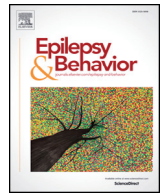




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Comic book-based educational program on epilepsy for high-school students: Results from a pilot study in the Gran Chaco region, Bolivia

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ABSTRACT

Introduction: In low- and middle-income countries (LMIC), epilepsy still represents a significant health challenge. In the Bolivian Chaco, we have previously found high levels of stigma towards people with epilepsy (PWE) especially expressed by high school students. In order to increase the knowledge about epilepsy, we have tested a comic book-based intervention on a sample of high school students.

Methods: The study has been conducted in the Bolivian Chaco region where two urban and two rural classrooms have been randomly selected. Students have been administered a knowledge, attitudes, and practices (KAP) questionnaire, and then they underwent a comic book-based educational program where they were randomly assigned either to an autonomous reading or a character interpretation methodology. The same KAP questionnaire has been administered after the teaching session and at a three months follow-up. Mean KAP scores at the baseline were compared with the after teaching and the three-month assessment.

Results: Eighty-three students with a mean age of 15.5 ± 0.9 years, of whom 38 (45.8%) males, were recruited. After the comic book session, students improved in the global score ($p < 0.001$) and in the knowledge ($p < 0.001$), attitudes ($p = 0.004$), and practices ($p < 0.001$) subscores. Both the autonomous reading and the character interpretation groups significantly improved in the global score, but only the latter improved in all the subscores. At the three months follow-up, there were no differences in the global, knowledge, and attitudes subscores, compared with scores immediately after the intervention.

Conclusion: Using a comic book to teach about epilepsy led to a significant improvement in the knowledge, attitudes, and practices about the disease in high school students of LMIC. This teaching strategy can be easily implemented in LMIC.

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1. Introduction

Epilepsy represents one of the major sources of disability in the world, responsible for the 0.56% of total disabilities-adjusted life years [1]. The burden of the disease, however, falls upon low- and middle-income countries (LMIC), where almost 13 million people with epilepsy (PWE) live [1]. In particular, in the Plurinational State of Bolivia, a lifetime epilepsy (LTE) prevalence of 12.3/1000, an active epilepsy (AE)

prevalence of 11.1/1000, and a treatment gap (TG) of 90% were estimated in 1994, in the rural communities of the Chaco region [2].

Epilepsy affects people not only by the presence of the disease itself, but also because of the stigma that encloses it. Stigma is defined as the "cooccurrence of labeling, stereotyping, separating, status loss, and discrimination associated with a specific disease in the context of power imbalance" [3] and affects PWE because of the superstitions and cultural beliefs that surround them [4]. The presence of stigma deeply impacts the quality of life of PWE, contributing to the reduced access to health services especially in LMIC. Addressing the stigma determinants is one of the most feasible strategies that can be used to increase the quality of life of PWE and their access to care [5]. Education-focused interventions are the most effective methods in reducing stigma [5,6], especially when tailored to address the different social backgrounds of the

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populations where they are implemented. Contents and methodologies of educational programs need to be different when directed to the various key persons responsible for the treatment and social inclusion of PWE such as physicians, nurses, community health workers (CHWs), and community dwellers.

In the rural areas of the Bolivian Gran Chaco region, several surveys have been conducted by our group aimed at assessing the prevalence and causes of epilepsy in the rural communities [2,7]. Furthermore, we have conducted an anthropological study on the perception of epilepsy by the local Guaraní culture, finding that PWE face stigma-associated limitations in their daily life [8]. In order to reduce the impact of stigma on PWE, we have conducted a two-year educational program directed towards general practitioners (GPs), nurses, CHWs, and community dwellers [9–11]. In our surveys, we found that the highest levels of stigma were expressed by high school students [11].

Educational campaigns targeted towards students have demonstrated to be very efficacious in improving their knowledge about epilepsy, both in high-income countries (HIC) and LMIC [12,13].

The aim of our study was to evaluate an educational comic book-based strategy to improve knowledge, attitudes, and practices (KAP) about epilepsy among schoolchildren in rural and urban areas of the Bolivian Gran Chaco.

2. Materials and methods

2.1. Study area

Bolivia is considered a LMIC with high levels of poverty especially in rural areas, where a high percentage of the population lives. The south-east region of Bolivia is part of the “Gran Chaco”, a subtropical area of low forests and savannas, covering approximately 1,000,000 km² of South America also including the central-north region of Argentina and the western Paraguay. The study has been conducted in the Santa Cruz Department. Indeed, the majority of the rural population is represented by the Guaraní population, particularly vulnerable to poverty and food insecurity.

2.2. Study population

The school system in Bolivia is composed of public, private, and professional institutions, and is divided into “Primary school” and “Secondary or high school” each of 6 years duration. The study has been conducted in high school students from an urban and rural background in the Chaco region. Urban areas are those defined as areas with more than 2000 inhabitants, while rural areas are those with less than 2000 inhabitants [14]. Urban schools have been considered as those situated inside the Camiri city limits. Camiri is an urban city with 36,573 inhabitants [14]. From the urban setting, a random school has been selected. Rural schools have been considered as those situated in two randomly selected rural communities surrounding Camiri: Ivamirapinta and Pueblo Nuevo whose inhabitants are 1215 (2017) and 623 (2017), respectively. For each setting, both in urban and rural settings, two classrooms have been randomly selected to be involved in the study.

2.3. Questionnaire to assess knowledge, attitudes, and practices

To assess the KAP of high school students, a questionnaire in Spanish language originally developed for Argentinian high school students was used. The questionnaire has been previously tested in a smaller sample of Argentinian high school students and subsequently adapted to the local sociocultural background by an anthropologist (SP) previously involved in several anthropological studies in this area.

The questionnaire is divided into the knowledge section (7 questions), attitudes section (3 questions), and practices section (4 questions). For each question, a score of 1 has been assigned for each

“correct” answer, leading to the computation of section subscores and a total score.

2.4. Teaching instrument and methodologies

The teaching instrument used is a 44-page educational comic book entitled “Guitar Heroes”, which was developed by neurologists from Latin America and France, and an artist-cartoonist specializing in Behavior Change Communication (BCC). This project was funded by Sanofi Global Health. The sociocultural background of the main characters of the comic book has been designed to be familiar for both rural and urban children of south American regions (Fig. 1).

Two different teaching methodologies have been tested in our study. In the “autonomous reading” method, children were asked to individually read the book in a 1-hour timeframe. In the “character interpretation” method, children were divided in 5-people groups, and a different section of the story was assigned to each group. An instructor assigned a role to every student. After a 20-minute group preparation, every group was asked to impersonate its own section in front of the class, in a 40-minute timeframe. In order to test the best teaching methodology for both urban and rural setting, each classroom has been randomly assigned either to the “autonomous reading” or “character interpretation” methodology.

2.5. Study procedure

The study has been conducted from June 2019 to November 2019. Students have been administered the KAP questionnaire before the teaching session and after its ending. At the end of the evaluation, a Question and Answer session with the instructors has been conducted in order to answer the questions of the students. The students have been tested with the same questionnaire three months after the teaching module in order to evaluate the level of retention of the acquired knowledge. The study was developed in accordance with the Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) guidelines. (Supplementary Table 1).

2.6. Statistical analysis

Demographic and questionnaire data have been registered for each participant and have been entered in an ad-hoc created database. Quantitative variables were described using mean and standard deviations while qualitative variables using percentages. Variables have been checked for consistency before analysis. Comparisons between means have been conducted using the Mann-Whitney test. Frequencies have been compared with the chi-squared test or the Fisher's test when appropriate. For the comparisons of paired data, appropriate tests were used (Wilcoxon matched pairs test and one-tailed McNemar test). The Bonferroni correction was applied for multiple comparisons. All the analyses have been performed using STATA 12 software (College Station, TX).

2.7. Ethics

The study has been approved by the Ethical committee of the Bolivian Neurological Society.

3. Results

3.1. Demographic characteristics of the participants

A total of 83 students with a mean age of 15.5 ± 0.9 years, of whom 38 (45.8%) were males, have been recruited. Among them, 49 (mean age: 15.1 ± 0.7 ; 22 males [44.9%]) were from two classes in the city of Camiri and 34 (mean age: 15.9 ± 0.9 ; 16 males [47.1%]) from two schools from the rural communities (Ivamirapinta and Pueblo Nuevo).



Fig. 1. The main story follows the life of a young girl from a small city who dreams of becoming a rockstar. She spends the summer visiting some relatives in a small rural village where she meets a boy affected by epilepsy who is stigmatized by his peers. When she moves back to the city, after a while, she experiences seizures for which she is visited by a neurologist that diagnoses her with epilepsy and explains what it means to live with this disease, giving helpful advices, and confuting common misconceptions. After she starts the treatment, she stops having seizures and, recalling the boy with epilepsy who she previously met, she tries to reach out for him and send him to the doctor. At the end, both of them succeed in their lives.

Rural students had a significant higher age than urban students ($p < 0.01$).

3.2. Knowledge before and after the intervention

Almost half of the sampled population had witnessed a seizure (56.6%) with no differences between urban and rural students (51% vs 64.7%; $p = 0.21$). Concerning the knowledge about epilepsy, when asked about the causes of epilepsy, less than half of the respondents were aware that it was a neurologic disorder (36.6%) and almost a third of the students did not know the causes of the disease (29.3%). Furthermore, 14.6% thought epilepsy had an infectious cause, and 23.2% of the sample thought it was a communicable disease. More than a half of the students thought that a treatment was available (54.9%). All the answers to the questionnaire are reported in Supplementary Tables 2 and 3.

After the intervention, students improved their knowledge on the causes of epilepsy, with a significant increase of recognition of epilepsy as a neurologic disorder (36.6% vs 74.7%; $p < 0.001$), and a complementary decrease of people not knowing any cause of epilepsy (29.3% vs 2.4%; $p < 0.001$). Furthermore, they considered epilepsy as a disease

that can be successfully treated with medications (54.9% vs 96.3%; $p < 0.001$) (Supplementary Table 3). Nonetheless, it should be noted that after the intervention, a significant higher number of participants (23.2% vs 43.4%; $p < 0.001$) considered epilepsy as a communicable disorder, transmitted by simple contact with someone with the disease (63.9%) or by breathing the same air (30.6%).

Considering the global scores, after the comic book intervention, students significantly improved in their total score (9.4 ± 4.3 vs 12.5 ± 3.9 ; $p < 0.001$) and also in the knowledge subscore (2.7 ± 1.7 vs 4.8 ± 1.4 ; $p < 0.001$) as shown in Fig. 2.

3.3. Attitudes before and after the intervention

Before the intervention, when witnessing someone having a seizure, 55.6% of students would call a doctor, while only 37% would act by moving the patient to lie on one side and 24.7% thought it was important to remove objects that may cause harm to the patient. The majority of the participants (65.8%) would take a PWE to the physician; however, almost one quarter of the students (24.4%) still thought that the traditional healer was more indicated. These attitudes were also confirmed when asking who was responsible for the treatment and care of a

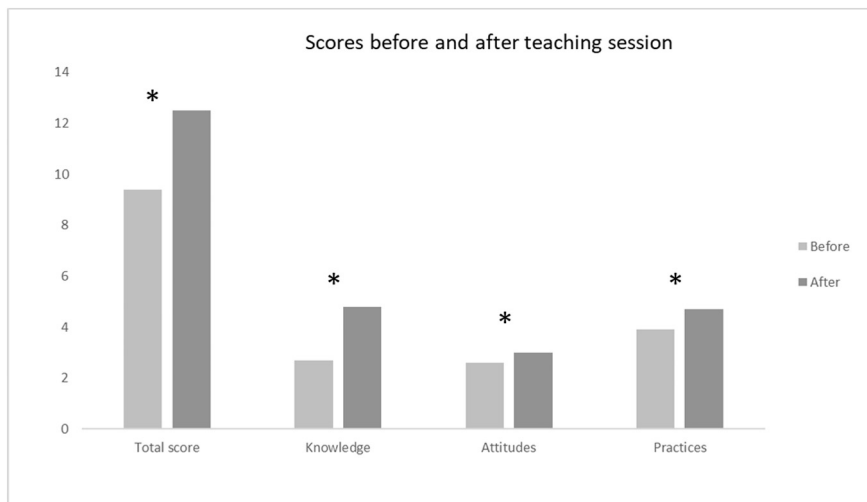


Fig. 2. Scores before and after teaching session (* = statistically significant).

PWE, with the physician being suggested by the most (63%) (Supplementary Table 3).

After the intervention, results were mixed with improvement in some concepts, such as calling a doctor (55.6% vs 84.3%; $p < 0.001$). Moreover, considering the key figures involved in the care of PWE, a significant improvement has been recorded with more students suggesting the physician (65.8% vs 87.9%; $p < 0.001$) (Supplementary Table 3).

Considering the scores, a significant improvement has been found after the intervention in the attitudes subscore (2.6 ± 1.2 vs 3 ± 0.9 ; $p = 0.004$) (Fig. 2).

3.4. Practices before and after the intervention

When investigating the practices of students towards PWE before the intervention, only a few of them expressed negative behaviors such as “to avoid contact” (8.6%), “asking to change classroom” (1.2%) and “to suggest them to not play sport” (16.1%) (Supplementary Table 3). Furthermore, among the good practices to improve the knowledge on epilepsy and the lives of PWE, the most suggested were: “to push PWE to visit a doctor and start the treatment” (57.3%); “to tell people that this disease can be treated” (39%). Finally, 59.3% of the students would have supported a brother/sister marrying a PWE and 46.3% thought that children with epilepsy could attend school.

After the comic book intervention, a higher number of participants agreed on letting a sibling marry a PWE (59.3% vs 74.7%; $p = 0.003$), and thought PWE could go to school (46.3% vs 60.2%; $p = 0.03$) (see Supplementary Table 2 and 3).

A significant improvement has been found in the practices subscore (3.9 ± 2.3 vs 4.7 ± 2.4 ; $p < 0.001$) after the intervention (Fig. 2).

3.5. Urban vs rural setting

Overall, urban students performed better than rural students at both the baseline assessment and follow-up assessment as shown in Fig. 3 and Supplementary Table 2.

3.6. Autonomous reading vs character interpretation

After the baseline assessment 34 (41.0%), students were randomly assigned to the individual reading, while 49 (59.0%) to the character interpretation, without any significant difference of age (15.4 ± 0.85 vs 15.5 ± 0.89 ; $p = 0.7$) or sex distribution (55.9% vs 38.8% males; $p = 0.124$).

When stratifying according to the different teaching methodology, students who were randomized to the autonomous reading improved only in the total score (11.2 ± 4.7 vs 13.6 ± 4 ; $p = 0.002$) and knowledge score (3.4 ± 1.8 vs 4.8 ± 1.5 ; $p < 0.001$), while students who

performed the character interpretation significantly improved in the total score (8.3 ± 3.7 vs 11.7 ± 3.6 ; $p < 0.001$) and in each of the subscores (knowledge: 2.3 ± 1.5 vs 4.7 ± 1.3 , $p < 0.001$; attitudes: 2.5 ± 1.1 vs 2.8 ± 0.9 , $p = 0.01$; practices: 3.5 ± 1.9 vs 4.2 ± 2.2 ; $p < 0.001$).

The rate of improvement, compared with the baseline, stratifying for teaching methodology, showed the highest rates for the character interpretation methodology compared with the autonomous reading (41% vs 21.4%) especially for the knowledge subscore (104.3% vs 41.2%) (Fig. 4).

3.7. Retention assessment at three months follow-up

At the three-month reevaluation to assess knowledge retention rate, 66 students out of the 83 original participants (79.5%) were available for the questionnaire administration. Students lost at the reevaluation were slightly older (16 ± 1.1 vs 15.3 ± 0.8 years; $p = 0.009$), and the majority of them belonged to the rural setting (29.4% vs 70.6%, $p = 0.005$). No significant differences were found in the large majority of answers compared with the results obtained after the original intervention. However, a significant lower number of subjects (13.6% vs 43.4%; $p < 0.001$) thought that epilepsy is a communicable disease (Supplementary Table 3).

Considering the global score and the subscores, students showed no difference at the three months follow-up compared with just after the intervention. At the three months reassessment, there were no differences between urban and rural students in the total score (13.3 ± 5.3 vs 12.1 ± 3.8 ; $p = 0.48$), knowledge (4.8 ± 1.8 vs 4.3 ± 1.5 ; $p = 0.15$), attitudes (2.9 ± 1.3 vs 3 ± 1.0 ; $p = 0.64$), and practices (5.4 ± 2.9 vs 4.7 ± 1.8 ; $p = 0.49$) subscores. When evaluating the differences in the scores between the postteaching assessment and the three months reassessment according to the different methodologies used, no differences were found in both the autonomous reading and character interpretation groups.

4. Discussion

The burden associated with epilepsy in LMIC influences both the healthcare aspects of the disease and the sociocultural dimension of those who are affected [5]. Indeed, epilepsy is frequently not recognized as a treatable condition, and PWE suffer from social exclusion and reduced access to care due to the social stigma associated with the disease. As such, increasing knowledge on epilepsy has been demonstrated to reduce stigma levels [5].

Among the most effective strategies, educational programs directed towards the professional figures responsible for the treatment and care of PWE are feasible and economic and thus can be easily implanted in the LMIC setting, where the low level of knowledge about epilepsy is

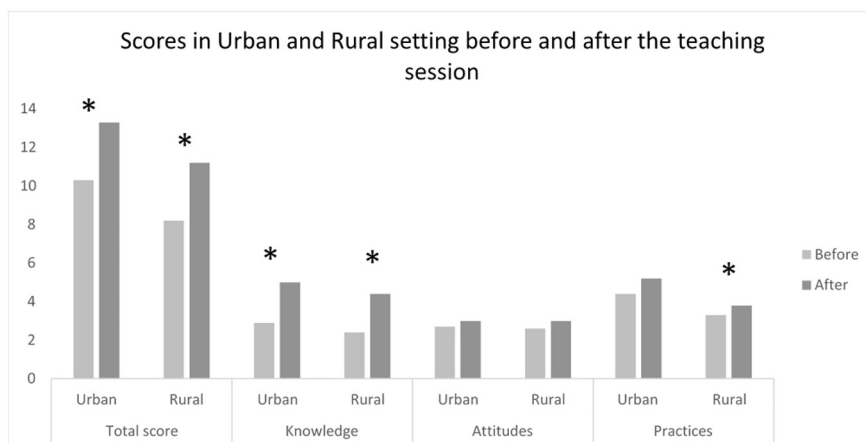


Fig. 3. Scores before and after teaching session (* = statistically significant).

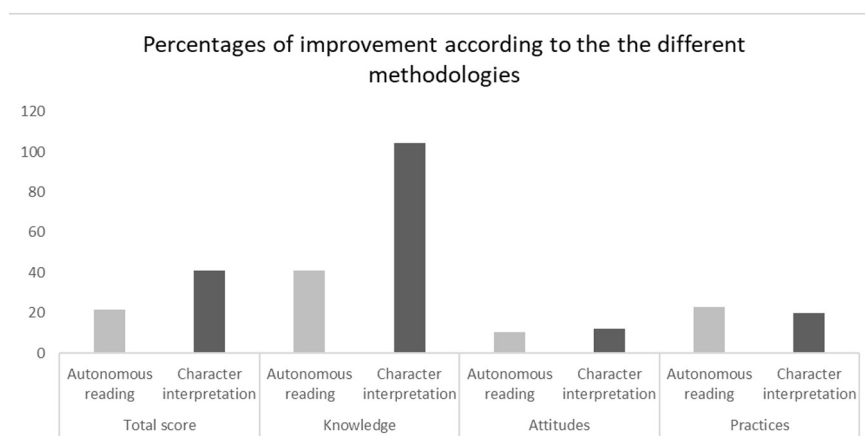


Fig. 4. Percentages of improvement according to the different teaching methodologies.

one of the main determinants of TG. However, interventions have to be aimed also at the general population level, because this is the environment where PWE grow and live their daily lives, and thus where they suffer the highest levels of stigma [11].

In the rural communities of the Bolivian Gran Chaco, among community dwellers, the highest levels of stigma have been expressed by high school students [11]. However, in this small sample, a significant reduction in the stigma levels was recorded after an educational program directed towards all the community members [11], demonstrating the effectiveness of educational interventions in reducing stigma [5,6].

Our study has demonstrated that a comic book-based intervention directed towards school children is feasible and effective in improving the knowledge, attitudes, and practices of high school students in a LMIC setting, both in the rural and urban areas.

Educating schoolchildren can be a highly effective strategy because of the big impact that an early acquisition of knowledge can have, not only at the school level, but for the society as a whole, possibly leading to an effective reduction of stigma and more positive attitudes towards PWE. Moreover, children and adolescents with epilepsy can suffer more than others from stigmatization and discrimination at school, which in turn leads to poor self-esteem and reduced quality of life [15].

However, designing an educational program that can be effectively used for high school students is still a challenge. While the large majority of KAP studies on epilepsy for students focused on assessing the baseline knowledge, attitudes, and practices, only few of them actually designed and tested an educational intervention [12,13,16,17] and only two were set in LMIC [13,16].

The studies assessing students' baseline KAP [13,16,18–23] showed different levels of knowledge across different countries, almost all demonstrating that schoolchildren are not aware of the causes of epilepsy which in turn leads to wrong attitudes and poor practices towards the disease.

Regarding interventional studies, up to now, only one study has evaluated the use of a comic book as a tool for an educational program among school students in Ethiopia, both from the urban and rural settings [16]. In this study, the authors demonstrated a low level of knowledge and the presence of misconceptions among students before reading the comic book with an improvement in awareness afterwards [16]. However, in this study, the comic book has been autonomously read by the students and no other teaching strategy has been tried. Moreover, a reassessment to evaluate the retention of the information has not been performed.

In our study, we were able to demonstrate a global efficacy of our educational program in all the settings where it has been implemented. Indeed, the different settings, urban and rural, showed different levels of knowledge about epilepsy, reflecting the different backgrounds of the

two groups. For example, urban students had a higher knowledge about epilepsy as a brain disease, compared with rural students. On the other hand, regardless of the level of knowledge, the large majority of the respondents (both urban and rural) expressed positive attitudes towards PWE. This is in line with the previous observations carried out in an anthropological study in the same region that showed how the community perceives PWE as subjects who need protection [8]. This is also true for the practices section, where rural students were also keen to suggest to PWE to go and seek help from physicians. At any rate, it is important to underline that more than one out of two students (56%) stated to have witnessed a seizure. This surprisingly high result cannot be explained only by the high prevalence of seizures in Bolivia [2] but it can probably be due to a frequent misinterpretation of other paroxysmal events such as psychogenic nonepileptic seizures or syncopes.

After the intervention, there was a significant improvement in the number of correct answers, a trend that was maintained even at the three months retention assessment, strongly suggesting the efficacy of this intervention in increasing the knowledge, attitudes, and practices of students.

Moreover, in our study, we were able to assess the differences in efficacy between two different teaching strategies: the autonomous reading and the character interpretation. We found that the choice to impersonate a role in front of the class was a better way for the students to learn, with significant improvements in all sections immediately after the teaching session. This could be explained by a possible higher tendency to identification and a greater personal involvement of the students given by the interpretation of a character [17]. However, our results cannot be compared with the only other study performed using a character interpretation strategy, because in this case, this strategy was not compared with an autonomous reading methodology but to an educational video session [17].

Certainly, our study has some limitations. Since it is a pilot study, we did not perform a sample size calculation, thus limiting the representativeness of our population. Furthermore, after the educational program, a significantly higher number of students declared that epilepsy is a contagious disease. This surprising negative result can be explained by the storyline of the comic book, in which the main character meets a boy with epilepsy in a rural village and then, going back to the city, she develops epilepsy herself. This coincidental occurrence could have been interpreted as causally linked, thus leading to the thought that epilepsy can be transmitted, possibly explaining the low number of correct answers to some attitudes' questions at the postintervention assessment. However, in the Question and Answer session with the instructor at the end of the first evaluation, this misinterpretation has been clarified and a significant higher number of students answered correctly after three months.

Moreover, poor information has been provided in the comic book about first aid in case of a seizure, as demonstrated by the low number of correct answers to the question “What would you do if you are facing someone having a seizure?” both at baseline and after the teaching session.

However, based on these findings, after an expert meeting, the comic book was modified by adding a dialog in which the physician clearly states that epilepsy cannot be transmitted and by including a section at the end of the storyline that briefly explains how to act in front of a convulsive seizure.

Nonetheless, this is the first KAP interventional study specifically conducted in schoolchildren in a Latin American Country. In fact, the previous study conducted by our group among community members only involved a small sample of students [11].

Moreover, in our study, we tested a methodology that can be easily performed by a trained instructor; it is not expensive and requires only a small amount of time (almost 1 h). Thus, it can be easily implemented in other LMIC with good results.

However, this was a pilot study and a larger multicentric study needs to be conducted in order to improve the teaching methodology and tailor the sessions to the different backgrounds.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2020.107076>.

Declaration of competing interest

None.

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