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Sociocultural dimension of epilepsy: An anthropological study among Guaraní communities in Bolivia—An International League Against Epilepsy/International Bureau for Epilepsy/World Health Organization Global Campaign Against Epilepsy Regional Project

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ABSTRACT

This study was performed to analyze sociocultural beliefs about epilepsy among Guaraní communities in Bolivia. People with epilepsy, their family members, the general population, and local health care personnel were interviewed about the meaning of and beliefs, feelings, and practices concerning epilepsy. Epilepsy is called *mano-mano*, a term that means being in a constant passage between life and death. The disease is attributed mainly to a failure to observe a fasting period and to other eating habits. Natural remedies are the most recommended treatments even though half of respondents reported that antiepileptic drugs may be effective. The concept of epilepsy as an embodied disease with natural causes appears to differ from that documented in other traditional societies. People with epilepsy do not represent a threat to the community, which seems to have an attitude aimed at their protection. Moreover, people from these communities appear to favor a combination of biomedical and traditional care systems.

1. Introduction

The epilepsy treatment gap, defined as the proportion of people with epilepsy (PWE) who require but do not receive appropriate treatment [1], varies worldwide, with a significantly higher peak in lower-income countries and rural areas [2,3]. In most of these settings it exceeds 75% for active epilepsy [4], reflecting a multidimensional nature linked to the lack of health resources, personnel, infrastructure, and treatment programs [5]. Moreover, the stigma associated with epilepsy and the cultural attitudes and beliefs of the local population often hinder adequate management and, thus, are considered additional factors that may contribute to the treatment gap [6–10].

A study conducted in the southeastern part of Bolivia (Cordillera province) among the Guaraní, a rural native society of South America, reported that only 10.5% of the identified PWE had ever taken antiepileptic drugs (AEDs) longer than 2 months, resulting in a treatment gap near 90% [11,12]. A 10-year follow-up study carried out on the same population in 2009 showed a substantially similar situation: 26.7% of PWE had taken AEDs for at least 2 months, but only 12.7% continued treatment for at least 1 year [13].

The Guaraní have a traditional magical and natural medical system as well as rites and traditions of ancestral origin. Knowledge is still orally transmitted and epilepsy is a well-recognized disease. Different surveys have reported that the cultural basis and preserved traditions of American societies influence their perception of diseases, social behavior, and maintenance of local treatments [14–17], affecting the relationship with public health services. The anthropological approach could represent an efficacious method to study this aspect and could also provide significant information to improve health strategies [18] and narrow the treatment gap at the community level. The latter point represents one of the main aims of the International League Against Epilepsy (ILAE)/International Bureau for Epilepsy (IBE)/World Health Organization (WHO) Global Campaign against Epilepsy (GCAE) Out of the Shadows initiative [19]. This study was performed as a part of the first phase of the recently approved GCAE

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Regional Project in Bolivia. The aim was to analyze sociocultural beliefs about epilepsy among the Guaraní, by exploring meaning attached to the disease and describing attitudes, traditional practices, and treatment strategies. The knowledge obtained might provide the basis for development of a biomedical program to treat epilepsy in this area.

2. Methods

2.1. Study setting

This work comprised anthropological fieldwork performed from January to March 2009 in the communities of Cañon de Segura and Rodeo in Bolivia (Latin America). The communities are located in the area of Camiri (Cordillera province), a city in the southwestern section of Santa Cruz Department in the area called the Gran Chaco. The study populations consisted of native Guaraní and descendants of intermarriage between Spanish colonists and the native tribes (mestizos). The Guaraní are one of the largest indigenous societies of Latin America. The country that is home to the largest group is Bolivia, with around 80,000 Guaraní living in the Gran Chaco area, according to the data of the Guaraní People Assembly (APG), an entity that represents more than 300 Guaraní communities of this country. Inhabitants in the rural areas near Camiri number about 3300 [20]. The community of Cañon de Segura has a population of 208, and the community of Rodeo, 322, according to the last census. Among the Guaraní, the first language is Guaraní, taught both informally within the communities and formally in public school. Currently, the language is still the main characteristic binding Guaraní society, even though most younger Guaraní are bilingual (speaking Spanish and Guaraní). In rural areas, the Guaraní live in poor dwellings and the local economy is based predominantly on agriculture and animal breeding. Cordillera province is administratively divided into 10 areas covering 86,245 km^2, and the health care infrastructure in the province comprises a district hospital, nine area hospitals, and rural health centers situated in each community and managed by nurses and local health care personnel.

2.2. Sample

All the people included in the survey were Guaraní living in the communities at the time of the study. Community leaders and local health workers identified PWE living in the areas, their family members, and other relevant community members able to provide information about epilepsy and traditions (like the community's elders).

2.3. Procedures

The fieldwork was divided into two phases. As a first step, an ad hoc selected sample of the above-mentioned groups was invited to participate in focus group discussions (FGDs). The second phase of the work consisted of semistructured interviews of all responders identified in the communities as well as interviews of local health care personnel. The study was conducted with the agreement of the National Department of Epidemiology of the Ministry of Social Welfare and Public Health and with the support of the Guaraní political organization (APG).

2.3.1. Focus group

Two focus groups consisting of 10 persons each were held. FGDs were conducted in the local language by health workers and personnel (Spanish/Guaraní bilingual) of the Centre for Anthropological Research of the Teko Guaraní, an institution aimed at restoring and enhancing Guaraní culture. The discussions took place at local health facilities. Anthropologists introduced topics for discussion focusing mainly on local terminology, the meaning attached to having epilepsy, orally transmitted beliefs, personal experiences, feelings toward PWE, and practices usually used by the communities to heal this disease. Each discussion was recorded. The aim of these FGDs was to to look at people's beliefs, attitudes, and opinions concerning the major topics during the first phase and then explore this information further during the second phase comprising the interviews.

2.3.2. Interviews

Semistructured interviews were conducted with PWE, their family members, the general Guaraní population, and community elders. The interviews were conducted in the native language and comprised 29 open-ended questions to encourage extended responses and explanations. Demographic characteristics were also recorded. Questions evolved from the FGDs covered presumed causes of epilepsy; actions and factors that could promote the disease; individual and community attitudes toward PWE such as prohibitions, forbidden activities, contacts, or places; traditional treatment options; knowledge of medical and social practices; identification of persons capable of dealing with the disease; places in which treatment should be carried out; and local perceptions regarding the biomedical approach (attitudes toward doctors, level of confidence). Separate interviews were conducted with local health care personnel focusing not only on their sociocultural vision of epilepsy, but also on the relationship between the communities and local health specialists and facilities.

2.4. Data analysis

Focus group discussions were recorded, and the transcripts were translated and reviewed by the research investigators. Qualitative analysis was performed by anthropologists who identified the main recurrent themes and subthemes, which were subsequently listed in tables and coded for retrieval and analysis. Quantitative data obtained by the interviews were processed using Stata Version 10 (Stata Corp., College Station, TX, USA) and Windows SPSS (Statistical Package for Social Sciences) Version 14.0 (SPSS Inc., Chicago, IL, USA). Results for quantitative variables are expressed as means, and those for qualitative variables, as frequencies and percentages.

3. Results

3.1. Sample characteristics

The questionnaire was administered to 47 people, 22 in Cañon de Segura and 25 in Rodeo. The study sample comprised 19 men and 28 women (M/F ratio: 0.68), and the mean age was 41.4 ± 15.0 years (range: 15–86). Five respondents had epilepsy, 10 were family members of PWE, 7 were community elders, and 25 were other members of the community.

3.2. Guaraní view on epilepsy

3.2.1. Meaning of the term

Before investigating the origin, causes, and treatment of epilepsy in Guaraní communities, we focused on the local terminology used to refer to seizures and its meaning. Among the Guaraní, epilepsy is called *mano-mano*, which literally means “die-die” and refers to the concept of death with a notion of frequency (die several times) and also of being in a constant passage between life and death. In other terms, this word means always being on the border between life and death, reflecting the fact that *mano-mano* produces a constant interruption of life or a "partial death.”

3.2.2. Knowledge about epilepsy and its causes

With respect to the nature and causes of epilepsy, the majority of respondents (45.0%) indicated an unknown origin, 21.0% a natural origin, 15.0% a social origin, and 10.0% a supernatural origin. However,