases by an expert neurologist. All the PWE identified in the DTD survey were included.

2.3. Data collection

The questionnaires were administered to people with a confirmed diagnosis of epilepsy after written informed consent was obtained. All the participants were individually interviewed to complete a questionnaire. The interviews were conducted by 2 specialist investigators, a physician and an epidemiologist. The questionnaire was translated from Spanish to Quechua and vice versa by two independent certificated translators. The investigators were assisted in the interview process by a trained local community health care person, who was a Spanish–Quechua native speaker.

People with epilepsy were surveyed using questionnaires to assess stigma, the use of AEDs, and the seeking of medical care. Moreover, we evaluated the factors associated with levels of perceived stigma.

2.3.1. Stigma scale

We used a revised scale that has been validated by Jacoby et al. using three questions posed to PWE, which inquired that because of their epilepsy, they feel that other people are: 1. uncomfortable with them, 2. treat them as inferior, and 3. prefer to avoid them. PWE have to answer each item using the following scale: 0 = not at all, 1 = yes, maybe, 2 = yes, probably, 3 = yes, definitely. A greater score in the scale represents a high level of perceived stigma. The

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