Revista O Mundo da Saúde

DOI: 10.15343/0104-7809.202347e14972023I

# Factors associated to the quality of life in children with epilepsy in a national hospital in Honduras

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## Abstract

Epilepsy represents a large-scale problem that affects the social sphere of the patients who suffer from it. The following study aims to assess the quality of life of pediatric patients with epilepsy and to identify the factors associated with a lower quality of life. A cross-sectional, descriptive and analytical study was carried out in patients with clinical and electroencephalographic diagnosis of epilepsy, who attended the outpatient clinic of the neuropediatric service of the Teaching Hospital. A survey was administered, subdivided into data on the child, data on the parents or caregiver, type of epilepsy, treatment and the Quality of Life Scale for Children with Epilepsy (CAVE). The variables were analyzed using descriptive statistics and a multiple regression model to find predictors of quality of life. Of the 187 patients, 68 (36.4%) had a good quality of life. No significant gender differences were observed, nor in the overall score of the survey. Having fewer unmet basic needs (P=<0.0001) and not having refractory epilepsy were predictors of better quality of life (P=<0.0001). Parent-reported quality of life was mostly good or fair, having a higher number of unmet basic needs and being classified as having difficult-to-manage epilepsy were predictors of worsening quality of life as measured by the CAVE scale.

**Keywords:** Epilepsy. Quality of Life. Indicators of Quality-of-Life Socioeconomic Factors.

## INTRODUCTION

Epilepsy is a worldwide problem, with a prevalence of 57 cases per 1000 inhabitants[1]. In recent years, there has been a boom in the literature on the quality of life of patients with chronic pathologies; this goes hand in hand with the concept of health of the World Health Organization (WHO), which establishes the importance of comprehensive patient care beyond pharmacological treatment in isolation. According to WHO, quality of life is defined as the perception that an individual has of their existence and values in the context of the culture in which he or she lives and in relation to his or her objectives, expectations, norms, and concerns[2].

Epilepsy has unfavorable effects in the quality of life of children who suffer from it; it has been described that children with epilepsy have a higher risk of depression and anxiety, low self-esteem, behavioral problems, and academic difficulties[3,4]. The factors that influence their quality of life can be clinical, demographic, social, and familial; it has been described that those demographic and clinical variables are essential factors in aspects such as adaptive and cognitive function[5].

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Some of these factors are more amenable to modification, and some, such as those intrinsic to the disease, are more difficult to modify[5,6]. Those characteristics that have more evidence as factors that decrease quality of life include side effects of antiepileptic drugs (AEDs), presence of comorbidities, longer duration of epilepsy, parental or caregiver anxiety, seizure frequency, seizure severity, and low socioeconomic status[6].

Assessing the quality of life is essential in clinical practice to comprehensively manage the patient with epilepsy. The importance of assessing psychological well-being and quality of life in low-income countries has yet to be studied in depth. Therefore, there needs to be more data about it in these countries. In Honduras, the available literature on quality of life in epilepsy is scarce, especially in pediatric age. A study that evaluated the quality of life using the QOLIE-31 instrument in patients with epilepsy aged 15 to 58 found a quality-of-life index of 67.5%[7]. This study aimed to describe the quality of life and analyze how the perception of quality of life is related to some clinical and sociodemographic variables. Generating data on the factors related to a decrease in quality of life in the pediatric age group may contribute to a better understanding of the subject in the regional context, an area of research that has been neglected and warrants further research. Furthermore, studies on the quality of life of children with epilepsy may aid in the development of new models to support and to better work with children, as well as a whole new schedule of support offered for these children and their families, which may lessen the detrimental impact the illness has on the family's functioning.

## METHODS

A descriptive and cross-sectional study was carried out in a conveniently-sized sample of patients, aged 4 to 18 years, with a clinical and electroencephalographic diagnosis of epilepsy according to the International League Against Epilepsy, who attended the outpatient clinic of the neuropediatric service of the Hospital Escuela in Tegucigalpa, Honduras. The exclusion criteria were: severe intellectual disability or severe concomitant diseases such as infantile cerebral palsy with an impairment of quality of life that could have an independent impact on quality of life. Data collection was conducted periodically from January 2021 to August 2022. It was partially interrupted due to the closure of the outpatient clinic as a measure issued to contain the outbreak of COVID 19 in the country.

The study was approved by the Ethics Committee on Biomedical Research (CEIB) of the Faculty of Medicine of the National Autonomous University of Honduras (No. IRB 00003070). The participants' parents signed an informed consent document, and children over 12 gave their informed consent. The children who were found to have a fair, poor, or very poor quality of life were referred to the psychology service of the hospital to provide them with close follow-up.

A survey was administered, which was subdivided into child data, parent or caregiver data, type of epilepsy, treatment and the Child with Epilepsy Quality of Life Scale (CAVE). The patients were classified as refractory epilepsy according to the ILAE definition[8]. It was determined to classify as good adherence: less than 2 days without taking AEDs in the last month. Regular: 2 to 5 days without taking AEDs in the last month. Poor adherence: More than 5 days without taking AED in the last month and/or suboptimal

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serum levels.

The socioeconomic level was measured through the method of unsatisfied basic needs (UBN). The UBN indicator was proposed in the 1970s by ECLAC, and seeks to identify households and individuals who are unable to satisfy a set of needs considered indispensable, according to levels of well-being. The UBN method provides a characterization of the situation in which households find themselves. It is a method frequently used in Latin America, and the more of these needs that are not met, the higher the degree of poverty is considered[9].

The NBI includes 5 simple indicators: a) type of substandard housing: access to housing that meets minimum standards of habitability; b) poor sanitary conditions: access to basic services that ensure adequate levels of sanitation; c) critical overcrowding: more than three people per room; d) schooling: children aged 6 to 12 not attending school; and e) subsistence capacity: 4 or more people per occupied  member, economic capacity to ensure minimum levels of consumption.

To assess the quality of life, the CAVE survey was used. CAVE is a survey that is applied to the  caregiver/parent of the patient with epilepsy and was designed in Spain, can be applied from the moment of diagnosis and has been widely validated and applied in countries of the region[10].

This scale was chosen because of its simplicity, wide use in Spanish-speaking countries, and ease of follow-up, since it is designed to be applied continuously and to see its evolution over time. Considering the limited time in the outpatient clinic, it was considered the ideal survey.

In this study we determined Cronbach's alpha coefficient for the different domains of the survey and found it to have acceptable internal consistency (>0.7). The scale considers eight parameters including six subjective: Behavior, Learning, Autonomy, Social relationship, Intensity of seizures, and Opinion of parents or caregiver, and two objectives: School attendance and frequency of seizures. The maximum number of points to be obtained is 40 (very good quality of life) and the minimum is 8 (very poor quality of life). The survey was applied electronically by the researchers through the Epicollect 5 application, using a mobile device. To assess the reliability and validity of the data collection form, a pilot test was conducted with 20 patients. Patients who participated in the pilot study were excluded from the target sample of the study.

Categorical variables were described as percentages and continuous quantitative variables as mean ± standard deviation or median (range), as appropriate. To evaluate the assumption of normality of the variables, the Kolmogorov-Smirnov test was applied, which showed that they did not have a normal distribution. A Multiple Regression model was performed to find the predictors of quality of life. The Genmode process of SAS© was used to perform the multiple regression. Quality of life was  analyzed as a continuous variable. The variables who were entered into the model were clinically selected, and  the collinearity and correlation of the variables were evaluated prior to entering them into the model. Data analysis was carried out with the SAS studio© program. A P value <0.05 and [95 % CI]) was used to declare statistical significance.

## RESULTS

Among the 187 pediatric patients with a diagnosis of epilepsy studied, the median age was 10 years (SD 4.4). Of the patients, 55.6% were male. Table 1 shows the sociodemographic data of the sample. Regarding paternal schooling, 30.5% of the fathers

DOI: 10.15343/0104-7809.202347e14972023I

had completed primary school and 3.2% were illiterate. In the case of maternal schooling, 34.8% of the mothers had a completed primary school level and 1.6% of the mothers were illiterate. The socioeconomic level was measured by Unsatisfied Basic Need (UBN), The socioeconomic level was measured by basic needs satisfied, finding that 17.6% had no UBN, 42.2% of the families had one UBN, 26.2% had two UBN, and 13.9% had three or more UBN. The most frequent UBN was subsistence capacity or economic dependency, found in 36.1% of the families.

**Table 1 -** Sociodemographic characteristics of patients with epilepsy. Tegucigalpa/FM, Honduras 2021-2022.

| Characteristic | Frequency (n) | Percentage (%) |
|---|---|---|
| **Gender** | | |
| Male | 104 | 55.6 |
| Female | 83 | 44.4 |
| **Origin** | | |
| Urban | 117 | 62.6 |
| Rural | 70 | 37.4 |
| **Education** | | |
| None | 40 | 21.4 |
| Incomplete elementary | 91 | 48.7 |
| Complete elementary | 10 | 5.3 |
| Incomplete high school | 40 | 21.4 |
| Complete high school | 6 | 3.2 |
| **Marital status of parents** | | |
| Married | 40 | 21.4 |
| Single | 24 | 12.8 |
| Free union | 88 | 47.1 |
| Widow(er) | 2 | 1.1 |
| Absent father | 26 | 13.9 |
| Absent Mother | 4 | 2.1 |
| Absent father and mother | 3 | 1.6 |

The relationship between quality of life and the amount of UBNs in the home is shown in Figure 1. The most frequent type of seizure was generalized tonic-clonic 42.2%, followed by complex partial 19.8%. At the time of the study, the highest percentage of patients using one antiepileptic drug was of 71.1%, two AEDs 21.9%, and 3 or more AEDs 5.8%. The most commonly used antiepileptic drugs were valproic acid 36.0%, phenytoin 25.6%, and levetiracetam 13.6%, in addition, 18.2% of patients were classified as treatment-refractory epilepsy. Adherence to treatment was mostly good at 75.9%, the most common reason why patients presented poor adherence to treatment was due to low economic resources at 38.6%. The relationship between quality of life and adherence to treatment is shown in Figure 2.

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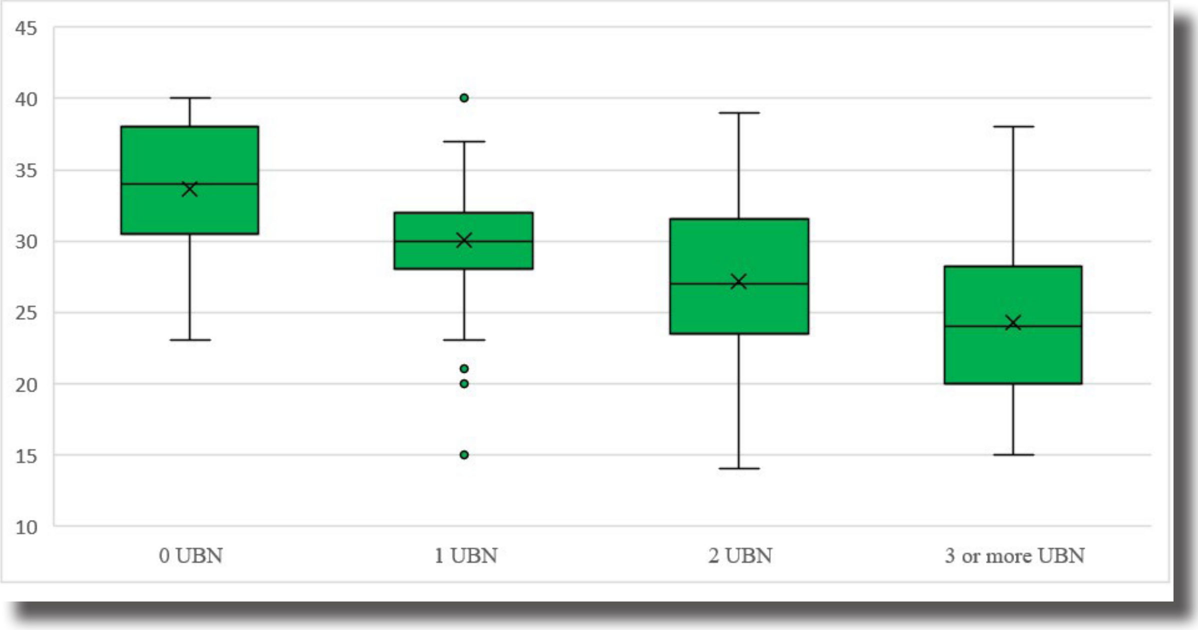

Non-poor = 0 unsatisfied basic needs (UBN), Poor = 1 UBN, Extreme poor = 2 UBN, and Misery = 3 or more UBN.

**Figure 1 -** Total quality of life scores according to socioeconomic level.

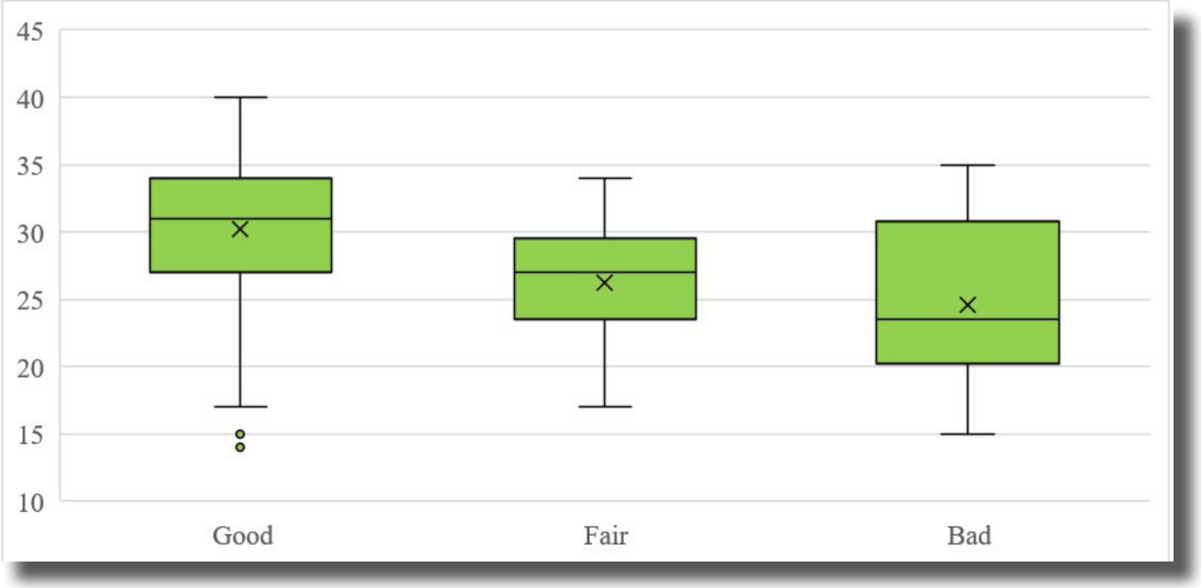

**Figure 2 -** Total quality of life scores according to treatment adherence.

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According to the quality-of-life assessment of the scale used, of the 187 pediatric patients, 36.4% of patients had a good quality of life, 33.2% of patients had a fair quality of life, 18.2% of patients had a very good quality of life, 10.2% of patients had a poor quality of life and finally, 2.1% of patients had a very poor quality of life. The mean scores of the CAVE scale were: conduct, 3 (moderate behavioral disorders although children conform to behavioral norms); school attendance, 4 (less than 7 school days missed per trimester); learning, 3 (modest but steady learning, slow acquisition of knowledge); autonomy, 4 (Good: no additional comments); social relationships, 4 (good, no additional comments); seizure frequency, 4 (Good: with 1 day with seizures during the past month); and seizure intensity, 4 (Good: single seizures, or very infrequent nonconvulsive seizures). (Table 2).

**Table 2 -** Percentages for each parameter of the quality of life scale for children with epilepsy. Tegucigalpa/FM, Honduras 2021-2022.

| | Very Poor (%) | Poor (%) | Fair (%) | Good (%) | Very good (%) |
|---|---|---|---|---|---|
| Conduct | 5.3 | 16.6 | 30.5 | 31.6% | 16.0 |
| Attendance | 17.6 | 5.3 | 17.6 | 29.4% | 29.9 |
| Learning | 7.5 | 17.6 | 29.4 | 26.2% | 19.3 |
| Autonomy | 2.1 | 5.9 | 12.3 | 42.8% | 36.9 |
| Social relationships | 3.2 | 9.6 | 21.9 | 38.0% | 27.3 |
| Frequency of seizures | 5.3 | 8.6 | 20.9 | 38.0% | 27.3 |
| Intensity of seizures | 2.7 | 8.6 | 25.1 | 36.9% | 26.7 |
| Parents opinion | 0.5 | 8.0 | 33.7 | 43.9% | 13.9 |

Regarding the quality of life, it was found that 36.5% of the male patients had a "good" quality of life while 36.1% of the female patients also had a "good" quality of life. No significant differences by gender were observed in any of the items studied, nor in the overall score of the survey (P = 0.660). Regarding learning, it was found that 29.4% of the patients were able to maintain regular learning despite their condition. In relation to behavior, 31.5% of the patients indicated having "good" behavior. Of the patients analyzed, 38% reported having a "good" control of the frequency of their seizures.

Regarding seizure intensity, 36.9% of the patients mentioned having "good" control. The following variables were included in the multiple regression model: socioeconomic level, adherence to treatment, gender, age, refractory epilepsy, and AED use. The following factors were significantly associated with quality of life: Unsatisfied Basic Need (socioeconomic status) and refractory epilepsy. Having unmet basic needs (OR10.00; 95% CI : 3.20-15.30; P<0.0001) or one unmet basic need (OR 4.10; 95% CI : 2.00-8.20; P = 0.00017) were predictors of a better quality of life, compared to those with three or more unmet basic needs. Not having difficult-to-manage epilepsy also predicted better quality of life (OR 9.30; 95%CI: 2.50-12.00; P <0.0001). Good (OR 4.41; 95%CI: 0.32-5.30; P = 0.1088) or fair (OR 1.22; 95%CI: 0.50-4.00; P = 0.8654)

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treatment adherence, compared to poor treatment adherence, were not statistically significant. The use of antiepileptic drugs and gender were also not predictive factors of better or worse quality of life (P = 0.62267) (P = 0.3371) (Table 3).

**Tabela 3 -** Predictors of quality of life in children with epilepsy using a multiple regression model.

| Variable | OR (CI 95%) | P |
|---|---|---|
| **Unsatisfied Basic Needs** | | |
| 0 UBN | 10.00 (3.20- 15.30) | <0.0001 |
| 1 UBN | 4.10 (2.00-8.20) | 0.0017 |
| 2 UBN | 3.00 (0.50 – 6.00) | 0.1207 |
| 3 or more UBN (reference) | | |
| **Treatment adherence** | | |
| Good | 4.41 (0.32-5.30) | 0.1088 |
| Fair | 1.22 (0.50-4.00) | 0.8654 |
| Poor (reference) | | |
| **Gender** | | |
| Female | 0.52 (0.14-1.94) | 0.3371 |
| MALE (REFERENCE) | | |
| **Age** | 0.93 (0.79-1.10) | 0.3371 |
| **Refractory epilepsy** | | |
| No | 9.30 (2.50 -12.00) | <0.0001 |
| Yes (reference) | | |
| **Takes AEDs** | | |
| No | 0.20 (0.01-2.99) | 0.62267 |
| Yes (reference) | | |

## DISCUSSION

The quality of life of the children attending this health care center is primarily good or fair. In this population, having less unsatisfied basic needs and non-refractory epilepsy were predictive factors for a better quality of life, which is in accordance with what is described in the literature on social determinants and their influence on epilepsy care, clinical outcome and access to health services and, therefore, on the quality of life of patients[11]. In this population, sociodemographic characteristics such as origin and predominance of the male gender are similar to those described in other studies in the region; however, the median age was ten years, which is slightly higher than that reported in other studies[12,13].

Parents play a crucial role in the end result of their children's disease; the level of schooling, income, and health literacy can influence the clinical result of a child with epilepsy[14,15,16]. In the case of the caregivers in the study, the level of schooling in more than 50% was some elementary schooling or no schooling at all. This could be an essential factor in the clinical outcome and, therefore, in patients' quality of life with epilepsy. Another factor mentioned

DOI: 10.15343/0104-7809.202347e14972023I

was the socioeconomic level, measured according to unsatisfied basic needs, finding that at least 68.4% live in poverty. This situation may interfere with the seizure control of patients, considering that antiepileptic drugs can be a group of expensive drugs and are not always readily available in the public health system. This also relates to the most frequent cause of poor adherence to drug treatment in this study: low availability of financial resources, which has already been reported. A systematic review found that financial income, caregiver marital status, and education level significantly influence drug adherence, which correlates with seizure control and, thus, with the quality of life of the patient with epilepsy[6,17].

Generalized tonic-clonic seizures were the most frequent type of seizures found; this is similar to that reported in other studies in Latin America, such as a study in Mexico that found 92.9% of the population studied presented generalized seizures[18]. However, this differs from that reported in other countries, such as Canada, where focal seizures tend to be more frequent in adults and children; this specific study found that 59.6% of the population studied presented focal seizures[19]. The most commonly used drug was valproic acid, followed by phenytoin, similar to what was previously reported in two studies conducted in Honduras[12,20]. It was also found that most patients receive monotherapy with antiepileptic drugs, which is in accordance with internationally recommended clinical standards[21]. However, there is a significant proportion 27.7% of patients received two or more drugs - which could be partly explained by the fact that the study was conducted in a tertiary hospital and the main referral hospital in Honduras - were patients with difficult-to-manage epilepsies typically followed up.

The quality of life measured by the CAVE survey was primarily good, 36.4%, or fair, 33.2%; no significant differences by gender were observed in the overall score of the CAVE survey. As for the domains, behavior and learning are the most affected; this is consistent with what has been described in other studies that describe the cognitive sphere as the parameter with the lowest score in quality of life[18,22]. As for the factors related to the quality of life, having fewer unmet basic needs and the type of therapeutic response (non-drug resistant epilepsy) were positively associated with the quality of life of patients. Our findings on the influence of socioeconomic status and refractory epilepsy on quality of life have been previously described in systematic studies[6,23]. This could be due to differences in access to health services and availability of resources to ensure permanent drug use. In patients with refractory epilepsy, chronic exposure to epileptic seizures could pose significant challenges and adaptive demands that could compromise their quality of life.

One of the main limitations identified in this research was the lack of previous studies on the quality of life in patients with epilepsy in Honduras or Central American countries with similar socioeconomic and cultural situations, making it difficult to choose the scale to measure the quality of life. In addition, the subjectivity of the responses should be considered since it is a survey answered by the caregiver of a child with epilepsy. The family plays a crucial role in managing the disease, primarily because seizures happen randomly and require mandatory and ongoing supervision. Because childhood epilepsies have a wide range of effects on the family environment, using surveys filled out by parents is still a good tool for evaluating quality of life. The restrictions installed in the hospitals during the critical moments of the COVID-19 pandemic, such as the closure of the pediatric outpatient clinic, represented a challenge in data collection due to the decrease in the number of patients.

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## CONCLUSIONS

The quality of life reported by the parents of the children with epilepsy who attended the outpatient clinic of this health care center was mostly good or fair; having a greater number of unmet basic needs and being classified as difficult to manage epilepsy were predictors of worsening quality of life as measured by the CAVE scale. The total quality of life score did not vary significantly according to gender. The most affected domains in the population evaluated were behavior and learning. Many families had one or more unsatisfied basic needs, and the highest percentage of mothers and fathers had some primary education. This study aims to approximate the aspects of daily life that have a significant impact on pediatric patients with epilepsy and or their families. Although the factors found here are difficult to modify, the healthcare system can play an important role in achieving more equitable health outcomes for children of lower socioeconomic status or for children with difficult-to-control epilepsy.

**ACKNOWLEDGMENT**: To Leyla Depret-Bixio for her support in the completion of this manuscript.

### CREdiT author statement

Conceptualization: González, DMV; Gutierrez, MZ; Romero, MJF; Moncada, MAM. Methodology: González, DMV; Gutierrez, MZ; Romero, MJF; Moncada, MAM. Validation: González, DMV; Gutierrez, MZ; Romero, MJF; Moncada, MAM; Cáceres, F. Statistical analysis: González, DMV; Gutierrez, MZ; Cáceres, F. Formal analysis: González, DMV; Gutierrez, MZ. Investigation: González, DMV; Gutierrez, MZ; Romero, MJF; Cáceres, F. Resources: González, DMV; Gutierrez, MZ; Romero, MJF; Cáceres, F. Preparation of the original draft: Gutierrez, MZ; Romero, MJF; Cáceres, F. Writing-review and editing: González, DMV; Moncada, MAM. Viewing: González, DMV; Gutierrez, MZ; Romero, MJF; Cáceres, F. Supervision: González, DMV; Moncada, MAM. Project administration: González, DMV; Gutierrez, MZ.

All authors read and agreed to the published version of the manuscript.

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Received: 19 march 2023.
Accepted: 28 august 2023.
Published: 10 october 2023.