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Validation of Questionnaire for Detection of Epilepsy in Guaraní

Abente Silvia [α], Arbo Carlos [σ] & Cabrera Marta [ρ]

Summary- In Paraguay, as a bilingual country and with a characteristic historical context, it has always been considered a challenge to reach the Guaraní-speaking population, especially those from the most vulnerable sectors, through the use of tools that bridge the gap in the language barrier in care services in general. By translating the epilepsy diagnostic questionnaire aimed at its use in primary care, the aim is to bring to the medical professional a useful element in clinical practice that also provides data of diagnostic value and treatment guide. In this work, the validation of the questionnaire, originally conceived in Spanish, was carried out, distinguishing some idiomatic aspects that add richness to the clinical history in epilepsy and define the therapeutic aspect, providing the medical professional with a material of practical use and easy to apply in clinical practice daily.

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I. Introduction

Guaraní is the most widespread native language in Paraguay, considered a bilingual country, it comes from one of the majority ethnic groups in the original population of Paraguayan territory during the pre-Columbian period. For various historical and cultural reasons, it is today the second official national language, after Castilian, due to its wide range of use and socio-cultural characteristics that make it very popular, particularly in the most vulnerable economic strata.

Accompanying this linguistic peculiarity, the population that uses it is of Hispanic-Guarani mestizo origin, which is why throughout colonial history and independent life it has undergone the transformation of the linguistic evolution of the conjunction of both languages, Spanish and Guaraní, which is currently known as yopará.

We consider, therefore, very interesting to carry out an appropriate adaptation and validation of the pathology detection tools, especially in the case of Epilepsy, where the clinical manifestations can be numerous and highly variable. Through its analysis, a distinction could be made between the most appropriate terms (in the Guaraní language) to define the different symptoms of this vast pathology.

The World Health Organization estimates that there are currently around 50 million people with Epilepsy in the world. It is also estimated that approximately 70% of patients live in underdeveloped countries and there is, as if that were not enough, a treatment gap of approximately 50% in most of them. In other words, only half of the patients with epilepsy ever arrive for consultation and treatment.

The incidence of epilepsy in Latin America is around 50 per 100,000 inhabitants (new cases/year) and a prevalence of 8-10 per 1000 inhabitants (population with active epilepsy). Both figures, although estimates due to the lack of homogeneity in the statistical studies, still show much higher values than in developed countries due to various socio-cultural factors that can be intuited such as epilepsy associated with perinatal problems, in addition to that associated to head trauma (for example, in car accidents), etc. All this making the indexes considerably higher in our environment. Although there are no official statistics yet, it has been estimated that the figure at the local level is between 100,000 and 200,000 inhabitants throughout the country.

The factors identified as responsible for the treatment gap lie in the limited capacity of health systems and unequal distribution of resources, the lack of trained personnel or even a shortage of it, the lack of access to affordable medicines, in addition to the social ignorance and stigma that prevail above all in vulnerable populations and the still low priority that the majority of the countries in this region give them.

With this panorama, it goes without saying that it is our obligation as health professionals dedicated to the area of Epilepsy, to work consistently to improve and facilitate the detection of these patients in primary care, which should be the first level of care.

The objective of this work is to evaluate the usefulness of the questionnaire for the detection of epilepsy proposed by the "Manual of procedures for the early detection and treatment of epilepsy" (PAHO 2007) to establish the diagnosis and classify epilepsy seizures in primary care services for the Guaraní-speaking population.

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II. Materials and Methods

Initially, the questionnaire was translated with an expert in the popular Guarani language who proposed to adjust the best version possible for the general public to understand. Subsequently, the completion of the questionnaire was defined consecutively for all patients who come to the Neurology Service of a reference hospital in the interior of the country for the first time (Hospital Nacional de Itaugua), from August 2018 to March 2019. The questionnaire was carried out by the nursing staff who, after initial screening with the main question:

"During the past 12 months, has the patient had seizures or seizures, brief periods of loss of consciousness, involuntary shaking of the arms or legs, seemed to be disconnected from reality or unable to respond?"

in its version in Guaraní:

"Ary (year) paha jave tekovepa oguereko seizure epilepsy gua mbykymi oho chugui teko ñee, oryryi pa oipotayme, ijyva ha hetyma ndaikatuiva ombohovai mbaeve?".

Faced with an affirmative answer, the patient was at risk of presenting Epilepsy and was considered to complete the questionnaire and undergo a specialized evaluation.

Before the application of the diagnostic questionnaire, the target personnel in charge of passing the questions were trained in the management of the basic concepts of this condition, specifically in clinical diagnosis, by the neurologists of the project.

Diagnostic discrimination (validity) of the questionnaire was measured by sensitivity (ability to detect patients with epilepsy), specificity (ability not to diagnose a patient who does not suffer from epilepsy with epilepsy) and the prognostic value of a positive or negative result., considering homogeneous evaluation groups to work with a prevalence of approximately 50% among double-blind patients. The reference criterion for calculating these measures was the clinical diagnosis of epilepsy made by a neurologist and the ruling out of the diagnosis of epilepsy by the same professional.

Table of the Questionnaire in Spanish and Guaranì

ENGLISH	GUARANÍ
CENTRAL QUESTION	
Do you know a person who has epilepticseizures?	Nde eikuaa petei tekove oguerekova ataque epilepsia gua?
During the past 12 months have had this person epileptic seizures such as brief periods or loss of consciousness, involuntary shaking of the arms and legs, it was impressive to be disconnected from reality or unable to respond?	Ary (año) paha jave tekovepa oguereko achaque epilepsia gua mbykymi Oho chugui teko ñee, oryryipa oipotayme, ijyva ha hetyma Ndaikatuiva ombohovai mbaeve
SUPPLEMENTARY QUESTIONS	
1. Was the person unconscious and incapable to respond during the episode?	1. Oipa rae la tekoveakamejehe apa Ndaikatuiva ombohovai mbaeve
2. Do he/she regain consciousness after the episode?	2. Imanduapaupe ataque rire la oiko Vaekuehese?
3. How many of the indicated episodes hashe/shehad in the last 12 months?	3. Mboy ataque oguerekoumiary pahajave?
4. When was the last time and how long was it?	4. Arakae ome e chupe ipaha ha mbo y aravo hi are?
5. Has he/sheany known neurological problem?	5. Oreko pa tekove petei mba asy iñakame gua (meningitis, akambota, o u vai)
6. How long hashe/she had seizures?	6. Mbo y ochapo oguereko ha la achaque?
7. Has it gotten worse over time?	7. Oivaivepako ataque oguereko rire?
8. During the episodes was he/she with the 9. fixed gaze, blinking or did not pay attention?	8. Umi ataque jave, oma ña hata, hesapiri ndo jesarekoi mbaevere?
10. During the episodes, had he/she involuntary movements, abnormal, uncontrollable, jerks or muscle contractions?	9. Umi ataque jave oi pa je kue pota yre ndaikatuiva oñesambyhy ha oñemokuruchi?
11. Were there automatisms such as movements swallowing or savoring, purposeless repetitive hand movements?	10. Oi pa ijehegui omomyva ijehegui ijuru, Ijyva ndaikatuiva ombohova?
12. Does he/she have any warning before the crisis?	11. Oguereko mbae ohechaukava pe ataque outaha jupe?
13. Washe/she conscious after the crisis?	12. Upe ijataque rire okatu ombohovai?
14. Are these episodes related to some specific situation (fever, after crying, feeding, blow, trauma)?	13. Ko ataque ome e jupe akanundu, tase, karu, akambota rire?

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III. Results and Discussion

The questionnaire was carried out on a total of 140 patients and companions, between the ages of 16 and 70, Guaraní-speaking of both sexes, of which 6 patients were excluded because they did not complete the questionnaire, leaving the groups made up of 74 patients with diagnosis of Epilepsy performed by specialists and 60 patients with discard of the day Gnostic of Epilepsy, assessed by the same team of Neurologists.

It was observed that in comparison with Sensitivity / Specificity values evaluated separately in the different clinical signs / symptoms found (Avbersek A, Sisodiya) this scale presents an exceptional level of detection (Sensitivity = 91.89%) after the first question of the questionnaire. That is, only with the analysis of response to the first question can the expected level be obtained for the detection of the condition and for an approximate prevalence of 50% in our population (since the questionnaire was carried out in 2 groups with and without the condition of similar double-blind frequency) it can be said that the sensitivity is associated with a high negative predictive value of 0.89 (NPV = 89%) in our sample, which is interpreted as a high effectiveness to rule out the condition given a negative result. Furthermore, in comparison with the reference values of another similar study carried out in the pediatric population of Ecuador (in Spanish) whose Sensitivity value was 95.10%, a fairly homogeneous result of our questionnaire in Guarani can be observed. (Carpio, Lisanti).

Diagnosis According to Questionnaire Patients with Epilepsy Patients without Epilepsy Total

Diagnosis according to questionnaire	Patients with epilepsy	Patients without epilepsy	Total
Positives	68	10	78
Negatives	6	50	56
Total	74	60	134

In the Specificity analysis, however, a drop to 83.33% was evidenced, which is to be expected since there are numerous conditions that can increase the number of false positives in the test (paroxysmal non-epileptic events). In the same way as the previous reasoning, given the equitable distribution between the participants who suffered and not the condition evaluated, this value can be associated with the positive predictive value of the test (interpreted as the possibility that the patient who tests positive actually suffers from the disease), which in our series is 0.89 (PPV = 89%). Compared with another series, a decrease in this value was observed (E = 97.06% according to Carpio et al). The difference found could be attributed to the language gap in the interpretation of the terms of the questionnaire. For example, in the Guaraní language there is no specific term for the definition of loss of consciousness due to seizures or other manifestations of focal seizures, as the term seizure used in the English language or even seizures for Spanish speech could be interpreted. although in the latter case the word used is indicative since it translates into ailment in Guaraní.

Of course, with the disaggregated analysis of the other questions it is even possible to approximate in diagnostic terms the subtype of epilepsy that the patient may be presenting or even its etiology. This evaluation has not been determined because it required a greater diagnostic detail per patient that would prolong the time required and increase costs, which was not supported for the purposes of the study.

Even so, we have found certain questions that, in the Guaraní language, have been clearly understood and have indicated with special punctuality some aspect of the clinic manifested by the patient with Epilepsy to mention: *"omaña hata" (fixed gaze) "ndo jesarekoi mbaevere "(not paying attention)" Oi pa ijehegui omomyva ijehegui ijuru, Ijyva ndaikatuiva ombohova?"* (description of automatic chewing, swallowing, etc.). Of course, the findings are not surprising considering that the main diagnostic tool in Epilepsy, even today, is still the clinic. And it is through a detailed evaluation of the patient that high levels can be reached in the diagnostic and etiological discrimination of each case. In any case, our intention through this validation is to make available to our primary care physicians a simple diagnostic detection method that also shows a high level of discrimination in seizure subtypes, when approaching a patient with suspected Epilepsy. Giving the professional a clear possibility of guidance in the initial therapy of each case.

IV. Conclusion

Epilepsy as a neurological condition, despite its significant frequency, still represents a diagnostic challenge in primary care medicine. The main factor would be the delay in the consultation by patients and relatives, because, still covered with an aura of mysticism, they resort to traditional medicine, whose representatives are healers or shamans and their interpretation and approach to epileptic seizures, is they

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are closer to ancestral religious beliefs and practices than to medicine, which logically delays the diagnosis. The other side of the coin highlights the difficulty sustained by the distance that patients and their families must travel to reach a healthcare center, coupled with the lack of the necessary financial resources that displacement makes nto on a slow and painful journey. But the difficulties do not end with the arrival at a health center for primary medical care, there we run into the lack of necessary training of medical professionals in the diagnosis and therapy of epilepsy and even if that were the diagnosis, in many cases they do not have the drugs needed for treatment. Finally, it is worth mentioning that the presence of a medical professional in primary care centers may not be permanent and even in cases absent, leaving health care in the hands of nursing personnel. Everything previously exposed could be summarized in a single word, the need to Educate. At the population level, campaigns aimed at teaching how to recognize epileptic seizures prematurely and encourage their immediate consultation at a medical center. State policies that encourage the creation of a greater number of primary health care centers, with duly trained medical and nursing professionals and with the therapeutic means to deal with the cases that arise. Approach community leaders, mainly those who play roles in the health area, in such a way as to include them in the health chain without damaging their culture and beliefs. As part of our commitment and with the help of the authorities, the first steps are being taken both in the area of education and the provision of technology, as well as tools of simple and practical use such as this easy-to-apply questionnaire in the Guarani language and interpretation in health units, and any other level of the health chain. We are aware that there is still a lot of work to be done, but we will not give up the commitment made with small interventions that will generate big changes in the long run.

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