

# Barriers to Pediatric Epilepsy Care at Hospital Del Nino in La Paz, Bolivia, and Traditional-Medicine-Alternatives

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**Abbreviations:** LMIC: Low-And-Middle-Income Countries

## Introduction

Of the 70 million people with epilepsy worldwide, nearly 90% reside in developing regions without access to essential medicines [1,2]. In high-income countries, annual new cases are between 30 and 50 per 100,000 people in the population; in low-and-middle-income countries (LMICs), this figure can be up to two times higher given the increased risk of endemic conditions like malaria and neurocysticercosis, as well as the higher incidence of birth-related injuries and road traffic injuries. Through collaboration with leadership at Hospital Del Niño, insight was ascertained into various political, social, and economic factors limiting patients and families from accessing appropriate epilepsy treatment longitudinally.

## Management of Epilepsy in La Paz, Bolivia via Unified Healthcare System (SUS)

Under the direction of President Evo Morales, Unified Healthcare System (SUS) was implemented in Bolivia in 2019. SUS expanded the publicly sponsored provision of free healthcare from what was previously limited to pregnant women, recent mothers, children under the age of five, persons older than 60, and people with disabilities to include

all impoverished citizens and Bolivians lacking coverage. However, geopolitical challenges interfered with the successful implementation of SUS, including the contested 2019 election (which drove President Morales to resign), a shortage of financial resources, and the COVID-19 pandemic, which further strained the region's healthcare infrastructure and drove the Medical Association of Bolivia to oppose the systemic transition, declaring that it could not be sustained [3].

Since the enactment of Law #475, the legislation that officially established the "only healthcare system," all public hospitals have been mandated to manage patients according to clinical guidelines in Manual de aplicación de prestaciones del SUMI aplicado al Sistema Único de Salud (translation: SUMI Benefit Application Manual Applied to the Unified Healthcare System). Due to limited public funding, these guidelines specify all pathologies, the appropriate treatment regimen, and the specific quantity of drugs to be given to patients – laying protocols that are challenging to tailor despite the varying needs of patients. Physicians are required to input their treatment choice into an electronic chart that



requires completion of several fields: the diagnosis, drugs and materials needed, presentation, drug concentration, pediatric dose, adult dose, route of medication administration, and the maximum quantity of drugs permitted to be prescribed. Each detail is closely regulated, and if a physician was to deviate from the guidelines-based treatment and dosage recommendation, the system would not accept the entry, ensuring that treatment is constrained to what the government's funding is capable of affording for the entire population. Thus, physician autonomy has been markedly eroded. Furthermore, with the nation's public resources directly influencing these guidelines, clinicians are often unable to meet the needs of their patients to the best of their ability due to economic factors beyond their control.

### **Pediatric Epilepsy Management**

These barriers to care are evidenced by the challenges associated with pediatric epilepsy management at Hospital Del Niño, the only publicly funded hospital in La Paz, Bolivia. It should be noted that Hospital Del Niño is part of the Health Services Network of Bolivia's central government. In accordance with current regulations, it depends on the Government of La Paz through the Departmental Health Services (SEDES) and is engaged in activities related to the promotion of good health, prevention of illness, outpatient and hospital care, healing, rehabilitation, and research. Daily, six to eight patients arrive needing epilepsy treatment, though far more children with seizures lack access to reliable transportation and are required to manage their condition independently with the unpredictability of life-threatening seizures.

While various treatments are available for epilepsy, physicians at Hospital Del Niño can only prescribe treatments for a 1-month duration at best. This poses substantial obstacles for patients and families who reside in rural communities far from La Paz, who are forced to set an appointment every 15-30 days to acquire another prescription and continue their treatment. Moreover, for families of patients over the age of 5, there are substantial costs associated with each medical visit, including the cost of treatment. This leads to pediatric epilepsy patients receiving medical care episodically; in the long-term, patients and families are ultimately forced to manage epilepsy care

through other approaches as they are unable to financially cover the cost of transportation and care.

### **Traditional Medicine Perspective**

The city of La Paz, Bolivia hosts a heterogenic demographic with significant social, cultural, linguistic, and economic diversity. While some citizens view epilepsy as a disease that should be medically managed by a physician, many believe that a traditional medical practitioner should instead be sought out to provide guided treatment with potions and rituals. Myths surrounding the etiology and treatment of epilepsy persist alongside the common misperception that religious figures can administer a cure to seizures [4].

There is a pervasive belief that bat blood has healing properties and can be effective in the treatment of seizures, an impression that is rooted in Bolivians' deep cultural commitment to traditional medicine. Similarly, there is a widespread view that the blood of bats contains a strong life force that can transfer curative properties for epileptic seizures.

While the exact origin of the putative powers of bat blood remains obscure, it has been said that the value of bats stems from the fact that they are viewed as creatures with unique characteristics: their capacity for flight, as well as the fact that they are mammals and not birds, prevents them from neatly fitting into any animal classification, and it is such distinctiveness that is the source of their purported curative capacity.

Consequently, there is a tremendous demand for bats as the myth and killings persist. Officially, bat hunting is illegal as Bolivian law forbids the killing or sale of any animal without proper permitting. Still, upwards of 3,000 bats are sold every month in cities such as La Paz [5]. In the city's marketplaces, shoeboxes are illegally sold with as many as 20 live bats packed together. Typically, fruit bats, insect-eating bats, and vampire bats are hunted and obtained alive, their head is chopped off, and the blood is drunk fresh; alternatively, if the bat is already dead, it is fried with its fur on and placed into a cloth bag that will then be soaked in alcohol for future quaffing, a practice that is akin to drinking mezcal, a distilled alcoholic beverage served with a worm inside the bottle [6]. This myth has prevailed because users oftentimes misguidedly assume that if seizures return following the



consumption of blood, then the blood simply lost its curative potency during the brief duration between the death of the bat and consumption. This misattribution drives consumers to seek more bats and repeat the traditional treatment. These insights were derived from discussions with hospital leadership.

## Conclusion

The intent of this editorial is to shed light on the political, socioeconomic, and cultural factors limiting pediatric epilepsy patients from accessing care in La Paz, Bolivia. The challenges delineated in this writing were exacerbated during the implementation of SUS, which sought to markedly reduce the private sector. Geopolitical challenges, including election disputes, insufficient funding, and the COVID-19 pandemic, strained the region's healthcare infrastructure and compromised the policy transition. Discussions with leadership at Hospital Del Niño revealed that, due to major resource limitations, the government is stringently regulating medical treatment. This has eroded physician autonomy and limits providers from supporting their patients longitudinally. This is especially apparent in the context of pediatric epilepsy management.

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