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Translation and validation of the Spanish version of the Quality of Life Inventory for Adolescents (QOLIE-AD-48)

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TRANSLATION AND VALIDATION OF THE SPANISH VERSION OF THE QUALITY OF LIFE IN EPILEPSY INVENTORY FOR ADOLESCENTS (QOLIE-AD-48)

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Preface

I want people with epilepsy to know that there are ways in which they can play a role in their own recovery. It’s all in how they approach what is happening and how they can use that as a catalyst for their own growth. If there’s one thing that I’ve learned, it’s that people are willing to embrace you if you share your story.”

Danny Glover

TRANSLATION AND VALIDATION OF THE SPANISH VERSION OF THE QUALITY OF LIFE IN EPILEPSY INVENTORY FOR ADOLESCENTS (QOLIE-AD-48)

by

PERLA MICHELLE MARTINEZ M.D

THESIS

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Abstract

Background: In 1999, an instrument was developed to assess quality of life (QoL) among adolescences with epilepsy. To our knowledge there is not a validated Spanish version of this questionnaire. There is a gap in the literature about QoL and epilepsy among speaking Spanish populations. **Objectives**: 1) To conduct an English-Spanish translation of the QOLIE-AD-48; 2) to evaluate the reliability of the Spanish version of the QoLIE-AD-48; and 3) to assess the validity of the Spanish version of the QoLIE-AD-48. **Method**: *Phase 1 translation:* Methods followed the published work of Sousa and Rojjanasrirat (2010). *Phase 2 Pilot study:* the sample population was comprised of speaking Spanish adolescents with a history of epilepsy who were members of the two Facebook groups about epilepsy that were selected. The inclusion criteria included: being between the ages of 10 and 19 years; diagnosed with epilepsy for at least 2 years; active epilepsy; Spanish speaking; able to read Spanish texts; currently attending school. Descriptive analyses and correlations across the sample were conducted. A sociodemographic survey and the Illness Severity Index (ISI) were also administered to all participants. **Results:** 78 individuals participated in our survey. Only 6 participants fulfilled the inclusion criteria. The age range was 12-19 years, mean age of 15.8 years (SD=3.11 years). 50% presented a high illness severity, and 50% had a moderate illness severity. Statistical analyses indicate some high reliability and validity correlations indicating that the Spanish instrument is usable **Conclusion:** Even though our sample was small, we concluded that the Spanish version of the QOLIE-AD-48 can be used among individuals of Spanish speaking countries, including the Latin population in the United States. We believe that a third phase should be conducted among a larger sample to verify the validity of our instrument and describe the quality of life among adolescents with epilepsy.

Keywords: epilepsy, adolescents, quality of life, validated instruments

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Introduction

Background

Epilepsy is one of the most common neurological illnesses. In fact, it is the most frequent neurological disease during childhood. Epilepsy is a chronic non-communicable brain condition that affects approximately 1% of the entire population in the globe. It can affect individuals in different ways. People with epilepsy (PWE) compose a very heterogeneous group, as a result, it is very challenging to provide a holistic care to this population. (Stafstrom & Carmant, 2015).

Epilepsy is associated with several social concerns. For example, it is frequently associated with high levels of stigma, depression, and other comorbidities which negatively impact the Quality of Life (QoL) of the people who are affected by this condition.

During adolescence individuals experience a lot of changes. Hence, most of the times QoL decreases during this stage of life. Adolescents with chronic conditions experience diverse changes in QoL. Studies have been conducted in this matter across different population and medical conditions. In 1999, an instrument was developed to assess QoL among adolescences with epilepsy. However, to our knowledge there is not a validated Spanish version of this questionnaire.

The Latino population is rapidly increasing in the United States. A great percentage of this population rather to answer health-related questions in Spanish. There is a gap in the literature about HRQOL and epilepsy among speaking Spanish population. It is necessary to assess the QoL of speaking Spanish Adolescents with epilepsy, to know and understand their needs. Therefore, public health professionals can use this information to create interventions or continue the research in this topic.

Problem Statement

Epilepsy is a common neurological disease that in most instances has a negative impact in the Quality of Life (QoL) of the individuals who have it. However, most of the scope of research about epilepsy focus on the improvement of diagnostic tools, surgical techniques, and antiepileptic drugs (AED). Little attention is given to social, economic and policy needs, especially among adolescents. QoL has gained great significance as a health indicator. Although, the English version of a validated instrument to assess QoL among adolescents with epilepsy has been available for 20 years, an exhaustive literature review did not allow us to identify a validated instrument in Spanish. The Hispanic population is an increasing population in the U.S. 13% of the population of the U.S are Spanish-speaking Latinos. There is a need to conduct studies on QoL in Spanish to avoid segregation and extend the knowledge about QoL of Spanish-speaking Latinos with epilepsy. By validating a Spanish instrument and conducting a pilot study, it will be possible for healthcare providers and public health professionals to standardize and increase the assessment of QoL of adolescents with epilepsy who speak Spanish in the U.S. Eventually, it will enable public health professionals to understand the needs of this population which may lead to the development of appropriate interventions and potentially provide a background for future policy.

Research Questions

- How reliable is the Spanish version of the QOLIE-AD-48?
- What is the validity of the Spanish version of the QOLIE-AD-48?

Goal

- To implement an instrument to assess HRQOL among speaking Spanish adolescents with epilepsy.

Aim

- To translate and validate an instrument to assess the HRQOL among speaking Spanish adolescents with epilepsy

Objectives

1. To conduct an English-Spanish translation of the QOLIE-AD-48.
2. To evaluate the reliability of the Spanish version of the QoLIE-AD-48.
3. To assess the validity of the Spanish version of the QoLIE-AD-48.

Hypothesis

- The Spanish version of the QOLIE-AD-48 instrument to assess HRQOL among adolescents with epilepsy will maintain the same external validity and internal consistency as the English version.

Assumptions

- The QOLIE-AD-48 is the most widely used instrument to assess HRQOL among adolescents with epilepsy.
- The sample of participants will share the same ethnicity, because they will be recruited among Facebook groups created in Mexico.
- Participants or caregivers will answer the questionnaire in the most accurate and honest manner.
- Committee members and linguistic experts will conduct their task in a proper and ethical manner.
- The survey will be accessible to all the members of the selected groups.
- There are not geography restrictions. Spanish will be assessed in different areas of Mexico.

Limitations

- Only a pilot study will be conducted to assess usability and validity of the Spanish version of the QOLIE-AD-48
- The majority (or all) the participants will be Mexican; therefore, the pilot study will only assess Spanish as spoken in Mexico.
- Budget will be limited because no grant was conferred to conduct this research project.
- Time will be limited because researcher must meet university's deadlines to finish this protocol.
- Population cannot be described/ Survey will be distributed among an unknown audience.
- Participants with biases could select themselves into the study.

Literature Review

Definition

The conceptual definition of epilepsy describes it as a disease of the brain represented by a continuous susceptibility to develop seizures, and all the consequences it might involve such as psychological, neurobiological, and cognitive. Moreover, the operational definition of epilepsy establishes that, “there must be at least 2 unprovoked seizures occurring more than 24 hours apart or one unprovoked seizure and a probability of further seizures similar to the general recurrence risk after two unprovoked seizures, occurring over the past 10 years”. This new operational definition was established by the ILAE in 2014. The definition was introduced as an attempt to improve the diagnosing, treating and supporting of epileptic patients. One of the majors accomplishes of the new conceptual definition is the recognition of the comorbidities as part of the disease. As a result, they must be diagnosed and treated by healthcare providers (Fisher R et al, 2014).

The term seizure, also known as epileptic convulsions, refers to an alteration produced by desynchronies, alterations and rhythmic peaks among a group of neurons that develop a transient occurrence of sensorial and motor clinical manifestations (Stafstrom & Carmant, 2015). The most recent classification of seizure types was presented by the ILAE in 2017. This classification is based in the type of onset such as focal, generalized, and unknown. First, focal onset refers to seizures, which originate in one hemisphere of the brain; they can be either discretely localized or far spread. Second, generalized onset refers to seizures that start at some spot of the brain but rapidly distributes to both hemispheres. Third, an unknown onset seizure may still be described according to the motor nor non-motor characteristics (Fisher R et al, 2017).

In 2017, the ILAE published an updated classification of epilepsy based in the etiology. There are six categories of epilepsy, structural, genetic, infectious, metabolic, immune, and unknown. A patient can present an epilepsy with two etiology categories. It is important for physicians to determinate the cause of epilepsy because some etiologies are associated with specific treatment approaches, complications, and prognosis (Shceffer et al, 2017).

One of the major problems regarding epilepsy is the lack of adequate treatment or lack of treatment at all, also known as treatment gap. In low-income countries, it can go from 10% to an alarming 75% (Guerreiro C. A., 2016). It is estimated that with the proper treatment 70% of the patients with epilepsy could live seizure free (Megiddo et al, 2016). Epilepsy is usually managed with antiepileptic drugs (AED). Furthermore, epilepsy can be refractory; this means that a patient has been treated with two effective AED and the seizures cannot be controlled. One third of patients who have been recently diagnosed present refractory epilepsy. Other treatment approaches include, epilepsy surgery, diets and neurostimulation. Overall, all therapies have as main goal to control seizures and improve QoL (Guerreiro C. A., 2016).

Another classification of epilepsy is based on the seizure activity. Epilepsy can be classified as active, in remission and resolved. The first two terms are poorly defined and there is not a consensus of how to decide that the epilepsy of a patient is in remission. On the other hand, according to the ILAE epilepsy resolved refers to a patient that has been seizure free for 10 years, of which at least 5 years were without any AED (Abramovic & Bagic, 2016).

Prevalence & Incidence

The WHO estimates that there are more than 50 million of people around the world with epilepsy. Approximately, each year around 2.4 million people are diagnosed with epilepsy. Nevertheless, epidemiologists have predicted that this number has increased. The incidence of epilepsy among high-income countries is calculated in 50 per 100,000 population and the prevalence rate is 700 per 100,000 population. Nonetheless, 80% of PWE live in developing countries (Abramovicin & Bagic, 2016).

According to data presented by the Centers for Disease Control and Prevention (CDC), in 2015 there were 3.4 million of people diagnosed with epilepsy in the US; this number is representing the 1.2% of the entire population. 3 million of patients were adults and 470,000 patients were children. Furthermore, in Texas there are 292,900 PWE. 16% (n=47,200) are children. (Zack & Kobau, 2015)

Epilepsy affects people of all ages. But it is the most frequent neurological disease among pediatric populations. It is estimated that affects 0.5% to 1% of children. In 2015 Kim et al, published a study which aim was to calculate the prevalence and incidence of epilepsy among the pediatric population in the US. Their results showed that the prevalence for 2012 was 6.8 cases per 1,000 children. Moreover, the overall incidence was calculated 104 cases per 100,000 children.

Aaberg et al (2017) conducted a prospective cohort to calculate the rates of epilepsy among Norwegian children. The results showed an incidence rate of 144 person-years in the first year of life and 58 per 100,000 person-years through the next years up to the age 10 years. At the age of 5 years, the cumulative incidence was 0.45% and at age 10 years, it was 0.66%

Comorbidities

The population of PWE is not homogenous. There are wide variety of symptoms, etiology, and prognosis. In addition, epilepsy is a complex and systemic disorder, which should not be approached as a pure neurological disease. It is a well-kwon fact that epilepsy is associated with different medical conditions. Moreover, recent studies have shown that PWE have a higher risk of premature death compared with people without this disorder. Even patients in remission seem to be at higher risk of premature death (Keezer et al, 2016; Huang H, et al, 2015; Yuen et al, 2018).

It is estimated that 50% of the PWE present at least one comorbidity. For instance, there are epidemiological studies that showed that some diseases are 8 times more frequent among this population for example, arthritis. (Keezer et al, 2016). The treatment of epilepsy should not be restrained to manage seizures. Protocols and algorithms to treat epilepsy should include the management and diagnostic of associated conditions. Moreover, it is essential to diagnose and manage these comorbidities because they have an effect in the prognosis and the QoL of PWE. Research findings have shown that neurological and psychiatric comorbidities have a greater impact in the health-related quality of life (HRQOL) among PWE than the lack of seizure control. This statement is true even in patients with treatment-resistant-focal epilepsy. (Keezer et al, 2016; Kanner, 2016).

The most prevalent comorbidities among PWE are psychiatric disorders such as depression and anxiety. Research has showed that the prevalence of psychiatric disorders among children and adolescents with epilepsy can vary between 20-60%. Some risk factors include, stress, stigma and brain function. Moreover, psychiatric disorders are more common in children and adolescents with epilepsy than in pediatric populations diagnosed with asthma or diabetes mellitus. Other common comorbidities include neurological diseases like dementia and migraine. Both neurological and psychiatric comorbidities are correlated with poor seizure control. Additionally, QoL is negatively impacted by depression (Keezer et al, 2016; Schraegle & Titus, 2017)

As mentioned before, neurological, and psychiatric conditions are tightly associated with epilepsy. However, reports have consistently demonstrated that PWE have a higher risk of present other chronic conditions compared with individuals without epilepsy, such as heart disease, peptic ulcers, and arthritis (Keezer et al, 2016; Huang H, et al, 2015; Yuen et al, 2018).

Even though several comorbidities are more prevalent among epileptic patients. There is little information about how to address and manage them. The best tool to measure these associated conditions is prevalence. However, it is vital to understand how these diseases in conjunction with epilepsy affect the lives of PWE. Although, it is very complex to determinate the mechanisms that lead to the development of comorbidities in epilepsy patients, it is highly important to study all the factors that increase the risk to develop these associated conditions. (Keezer et al, 2016).

For clinicians the diagnosis of an associated disease among patients with epilepsy changes the therapeutic approach. Some conditions might be causing interactions in the electrical activity of the neurons, pharmacokinetics of AED, or other mechanisms that are not fully described yet. By knowing the comorbidities of the patient with epilepsy, physicians have more tools to provide a more accurate prognosis and treatment.

Quality of life

The prognosis of chronic diseases is hard to measure or predict. Epidemiologic studies often measure two outcomes, mortality, and morbidity. The first term refers to mortality and the second to dysfunction. However, over the past three decades, researches have tried to develop better instruments to measure wellness. These new approaches try to evaluate the QoL (Kaplan & Ries, 2007).

It is challenging to define QoL. Although, this concept is frequently perceived as a subjective measure, research has proved that it can be systematically assessed. In 1985, Ferrans defined QoL as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her”. This concept takes into account several factors such as, health, income, freedom and environment (Poradzisz & Florczak, 2013). Nevertheless, most of the times, researchers assess the health status of individuals with chronic diseases. As a result, in clinical research it is more frequent to measure HRQOL (Kaplan & Ries, 2009; Poradzisz & Florczak, 2013).

HRQOL refers to the assessment of health and well-being with medical conditions that might cause dysfunction or symptoms that could affect daily activities (Kaplan & Ries, 2009). In addition, the definition of HRQL takes into consideration factors such as psychological, physiological, social and spiritual. Consequently, this definition is consistent with the definition of health by the WHO, which is “a state of complete physical, mental and social well-being, and not merely the absence of disease (Helseth & Misvaer, 2010).

Frequently there is data, which supports the impact that certain disease has on QoL. However, to influence medical decisions and health policies is important to have evidence-based medicine and evidence-based public health. In order to obtain validated scientific knowledge, it is crucial to develop instruments to measure outcomes (Finlay, 2017). Consequently, it is important to create and use validated instruments to assess HRQOL. By doing this, researchers can compare results between different populations, diseases and over time (Hanmer & Kaplan, 2016).

Quality of life among general population

Researchers have conducted several studies to assess the HRQOL in the US. To compare results across populations and time it is recommended to utilize validated instruments. For example, in 2016 Hammer and Kaplan used four validated instruments to assess the HRQOL of 47,165 participants in the US. The results showed that females from all ages reported lower scores compared with males. Moreover, older populations had lower scores in comparison with younger populations. As mentioned before, researchers used validated instruments. Therefore, they compare they results with previous assessments such as, The National Health Measurement Survey of 2005-2006, The Joint Canada/United States Survey of Health of 2002-2003 and the US Validation of the EuroQol of 2002. The standardization of the surveys and instruments to assess HRQOL among the general population or specific populations allows the public health professionals to evaluate and compare different results and provide a better understanding of the health trends in the country.

Quality of life among healthy adolescents

Adolescence is a stage of transition between childhood and adulthood. According to the WHO adolescence age between 10 and 19 years. The lancet commission in adolescence health and well-being stratified adolescence in early adolescence which comprises those individuals between 10 and 14 years, and late adolescence which considers individuals between 15 and 19 years. There are different factors that predominate in each stage. For example, early adolescence is characterized by puberty and sexual development. Contrarily, during late adolescence the pubertal maturation is less obvious (Das et al, 2017)

Individuals experience several physical, emotional, and cognitive changes. Although, most of the adolescents experience this stage with no negative outcomes, research showed that life satisfaction and QoL decrease during this period (Helseth et al, 2010). There is little evidence of how adolescents perceive QoL. Few studies had been conducted to determinate the QoL and HRQOL among this group.

Cui et al (2016) conducted an assessment to evaluate changes in HRQOL among adolescents from the US. They used data from the 2001-2010 National Health and Nutrition Survey (NHANES). The sample size was 7,087 adolescents' ages 12-17 years. The participants completed a HRQOL questionnaire. The results showed that between 2009 and 2010, 51.8% of participants reported excellent or very good health, which was a lower percent compared with previous periods 2001-2002 (64%) and 20003-2004 (64.0%). In addition, between 2007 and 2008, 10% of adolescents reported fair or poor health.

Furthermore, Lima-Serrano et al (2013) studied the QoL among 135 adolescents who attended high school in Spain. They found that around three quarters of the participants perceived their family as functional and reported their health as good or very good. In addition, they found that factors such as family functionality and physical activities were associated with better QoL. Overall, males reported a better QoL compared to females.

Quality of life among adolescents with chronic diseases

Chronic conditions represent a burden to the QoL and HRQOL of individuals. As mentioned above, QoL tends to decrease during the adolescence. It is expected that the HRQOL and QoL among adolescents with chronic conditions are negatively affected (Helseth et al, 2010). There are two types of factors that have an impact in chronic diseases in adolescents. The first one is disease-related factors such as, disease severity, age of onset, complications, perception of normality, attitudes toward the condition and treatment. The second category is non-disease related factors like, age, gender, SES, support by social networks, especially parents (Zashikhina et al 2014).

There are studies that assess HRQOL in adolescents. For example, there are several research protocols which aim is to asses HRQOL among adolescents with chronic conditions. Such as, type 2 diabetes, asthma, HIV, cancer and neurological conditions like migraine and cerebral palsy.

Rhodes et al (2012) conducted a study among adolescents and their parents (ages: 12-18) with type 2 diabetes mellitus, obesity and insulin resistance to determinate their HRQOL. 5% of the surveys were answered in Spanish and 38% of the sample was Hispanic. The results showed that low scores in HRQOL among this population were associated with severity of obesity, race/ethnic, and family's functionality. Type 2 diabetes mellitus and its comorbidities were an important factor while assessing HRQOL in the participants. Parents perceived their children's HRQOL lower that the adolescents.

On recent research about asthma a correlation was stablished between HRQOL and common comorbidities and psychiatric disorders. In 2016, Sundbom et al studied the association between HRQOL and asthma control, insomnia, anxiety, and depression in 369 participants (aged 10-35 years) in Sweden. Low levels of the mini-Asthma Quality of life Questionnaire (mAQOLQ) were associated with highest level of medications, poor asthma control, insomnia, anxiety and depression.

There are research projects that compare HRQOL between individuals with different chronic diseases. For example, Zashikhina et al (2014), conducted a cross-sectional study in Russia which aim was to determinate the HRQOL among 173 adolescents (aged 13-16 years) diagnosed with asthma, diabetes mellitus and epilepsy. Participants answered three disease-specific surveys. The findings of the study showed that 52% of participants with diabetes described their health status as fair. HRQOF was not associated with level of control of the disease. Moreover, the majority of adolescents with asthma rated their HRQOL as satisfactory and reported more concern regarding physical activity. On the contrary, PWE reported more concern about attitudes toward epilepsy and stigma. These findings in epilepsy are consistent with previous research where stigma has a negative impact among mental health and QoL among PWE. Overall, high levels of HRQOL were associated with less disease severity, higher Socio-Economic Status (SES) and older age.

Association between epilepsy and quality of life

HRQOL is reduced in PWE. There are some factors associated with reduced levels of HRQOL such as, adjustment to living with seizures, experiencing stigma and comorbidities, the most studied are psychiatric disorders (Rawlings et al, 2017).

An important factor associated with QoL among PWE is stigma. It is produced by the lack of awareness about this neurological condition, which can cause negative attitudes toward PWE. Yeni et al (2018), conducted a study to determinate the association between knowledge, attitude, stigma depression, anxiety and QoL in Istanbul. 205 adults participants were recruited, 72% of the sample had generalized seizures and 46.3% reported to have at least one seizure per month. According to the results, QoL is tightly associated with level of knowledge, attitude and perceived stigma. The authors concluded that education and support strategies should be implemented among this population and social networks to increase the QoL in this population (Yeni et al, 2018).

Quality of life among adolescents with epilepsy

Over the past decades, there have been an increase in research about QoL in pediatric populations with epilepsy. Quantitative and qualitative methods had been used to assess HRQOL (Elliot et al, 2005). However, there is a research gap in HRQOL among adolescents.

As previously stated, adolescence is a stage of life. During this phase individuals start to experience independence and wide range of emotions. Adolescents cannot be perceived as young adults or big children. It is imperative to create strategies that address this population and to consider their daily activities, responsibilities and interests. With that in mind, in 1999 Cramer et al developed a questionnaire to assess HRQOL among adolescents with epilepsy. At the time there were questionnaires designed for children and adults. However, there was not a survey to assess HRQOL during adolescence. They created an instrument which was tested in pilot study with 197 participants (aged 11-17). They aim was to establish the construct validity. The authors found that their test –retest reliability was 0.83 for the total score. In addition, the results showed that the test had validity, internal consistency and reliability. This instrument has 54 items, which include domains such as emotional well-being, physical function, and epilepsy-targeted items. This instrument can be completed in 15-20 minutes. Since it was first published, QOLIE-AD-48 has been used in several studies, which try to assess HRQOL among adolescents. It has been used in China, Serbia, Iran and Brazil. However, to our knowledge there is not a Spanish version of this instrument.

Elliot et al (2005), conducted a study to determinate the components of HRQOL among 49 participants aged 7-18 years diagnosed with refractory epilepsy. Results showed that 76% of the participants identified excessive fatigue as their main complain. Fatigue was associated with need for more sleep and school absence. Even though 63% of the participants expressed they were happy, the vast majority of the participants reported intense emotional stress and sadness. These feelings were caused by the unpredictability of seizures, frustration and social isolation. Moreover, participants experienced barriers to inclusion imposed by themselves, peers, parents and teachers (Elliot et al, 2005).

Measurements of validation, reliability, and validity

In clinical research it is crucial to measure some concepts that can be abstract such as QoL, HRQOL, patient adherence, among others. To be able to systematically measure those outcomes, researchers use validated questionnaires or instruments. Reliability and validity are key concepts to the development of qualified instruments that can be used in research and clinical practice. These concepts are the most widely used to create quality instruments to conduct research (Bannigan & Watson, 2009).

In 2008, Boparai et al developed a guide to validate an instrument which can be utilized by researchers to avoid bias, decreased power of study and to compare the study findings across time and populations. They described that the questionnaire design should have reliability and validity. For validity, content validity, construct validity and criterion validity should be accomplished. On the other hand, for reliability stability, internal consistency and equivalence should be demonstrated. To design a validated instrument, it is highly important to comprehend several concepts, being validity and reliability the most important ones (Bannigan & Watson, 2009).

Reliability also known as consistency is defined as “the stability of a measurement scale” which refers to the capacity of the instrument to provide the same results across different occasions, which will allow replication. In other words, reliability means that something can be measured consistently. In addition, there are different kinds of reliability such as stability, internal consistency, and equivalence. Last, reliability can be calculated using a range between 0.00 and 1.00 being higher coefficients indication of higher score of reliability (Boparai et, 2008; Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017)

Stability which is a type of reliability can be determined by applying the scale or instrument to the same participant in separate occasions in which the scores would remain similar. This means that similar results can be obtained on different administrations of the instrument. Some considerations that should be taking into account are, the construct that is intended to measure might change over time, participant might be familiar with the questionnaire which may influence the responses, and participants could answer without the same precaution as the first time. For an instrument to be considered with this quality it should be a high correlation between the scores of the different times a participant completed the questionnaire. A strong stability refers to a correlation coefficient greater that 0.5 (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017)

Internal consistency also called homogeneity is another type of reliability. This concept is defined as "the extent to which the items relating to a particular dimension in an instrument tap only this dimension and no other". This means that different questions can assess the same domain or concept. This property is most assessed using Cronbach's α which calculates the average intercorrelations of items and the number of items in the scale. An instrument has a strong internal consistency when the result of the calculation is 0.7 or above, results can be obtained in a scale of 0 to 1 (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017).

Lastly, equivalence refers to the level of agreement between two or more observers. A common way to measure equivalence is by asking a panel of experts in a subject to give a score of the relevancy for each item of the instrument. If there is consistency among the scores of the panel, then the instrument is considered to have equivalence (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017).

Furthermore, validity refers to “the degree to which a scale measures what it is intended to measure”. There are several categories of validity. However, three categories are considered the most important for instrument validation. Those categories are content validity, construct validity and criterion validity (Boparai et, 2008; Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017)

Content validity refers to the authenticity of the instrument. In other words, how well the content of the instrument was developed and how well it covered all the content that should in accordance to the variable that is intended to assess. It is considered the minimum requirement an instrument must prove to have validity. It is not assessed by using a statistical analysis. Instead, participants, experts and researchers can help to determine if an instrument has relevance and utility. Another way to assess this category is by conducting a literature review (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017).

The second category is construct validity which refers to “whether you can draw inferences about test scores related to the concept being studied”. This category can be evaluated using correlations with previous results of the construct that is being studied. For example, if s researchers are measuring the QoL it is expected that participants with severe forms of a disease will score lower compared to young athletes (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017).

Finally, the third category is criterion validity. This concept refers to the correlation that can be made to a different instrument which is designed to measure the same construct or variable. If there is an existing validated instrument which is measuring the same outcome the analysis is very straightforward (Kimberlin & Winterstein, 2008; Oluwatayo, 2012; Tsang et al, 2017).

Methods

The study design of this research project was developed in two phases. First, an English-Spanish translation of the questionnaire named QOLIE-AD-48 was conducted. The translation of the instrument was performed following the Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline (Sousa and W. Rojjanasrirat, 2010) During the second phase, a cross sectional approach was used to assess the reliability and validity of the Spanish version of the QOLIE-AD-48. This project was submitted to obtain approval from the UTEP institutional review board (IRB) (1713644-1).

The sample population of this study was composed by speaking Spanish adolescents with a history of epilepsy who were members of the two Facebook groups related to epilepsy that were selected. To participate in this study individuals had to meet the following criteria, be between the ages of 10 and 19 years (WHO definition of adolescent), diagnosed with epilepsy for at least 2 years, active epilepsy (at least 1 seizure over the past 2 years) Spanish speakers, able to read Spanish texts, currently attending school. The following constituted the exclusion criteria: history of being hospitalized one year prior the study or hospitalized at the time of the study, being diagnosed with psychiatric disorders or other chronic condition, neurological impairment, and history of brain surgery. This protocol had a non-randomized design. Descriptive analysis and correlations across the sample was conducted by convenience.

In conjunction with the QOLIE-AD-48 and additional questionnaire was created to collect data from the participants. This questionnaire was designed to collect sociodemographic characteristics such as age, educational level, current occupation, marital status etc. and clinical measures like age of diagnosis of epilepsy, type of seizures, etiology of epilepsy etc. Moreover, the Illness Severity Index (ISI) proposed in 2004 by Raty et al, was used to assess the sensitivity of our instrument.

As previously mentioned, the instrument selected for this study was the QOLIE-AD-48. This is an instrument designed to assess HRQOL among adolescents with epilepsy. It was developed in 1999 by Cramer et al. This questionnaire allows to obtain information about several topics of interest of this specific age group. Moreover, it can be answered in a range of time of 15 to 20 minutes. QOLIE-AD-48 is intended to be answered by the adolescent with epilepsy, because it provides a better understanding of how the individual really feels. Hence, parents, legal guardians and researchers should not answer it. The instrument has 48 items divided in several domains, which are epilepsy impact (12 items), memory/concentration (10 items), attitudes towards epilepsy (4 items), physical functioning (5 items), stigma (6 items), social support (4 items), school behavior (4 items) and health perceptions (3 items). To calculate the score, each response was converted to 0-100-point score. To obtain the score for each domain, the mean value of the partial score of each item was calculated. Subsequently, the score of each domain was summarized to obtain the total score. The Spanish version of the QOLIE-AD-48 was answered by each one of the participants.

Procedure

This protocol was be submitted to obtain an IRB approval from The University of Texas at El Paso (protocol #1713644-1). Subsequently, to complete the English-Spanish translation of the instrument named QOLIE-AD-48 the researcher team used the methodology proposed in the Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline (Sousa and Rojjanasrirat, 2010). First, two translators whose mother language was Spanish translated the questionnaire. One of the translators had medical knowledge the other did not. The translators met with the PI to compare their individual translations and merged them to develop a new version. A third translator translated the final version to English. The third translator was a native English speaker but was familiarized with the Mexican Spanish (he/she understands the cultural context). Finally, a group of experts in the subject evaluated the different versions of the translations and agreed on a consensus and definitive version. This version was used in the second phase of this study.

As indicated earlier, a survey with sociodemographic and clinical questions was developed to collect participants' data relevant to this study. The participants, their parents, or legal guardians answered this additional survey.

The two questionnaires, the informed consent, parental consent, and a child asset form were created in an electronic format using QuestionPro. This study was anonymous, no personal information, or any form of identification was asked during the pilot study.

A poster was created as a method of advertising, containing information about the project, such as, purpose, eligibility criteria, and contact information of the PI. It was published along with the link of the questionnaire. The invitation to participate in the study was posted in the selected Facebook groups three times per week, for 3 non-consecutive weeks. Data was collected between June 14, 2021, and July 22, 2021.

The individuals who were interested in participating in this study were able to access the questionnaire by clicking the link. They were directed to a webpage where they were asked to select their age group, 10-17 years, or 18-19 years. If they selected the group of 10-17 years, the asset form and parental consent was displayed. On the other hand, if they selected the group of 18-19 years, they were presented with the inform consent. Once participants agreed to join the study the inclusion criteria appeared in their screen. They had to select all of them and not select any of the exclusion criteria to access the questionnaire. If they did not qualify to answer the questionnaire they were directed to the last page or thank you page of the survey.

Once the participants accessed the questionnaire, they responded the Spanish version of the QOLIE-AD-48 followed by the sociodemographic and clinical survey.

QuestionPro recorded the answers of the participants. The research team downloaded the results as an Excel document. To conduct the descriptive and analytical analysis the SPSS package was used.

Statistical Analysis Plan

Statistical analysis was executed using the Statistical Package for Social Sciences Programme (SPSS). A descriptive analysis of the responses of the sociodemographic and clinical survey was conducted to describe the socio-demographic and clinical characteristics of this population. Measures of central tendency were calculated to report continuous variables. Additionally, proportions were obtained to describe the categorical, nominal, and binary variables. Finally, the illness of severity of the epilepsy of each participant was calculated.

The validity of this questionnaire was assessed by calculating the convergent validity, and content validity. To obtain the convergent validity a correlation between each score of an item of a subscale and rest of the scores of that subscale was calculated using Pearsons's coefficient. A score >0.4 was considered as a correlation moderate to high. In addition, the content validity was determined by a panel of experts during the phase one of this study.

The reliability of the Spanish version of the QOLIE-AD-48 was assessed through internal consistency. It was obtained using Cronbach's α which calculates the average intercorrelations of items and the number of items in the scale. The internal consistency was considered strong when the result of the calculation was 0.7 or above.

The relationship between the Illness severity index and the HQROL (QOLIE-AD-48) score was determined by comparing the means.

Results

Phase 1: Translation

Two certified translators conducted the English-Spanish translation. Translator A has more than 35 years of experience as translator. In addition, she has worked for UTEP and the FBI, she has medical knowledge, and she is Spanish native speaker. Prior to working in the translation of the instrument, she had a meeting with the principal investigator. During this meeting, the aim and objectives of the research project, and the purpose and characteristics of the instrument were discussed. She conducted the English-Spanish translation A.

A qualified translator of the language center of the Autonomous University of Ciudad Juarez (UACJ) conducted translation B. The PI contacted the main office of this department. It was requested that the translator was a native Spanish speaker and had not medical knowledge. Translator B was not informed about the purpose of the research project or about the instrument. A certified translation was sent to the research team.

A merged Spanish version of the translation A and B was developed. To conduct this task the principal investigator had a meeting with the translator A. Together we developed a merged version. A third translation was conducted. Once again, the research team contacted the office of the language center of the UACJ. They were asked to conduct a Spanish-English translation of the merged Spanish version of the QOLIE AD 48. The characteristics of the translator were discussed. It had to be a certified translator, English speaker native, and familiarized with the Mexican culture and slang. Once this version was delivered. The principal investigator and translator A compared this document with the original version of the QOLIE AD 48 and the merged Spanish version. We agreed that the purpose of the instrument remained the same across all the different versions.

The last step of the phase 1 was a forum of experts. The aim of this forum was discuss the lingual, cultural, and appropriateness characteristics of the merged Spanish version of the questionnaire. The panel of experts was composed by 5 experts. The following is a list of the experts with their qualifications to participate in this research project.

- Susana James, translator A (her credentials were mentioned above)
- Dr. Octavio Lerma, a board-certified pediatrician who offered his expert opinion about the scholar level of the questions,
- Andrea Perez, MPH with a background in health communication among Hispanic populations. She was asked to participate to ensure that the questions were cultural relevant and appropriate.
- Diana Perez MD, MMedSc, PhD with more than 8 years of epilepsy research experience was in the meeting to ensure that the instructions and translation of the survey maintained the integrity of the English version.

The PI was the moderator of the discussion forum. At the beginning of the forum, the moderator explained the instructions to the rest of the team. The moderator was going to read the instructions of each section followed by the questions. After reading a component, she asked each one of the participants if they agreed with the translation. If a member of the team did not agree with the structure of the sentence. She/he had to explain the reasons; all the members were allowed to share their thoughts about the matter. To edit the sentence all the members had to agree. Then the moderator would read the next question or instruction.

The meeting was scheduled using Microsoft teams. All the versions of the instrument were shared with the group of experts prior to the meeting. The duration of the forum was 3 hours.

Changes were made to improve the translation and adaptation of the instrument. Some examples of the improvements made during this meeting are the following, 1) It was decided to use the informal manner of "tu" to address the adolescents, 2) several verbs and adjectives were edited to reach the health literacy level (5th grade), 3) the examples of extreme sports were changed to sports that are more common in Mexico, 4) it was decided that in this instrument the phrase "your epilepsy' (tu epilepsia) was going to be changed to the epilepsy (la epilepsia) to align this questionnaire with the linguistic prescription known as person-first language. At the end of this forum the final Spanish version of the QOLIE-AD-48 was developed. This version was used during the phase 2 of this project.

Phase 2, pilot study

Demographic and clinical characteristics

The survey was posted in the selected Facebook groups three times per week for a period of two months. A virtual poster with general information about the research study along with a brief text inviting individuals to participate in this project was published using the personal account of the PI, who is an active member of the groups.

Three hundred and fifty-seven people viewed our survey; the total of responses was 78, however only 15 participants (19.23% completion rate) completed our survey. 26.9% of the participants answered the survey in Mexico, followed by 24.36 in Argentina, 12.8% in Spain, 10.26% in Chile, 6.41% in Colombia, and 3.85% in the United States, Guatemala, Bogota, and Peru. Of the 78 potential participants only 13 (16.6%) fulfilled the inclusion criteria. The sample size was reduced to 6 after applying the exclusion criteria. 38.89% of the potential participants responded that they were admitted to a hospital during the previous year.

Our sample size was comprised by 6 participants. 4 boys (66.66%) and 2 girls (33.33%). Age range was 12-19 years, mean age of 15.8 years (SD=3.11 years). One (16.67%) participant was classified in the category of early adolescence; the other 5 (83.33%) were classified as late adolescents. Fifty percent of the sample was 19 years old 50% of the participants answered the questionnaire in Argentina; the scholar level more prominent was junior high school (83.3%). In addition, none of the participants was working at the time of the study. Half of the participants were single. The primary caregivers of the adolescents were their mothers (80%) and their partners (20%). Five (83.3%) of the caregivers were working at the time of the study. The most common age of epilepsy diagnostic was 15 years (33.33%0 followed by 7 years, 8 years, and 13 years with 16.66% respectively.

Most of the participants did not know the etiology of the epilepsy (66.67%), only 33.335 knew their epilepsy etiology. Among those who knew the cause of their epilepsy, 50% were a consequence of an anatomic malformation and 50% were genetic. The entire sample was under a pharmacologic treatment. The participants treated with one AED and that presented side effects were 33.33% of the sample, 33.33% were treated with two or more AED, and 16.6% were taking one AED and were not showing any side effect. Three patients were taking one AED. The following are the AED that were used among this patients, leveteracitam (n=1), oxcarbazepine (n=1), lamotrigine (n=1). The seizure frequency among this group was as follows, 50% had more than one seizure per month, 33.33% did not presented any seizure during the prior year and 16% presented one seizure per month or less.

Table 1
Sociodemographic and clinical characteristics

Characteristics	Results
Age of participant	10-17 years 50% (n=3) 18-19 years 50% (n=3) 19 years 50% (n=3)

Table 1
Sociodemographic and clinical characteristics

	12 years 20% (n=1) 14 years 20% (n=1) 15 years 20% (n=1) Early adolescent 20% (n=1) Late adolescent 80% (n=4)
Country	Argentina 50% (n=3) Mexico 16.66% (n=1) United States 16.66% (n=1) Spain 16.66% (n=1)
Educational Level	Junior high school 83.33% (n=5) College 16.67% (n=1)
Employment	No 100% (n=1)
Marital status	Single 50% (n=3) Married 16.67% (n=1) Consensual union 16.67% (n=1) Other 16.67% (n=1)
Caregivers	Mother and father 32.4% (n=2) Mother 16.6% (n=1) Parents and grandparents 16.6% (n=1) Partner 32.4% (n=2)
Primary caregiver	Mother 80% (n=4) Partner 20% (n=1)
Primary caregiver occupation	Employee 83.3% (n=5) Student 16.67% (n=1)
Primary caregiver marital status	Married 66.67% (n=4) Single 16.67% (n=1) Other 16.67% (n=1)
Age of epilepsy diagnosis	15 years 33.33% (n=2) 7 years 16.67% (n=1) 8 years 16.67% (n=1) 13 years 16.67% (n=1) 17 years 16.67% (n=1)
Type of epilepsy	Generalized tonic-clonic seizures 33.33% (n=2) Absence 33.33% (n=2) Myoclonic 16.67% (n=1) Unknown 16.67% (n=1)
Epilepsy etiology	Unknown 66.67% (n=4) Anatomic malformation 16.67% (n=1) Genetic 16.67% (n=1)
Current treatment status	Under treatment 100% (n=6)
Type of treatment	One AED with side effects 33.33% (n=2) Two or more AED 33.33% (n=2) One AED with no side effects 16.67% (n=1) Other 16.67% (n=1)
Type of AED	Monotherapy: • Levetiracetam 16.67% (n=1), • Oxcarbazepine 16.67% (n=1)

Table 1
Sociodemographic and clinical characteristics

	- lamotrigine 16.67% (n=1) Polytherapy: - Valproic acid, levetiracetam and topiramate 16.67% (n=1) - Valproic acid, topiramate and other 16.67% (n=1) - Levetiracetam and lamotrigine 16.67% (n=1)
Seizure frequency	More than one seizure per month 50% (n=3) No seizures in the last year 33.33% (n=2) One seizure per month or less 16.67% (n=1)

QOLIE-AD-48 analysis

As previously mentioned, the questionnaire has 48 items divided in 8 scales. Each item has a score range between 1-5 points. Except for questions 37-42 which are assessed using a range of 1-4. In both instances a bigger number is equal to a better HRQOL. To calculate the score of each participant we had to change the scale of 1-5 to 0-25-50-75-100 and to 0-33-67-100 for the 5 and 4 level variables respectively. After that, the mean of each subscale was obtained and then multiplied by the relative weigh of that specific subscale (Table 1). To calculate the total score each subscale's score was added. Finally, we converted the final score to t score (Table 3), (Table 4).

Table 2
QOLIE-AD-48 relative value of subscales

Subscale	Relative weigh value
Epilepsy impact	0.31
Memory/concentration	0.17
Attitudes	0.09
Physical function	0.09
Stigma	0.13
Social support	0.02
School behavior	0.06
Health perceptions	0.12

Table 3
QOLIE-AD-48 score and t score

Participant	**Score**	**T score**
01	78.97	63.17
02	29.71	44.13
03	23.83	41.85
04	75.99	62.01
05	22.47	41.33
06	38.47	47.51

The range of responses of the items was between 0 and 100. However, we noticed that some items had a different range. For example, the range of question 1 was 25-75, and question 19 had a range of 25-50. Means, SD, and medians were calculated for each item (Table 4) A correlation between each question and the total score was calculated to assess the convergent validity (Table 4). Furthermore, we correlate each item with the total score of its own subscale (Table 7).

In addition, the means and SD of each subscale were calculated. The range of all the subscales was 0-100. Finally, the Cronbach alpha score was calculated to assess the reliability of our instrument.

Following the methodology of the validation of the instrument (Cramer et al, 1999), we established an association between the Illness Severity Index and the mean scores of the participants (Table 6)

Table 4
Item analysis of the QOLIE-AD-48

No of question	**Subscale**	**Range**	**Mean (standard deviation); median**	**Correlation with total score**
1 2	Health perception	25-75 0-75	58.33 (25.81);75 50 (31.62); 62.5	-0.974 -0.881
3 4 5	Physical functioning	0-100 0-100 25-100	29.16(40.05);12.5 58.33 (37.63); 75 75 (38.72); 100	0.978 0.844 0.729

Table 4

Item analysis of the QOLIE-AD-48

6		0-100	58.33 (49.15); 75	0.639
7		0-100	33.33 (51.63); 0	0.802
8	Memory/ functioning	0-100	45.83 (45.87); 37.5	0.974
9	School behavior	0-100	50 (44.72); 50	0.883
10		0-100	66.66(43.77);87.5	0.537
11		0-100	75 (38.72); 87.5	0.520
12	Memory/ functioning	0-100	83.33 (40.82);100	0.898
13		0-100	33.33 (37.62); 25	0.954
14		0-100	37.5 (37.91); 37.5	0.388
15		0-100	41.66 (46.54); 25	0.887
16		0-100	41.66 (46.54); 25	0.851
17		0-100	50 (38.72); 50	0.972
18		0-75	41.66 (38.72); 50	0.972
19		25-50	41.66 (12.9); 50	0.846
20		25-100	37.5 (26.22037.5	0.900
21	Social support	25-100	54.16(29.22);50	0.639
22		0-75	20.83(29.22);12.5	0.854
23		0-75	29.16 (29.22); 25	0.915
24		0-75	20.83(29.22);12.5	-0.217
25	Epilepsy impact	0-75	20.83(29.22);12.5	-0.053
26		0-100	45.83(51.03);37.5	-0.242
27	School behavior	0-100	37.5 (41.07); 25	0.024 0.733
28	Epilepsy impact	0-100	54.16 (43.06); 50	0.760
29		25-100	28.33 (25.81); 50	0.502
30		0-100	45.83 (43.06); 25	0.902
31		0-100	41.66 (46.54); 25	0.927
32		0-100	33.33 (51.63); 0	0.974
33		0-100	37.5 (49.37); 12.5	0.954
34		0-100	41.66 (46.54); 25	0.964
35	Health perceptions	0-100	45.83(45.87);37.5	0.978
36	Epilepsy impact	0-100	45.83(45.87);37.5	0.919
37	Stigma	0-100	50 (41.82); 37.5	0.812
38		0-100	50 (45.99); 50	0.970
39		0-100	44.5 (40.46); 50	0.937
40		67-100	83.5 (18.07); 83.5	0.660
41		0-100	57 (35.20); 67	0.837
42		0-100	50 (35.08); 50	0.554
43	Attitudes towards epilepsy	33-100	72.16(32.92);82.5	0.337
44		0-100	33.33 (37.92); 25	-0.122
45		0-100	25 (41.83); 0	0.868
46			16.66 (25.81); 0	0.919
47	Epilepsy impact	0-50	12.5 (20.91); 0	0.974
48		0-100	20.83 (40.05); 0	1

Table 5
Characteristics of the QOLIE-AD-48 subscales

Subscale	**No. Items**	**Mean score**	**SD**	**Cronbach's alpha coefficient**	**Minimum score**	**Maximum score**
Epilepsy impact	12	38.19	41.10	0.955	0	100
Memory-Concentration	10	45.41	37.24	0.952	0	100
Attitudes	4	36.79	39.24	0.648	0	100
Physical Function	5	50.83	44.27	0.920	0	100
Stigma	6	55.83	36.83	0.850	0	100
Social Support	4	31.25	30.61	0.813	0	100
School Behavior	4	57.29	42.01	0.488	0	100
Health Perceptions	3	51.38	33.72	-5.217	0	100
Total score	48	45.87	3.98	0.974	0	100

Table 6
Association between Illness of Severity Index and QOLIE-AD-48

	Low illness severity	**Moderate illness severity**	**High illness severity**
Mean (SD)	N/A	46.63 (29.12)	43.18 (28.56)

Table 7
Correlation between item vs score of the scale

Item	**Correlation**	**Sig (2-tail)**
1	-0.791	0.061
2	-0.516*	0.294
3	0.776	0.70
4	0.878*	0.022
5	0.853*	0.031
6	0.949**	0.004
7	0.853*	0.031
8	0.955**	0.003
9	0.867*	0.025
10	0.866	0.026
11	0.870*	0.024
12	0.349	0.498
13	0.935**	0.006
14	0.945**	0.004
15	0.945**	0.004
16	0.945**	0.004
17	0.942**	0.005

Table 7

Correlation between item vs score of the scale

18	0.941**	0.005
19	0.617	0.192
20	0.919**	0.010
21	0.207	0.694
22	0.956**	0.003
23	0.944**	0.005
24	0.956**	0.003
25	-0.005	0.993
26	0.826*	0.43
27	0.923**	0.009
28	0.664	0.150
29	0.621	0.189
30	0.940**	0.005
31	0.932**	0.007
32	0.984**	<0.001
33	0.965**	0.002
34	0.979**	<0.001
35	0.890*	0.17
36	0.937**	0.006
37	0.776	0.070
38	0.789	0.062
39	0.891*	0.017
40	0.663	0.152
41	0.585	0.223
42	0.747	0.088
43	-0.152	0.774
44	0.885*	0.019
45	0.921**	0.009
46	0.991**	<0.001
47	0.958**	0.003
48	0.866*	0.026

*confidence level 0.05, **confidence level 0.001.

Discussion

It has been widely accepted that there is a need for standardization when it comes to clinical research. One of the best tools to achieve this goal are validated questionnaires or surveys. Sometimes there is a limited availability of validated translations or, even translations. Evidence suggests that validated instruments should be properly translated and validated to different languages. This exercise should lead to a better understanding of clinical problems and needs among multinational and multicultural populations. Health care professionals should be able to assess different outcomes among their patients, knowing that the questionnaire or survey they are using is cultural and linguistically equivalent to the original one.

During our literature review, we found different translations and validations of the QOLIE-AD-48. In 2005 the Serbian version of the instrument was generated by Stevanovic et al. There is a Brazilian version developed by Barbosa et al in 2008. Moreover, in 2009 Wang et al, published the Chinese version of the survey. Brabcova et all created a Czech version in 2021.

All the methodologies followed about the same statistical analysis to assess the reliability and validity of their respective versions. Nevertheless, we noticed that each research team used a different methodology to conduct the translation process. We identify several guidelines to conduct this task. However, we noticed that there is not a universal guideline that researchers across different areas can use to standardize this process. We decided to utilize the methodology proposed by Sousa and Rojjanasrirat (2010). After identifying a gap in this topic, they reviewed the literature and developed clear steps to conduct the translation, adaptation, and validations of instruments. In addition, they emphasized the adaptation and cross-cultural validation in their paper, which we believed is highly important to the quality of the translation.

During the phase 1 of this research project, we developed the Spanish version of the QOLIE-AD-48 questionnaire. Certified translators conducted two English-Spanish translations. In addition, a third translator developed a Spanish-English translation. Finally, a group of experts reviewed the merged version of the instrument. The final version is cultural relevant and has an appropriate language. Our version has the next characteristics, adequate level of formality, and health literacy. Consequently, it does not contain any specialized language, deceitful language, and biased language.

As mentioned before the QOLIE-AD-48 was developed in 1999. It was created before the growing of the movement that advocates the use of person-first language. During the last 20 years, we have witnessed the evolution of language regarding disability. The aim of this movement is to recognize that people are more than their disabilities or diseases. It has slowly gained recognition in medicine and epidemiology. It was important to apply the person-first language to the instrument because as described in the literature, epilepsy is a disease that is frequently associated with social stigma and discrimination. The purpose of the questions did not change by using this type of language.

We decided to generate the Spanish version of the instrument using the Spanish as spoken in Mexico for several reasons. First, this country has the biggest number of Spanish speakers in the globe; among the people whose first language is Spanish 1 out of 3 are Mexican. Secondly, the Spanish spoken in Mexico is often used as reference to translate movies and books. Third, the majority of the Latin population in the United States are Mexican, Mexican American or Chicanos.

As recommended in the guideline that we used, we carefully selected the members of the committee of experts that assessed the merged version of the instrument. We believed that the perspective of each member of the team was important to develop a final product with quality. We decided to form a multidisciplinary team to conduct this task. It can be noted that each individual has a different background that was relevant to construct the final version that was used in the pilot study. The committee of experts made several changes to questions and instructions of the instrument. The meeting was conducted according to the recommendations of the guidelines.

As previously mentioned, the QOLIE-AD-48 has been translated and validated in a wide variety of countries. For example, Brazil, Iran, China, and Czech Republic. We analyzed each version and the methodology the authors followed to develop them. The statistical analysis of the data gathered in the pilot studies is fully described in each publication, all the versions share some similitudes in their statistical analysis. Therefore, we tried to incorporate the same elements they used to our pilot study.

Table 8
Comparison of translations of the QOLIE-AD-48

Version	Authors	Year	Sample size	Mean score	Reliability
Serbian	Stevanovic et al	2005	67	75.4 to 91.3,	0.92
Brazilian	Barbosa et al	2008	93	83.2-39.3, (21.9-11.4)	0.87
Chinese	Wang et al	2009	99	66.1	0.94
Iran	Zamani	2014	197	61.5 (10.4)	N/A
Czech	Brabcova	2021	248	N/A	0.95
English	Cramer	1999	197	39.8 -90.3	Range: 0.73-0.94
Mexican	Martinez	2021	6	44.90 (25.87)	0.94

Our results can be compared to those obtained by the authors of other translations. We want to emphasize that the little participation that we obtained, might not allow us to completely compare our results to previous works. However, our results show a pattern that might be confirmed during a third phase. Because our sample was remarkably small, we decided not to calculate correlations between the sociodemographic and clinical characteristics and the HRQOL of our participants.

Limitations

During the early stages of this project, it was expected to conduct the pilot study differently. For example, the PI was going to collect clinical data from the medical records of the participants. The recruitment was going to take place in the waiting room areas of doctors' offices who were neurologists or pediatric neurologists in Ciudad Juarez, Mexico. The research team was going to read and explain the purpose of this study to the potential participants and their parents/tutors. After that, using a tablet the participant was going to answer a socio-demographic survey followed by the Spanish version of the QOLIE-AD-48. A partnership between the research team and the physicians was established. They were willing to borrow us their physical space and were highly interested in this project. However, the pandemic did not allow us to continue this methodology. We were planning to start collecting data in September 2020. During that time in Mexico there was an increase in the incidence of COVID-19 cases. Therefore, the state of Chihuahua was under lockdown, and the state government mandated a curfew. Most of the medical appointments of patients with controlled chronic conditions were postponed. In addition, the non-essential travel between Mexico and the United States were restricted. As a state employee the PI was not allowed to go to Mexico. It was proposed to hire a person who would recruit participants and implement the surveys. This option was no longer viable during the second wave of the pandemic in Mexico, because of the sanitary risk this person would have to face. At that time, the vaccines were not developed, and the PI had to finish her degree.

The research team decided to modify the methodology of the pilot study. Multiple changes were made to adapt the pilot study to the unique circumstances that we were facing. The following are some changes that the research team established. The study was changed to an anonymous type of study, instead of confidential. We allowed the participants to self-report the clinical characteristics of their epilepsy. The recruitment process was completely adapted to follow the social distancing policies. We decided to look for Facebook groups about epilepsy that were created in Mexico. Moreover, partnerships were established with the administrators of Facebook groups about epilepsy. Establishing the partnerships was challenging, some administrators were not willing to create letters of collaboration that included some personal information. We believe this is because of the extortions that are occurring in Mexico nowadays and because they were contacted through the personal Facebook of the PI instead of an official account of the program or the university. We contacted 10 groups and pages; unfortunately, we were able to obtain letters of collaboration from 2 administrators.

One of the things we noticed was that individuals were curious about our research project. However, we had several of dropouts. As a result, our percentage of competition was very low. Because it was an anonymous study, we could not give away any gift to encourage the participants to complete the survey. Once we noticed the low percentage of competition, we considered changed once again the nature of the study to confidential. However, we would have had to submit the protocol again to the IRB, which would have delayed the academic progress of the PI.

It is important to note that the aim of our study was not to describe the quality of life of the adolescents with epilepsy in Mexico. Our goal was to validate the Spanish version of the instrument. We decided to conduct a pilot study we expected a small sample. Although we knew the level of competition was going to be low, we did not expect it was going to be as low as it was at the end.

As previously stated, the pilot study was conducted during the pandemic in Mexico, at that time the classes remained in the online format. It was expected that some of the daily routines of the participants were different to the ones described in the instrument. However, a situation was the new normal in Mexico. Therefore, we decided that we could run the analysis and it would show if the instrument was reliable. A third phase of the project is projected. During this new face, we will try to describe the quality of life of the adolescents with epilepsy in Mexico and conduct live interviews to achieve our goal.

Social Media

The previous adaptations of the QOLIE-AD-48 were developed before the pandemic. Furthermore, the recruitment of the participants was through medical offices or hospitals. This is the first time that the process of validation of this instrument is conducted using social media as a space to recruit participants.

We presume that our work could be a precedent to continue recruiting participants using this technology. There are some key points that we learned during the recruitment of participants. For example, we assumed that our percentage of competition was so small because individuals were overwhelmed by the length of the consent form, and the instructions.

We noticed that when we were asking for letters of collaboration from the administrators of the groups, they were very hesitating to give any personal information. Given that it was decided that the study will be anonymous. When we started posting our poster in the Facebook groups and started noticing that our survey was trending in the group. However, members of the group did not pass from the informed consent. We hypothesize that the lack of a stimulus to finish the survey might be a reason. We think that a confidential model might allow researchers to provide electronic gifts, such as a gift card, or a beverage from a coffee shop, may encourage individuals to participate in the research project.

Conclusion

The aim of our study was to design a Spanish version of the QOLIE-AD-48 that maintained the same validity and reliability of the original (English) version. After we completed the phase 1 of this research project, we developed a Spanish version that has consistency, relevancy to the target population, and appropriate health literacy level. To align with the work of previous translations and validations of the same instrument, a pilot study was conducted. Although, our sample was smaller than we expected, and smaller than the previous translations. The results of this phase gave us data to conduct the statistical analysis that allowed us to conclude that that the Spanish version of the QOLIE-AD-48 has validity, internal consistency, and reliability. Therefore, it can be used in Mexico and among individuals of other Spanish speaking countries, including the Latin population in the United States.

As explained before, we are confident that our version can be used to assess the HRQOL among adolescents with epilepsy. In addition, this Mexican version can be used to conduct pilot studies in different regions of Latin America, such as Argentina, Costa Rica, Peru, etc. As we mentioned before the Spanish spoken in Mexico is a reference to translations. Thus, we could standardize the assessment of HRQOL among adolescents with epilepsy by using this version. This standardization will allow the research community to compare the needs of this population across the different regions of America, including the United States.

In addition, this is the first time that the pilot study is distributed through social media. The rest of the translations recruited their participants in clinical settings. This difference in the methodology could set a precedent to future translations and validations. We believe that by giving incentives or using a more friendly and shorter informed consent, sample sizes could be bigger.

The future direction of our project is to conduct a third phase, that will allow us to increase our sample size and verify the validity and reliability of our instrument. Moreover, we aim to describe the quality of life among adolescents with epilepsy in Mexico.

MPH Program Foundational Competencies

- Evidence-based Approaches to Public Health

  1. Apply epidemiological methods to the breadth of settings and situations in public health practice

  2. Select quantitative and qualitative data collection methods appropriate for a given public health context

  3. Analyze quantitative and qualitative data using biostatistics, informatics, computer-based programming and software, as appropriate

  4. Interpret results of data analysis for public health research, policy or practice

- Planning & Management to Promote Health

  7. Assess population needs, assets and capacities that affect community health

  8. Apply awareness of cultural values and practices to the design or implementation of public health policies or programs

- Communication

  19. Communicate audience-appropriate public health content, both in writing and through oral presentation

  20. Describe the importance of cultural competence in communicating public health content

- Inter-Professional Practice

  21. Perform effectively on inter-professional teams

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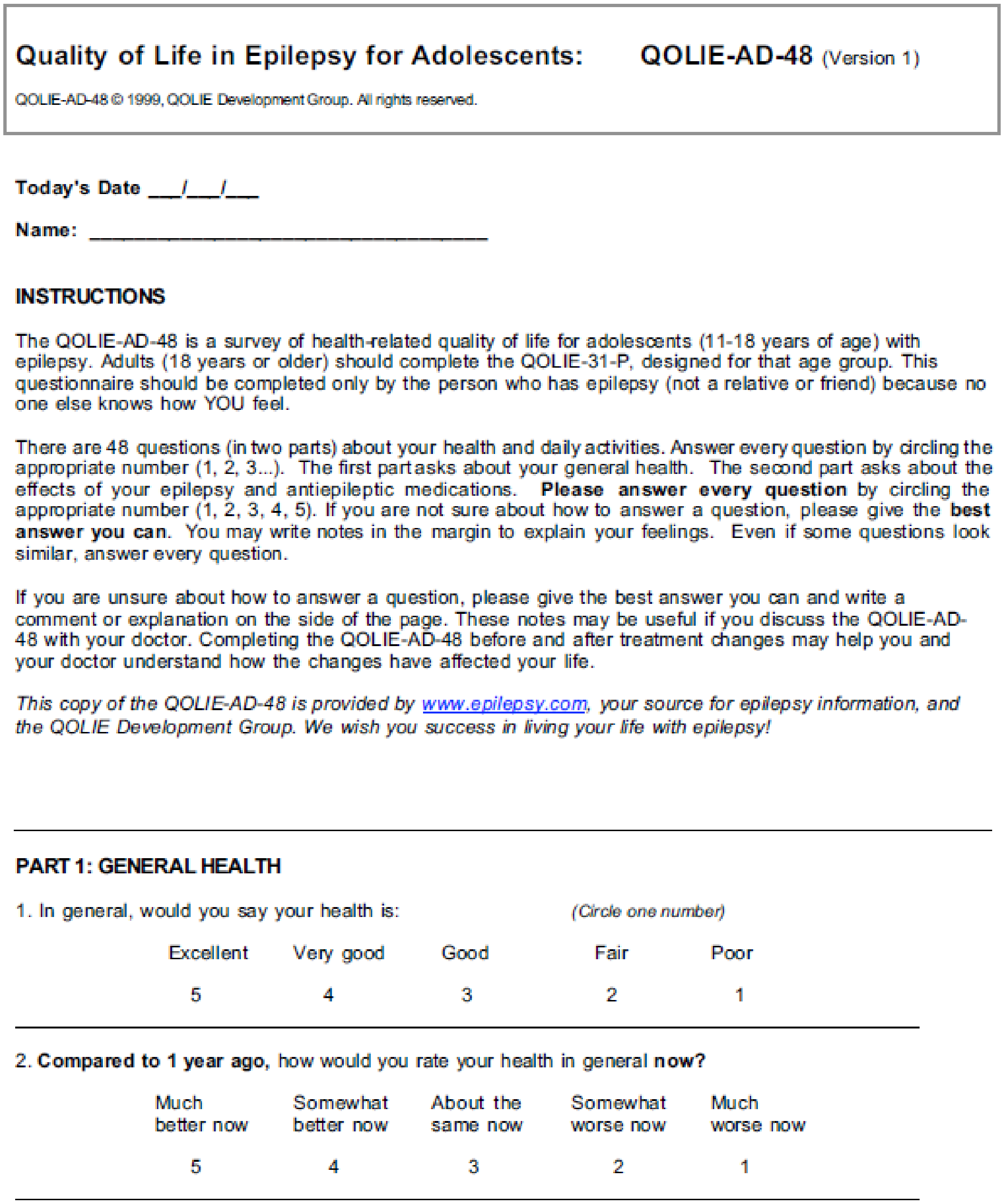
Appendix

< QOLIE-AD-48 English version



Quality of Life in Epilepsy for Adolescents: QOLIE-AD-48 (Version 1)

Today's Date ___/___/___

Name: ______________________________________

INSTRUCTIONS

The QOLIE-AD-48 is a survey of health-related quality of life for adolescents (11-18 years of age) with epilepsy. Adults (18 years or older) should complete the QOLIE-31-P, designed for that age group. This questionnaire should be completed only by the person who has epilepsy (not a relative or friend) because no one else knows how YOU feel.

There are 48 questions (in two parts) about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3...). The first part asks about your general health. The second part asks about the effects of your epilepsy and antiepileptic medications. **Please answer every question** by circling the appropriate number (1, 2, 3, 4, 5). If you are not sure about how to answer a question, please give the **best answer you can**. You may write notes in the margin to explain your feelings. Even if some questions look similar, answer every question.

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation on the side of the page. These notes may be useful if you discuss the QOLIE-AD-48 with your doctor. Completing the QOLIE-AD-48 before and after treatment changes may help you and your doctor understand how the changes have affected your life.

This copy of the QOLIE-AD-48 is provided by www.epilepsy.com, your source for epilepsy information, and the QOLIE Development Group. We wish you success in living your life with epilepsy!

PART 1: GENERAL HEALTH

1. In general, would you say your health is: *(Circle one number)*

Excellent	Very good	Good	Fair	Poor
5	4	3	2	1

2. **Compared to 1 year ago,** how would you rate your health in general **now?**

Much better now	Somewhat better now	About the same now	Somewhat worse now	Much worse now
5	4	3	2	1

The following questions are about activities you might do during a TYPICAL DAY. We want you to answer how much **your health** limits you in these activities. *(Circle one number on each line)*

In the past 4 weeks, how often has your health limited:	Very often	Often	Some-times	Not often	Never
3. Heavy activities, such as running, participating in very active sports (such as gymnastics, rollerblading, skiing)?	1	2	3	4	5
4. Moderate activities (such as walking to school, bicycle riding)?	1	2	3	4	5
5. Light activities (such as carrying packages or a school bag full of books)?	1	2	3	4	5
6. Other daily activities (such as taking a bath/shower alone, going to and from school alone)?	1	2	3	4	5

The following questions are about your regular daily activities, such as chores at home, baby-sitting, attending school, being with friends and family, doing homework, or taking part in after-school activities and lessons. We want to know if you had any of the following difficulties with your regular activities as a result of any **physical problems (such as illness) or emotional problems (such as feeling sad or nervous)?**

In the past 4 weeks, how often have physical or emotional problems caused you to:	Very often	Often	Some-times	Not often	Never
7. Do fewer things than you would have liked to do?	1	2	3	4	5
8. Limit the ***kind*** of schoolwork, chores, sports, or other activities you did?	1	2	3	4	5
9. Have ***difficulty*** performing the schoolwork, chores, sports, or other activities you did (for example, it took extra effort) ?	1	2	3	4	5

In the past 4 weeks, how often:	Very often	Often	Some-times	Not often	Never
10. Did you skip school for no reason?	1	2	3	4	5
11. Were you in trouble <u>in</u> school (with teachers or other staff)?	1	2	3	4	5

	Very often	Often	Some- times	Not often	Never
12. Were you in trouble <u>out</u> of school (with police, security guards, bus driver, etc)?	1	2	3	4	5

These questions are about how you FEEL and how things have been for you during **the past 4 weeks.** For each question, please indicate the one answer that comes closest to the way you have been feeling. *(Circle one number on each line)*

In the past 4 weeks, how often have you:	All of the time	Most of the time	Some of the time	A little of the time	None of the time
13. Had trouble concentrating on an activity?	1	2	3	4	5
14. Had trouble concentrating on reading?	1	2	3	4	5

The following questions are about mental activities and language problems that may interfere with your normal schoolwork or living activities. *(Circle one number on each line)*

past 4 weeks, how often have you:	All of the time	Most of the time	Some of the time	A little of the time	None of the timeInthe
15. Had difficulty thinking?	1	2	3	4	5
16. Had difficulty figuring out and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5
17. Had a problem with complicated projects that require organization or planning like computer games or difficult homework)?	1	2	3	4	5
18. Had trouble remembering things you read hours or days before?	1	2	3	4	5
19. Had trouble finding the correct word?	1	2	3	4	5
20. Had trouble understanding your teachers?	1	2	3	4	5
21. Had trouble understanding what you read?	1	2	3	4	5

The following questions ask about the support you get from others (including family and friends).
(Circle one number on each line)

In the past 4 weeks, how often did you:	Very Often	Often	Some-times	Not often	Never
22. Have someone available to help you if you needed and wanted help?	5	4	3	2	1
23. Have someone you could confide in or talk to about things that were troubling you?	5	4	3	2	1
24. Have someone you could talk to when you were confused and needed to sort things out?	5	4	3	2	1
25. Have someone who accepted you as you were, both your good points and bad points?	5	4	3	2	1

PART 2: EFFECTS OF EPILEPSY AND ANTIEPILEPSY MEDICATIONS

The following questions ask about how your epilepsy or medications (antiepileptic drugs) have affected your life in the past 4 weeks. *(Circle one number on each line)*

In the past 4 weeks, how often did you:	Very Often	Often	Some-times	Not often	Never
26. Feel that **epilepsy or medications** limited your social activities (such as hanging out with friends, doing extra-curricular activities)compared with social activities of others your age?	1	2	3	4	5
27. Feel alone and isolated from others because of your epilepsy/seizures ?	1	2	3	4	5
28. Miss classes because of seizures or medications?	1	2	3	4	5
29. Use epilepsy or medication side effects as an excuse to avoid doing something you didn't really want to do?	1	2	3	4	5
30. Feel embarrassed or "different" because you had to take medications?	1	2	3	4	5
31. Feel that epilepsy or medications limited your school performance?	1	2	3	4	5
32. Feel you had limitations because of your seizures?	1	2	3	4	5
33. Feel that epilepsy or medications limited your independence?	1	2	3	4	5
34. Feel that epilepsy or medications limited your social life or dating?	1	2	3	4	5
35. Feel that epilepsy or medications limited your participation in sports or physical activities?	1	2	3	4	5

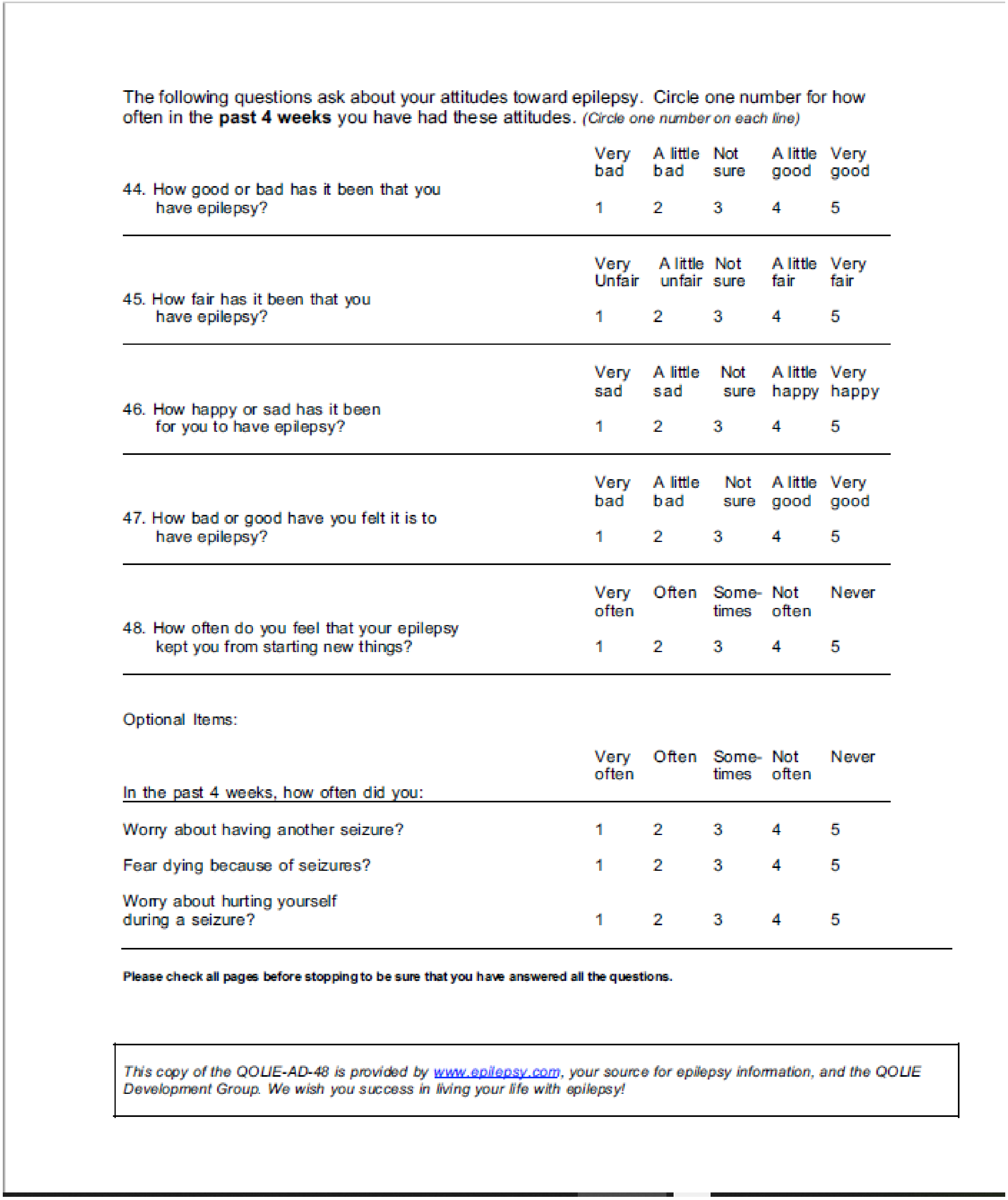
The following question asks about possible side effects from antiepileptic drugs.
(Circle one number on each line)

In the past 4 weeks, how did you feel:	Very Bad	Bad	OK	Good	Very good
36. About how you looked (side effects such as weight gain, acne/pimples, hair change, etc.)?	1	2	3	4	5

In the past 4 weeks, how much were you bothered by:	A Lot	Some	Not much	A little	Not at all
37. Limits set by parents/family because of your epilepsy or medications?	1	2	3	4	5

Next are some statements people with epilepsy sometimes make about themselves. For each statement, circle the answer that comes closest to the way **you** have felt about **yourself** in the **past 4 weeks.** *(Circle one number on each line)*

	Strongly agree	Agree	Disagree	Strongly disagree
38. I consider myself to be less than perfect because I have epilepsy.	1	2	3	4
39. If I applied for a job, and someone else also applied who didn't have epilepsy, the employer should hire the other person.	1	2	3	4
40. I can understand why someone wouldn't want to date me because I have epilepsy.	1	2	3	4
41. I don't blame people for being afraid of me because I have epilepsy.	1	2	3	4
42. I don't blame people for taking my opinions less seriously than they would if I didn't have epilepsy.	1	2	3	4
43. I feel that my epilepsy makes me mentally unstable	1	2	3	4



The following questions ask about your attitudes toward epilepsy. Circle one number for how often in the **past 4 weeks** you have had these attitudes. *(Circle one number on each line)*

	Very bad	A little bad	Not sure	A little good	Very good
44. How good or bad has it been that you have epilepsy?	1	2	3	4	5

	Very Unfair	A little unfair	Not sure	A little fair	Very fair
45. How fair has it been that you have epilepsy?	1	2	3	4	5

	Very sad	A little sad	Not sure	A little happy	Very happy
46. How happy or sad has it been for you to have epilepsy?	1	2	3	4	5

	Very bad	A little bad	Not sure	A little good	Very good
47. How bad or good have you felt it is to have epilepsy?	1	2	3	4	5

	Very often	Often	Some-times	Not often	Never
48. How often do you feel that your epilepsy kept you from starting new things?	1	2	3	4	5

Optional Items:

In the past 4 weeks, how often did you:	Very often	Often	Some-times	Not often	Never
Worry about having another seizure?	1	2	3	4	5
Fear dying because of seizures?	1	2	3	4	5
Worry about hurting yourself during a seizure?	1	2	3	4	5

Please check all pages before stopping to be sure that you have answered all the questions.

This copy of the QOLIE-AD-48 is provided by www.epilepsy.com, your source for epilepsy information, and the QOLIE Development Group. We wish you success in living your life with epilepsy!

QOLIE-AD-48 Translation A

Calidad de Vida para los Adolescentes con epilepsia: **QOLIE -AD-48** (Versión 1)

Fecha de hoy: ___/___/___
Nombre: ___________________________________

INSTRUCCIONES

La forma QOLIE-AD-48 es una encuesta sobre la calidad de vida en lo relacionado con la salud para los adolescentes (entre los 11 y los18 años) que padezcan epilepsia. Los adultos (de 18 años en Adelante) deberán llenar la forma QOLIE-31-P, que se ha diseñado para ese grupo. Solamente la persona que tenga epilepsia deberá llenar este cuestionario, no podrá llenarla ni un pariente ni un amigo porque nadie más sabe lo que USTED sente.

Hay 48 preguntas (divididas en 2 partes) sobre su salud y sus actividades cotidianas. Conteste todas las preguntas encerrando en un círculo el número apropiado (1,2,3…). La primera parte cuestiona sobre su salud en general. La segunda parte pregunta tanto sobre los efectos de su epilepsia, como el de los medicamentos antiepilépticos. **Por favor conteste todas las preguntas** encerrando en un círculo el número apropiado (1,2,3,4,5). Si usted no está Seguro de cómo contestar una pregunta, por favor dé la **mejor respuesta que pueda.** Puede escribir notas en el margen para explicar sus sentimientos. Aún si algunas preguntas parecen similares, conteste todas las preguntas.

Si usted no está seguro sobre cómo contestar una pregunta, por favor anote lo mejor que pueda su respuesta y escriba un comentario o explicación en un lado de la página. Estas notas pueden ser muy útiles cuando usted comente el cuestionario QOLIE-AD-48 con su doctor. Llenar el cuestionario QOLIE-AD-48 antes y después de los cambios debidos al tratamiento, puede ayudarle a usted y a su doctor a comprender cómo han afectado su vida estos cambios.

Se le proporcionará una copia del cuestionario QOLIE-AD-48 en el sitio de Internet: www.epilepsy.com, que es también una fuente de información sobre la epilepsia y sobre el Grupo de Desarrollo QOLIE-AD-48. ¡Le deseamos todo el éxito posible al realizar su vida con epilepsia!

PARTE 1: LA SALUD EN GENERAL

1. En general, usted diría que su salud es: (encierre en un círculo un número)

Excelente	Muy buena	Buena	Regular	Mala
5	4	3	2	1

2. **En comparación con hace un año** ¿cómo calificaría usted su salud en general **ahora mismo**?

Mucho mejor ahora	Un poco mejor ahora	Más o menos igual ahora	Un poco peor ahora	Mucho peor ahora

Las siguientes preguntas se refieren a las actividades que usted pudiera realizar durante un **DÍA TÍPICO.** Nos gustaría que nos contestara qué tanto lo limita su salud en las siguientes actividades. (Encierre en un círculo uno de los números en cada línea)

En las últimas 4 semanas, ¿qué tan seguido lo ha limitado su salud?:

	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca
3. Participar en actividades muy pesadas, tales como correr, participar en deportes de mucha acción (como gimnasia, patinaje o esquiar)	1	2	3	4	5
4. En actividades moderadas (como ir a la escuela caminando o andar en bicicleta).	1	2	3	4	5
5. Actividades más ligeras (como cargar paquetes o llevar una mochila llena de libros a la escuela).	1	2	3	4	5
6. Otras actividades cotidianas (como darse un baño de tina o un regaderazo usted solo; ir a la escuela y regresar usted solo).	1	2	3	4	5

Las siguientes preguntas son acerca de sus actividades diarias normales, como las obligaciones que usted tiene en su casa, por ejemplo: cuidar un niño pequeño, asistir a la escuela, estar con los amigos y la familia, hacer la tarea, o tomar parte en otras actividades u otro tipo de clases para después de la escuela. Nos gustaría saber si usted tuvo cualquiera de las siguientes dificultades durante sus actividades regulares como resultado de **problemas físicos (como una enfermedad) o problemas emocionales (tales como sentimientos de tristeza o nerviosismo).**

En las últimas 4 semanas, qué tan seguido tuvo problemas físicos o emocionales causados por:	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca
7. ¿Tuvo que hacer más pocas cosas de lo que le hubiera gustado hacer?	1	2	3	4	5
8. ¿Tuvo que limitar **la clase** de tareas escolares quehaceres en casa, deportes u otras actividades que haya realizado?	1	2	3	4	5
9. ¿Tuvo dificultad al hacer sus tareas escolares sus quehaceres en la casa, sus deportes, u otras actividades que haya hecho (por ejemplo: tuvo que hacer un esfuerzo extraordinario)?	1	2	3	4	5

En las últimas 4 semanas, ¿qué tan seguido:	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca

10. …faltó a la escuela sin razón?	1	2	3	4	5
11. …se metió en problemas en la escuela (ya sea con los maestros u otros funcionarios)?	1	2	3	4	5
12. …se metió usted en problemas fuera de la escuela (con la policía, guardias de seguridad con el chofer del autobús, etc.)?	1	2	3	4	5

Estas preguntas se refieren a cómo se SIENTE y cómo han sido las cosas para usted **durante las últimas 4 semanas**. Para cada pregunta, por favor indique la respuesta que se acerque más a la forma en que se ha estado sintiendo. (Encierre en un círculo solo un número en cada línea).

En las últimas 4 semanas, ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
13. tuvo problemas para concentrarse en alguna actividad?	1	2	3	4	5
14. tuvo problemas para concentrarse en la lectura?	1	2	3	4	5

Las siguientes preguntas se refieren a actividades mentales y problemas del lenguaje que pueden interferir con las tareas normales de la escuela o con actividades de la vida diaria. (en cierre en un círculo un solo número en cada línea).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
15. ha tenido dificultades para pensar?	1	2	3	4	5
16. ha tenido dificultades para el planteamiento	1	2	3	4	5
y resolución de problemas (tales como hacer planes, tomar decisiones, aprender cosas nuevas)?	1	2	3	4	5
17. ha tenido problemas con proyectos complicados que requieran organización o planeación (como juegos de computadora o hacer la tarea escolar)?	1	2	3	4	5
18. ha tenido dificultad para recordar cosas que haya leído hace algunas horas o días?	1	2	3	4	5
19. tuvo problemas para encontrar la palabra					

correcta?	1	2	3	4	5
20. tuvo problemas para entender a sus maestros?	1	2	3	4	5
21. ha tenido problemas para entender lo que está leyendo?	1	2	3	4	5

Las siguientes preguntas se refieren al apoyo que usted recibe de otras personas (incluyendo familiares y amigos). (Encierre en un círculo un solo número en cada línea).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
22. tiene a alguien que lo ayude si usted ha necesitado y querido su ayuda?	1	2	3	4	5
23. tiene a alguien en quien usted pueda confiar o con quien pueda hablar sobre las cosas que lo estén inquietando?	1	2	3	4	5
24. tiene a alguien con quien pueda hablar cuando usted ha estado confuso y ha necesitado aclarar las cosas?	1	2	3	4	5
25. tiene a alguien que lo acepte tal como usted es, con sus cualidades y defectos?	1	2	3	4	5

PARTE 2: LOS EFECTOS DE LA EPILEPSIA Y DE LOS MEDICAMENTOS ANTI EPILÉPTICOS.

Las siguientes preguntas se refieren a la forma en que la epilepsia o sus medicamentos (las drogas antiepilépticas) le han afectado la vida durante las últimas 4 semanas. (Encierre en un círculo solo un número en cada línea).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca

26. siente que los medicamentos para la epilepsia lo han limitado en sus actividades sociales (tales como salir con sus amigos, llevar a cabo actividades extracurriculares)?

27. se siente solo y aislado de otras personas debido a su epilepsia o a las convulsiones?

28. pierde clases debido a las convulsiones o a los medicamentos?

29. usa la epilepsia o a los efectos secundarios de los medicamentos como una excusa para evitar hacer algo que usted realmente no quiere hacer?

30. se siente apenado o “diferente” por el hecho de que tiene que tomar medicamentos?

31. siente que la epilepsia o los medicamentos lo limitan en el desempeño de sus labores escolares?

32. siente que usted ha estado limitado debido a las convulsiones?

33. siente que la epilepsia o los medicamentos le han limitado su independencia?

34. siente que la epilepsia o los medicamentos le han limitado su vida social o conseguir una pareja?
35. siente que la epilepsia o los medicamentos le han limitado su participación en deportes o actividades físicas?

Las siguientes preguntas se refieren a los posibles efectos secundarios de los medicamentos antiepilépticos (encierre en un círculo solo un número en cada línea).

En las últimas 4 semana, ¿cómo se sintió…	Muy mal	Mal	Más o menos	Bien	Muy bien
36. Más o menos ¿cómo se sintió (en lo relativo a efectos secundarios tales como subida de peso, acné/espinillas, cambios en el cabello, etc.)?					

En las últimas 4 semanas, ¿qué tanto le molestó/ le molestaron:	Mucho	Un poco	No tanto	Un poquito	Nada
37. …los límites impuestos por sus padres/ otros familiares debido a su epilepsia o sus medicamentos?	1	2	3	4	5

Las siguientes son algunas frases que las personas que padecen epilepsia declaran sobre si mismas. Para cada una de estas frases, encierre en un círculo la respuesta que sea lo más cercana posible a la forma en que usted se ha sentido acerca de usted mismo en las últimas 4 semanas. (Encierre en un círculo un solo número en cada línea).

	Totalmente de acuerdo	De acuerdo	No estoy de acuerdo	En total desacuerdo
38. Me considero a mí mismo menos que perfecto debido a la epilepsia.	1	2	3	4
39. Si solicito un trabajo y también alguna otra persona lo solicita y esa persona no tiene epilepsia, el empleador debería mejor contratar a esa otra persona.	1	2	3	4
40. Yo puedo entender el porqué alguien no querría salir conmigo debido a mi epilepsia.	1	2	3	4
41. No culpo a la gente por tener miedo de mí por el hecho de tener epilepsia.	1	2	3	4
42. No culpo a la gente por no tomar tan en serio mis opiniones, de lo que lo harían si yo no tuviera epilepsia.	1	2	3	4
43. Siento que mi epilepsia me hace mental mente inestable.	1	2	3	4

Las siguientes preguntas se refieren a sus actitudes hacia la epilepsia. Encierre en un círculo qué tan seguido en las **últimas 4 semanas** ha tenido esas actitudes. (Encierre en un círculo solo un número en cada línea).

	Muy mal	Un poco mal	No estoy seguro/a	Un poco mejor	Muy bien
44. ¿Qué tan bueno o malo ha sido para usted tener epilepsia?					

45. ¿Qué justicia ha habido en que usted tenga epilepsia?

46. ¿Qué felicidad o tristeza ha sentido por el hecho de tener epilepsia?

47. ¿Qué tan bueno o malo ha sido para usted tener epilepsia?

48. ¿Qué tan seguido siente que su epilepsia lo priva de comenzar a hacer cosas nuevas?

Temas opcionales:

En las últimas 4 semanas, ¿qué tan seguido usted:	Muy seguido	Seguido	Algunas veces	No muy seguido	Nunca
¿Se preocupa de tener otra convulsión?					
¿Tiene miedo de morir por las convulsiones?					
¿Se preocupa de herirse usted mismo por una convulsión?					

Favor de revisar todas las páginas antes de dar por terminado el cuestionario para asegurarse de que ha contestado todas las preguntas.

Esta copia del cuestionario QOLIE-AD-48 la podrá encontrar en el sitio de Internet www.epilepsy.com, su fuente para la información sobre la epilepsia y del Grupo de Desarrollo QOLIE. ¡Le deseamos el mayor de los éxitos para tener una buena vida con epilepsia!

QOLIE-AD-48 Translation B

Calidad de Vida para Adolescentes con Epilepsia: QOLIE-AD-48 (Versión 1)

Fecha del Día de Hoy _____/_______/_______
Nombre: ____

INSTRUCCIONES

QOLIE-AD-48 es una encuesta de salud relacionada a la calidad de vida para adolescentes (11-18 años de edad) con epilepsia. Adultos (18 años de edad o mayores) deben llenar QOLIE-31-P, designada para el grupo de su edad. Este cuestionario debe de der llenado únicamente por la persona que tiene epilepsia (no un pariente o amigo) porque nadie más sabe cómo USTED se siente.

Hay 48 preguntas (en dos partes) acerca de su salud y actividades diarias. Conteste cada pregunta encerrando en un círculo el numero apropiado (1, 2, 3….). La primera parte le pregunta sobre su salud en general. La segunda parte le pregunta sobre los efectos de su epilepsia y medicamentos anti-epilépticos. **POR FAVOR conteste cada pregunta** encerrando en un círculo el numero apropiado (1, 2, 6, 4, 5). Si usted no está seguro de como contestar una pregunta, por favor de **la mejor respuesta que usted pueda**. Usted puede escribir apuntes en el margen para explicar sus sentimientos. Aun si algunas preguntas parecen que son similares, conteste todas las preguntas.

Si usted no está seguro de como contestar una pregunta por favor de la mejor respuesta que usted pueda y escriba un comentario o explicación al margen de la página. Estas anotaciones pueden ser útiles si usted habla de QOLIE-AD-48 con su doctor. El llenar QOLIE-AD-48 antes y después de cambios en el tratamiento puede ayudar a usted y a su doctor entender como los cambios han afectado su vida.

Esta copia de QOLIE-AD-48es otorgada por www.epilespsy.com, su fuente de información de epilepsia y el Grupo de Desarrollo QOLIE. ¡Le deseamos éxito en vivir su vida con epilepsia!

PARTE I: SALUD GENERAL

1. En general, usted diría que su salud es: (Encierre en un círculo un número)

Excelente Muy Buena Buena Regular Mala
5 4 3 2 1

2. **¿Comparado con 1 año antes,** como calificaría su salud en comparación con **el presente?**

Mucho mejor Algo mejor Igual Algo peor Mucho
peor
Ahora ahora ahora ahora
5 4 3 2 1

Las siguientes preguntas son acerca de actividades que usted desarrolle en un DIA TIPICO. Queremos que usted conteste que tanto **su salud** lo limita en estas actividades. (Encierre en un círculo un número por renglón).

En las últimas 4 semanas, que tan seguido su salud ha limitado:	Muy seguido	Algunas veces	Frecuentemente	No muy seguido	Nunca
3. ¿Actividades pesadas tales como correr, participar en deportes extremos (gimnasia, patinaje sobre ruedas, esquiar)?	1	2	3	4	5
4. ¿Actividades moderadas (como caminar a la escuela, andar en					

bicicleta)?	1	2	3	4	5
5. ¿Actividades ligeras (como cargar paquetes o una mochila llena de libros)?	1	2	3	4	5
6. ¿Otras actividades diarias (como tomar un baño/regaderazo solo, ir o venir de la escuela solo)?	1	2	3	4	5

Las siguientes preguntas son acerca de sus actividades diarias, tal como actividades en casa, cuidar niños, ir a la escuela, pasar tiempo con amigos y familia, hacer tarea, o participar en actividades escolares extra curriculares y clases. Queremos saber si usted ha tenido alguna de las siguientes dificultades con sus actividades como resultado de cualquier **problema físico (como enfermedades0 o problemas emocionales (como sentimientos de tristeza o nerviosismo)**?

En las últimas 4 semanas, que tan seguido su salud ha tenido problemas físicos o emocionales que le hayan causado:	Muy seguido	Frecuentemente	Algunas Veces	No frecuentemente	Nunca
7. ¿Hizo menos cosas de las que le hubiera gustado?	1	2	3	4	5
8. ¿Limito el **tipo** de trabajo escolar, actividades, deportes u otras actividades que hacía?	1	2	3	4	5
9. ¿Tuvo **dificultad** al hacer trabajo escolar, actividades, deportes u otras actividades que usted hacia (por ejemplo, le tomo más trabajo hacerlo)?	1	2	3	4	5
En las últimas 4 semanas, que tan seguido:					
10. ¿Falto a la escuela sin razón alguna?	1	2	3	4	5
11. ¿Tuvo problemas en la escuela (con maestros u otro personal)?	1	2	3	4	5
12. ¿Tuvo problemas fuera de la escuela (con la policía, guardias de seguridad, chofer del autobús, etc.)?	1	2	3	4	5

Estas preguntas son acerca de cómo se SIENTE como han sido las cosas para usted **en las últimas 4 semanas**. Por cada pregunta, por favor indique la respuesta que más se acerca a como usted se ha sentido. (Encierre en un círculo el número de cada renglón).

En las últimas 4 semanas , que tan seguido usted ha:	Todo el tiempo	La mayor parte del tiempo	Algunas veces	Poca parte del tiempo	Nunca
13. ¿Ha tenido problemas para concentrarse en alguna actividad?	1	2	3	4	5
14. ¿Ha tenido problema para concentrarse en una lectura?	1	2	3	4	5

Las siguientes preguntas son acerca de actividades mentales y problemas de lenguaje que puedan interferir con su trabajo escolar diario, actividades de su vida. (Encierre en un círculo un numero por renglón)

Ultimas 4 semanas, con que frecuencia usted ha:	Todo el tiempo	La mayor parte del tiempo	Algunas veces	Poca parte del tiempo	Nunca
15. ¿Ha tenido dificultad para pensar?	1	2	3	4	5
16. ¿Tuvo dificultad para entender y solucionar problemas (como hacer planes, toma de decisiones, aprender cosas nuevas)?	1	2	3	4	5
17. ¿Tuvo algún problema con proyectos complicados que requieren organización o planificación (como juegos de computadora o tareas difíciles)?	1	2	3	4	5
18. ¿Tuvo problemas para recordar cosas que leyó horas o días antes?	1	2	3	4	5
19. ¿Tuvo problemas para encontrar la palabra correcta?	1	2	3	4	5
20. ¿Tuvo problemas para entender a sus maestros?	1	2	3	4	5
21. ¿Tuvo problemas para entender lo que leyó?	1	2	3	4	5

Las siguientes preguntas son acerca del apoyo que usted recibe de otros (incluyendo familiares y amigos. (Encierre en un círculo un número por renglón)	Muy seguido	Frecuentemente	Algunas Veces	No frecuentemente	Nunca
En las últimas 4 semanas , que tan seguido usted:					

22. ¿Ha tenido alguien disponible para ayudarlo si necesitaba y quería ayuda?	5	4	3	2	1
23. ¿Ha habido alguien en quien usted pueda confiar o pueda hablar acerca de cosas que le molestaban?	5	4	3	2	1
24. ¿Ha tenido con quien hablar cuando usted estaba confundido y necesitaba entender las cosas?	5	4	3	2	1
25. ¿Ha tenido a alguien como lo acepte como usted era, tanto sus buenos y malos puntos?	5	4	3	2	1

PARTE 2: EFECTOS DE EPILEPSIA Y MEDICAMENTOS CONTRA LA EPILEPSIA

Las siguientes preguntas son acerca de que si su epilepsia o medicamentos (medicinas contra la epilepsia) le han afectado en su vida en las últimas 4 semanas. (Encierre en un círculo un número por renglón).

En las últimas 4 semanas, usted:	Muy seguido	Frecuentemente	Algunas Veces	No frecuentemente	Nunca
26. ¿Sintió que la **epilepsia o los medicamentos** limitaron sus actividades sociales (como estar con sus amigos, llevar a cabo actividades extra curriculares) comparándolo con actividades sociales de otras personas de su edad?	1	2	3	4	5
27. ¿Se sintió solo y aislado de otros por su epilepsia/ataques?	1	2	3	4	5

28. ¿Perdió clases por sus ataques o medicamentos?	1	2	3	4	5
29. ¿Uso la epilepsia o los efectos secundarios de los medicamentos como excusa para evitar hacer cosas que usted realmente no quería hacer?	1	2	3	4	5
30. ¿Usted se sintió avergonzado o "diferente" porque tiene que tomar medicamentos?	1	2	3	4	5
31. ¿Sintió que la epilepsia o los medicamentos limitaron su desarrollo académico?	1	2	3	4	5
32. ¿Sintió que tenía limitantes a causa de sus ataques?	1	2	3	4	5
33. ¿Sintió que la epilepsia o los medicamentos limitan su independencia?	1	2	3	4	5
34. ¿Sintió que la epilepsia o los medicamentos limitan su vida social o amorosa?	1	2	3	4	5
35. ¿Sintió que la epilepsia o los medicamentos limitan su participación en actividades deportivas o físicas?	1	2	3	4	5

Las siguientes preguntas son acerca de posibles efectos secundarios de medicamentos contra la epilepsia. (Encierre en un círculo un número por renglón).

En las últimas 4 semanas, usted sintió:	Muy mal	Mal	Aceptable	Bien	Muy bien
36. ¿Acerca de cómo se veía (efectos secundarios como subir de peso acné/espinillas, cambio en el cabello, etc.)?	1	2	3	4	5

En las últimas 4 semanas, que tanto le molesto :	Mucho	Algo	No mucho	Un poco	Para nada
37. ¿Limites puestos por sus padres/familia por su epilepsia o sus medicamentos?	1	2	3	4	5

A continuación hay unas declaraciones que gente con epilepsia algunas veces hacen sobre ellos mismos. Por cada declaración, encierre la respuesta que más se acerca a la forma en que usted se ha sentido acerca de usted mismo en las últimas 4 semanas. (Encierre un numero por renglón)

	Totalmente de acuerdo	De acuerdo	No estoy de acuerdo	Fuertemente en desacuerdo
38. Me considero menos que perfecto porque tengo epilepsia.	1	2	3	4
39. Si aplique para un trabajo y alguien más también aplico que no tenía epilepsia, el empleador debe contratar a la otra persona.	1	2	3	4
40. Puedo entender porque alguien no quisiera salir conmigo ya que tengo epilepsia.	1	2	3	4
41. No culpo a la gente por tener miedo de mi porque tengo epilepsia.	1	2	3	4
42. No culpo a la gente por tomar mis opiniones con menso seriedad a que si yo no tuviera epilepsia.	1	2	3	4
43. Siento que mi epilepsia me hace ser mentalmente inestable.	1	2	3	4

Las siguientes preguntas son acerca de su actitud hacia la epilepsia. Encierre en un círculo un numero por qué tan seguido en las **últimas 4 semanas** usted ha tenido estas actitudes. (Encierre un circulo por cada renglón)

	Muy Mal	Un poco mal	No estoy seguro	Un poco Bien	Muy bien
44. ¿Qué tan bien o mal ha sido el que usted tenga epilepsia?	1	2	3	4	5

	Muy Injusto	Un poco injusto	No estoy seguro	Un poco justo	Muy justo
45. ¿Qué tan injusto ha sido para usted tener epilepsia?	1	2	3	4	5

	Muy mal	Un poco triste	No estoy seguro	Un poco feliz	Muy feliz
46. ¿Qué tan feliz o triste ha sido para usted tener epilepsia?	1	2	3	4	5

	Muy mal	Un poco mal	No estoy seguro	Un poco bien	Muy bien
47. ¿Qué tan bien o mal ha sentido que es el tener epilepsia?	1	2	3	4	5

	Muy seguido	Frecuentemente	Algunas veces	No muy seguido	Nunca
48. ¿Qué tan seguido siente que su epilepsia lo detiene de comenzar cosas nuevas?	1	2	3	4	5

Opcional:

En las últimas 4 semanas, usted que tan seguido:	Muy seguido	Frecuentemente	Algunas veces	No muy Seguido	Nunca
Le preocupa tener otro ataque.	1	2	3	4	5
Le teme a morir a causa de un ataque.	1	2	3	4	5
Le preocupa lastimarse a causa de un ataque.	1	2	3	4	5

Por favor revise todas las páginas antes de detenerse para asegurarse de que ha contestado todas las preguntas.

QOLIE-AD-48 Merged version

Calidad de Vida para los Adolescentes con epilepsia: **QOLIE -AD-48** (Versión 1)

Fecha: ___/___/___

Nombre: ___________________________________

INSTRUCCIONES

El cuestionario QOLIE-AD-48 es una encuesta sobre la calidad de vida en lo relacionado con la salud para los adolescentes (entre los 11 y los18 años) con epilepsia. Los adultos (de 18 años en Adelante) deberán llenar el cuestionario QOLIE-31-P, que se ha diseñado para ese grupo. Solamente la persona que tenga epilepsia deberá llenar este cuestionario, no podrá llenarla ni un pariente ni un amigo porque nadie más sabe lo que TÚ sientes.

Hay 48 preguntas (divididas en 2 partes) sobre tu salud y tus actividades cotidianas. Contesta todas las preguntas encerrando en un círculo el número apropiado (1,2,3…). La primera parte te pregunta sobre tu salud en general. La segunda parte te pregunta sobre los efectos de tu epilepsia y de tus medicamentos antiepilépticos. **Por favor contesta todas las preguntas** encerrando en un círculo el número apropiado (1,2,3,4,5). Si tú no estás seguro de cómo contestar una pregunta, por favor da la **mejor respuesta que puedas.** Puedes escribir notas en el margen para explicar tus sentimientos. Aún si algunas preguntas parecen similares, contesta todas las preguntas.

Si tú no estás seguro de cómo contestar una pregunta, por favor anota lo mejor que puedas tu respuesta y escribe un comentario o explicación al margen de la página. Estas notas pueden ser muy útiles cuando comentes el cuestionario QOLIE-AD-48 con tu doctor. Llenar el cuestionario QOLIE-AD-48 antes y después de los cambios debidos al tratamiento, puede ayudarte a ti y a tu doctor a comprender cómo han afectado tu vida estos cambios.

Podrás conseguir una copia del cuestionario QOLIE-AD-48 en el sitio de Internet: www.epilepsy.com, que es también una fuente de información sobre la epilepsia y sobre el Grupo de Desarrollo QOLIE-AD-48. ¡Te deseamos todo el éxito posible al vivir tu vida con epilepsia!

PARTE 1: LA SALUD EN GENERAL

2. En general, tú dirías que tu salud es: (encierra en un círculo el número apropiado)

Excelente	Muy buena	Buena	Regular	Mala
5	4	3	2	1

2. **En comparación con hace un año** ¿cómo calificarías tu salud en general en **el presente**?

Mucho mejor ahora	Un poco mejor ahora	Más o menos igual ahora	Un poco peor ahora	Mucho peor ahora

Las siguientes preguntas se refieren a las actividades que pudieras realizar durante un **DÍA TÍPICO.** Nos gustaría que nos contestaras qué tanto te limita tu salud en las siguientes actividades. (Encierra en un círculo uno de los números en cada renglón)

En las últimas 4 semanas, ¿qué tan seguido te ha limitado tu salud?:

	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca
3. Participar en actividades muy pesadas, tales como correr, participar en deportes extremos	1	2	3	4	5

(como gimnasia, patinaje sobre ruedas o esquiar)					
4. En actividades moderadas (como ir a la escuela caminando o andar en bicicleta).	1	2	3	4	5
5. Actividades más ligeras (como cargar paquetes o llevar una mochila llena de libros a la escuela).	1	2	3	4	5
6. Otras actividades cotidianas (como darse un baño de tina o un regaderazo tú solo; ir a la escuela y regresar tú solo).	1	2	3	4	5

Las siguientes preguntas son acerca de tus actividades diarias normales, como las obligaciones que tienes en tu casa, por ejemplo: cuidar niños, asistir a la escuela, pasar tiempo con los amigos y la familia, hacer la tarea, o tomar parte en otras actividades u otro tipo de clase para después de la escuela. Nos gustaría saber si tuviste cualquiera de las siguientes dificultades durante tus actividades regulares, como resultado de cualquier **problema físico (como una enfermedad) o problemas emocionales (tales como sentimientos de tristeza o nerviosismo).**

En las últimas 4 semanas, qué tan seguido tuvo problemas físicos o emocionales causados por:	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca
7. ¿Hiciste menos cosas de las que te hubiera gustado hacer?	1	2	3	4	5
8. ¿Tuviste que limitar **el tipo** de tareas escolares, obligaciones en casa, deportes u otras actividades que hacías antes?	1	2	3	4	5
9. ¿Tuviste dificultad al hacer tus tareas escolares, tus obligaciones en casa, tus deportes, u otras actividades que hacías antes (por ejemplo: tuviste que hacer un esfuerzo extraordinario)?	1	2	3	4	5

En las últimas 4 semanas, ¿qué tan seguido:	Muy seguido	Más o menos seguido	A veces	No tan seguido	Nunca
10. …faltaste a la escuela sin razón alguna?	1	2	3	4	5
11. …te metiste en problemas en la escuela (ya sea con los maestros u otro personal)?	1	2	3	4	5
12. …te metiste en problemas fuera de la escuela (con la policía, guardias de seguridad con el chofer del autobús, etc.)?	1	2	3	4	5

Estas preguntas se refieren a cómo te SIENTES y cómo han sido las cosas para ti **en las últimas 4 semanas**. Para cada pregunta, por favor indica la respuesta que más se acerca a cómo te has sentido. (Encierra en un círculo solo un número en renglón).

En las últimas 4 semanas, ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
13. tuviste problemas para concentrarte en alguna actividad?	1	2	3	4	5
14. tuviste problemas para concentrarte en la lectura?	1	2	3	4	5

Las siguientes preguntas se refieren a actividades mentales y problemas del lenguaje que pueden interferir con las tareas normales de la escuela o con actividades de la vida diaria. (en cierra en un círculo un solo número en cada renglón).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
15. has tenido dificultades para pensar?	1	2	3	4	5
16. has tenido dificultades para entender	1	2	3	4	5
y resolver problemas (tales como hacer planes, tomar decisiones, aprender cosas nuevas)?	1	2	3	4	5
17. has tenido algún problema con proyectos complicados que requieran organización o planeación (como juegos de computadora o hacer la tarea escolar)?	1	2	3	4	5
18. has tenido dificultad para recordar cosas que leíste hace algunas horas o días?	1	2	3	4	5
19. tuviste problemas para encontrar la palabra correcta?	1	2	3	4	5
20. tuviste problemas para entender a tus maestros?	1	2	3	4	5
21. has tenido problemas para entender lo que leíste?	1	2	3	4	5

Las siguientes preguntas se refieren al apoyo que recibes de otras personas (incluyendo familiares y amigos). (Encierra en un círculo un solo número en cada renglón).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
22. has tenido a alguien disponible para ayudarte si lo necesitabas y querías ayuda	1	2	3	4	5
23. tienes a alguien en quien tú puedas confiar o con quien puedas hablar sobre las cosas que te están molestando?	1	2	3	4	5
24. tuviste a alguien con quien pudieras hablar cuando estabas confundido y necesitabas aclarar las cosas?	1	2	3	4	5
25. tienes a alguien que te acepte tal como eres, con tus cualidades y defectos?	1	2	3	4	5

PARTE 2: LOS EFECTOS DE LA EPILEPSIA Y DE LOS MEDICAMENTOS ANTI EPILÉPTICOS.

Las siguientes preguntas se refieren a la forma en que la epilepsia o tus medicamentos (los fármacos antiepilépticos) han afectado tu vida en las últimas 4 semanas. (Encierra en un círculo solo un número en cada renglón).

En las últimas 4 semanas ¿qué tan seguido…	Todo el tiempo	Muchas veces	Algunas veces	Pocas veces	Nunca
26. sentiste que los medicamentos para la epilepsia te han limitado en tus actividades sociales (tales como salir con tus amigos, llevar a cabo actividades extracurriculares) comparándolo con actividades sociales de otras personas de tu edad.					
27. te sientes solo y aislado de otras personas debido a tu epilepsia o a las convulsiones?					

28. pierdes clases por las convulsiones o los medicamentos?

29. usas la epilepsia o los efectos secundarios de los medicamentos como una excusa para evitar hacer algo que tú realmente no quieres hacer?

30. te sientes apenado o "diferente" por el hecho de que tienes que tomar medicamentos?

31. sientes que la epilepsia o los medicamentos te han limitado en el desempeño de tus labores escolares?

32. sientes que has estado limitado debido a las convulsiones?

33. sientes que la epilepsia o tus medicamentos te han quitado tu independencia?

34. sientes que la epilepsia o tus medicamentos han limitado tu vida social o conseguir una pareja?

35. sientes que la epilepsia o tus medicamentos han limitado tu participación en deportes o actividades físicas?

Las siguientes preguntas se refieren a los posibles efectos secundarios de los medicamentos antiepilépticos (encierra en un círculo solo un número en cada renglón).

En las últimas 4 semana, ¿cómo te sentiste…	Muy mal	Mal	Más o menos	Bien	Muy bien
36. en cómo te veías (debido a los efectos secundarios tales como subida de peso, acné/espinillas, cambios en el cabello, etc.)?					

En las últimas 4 semanas, ¿qué tanto te molestó/ te molestaron:	Mucho	Un poco	No tanto	Un poquito	Nada
37. …los límites impuestos por tus padres/					

otros familiares debido a tu epilepsia o tus medicamentos?	1	2	3	4	5

Las siguientes son algunas frases que las personas que padecen epilepsia dicen sobre si mismas. Para cada una de estas frases, encierra en un círculo la respuesta que sea lo más cercana posible a la forma en que tú te has sentido acerca de ti mismo en las últimas 4 semanas. (Encierra en un círculo un solo número en cada renglón).

	Totalmente de acuerdo	De acuerdo	No estoy de acuerdo	En total desacuerdo
38. Me considero a mí mismo menos que perfecto debido a la epilepsia.	1	2	3	4
39. Si solicite un trabajo y también alguna otra persona lo solicito y esa persona no tiene epilepsia, el empleador debe mejor contratar a esa otra persona.	1	2	3	4
40. Yo puedo entender el porqué alguien no querría salir conmigo debido a mi epilepsia.	1	2	3	4
41. No culpo a la gente por tener miedo de mí por el hecho de tener epilepsia.	1	2	3	4
42. No culpo a la gente por no tomar tan en serio mis opiniones; sé que me tomarían más en serio si no tuviera epilepsia.	1	2	3	4
43. Siento que mi epilepsia me hace mental mente inestable.	1	2	3	4

Las siguientes preguntas se refieren a tus actitudes hacia la epilepsia. Encierra en un círculo qué tan seguido en las **últimas 4 semanas** has tenido esas actitudes. (Encierra en un círculo solo un número en cada renglón).

	Muy mal	Un poco mal	No estoy seguro/a	Un poco mejor	Muy bien
44. ¿Qué tan malo ha sido para ti tener epilepsia?					
45. ¿Qué tan injusto ha sido para ti tener epilepsia?					
46. ¿Qué tan triste te has sentido por el hecho de tener epilepsia?					

47. ¿Qué tan malo ha sido para ti tener epilepsia?

48. ¿Qué tan seguido sientes que tu epilepsia te detiene de comenzar cosas nuevas?

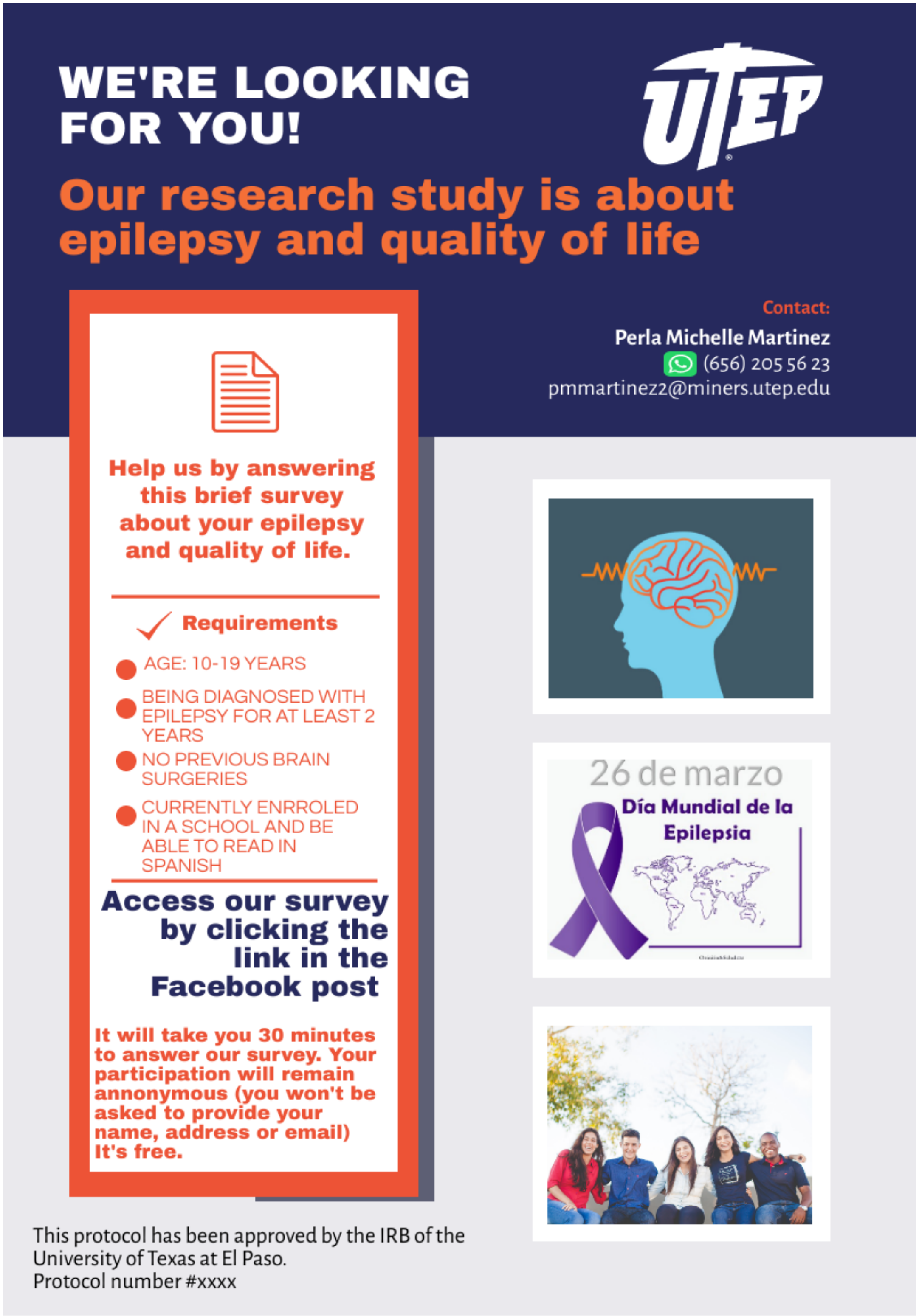
Temas opcionales:

En las últimas 4 semanas, ¿qué tan seguido:	Muy seguido	Seguido	Algunas veces	No muy seguido	Nunca
te preocupa tener una convulsión?					
tienes miedo de morir por las convulsiones?					
te preocupa herirte tú mismo a causa de una convulsión?					

Favor de revisar todas las páginas antes de dar por terminado el cuestionario para asegurarse de que has contestado todas las preguntas.

Esta copia del cuestionario QOLIE-AD-48 la podrás encontrar en el sitio de Internet www.epilepsy.com, tu fuente de información sobre la epilepsia y sobre el Grupo de Desarrollo QOLIE. ¡Te deseamos el mayor de los éxitos para tener una buena vida con epilepsia!

Poster, English Version



WE'RE LOOKING FOR YOU!

Our research study is about epilepsy and quality of life

Contact:
Perla Michelle Martinez
(656) 205 56 23
pmmartinez2@miners.utep.edu

Help us by answering this brief survey about your epilepsy and quality of life.

✓ **Requirements**

- AGE: 10-19 YEARS
- BEING DIAGNOSED WITH EPILEPSY FOR AT LEAST 2 YEARS
- NO PREVIOUS BRAIN SURGERIES
- CURRENTLY ENRROLED IN A SCHOOL AND BE ABLE TO READ IN SPANISH

Access our survey by clicking the link in the Facebook post

It will take you 30 minutes to answer our survey. Your participation will remain annonymous (you won't be asked to provide your name, address or email) It's free.

26 de marzo
Día Mundial de la Epilepsia

This protocol has been approved by the IRB of the University of Texas at El Paso.
Protocol number #xxxx

Poster, Spanish Version

ESTAMOS BUSCANDOTE

Estudio de investigacion de epilepsia y calidad de vida

Contacto:

Perla Michelle Martinez
(656) 205 56 23
pmmartinez2@miners.utep.edu

Ayudanos contestando un breve cuestionario sobre tu epilepsia y como afecta tu vida diaria.

✓ **Requisitos**

- TENER ENTRE 10 Y 19 AÑOS
- TENER EPILEPSIA DESDE HACE 2 AÑOS
- NO TENER ANTECEDENTES DE CIRUGIAS EN EL CEREBRO
- ESTAR INSCRITO EN UNA ESCUELA Y SABER LEER

Accede a nuestro cuestionario usando el link en la publicacion

Solo te tomara 30 minutos, tu participacion es anonima (no se te pedira tu nombre, direccion ni correo electronico) no tiene costo

Este protocolo ha sido aprobado por el departamento de IRB de la Universidad de Texas en El Paso. Bajo protocolo #1713644-1

Sociodemographic and Clinical survey (English Version)

Sociodemographic and Clinical questions

The following questions will help us to know you better. Remember that this study is Anonymous. Therefore, you will not be asked to disclose any personal information.

1. What is your level of education?
    a. Elementary school
    b. Junior high
    c. High school
    d. Some level of college

2. Currently, are you employed?
    a. Yes
    b. No

3. What is your marital status?
    a. Single
    b. Married
    c. Free union
    d. Divorced
    e. Widowed
    f. Other

4. Where do you live?
    a.
5. Who is/are your caregiver(s)?
    a. Mother and father
    b. Mother
    c. Father
    d. Grandparents
    e. Significant other
    f. Brother/ sister
    g. Other

6. How is the person who takes care of you most of the time?
    a. Mother
    b. Father
    c. Grandmother/ grandfather
    d. Significant other
    e. Brother/ sister
    f. Other

7. ¿What is the occupation of your primary caregiver?
    a. Home
    b. Employed
    c. Student
    d. Unemployed
    e. Other

8. What is the marital status of your primary caregiver?
    a. Single
    b. Married
    c. Free union
    d. Divorced
    e. Widowed
    f. Other

9. How old were you when you were diagnosed with epilepsy?

10. What type of seizures do you have?
    a. Absence
    b. Tonic-Clonic Generalized
    c. Partials
    d. Complex partials
    e. *Myoclonic*
    f. I do not know

11. What is the cause of your epilepsy?
    a. Brain anomaly
    b. Genetic
    c. An infection in the brain
    d. A disease of the immune system
    e. A metabolic cause
    f. I do not know

12. Are you currently receiving treatment?
    a. Yes
    b. No

13. *What kind of treatment are you receiving?*
    a. *One drug (with side effects)*
    b. *One drug (no side effects)*
    c. *Two or more drugs*
    d. *Ketogenic diet*

   e. Other

14. What drug are you taking? (Select all that apply)
    a. Valproic Acid
    b. Levetiracetam
    c. Carbamazepine
    d. Oxcarbazepine
    e. Topiramate
    f. Phenytoin
    g. Other

15. How old are you?

16. How frequently do you have a seizure?
    a. No seizures during the past year
    b. One seizure per month or less
    c. More than one seizure per month

Sociodemographic and Clinical survey (Spanish Version)

Las siguientes preguntas nos van a servir para conocerte mejor. Recuerda que este cuestionario es anónimo, por lo cual no te vamos a pedir ningún dato personal.

1. ¿En qué nivel escolar estas?
    a. Primaria
    b. Secundaria
    c. Preparatoria
    d. Universidad

2. ¿Actualmente estas trabajando?
    a. Si
    b. No

3. ¿Cuál es tu estado civil?
    a. Soltero
    b. Casado
    c. Union Libre
    d. Divorciado
    e. Viudo
    f. Otro

4. ¿En qué país vives?
    a.
5. ¿Quiénes son los encargados de cuidarte?
    a. Mama y papa
    b. Solo Mama
    c. Solo Papa
    d. Abuelos
    e. Pareja
    f. Hermano/a
    g. Otro

6. ¿Quién es la persona que te cuida la mayor parte del tiempo?
    a. Mama
    b. Papa
    c. Abuelo/a
    d. Pareja
    e. Hermano/a
    f. Otro

7. ¿A qué se dedica la persona que es responsable de cuidarte la mayor parte del tiempo?

    a. Hogar
    b. Empleado/a
    c. Estudiante
    d. Desempleado
    e. Otro

8. ¿Cuál es el estado civil de la persona que te cuida la mayor parte del tiempo?
    a. Soltero
    b. Casado
    c. Union Libre
    d. Divorciado
    e. Viudo
    f. Otro

9. ¿Cuántos años tenías cuando te diagnosticaron con epilepsia?

10. ¿Qué tipo de convulsiones presentas?
    a. Ausencia
    b. Generalizadas Tonico-Clonicas
    c. Parciales
    d. Parciales complejas
    e. Mioclónicas
    f. No se

11. ¿Cuál es la causa de tu epilepsia?
    a. Malformacion en el cerebro
    b. Genética
    c. Una infección en el cerebro
    d. Una enfermedad del sistema inmunológico
    e. Una causa metabólica
    f. No se

12. ¿Estás en tratamiento?
    a. Si
    b. No

13. ¿Qué tipo de tratamiento tienes?
    a. Un medicamento *(con efectos secundarios)*
    b. Un medicamento (sin efectos secundarios)
    c. Dos medicamentos
    d. Dieta cetógenica
    e. Otro

14. ¿Qué medicamentos tomas para la epilepsia actualmente? (Selecciona todos los que apliquen)
    a. Acido vaproico, Valproato de Magnesio, Valproato de Sodio
    b. Levetiracetam
    c. Carbamazepina
    d. Oxcarbamazepina
    e. Topiramato
    f. Fenitoina
    g. Otro

15. ¿Cuántos años tienes?

16. ¿Qué tan frecuente son tus crisis convulsivas?
    a. No crisis convulsivas en el último año
    b. Una convulsión por mes o menos
    c. Mas de una convulsión al mes

Informed Consent (English version)

University of Texas at El Paso (UTEP) Institutional Review Board
Informed Consent Form for Research Involving Human Subjects

Protocol Title: Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)

Principal Investigator: Perla Michelle Martinez

UTEP Department of Public Health Sciences

In this consent form, “you” always means the study subject. If you are a legally authorized representative, please remember that “you” refers to the study subject.

Introduction

You are being asked to take part voluntarily in the research project described below. You are encouraged to take your time in making your decision. It is important that you read the information that describes the study. Please ask the study researcher or the study staff to explain any words or information that you do not clearly understand.

Why is this study being done?

The purpose of this study is to validate the Spanish version of a questionnaire designed to assess the quality of life of the adolescents with epilepsy

Approximately, *135* adolescents*,* will be enrolling in this study. Participants will be recruited from Facebook groups about epilepsy. The administrators of these Facebook groups have agreed to collaborate with the research. You are being asked to grant your permission to participate in this study because you are an adult (18-19 years)

You are being asked to be in the study because you fulfill the criteria, we are using to select the participants. You were diagnosed with epilepsy more than 2 years ago and you are adolescent (10-19 years), and you can read in Spanish and are currently attending school. The exclusion criteria of this study are the following, history of being hospitalized one year prior de study, being diagnosed with psychiatric disorders or other chronic condition, neurological impairment, and history of brain surgery.

Your involvement will last about 25 to 30 minutes.

What is involved in the study?

If you agree to take part in this study, the research team will:

Provide an electronic questionnaire

You will: *answer a questionnaire of 48 questions about your quality of life and epilepsy and a survey with 14 questions about your epilepsy and life. The following are some examples of this type of questions educational level, occupation, marital status, age of diagnosis of epilepsy, type of seizures and cause of epilepsy.*

What are the risks and discomforts of the study?
The risks associated with this research are no greater than those involved in daily activities.

There are no known or anticipated risks or discomforts associated with participation. But you might experience some psychological discomfort while answering the questions.

You may decide to stop your participation if you think that being in the study may cause you psychological discomfort.

Are there benefits to taking part in this study?

You will not be likely to benefit by taking part in this study. However, if you participate in this study it will help the research team to understand the quality of life of speaking Spanish adolescents living with epilepsy

What are my costs?
There are no direct costs.

Will I be paid to participate in this study?
You will not be compensated for taking part in this research study.

What other options are there?

You have the option not to take part in this study. There will be no penalties involved if you choose not to take part in this study.

What if I want to withdraw, or am asked to withdraw from this study?

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you do not take part in the study, there will be no penalty or loss of benefit.

If you choose to take part, you have the right to skip any questions or stop at any time. However, we encourage you to reach out a member of the research group so that they know why you are leaving the study. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them.

Who do I call if I have questions or problems?

You may ask any questions you have now. If you have questions later, you may call this number (915) 256 3593 or send an email to this address pmmartinez2@miners.utep.edu

If you have questions or concerns about your participation as a research subject, please contact the UTEP Institutional Review Board (IRB) at (915-747-6590) or irb.orsp@utep.edu.

If you start to experience some psychological discomfort the following are some free resources, you *can reach out.*

Locatel 24 hours. Psychological medical and juridical help. Select operator option and you will be directed to correct area.

Phone: 55 5658 1111

24-hour crisis hotline. Call at no cost.

Phone: 01 800 227 4747.

What about confidentiality?

Your part in this study is anonymous. It will be impossible to researchers to trace data or information back to your child. No personal information will be asked during this study. All data collected will be anonymous. Research materials will be stored in locked filing cabinets with an identification number. Study information will not be available only to the investigators. No names or identifiable information will be collected or be used in any presentation or publication. The results of this research study may be presented at meetings or in publications.

All collected information will be transcribed into databases utilizing appropriate software and stored in an approved cloud service storage accessible through the main computer at the UTEP's PI office. Files will be encrypted for added security. Any paper records will be saved in a lock file cabinet in the PI's office and destroyed after five years.

Authorization Statement

I have read each page of this paper about the study. I know that being in this study is voluntary and I choose to be in this study. I will get a copy of this consent form now for me to keep. *Please feel free to print a copy for your records.*

☐ Yes, I agree to participate in this research project. I have read the following informed consent form and I understand what the research entails.
☐ No, I do not agree to participate in this research project.

Informed Consent (Spanish version)

University of Texas at El Paso (UTEP) Institutional Review Board
Informed Consent Form for Research Involving Human Subjects

Protocol Title: Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)

Principal Investigator: Perla Michelle Martinez

UTEP Department of Public Health Sciences

En esta forma "tu" siempre se refiere al participante. Si usted es un representante legal recuerde que "tu" se refiere al participante.

Introducción

Se te está pidiendo que de manera voluntaria participes el Proyecto de investigación que describiremos a continuación. Se te pide que tomes tu tiempo para decidir si quieres participar o no. Es importante que leas la información que describe el estudio. Por favor pregunta al investigador que te explique cualquier duda o pregunta que tengas.

¿Por qué se está realizando este estudio?

El propósito de este estudio es validar la versión en español de un cuestionario para evaluar la calidad de vida en adolescentes con epilepsia.

Aproximadamente, 135 adolescentes participaran en este estudio. Los participantes serán reclutados de grupos de Facebook relacionados con a la epilepsia. Los administradores de estos grupos han accedido a participar en este estudio. Se te está pidiendo que nos des tu permiso para participar en este estudio porque eres mayor de edad (18-19 años).

Se te está pidiendo que participes en este estudio por que cumples con los requisitos para estar en el mismo, los cuales son: haber sido diagnosticado con epilepsia por lo menos hace dos años, ser un adolescente (10-19 años), saber leer en español y estar inscrito en una escuela. Los criterios de exclusión de este estudio son los siguientes: haber sido hospitalizado en el ultimo ano, tener el diagnostico de una enfermedad psiquiátrica o alguna otra enfermedad crónica, tener una discapacidad neurológica o haber tenido alguna cirugía en el cerebro.

Tu participación en este estudio durara entre 25 y 30 minutos.

¿De qué se trata este estudio?

Si decides participar en este estudio, se te pedirá que respondas un cuestionario electrónico
Vas a: *contestar un cuestionario de 48 preguntas sobre calidad de vida y epilepsia y un cuestionario de 14 preguntas acerca de tu epilepsia y tu vida. Los siguientes son algunos ejemplos de este tipo de preguntas nivel de educación, ocupación, estado civil, edad de diagnóstico de epilepsia, tipo de convulsiones y causa de epilepsia.*

¿*Cuáles son los riesgos de este estudio?*

Los riesgos asociados a este estudio no son mayores a aquellos que involucran las actividades cotidianas.

No hay riesgos conocidos o anticipados asociados a tu participación en este estudio. Pero puedes experimentar algún malestar psicológico mientras respondes a las preguntas.

Puedes decidir suspender tu participación en este estudio si piensas que te está causando un malestar psicológico.

¿Existe algún beneficio por participar en este estudio?

Si decides participar en este estudio no tendrás ningún beneficio. Sin embargo, si decides participar estarás colaborando con los investigadores para entender la calidad de vida de los adolescentes con epilepsia que hablan español.

¿Cuáles son los costos por participar en este estudio?

No hay costos directos por participar en este estudio.

¿Se me pagara por participar en este estudio?

No se te pagara por participar en este estudio.

¿Qué otras opciones tengo?

Tienes la opción de no participar en este estudio. No hay penalizaciones si decides no participar en este estudio.

¿Qué pasa si decido no terminar el cuestionario?

Participar en este estudio es voluntario. Tienes el derecho de decidir no participar en este estudio. Si decides no participar en este estudio, no abra ninguna penalidad ni perderás ningún beneficio.

Si decides participar puedes saltarte preguntas o parar en cualquier momento. Sin embargo, te recomendamos contactar al equipo de investigadores para que ellos puedan saber por que estas abandonando el estudio. Si se encuentra nueva información sobre como este estudio pudiera afectarte se te avisara.

¿A quién llamo si tengo algún problema?

Puedes preguntar cualquier duda que tengas. Si tienes preguntas después puedes marcar este número (915) 256 3593 o enviar un correo electrónico a la siguiente pmmartinez2@miners.utep.edu

Si tienes alguna pregunta o duda sobre tu participación como sujeto de interés en este estudio por favor contacta la siguiente oficina UTEP Institutional Review Board (IRB) en el siguiente teléfono (915-747-6590) o al siguiente correo electrónico irb.orsp@utep.edu.

Si comienzas a experimentar alguna molestia psicológica los siguientes son recursos gratos que te pueden ayudar.

Locatel 24 horas. Ayuda médica, psicológica y jurídica. Selecciona la opción de hablar con una operadora y se te dirigirá al área correcta

teléfono: 55 5658 1111

línea de crisis 24 horas. Servicio totalmente gratuito.

teléfono: 01 800 227 4747.

¿Qué hay acerca de la confidencialidad?

Tu participacion en este estudio será anónima. Sera imposible para los investigadores relacionar tus respuestas contigo. Ningún dato personal se te preguntara en este estudio. Toda la información recabada será anónima (no se te pedirá nombre, dirección, teléfono). Los datos obtenidos durante este estudio serán guardados en archiveros con llave. La informacion estará disponible solo para los investigadores. Ningún nombre o información rastreable será obtenida o usada durante las presentaciones o publicaciones de este estudio.

Los resultados de este estudio serán presentados en congresos o publicaciones.

Autorización

He leído todas las páginas de este documento sobre el estudio. Se que mi participación en este estudio es voluntaria y deseo participar en este estudio. Conservare una copia de este consentimiento informado. Por favor imprima una copia de este documento.

☐ Si, deseo participar en este Proyecto de investigación. He leído el consentimiento informado y entiendo los detalles del estudio.
☐ No, no deseo participar en este estudio.

Child Asset Form (English Version)

University of Texas at El Paso (UTEP) Institutional Review Board
Minor Assent Form to Participate in a Research Study
(Assent form is required for participants ages 7-17)

Study Title: Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)
Principal Investigator: Perla Michelle Martinez
UTEP: Department of Public Health Sciences

This study is about validating a survey to understand how the adolescents living with epilepsy, who prefer to answer this type of questions in Spanish, do their daily activities, take their medications, etc.

You are being asked to decide if you want to be in this research study because *you were diagnosed with epilepsy and we would like to know how epilepsy is impacting your daily activities.* Your parent/guardian knows about the study, but you can decide if you want to be in it or not.

I know that to be in this study I will be asked to:

- Answer a survey of 48 questions about your daily activities and epilepsy.
- Answer a survey *of 14 questions about my epilepsy* which will include questions such as age of diagnosis, type of seizures, cause of epilepsy. I understand that no personal information will be asked during this study. This study is anonymous no one will know what I answered or that I participated.
- It will take you between 25 and 30 minutes to answer the questions.
- No one will know what you answered or your name.

Can anything bad happen to me?

- *We think that the risk of something bad happening to you is minimal. But, you may experience some psychological discomfort when answering the questions. If you start feeling uncomfortable, please tell your parents and the researcher and stop answering the questions.*

Can anything good happen to me?

- *We do not think that you will have any direct benefits from this study. However, if you decide to answer the questions you will help the research team to understand how the adolescents with epilepsy feel and their needs. Therefore, this information may be useful to create tools to improve the quality of life of adolescents who also are living with epilepsy.*

What if I have questions about this study?

- You can ask your parents or the investigators any questions that you might have before, during or after you answer the questions. This is the number you can call in case you have more questions 915 256 3593.

What if I don't want to do this or I change my mind later?

- I know that I can stop being in the study at any time without anyone being mad at me. I will not get in trouble if I stop being in the study.

I want to be in the study at this time. A copy of this paper will be given to you.

I have read each page of this paper about the study. I know that do not have to participate in this study if I do not want to. If I want, I can decide to stop my participation in this study at any time.

☐ Yes, I agree to participate in this research project. I have read the following asset form and I understand what the research is about.

☐ No, I do not agree to participate in this research project.

Child Asset Form (Spanish Version)

Informed Consent (Spanish version)
University of Texas at El Paso (UTEP) Institutional Review Board
Minor Assent Form to Participate in a Research Study
(Assent form is required for participants ages 7-17)

Study Title: Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)
Principal Investigator: Perla Michelle Martinez
UTEP: Department of Public Health Sciences

Este estudio se diseñó para validar un cuestionario. Este cuestionario fue creado para entender como los adolescentes que tienen epilepsia realizan sus actividades diarias, toman sus medicamentos etc.

Se te está pidiendo que decidas si quieres participar en este estudio por que fuiste diagnosticado con epilepsia y queremos saber como la epilepsia afecta tus actividades diarias y como es tu calidad de vida. Tu papa/mama o tutor sabe de este estudio, pero eres tu quien tiene que decidir si quieres participar o no.

Se que si decido estar en este estudio me van a pedir que:

- *Contestes un cuestionario de 48 preguntas sobre tus actividades diarias y la epilepsia.*
- *Contestes un cuestionario de 14 preguntas con preguntas clínicas y demográficas como por ejemplo: edad de diagnóstico de epilepsia, tipo de convulsiones, causa de epilepsia etc. Entiendo que no se ve va a preguntar ningún dato personal durante este estudio. Este estudio es anónimo por lo tanto nadie sabrá lo que conteste o que participe en el estudio.*
- *Te vas a tardar entre 25 y 30 minutos para contestar las preguntas.*
- *Nadie se va a saber que contestaste o tu nombre.*

¿Me puede pasar algo malo?

- Creemos que el riesgo de que algo malo te pase durante el estudio es mínimo. Pero podrías sentir una molestia psicológica mientras contestas estas preguntas. Si comienzas a sentirme mal o incomodo, por favor diles a tus papas y al investigador. Y Tambien deja de contestar el cuestionario.

¿Algo Bueno me puede pasar?

- *Nosotros no creemos que vas a tener un beneficio directo por participar en este estudio. Sin embargo, si decides contestar el cuestionario vas a ayudar a los investigadores a entender cuáles son las necesidades y sentimientos de los* *adolescentes con epilepsia. Por lo que esta información puede ser usada para crear herramientas para mejorar la calidad de vida de los adolescentes que viven con epilepsia.*

¿Qué pasa si tengo preguntas sobre este estudio?

- Le puedes preguntar a tus papas o a los investigadores cualquier duda que puedas tener antes, durante o después de contestar el cuestionario. Este es el número que puedes marcar en caso de que tengas más preguntas 915 256 3593.

¿Qué pasa si no quiero responder las preguntas o me arrepiento después de decir que sí?

- Se que puedo salirme del estudio en cualquier momento y nadie se va a enojar conmigo. No tendré ningún problema si decido dejar de estar en el estudio.

Quiero participar en este estudio de investigación. Puedo imprimir este documento.
Leí todas las páginas sobre este estudio. Se que no tengo que participar en este estudio si no quiero. También sé que puedo dejar de contestar el cuestionario en cualquier momento.

☐ Si, deseo participar en este estudio de investigación. Ya leí esta forma de asentimiento y entiendo de que es el estudio.

☐ No, no quiero participar en este estudio de investigación

Parental Permission Form (English version)

University of Texas at El Paso (UTEP) Institutional Review Board
Parental Permission Form for Research Involving Human Subjects

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Study Title: Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)
Principal Investigator: Perla Michelle Martinez
UTEP: Department of Public Health Sciences

Introduction

You are being asked to allow your child to take part in the research project described below. You are encouraged to take your time in making your decision. It is important that you read the information that describes the study. Please ask the study researcher or the study staff to explain any words or information that you do not clearly understand.

Why is this study being done?

The purpose of this study is to validate the Spanish version of a questionnaire designed to assess the quality of life of the adolescents with epilepsy.

Approximately, *135* adolescents, will be enrolling in this study. Participants will be recruited from Facebook groups about epilepsy. The administrators of these Facebook groups have agreed to collaborate with the research team. You are being asked to allow your child to participate because he/she is a minor (10-17 years)

Your child is being asked to be in the study because he/she fulfills the criteria we are using to select the participants. He/ she was diagnosed with epilepsy more than 2 years ago and is an adolescent (10-19 years), and he/ she can read in Spanish and is currently attending school. The exclusion criteria of this study are the following, history of being hospitalized one year prior de study, being diagnosed with psychiatric disorders or other chronic condition, neurological impairment, and history of brain surgery. His/her involvement will last about *25 to 30 minutes.*

What is involved in the study?

If you decide to allow your child to be in this study, the research team will:
Provide an electronic questionnaire to your child
Your child will: answer a questionnaire of 48 questions about what his/her quality of life and epilepsy and a clinical/demographic survey with 14 questions about your child epilepsy and life such as, educational level, occupation, marital status, age of diagnosis of epilepsy, type of seizures and cause of epilepsy.

What are the risks and discomforts of the study?

The risks associated with this research are no greater than those involved in daily activities.

There are no known or anticipated risks or discomforts associated with participation. But he/she might experience some psychological discomfort while answering the questions.

You may decide to stop your child's participation if you think that being in the study may cause her/him psychological discomfort.

Are there benefits to taking part in this study?

Your child is not likely to benefit by taking part in this study. However, if he/she participates in this study it will help the research team to understand the quality of life of speaking Spanish adolescents living with epilepsy.

What are my costs?

There are no direct costs to you or your child.

Will my child be paid to participate in this study?

Your child will not be compensated for taking part in this research study

Facebook groups

Group 1: Epilepsia tu y yo

- Administrators: Claudia Alejandra Gutierrez Villa
- Number of members: 3,506 members
- Type of group: Private, but visible to others
- History: created on June 24, 2016

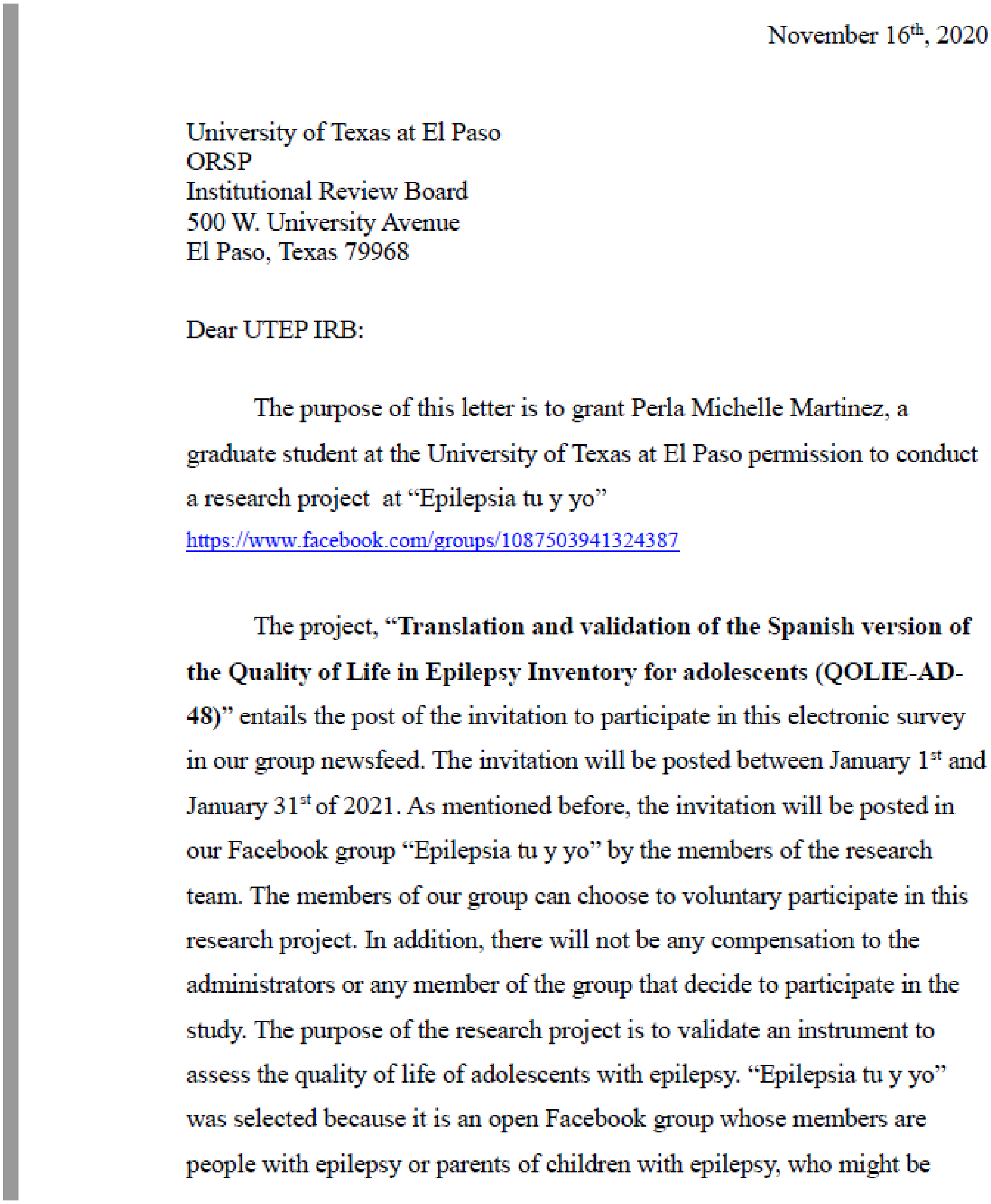
Group 2: Unidos por la epilepsia

- Administrators: Claudia Alejandra Gutierrez Villa
- Number of members: 7,860 members
- Type of group: Private, but visible to others
- History: created on February 8, 2018

Letter of Collaboration

The following are the letters of collaboration granted by the administrator of the Facebook groups that participated in this research project.

Facebook group: Epilepsia tu y yo



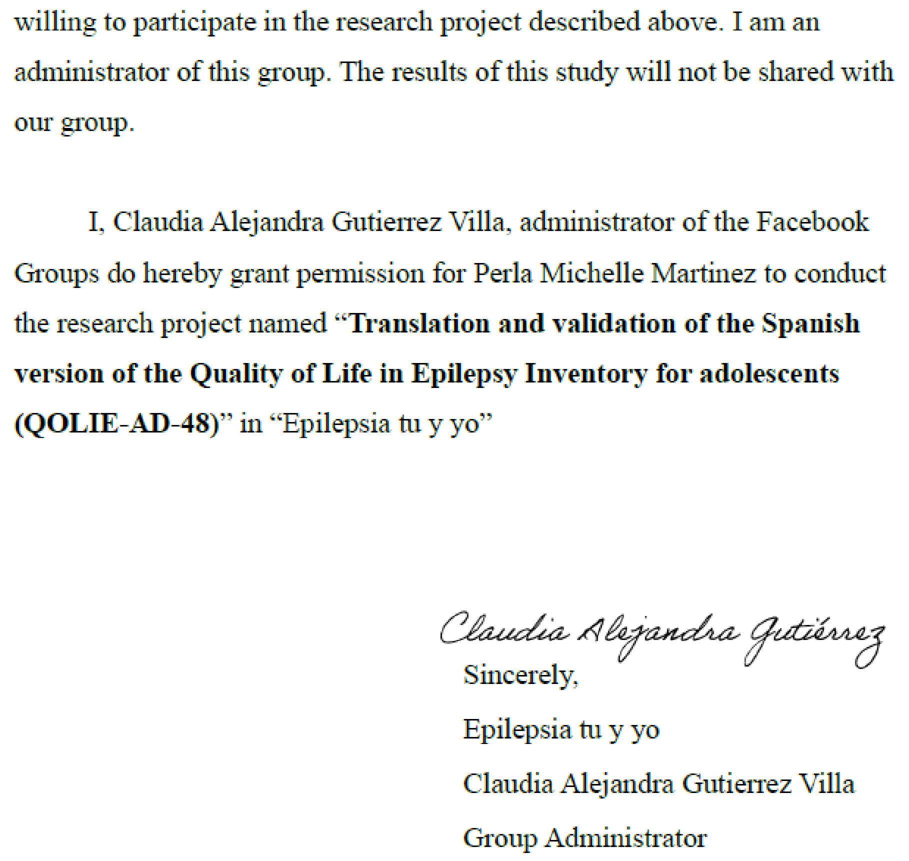
November 16th, 2020

University of Texas at El Paso
ORSP
Institutional Review Board
500 W. University Avenue
El Paso, Texas 79968

Dear UTEP IRB:

The purpose of this letter is to grant Perla Michelle Martinez, a graduate student at the University of Texas at El Paso permission to conduct a research project at "Epilepsia tu y yo" https://www.facebook.com/groups/1087503941324387

The project, "**Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)**" entails the post of the invitation to participate in this electronic survey in our group newsfeed. The invitation will be posted between January 1st and January 31st of 2021. As mentioned before, the invitation will be posted in our Facebook group "Epilepsia tu y yo" by the members of the research team. The members of our group can choose to voluntary participate in this research project. In addition, there will not be any compensation to the administrators or any member of the group that decide to participate in the study. The purpose of the research project is to validate an instrument to assess the quality of life of adolescents with epilepsy. "Epilepsia tu y yo" was selected because it is an open Facebook group whose members are people with epilepsy or parents of children with epilepsy, who might be



willing to participate in the research project described above. I am an administrator of this group. The results of this study will not be shared with our group.

I, Claudia Alejandra Gutierrez Villa, administrator of the Facebook Groups do hereby grant permission for Perla Michelle Martinez to conduct the research project named "**Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)**" in "Epilepsia tu y yo"

Claudia Alejandra Gutiérrez

Sincerely,
Epilepsia tu y yo
Claudia Alejandra Gutierrez Villa
Group Administrator

Facebook group: Unidos por la epilepsia

November 16th, 2020

University of Texas at El Paso
ORSP
Institutional Review Board
500 W. University Avenue
El Paso, Texas 79968

Dear UTEP IRB:

The purpose of this letter is to grant Perla Michelle Martinez, a graduate student at the University of Texas at El Paso permission to conduct a research project at "Unidos por la epilepsia" https://www.facebook.com/groups/706265659761141.

The project, "**Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)**" entails the post of the invitation to participate in this electronic survey in our group newsfeed. The invitation will be posted between January 1st and January 31st of 2021. As mentioned before, the invitation will be posted in our Facebook group "Unidos por la epilepsia" by the members of the research team. The members of our group can choose to voluntary participate in this research project. In addition, there will not be any compensation to the administrators or any member of the group that decide to participate in the study. The purpose of the research project is to validate an instrument to assess the quality of life of adolescents with epilepsy. "Unidos por la epilepsia" was selected because it is an open Facebook group whose members are people with epilepsy or parents of children with epilepsy, who might be willing to participate in the research project described above. I am an administrator of this group. The results of this study will not be shared with our group.

I, Claudia Alejandra Gutierrez Villa, administrator of the Facebook Groups do hereby grant permission for Perla Michelle Martinez to conduct the research project named "**Translation and validation of the Spanish version of the Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)**" in "Unidos por la epilepsia"

Claudia Alejandra Gutiérrez

Sincerely,

Unidos por Epilepsia
Claudia Alejandra Gutierrez Villa
Group Administrator

Curriculum Vitae

Perla Michelle Martinez was born in El Paso Texas. She attended the Autonomous University of Ciudad Juarez and obtained the degree of medical doctor. During the time she was a medical student she was a research assistant at the gastroenterology department of the Children Hospital of Mexico and at the neurology department at the National Institute of Pediatrics; both in Mexico City. During her year at the National Institute of Pediatrics she discovered her passion for clinic research in neurological conditions. After finishing medical school, she worked as a physician at two community centers, and a hospital in Ciudad Juarez. She decided to pursue a master's degree in public health at the University of Texas at El Paso. She has worked as s graduate teaching assistant at the UTEP School of Pharmacy for the last 2 years. Finally, she has been a poster presenter at several national and international meetings. Email: pmmartinez2@miners.utep.edu