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The impact of COVID-19 pandemic on frail health systems of low- and middle-income countries: The case of epilepsy in the rural areas of the Bolivian Chaco

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ABSTRACT

Introduction: The Coronavirus disease 2019 (COVID-19) has put some health systems under pressure, especially in low- and middle-income countries. We aimed at evaluating the impact of COVID-19 emergency on the management of people with epilepsy (PWE) living in the rural communities of the Gran Chaco area of the Plurinational State of Bolivia.

Materials and methods: We selected a sample of PWE living in the rural communities of the Bolivian Chaco. A standardized questionnaire was developed, consisting of six questions addressing drug availability, drug discontinuation, personnel responsible for drug retrieval during the lockdown, and the presence of seizures in the two months preceding the interview. Questionnaires were administered by community health workers of the rural health centers in September 2020.

Results: Seventy PWE (38 men, 54.3%; mean age 26.9 ± 16.7) were interviewed. During the lockdown the large majority of them (n = 51, 73.9%) reported an irregular medication intake mainly due to the lack of antiseizure medications in the local health posts, leading to an increase in seizure frequency.

Conclusion: The COVID-19 pandemic has unmasked the frailty of the Bolivian health system, especially for the management of chronic diseases such as epilepsy in the rural communities.

1. Introduction

The current pandemic of Coronavirus disease 2019 (COVID-19) has put some health systems under immense pressure and stretched others beyond their capacity [1].

In many countries the COVID-19 pandemic shook the healthcare systems, with unavoidable gaps in the management of patients with chronic diseases [1]. For instance, in European countries many activities related to chronic neurological diseases, such as Parkinson's disease or epilepsy, were dramatically reduced and deprioritized, hospitalizations were limited to emergencies, and the outpatient visits for new patients were postponed [2,3]. In this situation, telemedicine has often allowed to ensure remote medical consultation and assistance, above all for follow-up visits that have been mostly managed by telehealth [4]. Nonetheless, telemedicine cannot always guarantee access to care, above all in remote rural areas of low- and middle-income countries (LMIC). Indeed, resource-limited settings have been particularly stressed-out and have met huge challenges to re-adapt their services to the existing situation. Particularly, people with chronic illnesses including epilepsy faced difficulties in finding medical support in a period when people's access to health services needed to be minimized [1].

Epilepsy is a chronic disease, with more than 65 million people affected worldwide of which the 80% live in LMIC [5], where economic resources to contrast emergencies are scarce. Epilepsy management demands regular medical checkups and sustainable supply of anti-seizure medications (ASMs) and it represents an important public health issue, in particular in LMIC where significant disparities are present in the care available for patients with epilepsy [6]. In these areas, the epilepsy treatment gap (TG) is between 70% and 94% [5,6] with higher rates in the rural areas [7].

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Several drivers of the global TG have been identified, including inadequate access to trained professionals, lack of diagnostics, transportation issues, and scarce healthcare facilities; sociocultural factors including stigmatization, awareness, and acceptability of treatment; as well as poor availability and non-affordability of medicines [8–10]. In this scenario, the COVID-19 pandemic has dramatically impacted the already difficult access to care of people with epilepsy (PWE) in these areas, leading to a collapse of an already frail health system.

The reduction in epilepsy TG in the rural areas of the Bolivian Gran Chaco has been the main aim of different projects performed by our group over the last 20 years in this area [11–16]. In agreement with the WHO guidelines [17], and likewise other campaigns carried out in other LMIC [18,19], during our long-lasting activity in rural Bolivia, we performed several epidemiological and interventional surveys including an anthropological survey, training programs directed to General Practitioners (GPs), nurses and Community Health Workers (CHWs) of the rural communities of the Chaco region as well as communities awareness programs [13–15]. These activities have increased the level of knowledge and awareness about epilepsy in this region, and facilitated the access to care leading to a reduction in the TG in this area [20].

Nonetheless, the COVID-19 emergency unmasked the frailty of the health system, above all at a community level where many PWE might experience difficulties in obtaining their treatment, with serious consequences on their health.

We report the experience in the Bolivian Gran Chaco highlighting how the pandemic of COVID-19 and the associated disruption on the healthcare system has affected the access to care of PWE.

2. Materials and methods

2.1. Study setting, healthcare system, and population

Bolivia is a low-middle-income country with high levels of poverty especially in rural areas, where about 50% of the population lives [21]. The southeast region of Bolivia is part of the "Gran Chaco", a subtropical area also including Argentina and Paraguay. The prevalent ethnic group is represented by Guaraní people who live in small rural communities. In this setting, healthcare services are provided by CHWs, nurses, and GPs. The first care level consists in rural health centers, located in each community, and basic field hospitals, located in the larger communities. Primary care providers are mainly nurses and CHWs in the rural health centers while GP's consultation is mostly available in basic field hospitals. The second care level consists in area hospitals, located in urban environments, where basic medical specialties are available. The third and fourth care levels consist mainly in private institutes and specialized hospitals located in the larger cities. Here, advanced medical specialties and technologies can be found. However, physical distance and financial barriers mostly prevent access to rural population to these structures.

Up to 2019, ASMs should have been formally provided by the Ministry of Health only for people who were under 5 years old or over 60 years old, pregnant women or people with a certified disability. However, this program was not implemented in all areas and, in some municipalities, governments allocated funds to provide medication for PWE living in their communities. As a matter of fact, in a recent survey it was found that government funding of ASMs covered only 13.4% of patients of a sample of communities in the rural areas of the Bolivian Gran Chaco while the majority of ASMs costs were covered by non-governmental organizations (NGOs) (33.9%) [20]. More recently, on February 2019, a new health system, called the "Sistema Unico de Salud (SUS)" has been instituted, and it is being implemented all over the country. According to this system, the ASMs should now be funded by the Ministry of Health for all the people with a diagnosis of epilepsy and a drug prescription made by a specialist [22]. Generally, once purchased, ASMs are stored in the rural health centers or in basic field hospitals where PWE can get their medications. However, these centers are often very far from the communities, even more than two hours of walking, and CHWs have the task of bringing the drugs directly to the rural communities. This represents an obstacle to a regular drug supply, especially during adverse weather conditions or emergency situations, like a pandemic is. Moreover, medication availability may sometimes be missing because of administrative difficulties (e.g. drug supply scheduled with a yearly interval), causing severe risks of drug withdrawal for people who are under treatment.

2.2. Assessment of access to drugs during the pandemic

In order to evaluate the impact of COVID-19 emergency on the epilepsy management of PWE in the rural communities of the Bolivian Gran Chaco, we carried out a survey on a convenient sample of PWE living in that area. In particular, PWE were selected from the rural communities of the areas of Eiti, Gutierrez, Huacaya and Lagunillas. A standardized questionnaire was developed for the purposes of this study, consisting of six questions addressing drug availability, drug discontinuation, and personnel responsible for drug retrieval in the seven months following the beginning of the nationwide quarantine on March 2020; the last question investigated the presence of seizures in the two months preceding the interview (Supplementary File 1). Questionnaires were administered by CHWs working in rural health centers in September 2020.

2.3. Statistics

The STATA 16 software (version 16.0, College Station, TX) was used. Qualitative variables were described as percentages and quantitative variables as mean ± standard deviation (SD). The study was developed in accordance to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (Supplementary File 2).

2.4. Ethics

The study was conducted in accordance with the Declaration of Helsinki. It has been approved by the Ethics committee of the Bolivian Neurological Society.

3. Results

Seventy PWE (38 men, 54.3%; mean age of 26.9 ± 16.7 years) were interviewed. The majority (91.8%) reported in their clinical history the presence of tonic-clonic seizures, while concerning the ASMs, carbamazepine and phenobarbital represented the most commonly used (42.9% and 36.7%, respectively).

During the lockdown, the large majority of them (51; 73.9%) reported an irregular intake of ASMs mainly due to the lack of ASMs in the local health post, with a mean duration of treatment irregular intake of 5.1 ± 1.7 months (Table 1). During the two months before the interview, among those who reported an irregular ASM intake, 24 (47%) experienced at least one seizure, 19 (37%) of whom had at least one seizure per month.

Clinical information about the previous frequency of seizures was available for 32 out of the 51 PWE who had an irregular ASM intake during the pandemic. Among them, 15 (46.9%) reported a worsening of seizure frequency, while 17 (53.1%) were considered stable. None of the patients experienced status

Table 1
Characteristics of the recruited sample.

	PWE (n = 70)
Age	26.9 ± 16.7
Sex (men), n (%)	38 (54.3)
Last consultation with a neurologist	
<1 year	4 (5.7)
>1 year	66 (94.3)
Who is the responsible for the drug supply	
Family	3 (4.3)
Community Health workers	49 (70)
Nurses	18 (25.7)
Irregular ASM intake	51 (73.9)
Reasons for irregular intake of ASMs	
Forgetfulness	5 (9.8)
ASMs were not transported to the communities	1 (1.9)
ASMs were not available in the health center	39 (76.5)
Other reasons	6 (11.8)

epilepticus or other fatal complications during the period of irregular drug intake.

4. Discussion

Epilepsy represents an important public health issue, in particular in LMIC where significant disparities are present in the care available for patients with epilepsy and where the TG can reach rates over the 80% [6]. After several efforts carried out during the last decades in order to reduce the TG in the rural area of the Bolivian Gran Chaco, the advent of the COVID-19 pandemic has, in few months, erased the progresses done, leaving PWE in these areas without ASMs. Indeed, on the one hand, the lockdown measures have hindered the drug supply, worsening a situation that was already difficult in these areas, while on the other hand, many economic resources have been allocated to fight the COVID-19 emergency. Consequently, during these months, PWE were unable to reach the health centers where, at any rate, often ASMs were lacking. As well known, the lack of adherence to the ASMs treatment can lead to an increased frequency of seizures. Furthermore, the abrupt interruption of ASM intake represents one of the main risk factors for the development of status epilepticus and for sudden unexpected death in epilepsy (SUDEP) [23,24].

Our survey demonstrated that, due to the COVID-19 pandemic, almost three quarters of PWE have irregularly taken the treatment with subsequent lack of seizure control. Even if the questionnaire did not include specific questions aimed at assessing the previous irregular intake, it should be noted that according to a previous study recently carried out in the same areas [13], the frequency of pre-pandemic irregular intake was about 30% and that the main reason was the lack of medication mainly due to economic reasons. During the pandemic, this percentage increased up to 73.9%, and the lack of ASMs at the local health centers was the main reason for treatment discontinuation. Moreover, generally, the ASMs are distributed in the communities directly by the CHWs, who are usually members of the communities and might have experienced movement restrictions due to the lockdown. All of these findings underline the weakness of the health system in the rural communities of a LMIC. A similar situation has been recently described in Pakistan, where, however, the percentage of PWE who reported an irregular intake of ASMs during the lockdown was lower [25].

Our study accounts for some limitations which are all linked to the contingent pandemic situation. In particular, we were not able to perform a random sampling of PWE being forced to use a convenient sample. Moreover, the questionnaires were administered by non-medical health workers, thus possibly leading to less accurate results. To this reason, the structure of the questionnaire was very simple and containing only few items easy to administer. However, the CHWs working in this study area have a very good level of knowledge about epilepsy, as demonstrated in a previous study where they showed a high level of awareness toward epilepsy even before the educational campaign performed by our group [13].

The COVID-19 pandemic has stressed all the healthcare systems in both High-Income Countries (HIC) and LMIC, reducing the access to care above all for people affected by chronic diseases, but this impact has been dramatic in rural communities of LMIC. Telemedicine has represented an important support in the coronavirus era but, unfortunately in this scenario, it cannot reach the remote population living the rural areas and, more importantly, cannot guarantee the drug supply. In fact, PWE living in the remote communities of the Bolivian Gran Chaco area as well as in similar settings in LMICs have no current access to telemedicine. Therefore, even if telemedicine should be implemented in these areas and could provide an important support for the care of PWE in the rural communities [4], alone it cannot prevent drug discontinuation. We have previously shown that treating PWE in a resource limited setting is feasible if appropriate strategies are implemented [20]. In particular, after years of educational campaigns performed in this area, we recorded a significant reduction in TG, starting from about 90% in 1994 [11] to levels of about 70% in 2010 [12] and finally with a reduction down to 45% in our last population-based survey performed in 2016 [20,26]. However, these strategies need to be scaled up to the government level, otherwise the efforts that researchers, NGOs, and other funding organizations have put into such programs are destined to vanish in the short-term [27]. This is particularly dangerous when dealing with administration of ASMs, as the sudden and unexpected withdrawal is a major cause of clinical deterioration and risk of status epilepticus which carries a high death risk [23].

We must learn from this lesson, and the World Health Organization (WHO) as well as the International League Against Epilepsy (ILAE) should strengthen their ongoing pressure onto the governments of LMIC in order to develop strategic preparedness and response plan to be applied in a critical setting as a pandemic is.

The COVID-19 pandemic has reminded us to attend to the longer term strategic efforts to adjust the persistent inequalities and create more equitable conditions even after the public health emergency subsides.

5. Declarations of interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2021.107917.

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