

Closing the epilepsy treatment gap in Bolivia: Three decades of initiatives

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Gran Chaco region of Bolivia. Credit: International League Against Epilepsy

The epilepsy treatment gap in Latin America is approximately 60%, but the treatment gap in rural areas of the region can reach 90%. In Bolivia,

contributors to the treatment gap are similar to factors in other remote, lower-resource areas: A lack of trained medical staff. Expensive and inconsistent supplies of antiseizure medications. Cultural beliefs and stigma may prevent people from seeking Western-style medical care for epilepsy, though they often visit traditional healers.

Since 1994, Alessandra Nicoletti, from the University of Catania, Italy, and colleagues from Bolivia and Italy have been seeking ways to reduce the treatment gap in the Gran Chaco region of Bolivia. The Gran Chaco is a lowland region of South America that covers southeast Bolivia, western Paraguay, northern Argentina, and parts of Brazil. It is extremely rural and remote. Bolivian residents of the Gran Chaco are mostly Guaraní [native people](#). Communities are isolated, and dwellings lack electricity and running water.

The research activities are a long-lasting collaboration between the University of Catania and the University of Florence, in concert with local neurologists and the support of local institutions, such as the Assembly of Guaraní People and the Ministry of Health. Many of the projects were carried out as part of the Global Campaign Against Epilepsy, a joint initiative between ILAE, the World Health Organization, and the International Bureau for Epilepsy. Nicoletti said the projects have reduced the treatment gap from 90% to 50%.

Screening and follow-up of people with epilepsy

The researchers began their first epidemiological survey in Cordillera Province—the home of the Gran Chaco region in Bolivia—in 1994. At that time, the province held about 56,000 rural inhabitants. Researchers screened approximately 10,000 people for epilepsy and other neurological disorders: 1,130 screened positive and 1,027 of them were evaluated by Dr. Nicoletti, who spent more than a year in the region to conduct evaluations.

She diagnosed 124 people with epilepsy. Only 10.5% had previously received treatment for at least two months, resulting in an estimated treatment gap of about 90%.

Ten years later, the researchers tracked down nearly 90% of the original cohort. Approximately 27% had received treatment for at least two months, reducing the treatment gap to 73%. Although the cohort's mortality rate was not significantly higher than that of the general population, an increased mortality risk was found for people with remote symptomatic epilepsy (SMR 3.0; 95% CI 1.2–6.3).

About 44% of cohort survivors had been seizure free for more than 5 years, but only 10% of those who were seizure free had received treatment for more than one year.

While the remission rate in the cohort was similar to rates reported in similar studies, the treatment rate was comparatively low. "The retrospective design of the study does not allow us to exclude underrepresentation of more severe forms of epilepsy that possibly were missed from the prevalence survey, due to supposed higher case mortality."

Nicoletti also said it is impossible to exclude that some cases of functional seizures or syncope may have been misdiagnosed as epilepsy. Finally, she said another contributor to the high remission rate may be the high prevalence of neurocysticercosis in the cohort. "About 30% of the cohort fulfilled diagnostic criteria for neurocysticercosis," said Nicoletti. "Thus we cannot exclude that some active cases evolved into calcified neurocysticercosis, possibly leading to remission."

Cultural aspects and stigma

Nicoletti and colleagues undertook [an anthropological study and survey](#),

as well as a [study on epilepsy stigma in the region](#). The anthropological study found that in Guaraní communities, epilepsy is called "mano-mano," a term that literally means "die-die." People who have seizures are considered to be in a state between life and death.

The survey found that although 45% of respondents said the cause of epilepsy was unknown, 96% of respondents said that some aspect of human behavior—such as consuming forbidden food, or failure to observe a period of fasting—could cause epilepsy. Supernatural causes were rarely mentioned.

Natural remedies and special baths were the most recommended treatments in these communities, and some respondents considered the lunar cycle important in treatment. When asked about seeking treatment from [health professionals](#), respondents answered that a shaman's assistant (34%), community member with knowledge of treatments (23%), or shaman (19%) was best positioned to care for people with epilepsy. Only 13% said that medical doctors were appropriate.

However, when specifically asked about the appropriateness of biomedical care, half of respondents said that taking antiseizure medications could be effective. One-fourth of respondents said that medical doctors do not provide proper explanations about epilepsy, and one-fifth said they were cold and detached. Local nurses were more accepted than medical doctors.

Most respondents—83%—appeared to favor a combination of biomedical and traditional medicine. Some said that traditional medicine should be tried first, and people should only consult a medical doctor if traditional medicine does not help.

Financial reasons also may drive a preference for traditional healers, said Nicoletti. One of her group's studies found that the cost of antiseizure

medications was a barrier to care in at least 20% of people. "Generally, traditional healers can accept other forms of payment: for example, a chicken," she said. "The economic aspect is another important issue."

Unlike many other cultures, stigma was not pervasive in these rural communities. Survey respondents did say that people with epilepsy should not be in contact with children (47%) or pregnant women (31%), which suggests a belief that epilepsy is transmissible to more vulnerable populations. Other beliefs—that people with epilepsy should avoid heavy work or traveling alone—appear to stem from an attitude of protecting the person with epilepsy from harm.

Changing survey methods to reduce false positives

The research team completed a second extensive epidemiological survey in 2010-2012, covering 114 rural communities located in two municipalities of the Cordillera province. In contrast to the two-stage survey completed in 1994-1996, Nicoletti and colleagues used a three-stage survey, with Stages I and II administered at the same time.

The three-stage design was meant to reduce time and cost compared with the two-stage design, in which the entire population had to be interviewed face to face. The researchers validated the survey and three-stage design with a study including 792 households, and found high levels of sensitivity and specificity (76.3% and 99.6%).

Stage I consisted of a single question asked of the head of each household: Has someone of your family (including yourself) ever had a fit with loss of consciousness, without awareness of what was happening and/or uncontrolled limb movements, lasting more than one minute?

If the answer to this question was "Yes," the surveyor confirmed the answer with the appropriate person, and asked that person five questions

(Stage II):

1. Did you pass urine/stool in your clothes during the episode?
2. Have you ever injured yourself or had tongue/cheek bite during the episode?
3. Was there any frothing coming from your mouth during the episode?
4. Have you ever had such an episode while asleep?
5. Do you remember what happened during the episode?

Table 1. Epidemiological studies in areas of the Gran Chaco region of Bolivia

	1994-1996	2010-2012	2017 ^o
Number screened	10,000	18,907	3,562
Positive screens	1,130*	200	45
Epilepsy diagnoses	124	136	33
Lifetime prevalence	9.5/1,000	7.2/1,000**	5.8/1,000**
Estimated treatment gap	90%	70%	50%***

^o Validation survey

*Screened positive for different neurological disorders

**Tonic-clonic seizures only

***Personal communication, unpublished data

Credit: International League Against Epilepsy

People answering "Yes" to at least one of these questions were screened as positive and underwent an examination by a neurologist (Stage III).

"We were only detecting people affected by tonic-clonic seizures," said Nicoletti. "This is in agreement with the WHO recommendation that tonic-clonic seizures are the priority in this type of setting."

The three-stage design was meant to reduce the number of false-positive screenings, thereby reducing the time and resources needed to evaluate people. Compared with the two-stage design used in 1994-1996, many fewer people screened positive .

At the end of Stage II, 200 people screened positive and 185 (92.5%) of them were examined by neurologists at Stage III. Of those, 136 were diagnosed with epilepsy. Of the 136, 30% were being treated with anti-seizure medications at the time of the survey, resulting in a treatment gap of approximately 70%, lower than the gap established in the inaugural study and similar to the treatment gap calculated in the 10-year follow up study.

Stigma reduction through education

Nicoletti and colleagues completed studies on epilepsy knowledge, stigma, and quality of life in many areas of Bolivia. Key subjects from each community were randomly selected to be part of the research. Before and after attending an educational program, participants completed a questionnaire to assess their knowledge, attitudes, beliefs, and practices about epilepsy, a validated Stigma Scale of Epilepsy (SSE) and Quality of Life in Epilepsy Inventory-10 (QOLIE-10).

The research found significant improvements in knowledge, attitudes, and practices toward epilepsy after the educational program, as well as a reduction in stigma. People with epilepsy who participated in the program had reductions in depression, memory difficulties, work issues, social issues, and seizure-related worry.

The researchers also initiated training programs for medical and non-medical health workers to improve their knowledge about epilepsy. "It is particularly important to improve knowledge of the non-medical community health workers," said Nicoletti. "They live in the communities and play a central role in the recognition and management of epilepsy in these remote areas."

Third epidemiological survey

The third iteration of the epidemiological survey began in 2019. The study included all 25 rural communities in the Isozo area of the Gran Chaco region, which includes approximately 8,300 people, most indigenous Guaraní.

Though it was meant to follow the same three-stage process as the previous survey (2010-2012), this survey was interrupted by the COVID-19 pandemic. In an effort to continue the project, the researchers used telemedicine appointments to confirm epilepsy diagnoses and manage treatment.

The survey found 38 suspected cases of epilepsy in Stage II; 25 underwent a complete neurological evaluation (12 of them through telemedicine) and 22 were diagnosed with epilepsy.

The impact of stigma on prevalence estimates

While the 2019 survey was under way, educational and community awareness campaigns were carried out in this area. Awareness campaigns were run by a local anthropologist and a specialized nurse. The campaigns appeared to have an effect: In the months after the door-to-door screening and awareness campaigns, 22 people contacted community health workers and general practitioners to report a history

of seizures. They said they had denied having seizures during the screening, but the messages of the educational and community awareness campaigns eventually led them to seek medical attention. Of the 22, 15 were evaluated and 11 were diagnosed with epilepsy.

Overall, 33 people were diagnosed with epilepsy, with one-third self-reporting symptoms after the formal screening had been completed. This phenomenon suggests that stigma and fear may produce artificially low epilepsy prevalence estimates, which may have a ripple effect on resources, medication supplies, and policy.

"The educational and awareness campaigns are very important to reduce stigma and to improve knowledge, but they must be carried out with the respect of the local culture," said Nicoletti. "If possible, they should integrate traditional healers, who usually live in the rural communities and are part of the population."

Technology tools for rural care

Nicoletti and colleagues developed and validated a Spanish version of a smartphone app (Epilepsy Diagnosis Aid) to help confirm the need for neurological evaluation in cases of suspected epilepsy. This app was developed and validated in India and Nepal. It asks a series of questions and provides a probability score. In testing, the app had a sensitivity of 92% in the rural Bolivian setting. It was used in the third epidemiological survey (2019-2021) by community health workers.

The smartphone app and the use of teleconsultation may represent valuable tools for epidemiological research in lower-resource regions, said Nicoletti. Given the widespread use of mobile phones, the app may support community health workers in correctly identifying people with possible epilepsy in their communities and its use can allow to reduce the number of false positives in Stage III, reducing the need for neurologist

consultations. Video consultation allowed the researchers to continue the study during a pandemic; the technology also reduced the need for long-distance travel.

"In the end, [the pandemic] was an opportunity to test the usefulness of telemedicine and teleconsultation in this remote area," she said. "It was well accepted by the population and the community health workers. And I think that it's really a great opportunity to reduce the costs and time of traveling from a rural center to an urban one. Teleconsultation also can be useful to follow up these people and manage anti-seizure medications."

"We believe that treating people with epilepsy in remote rural areas is possible," said Nicoletti. "Community health workers usually know the health status of their community members very well, so they know who may be affected by epilepsy and can identify them quickly, at least those with tonic-clonic seizures," she said.

"And when you perform education and awareness campaign, the treatment is well accepted. So people with [epilepsy](#) seek medical attention. But these campaigns must be accompanied by governmental action in order to cover the costs and supplies of antiseizure medication."

The paper is published in the journal *Epilepsia Open*.

More information: Valeria Todaro et al, Prevalence of epilepsy in the rural area of the Bolivian Gran Chaco: Usefulness of telemedicine and impact of awareness campaigns, *Epilepsia Open* (2022). [DOI: 10.1002/epi4.12677](https://doi.org/10.1002/epi4.12677)

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