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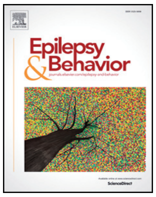

Knowledge, stigma, and quality of life in epilepsy: Results before and after a community-based epilepsy awareness program in rural Bolivia

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ABSTRACT

Introduction: Epilepsy represents around 0.7% of the overall global burden of diseases and is particularly prevalent and associated with significant disability in low- and middle-income countries (LMIC) in Latin American Countries (LAC). A community-based epilepsy awareness program was carried out by our group in the rural areas of the Chaco region, Plurinational state of Bolivia, to improve the knowledge about epilepsy, with a first part directed toward general practitioners and a second part toward nurses and community health workers (CHWs) of the rural communities with a positive outcome.

The objective of the study was to assess the level of knowledge, attitudes, and practices toward epilepsy, the stigma related to epilepsy and the quality of life in people with epilepsy (PWE) before and after the interventional campaign directed toward representative members of the rural communities in the Chaco region in Bolivia.

Methods: The study was conducted in three areas of Bolivia. Key subjects from each community were randomly selected. Before and after the courses they answered a questionnaire to assess their knowledge, attitudes, beliefs, and practices about epilepsy, a validated Stigma Scale of Epilepsy (SSE) and Quality of Life in Epilepsy Inventory-10 (QOLIE-10).

Results: Two hundred sixteen subjects were involved in the program. Only 133 (61.6%) subjects completed the questionnaires a month after the educational program. A significant improvement was recorded in knowledge, attitudes, and practices toward epilepsy, and a significant reduction was found in the mean SSE total score (38.3 ± 14.7 vs. 28.5 ± 12.3; $p < 0.01$), reflecting a reduction of stigma levels. Regarding the quality of life, after the training, PWE stated to experience less depression, memory difficulties, work or social issues, and seizure worry.

Conclusion: Our study confirms that continuous educational campaigns can lead to a significant change in the social perception and attitudes toward epilepsy.

1. Introduction

Epilepsy affects approximately 70 million people worldwide [1] of whom about 5 million people are in Latin American Countries (LAC). It represents around 0.7% of the overall global burden of diseases and in particular, in some low- and middle-income countries (LMIC) of LAC, epilepsy ranks as the 21th leading cause of disability-adjusted life years (DALYs) and as the 9th leading cause of years lived with disability (YLD) [2]. In the Plurinational State of Bolivia, a life-time 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 [3].

However, even if epilepsy is a common disorder, in many parts of the world people with epilepsy (PWE) and their families suffer from stigma and social discrimination. In particular, stigma in epilepsy is due to the presence of superstitions and wrong cultural beliefs that lead to social isolation of PWE contributing to their poor quality of life. Moreover, poor knowledge and consequent stigma constitute important barriers for epilepsy management, especially in LMIC, representing contributing factors to epilepsy TG [4].

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Under the aegis of the Global Campaign against Epilepsy, we previously performed a study to assess stigma perception among the Guarani population living in the rural communities the Chaco region in of Bolivia [5]. The findings of our study disclosed that PWE living in this region face everyday difficulties because of epilepsy-associated stigma, demonstrating the need of promoting community-based educational programs aimed at improving knowledge and reducing the stigmatization process. Education is considered the best method to reduce the stigma linked to epilepsy, but community-based programs performed with this aim should be based on the local perceptions of epilepsy taking into account the social and cultural backgrounds in each region [6]. As a matter of fact, many previous experiences in LMIC demonstrated that a systematic educational approach can significantly increase knowledge, reduce stigma, and decrease TG [6,7]. Such interventions should be targeted to specific groups such as health providers, PWE, their families, and other community key figures (i.e., teachers, students), and they should be tailored to the needs of each specific group, with a training focused on the diagnosis and management of epilepsy for health providers and educational sessions based on antiepileptic drug (AED) adherence and psychosocial issues for PWE [4].

A community-based epilepsy awareness program was carried out by our group in the rural areas of the Chaco region, Plurinational state of Bolivia, to improve the knowledge about epilepsy. A first part of the program was directed toward general practitioners (GPs) of the rural communities [8] and a second part toward nurses and CHWs [9] with positive results. In fact, after a structured training program, a significant improvement was recorded regarding GPs' practices toward epilepsy with an increased confidence to manage antiepileptic treatment and an increased level of satisfaction about their epilepsy knowledge [8]. Regarding nurses and CHWs working in the rural communities of the Chaco region, a good baseline level of knowledge about epilepsy was found, possibly because of the long-term epilepsy educational activities conducted by our group in the Chaco area over the years [9].

However, educational interventions, in order to obtain long-lasting results, should also be directed to the community members, including the PWE and their families, with the aim of enhancing knowledge, reducing stigma, and improving quality of life of PWE [7].

The objective of the present study was to assess the level of knowledge, attitudes, and practices (KAP) toward epilepsy, the stigma related to epilepsy, and the quality of life of PWE at baseline and after the interventional campaign directed toward the most representative members of the rural communities of the Chaco region in Bolivia.

2. Material and methods

2.1. Study area

Bolivia is divided into 9 departments and into 112 provinces. It is considered a lower-middle-income country with high levels of poverty especially in rural areas, where a high percentage of the population lives. Indeed, the majority of the rural population is represented by indigenous communities, particularly vulnerable to poverty and food insecurity.

The southeast region of Bolivia is part of the "Gran Chaco", a subtropical area of low forests and savannas, covering approximately 1000,000 km^2 of South America also including the central-north region of Argentina and the western Paraguay.

The program has been implemented in three main areas: the areas of Gutierrez (12,273 inhabitants) and Lagunillas (5366 inhabitants) located in the Cordillera Province (Santa Cruz Department) and the area of Huacaya (2426 inhabitants) in the Luis Calvo Province (Chiquisaca Department).

These areas were selected based on the following criteria: accessibility, presence of healthcare personnel living and working within the communities, homogeneous number of communities/inhabitants per area; presence of a centralized coordination of the community healthcare workers; and presence of local schools and facilities to develop the training. Using a cluster sampling method, from the three selected areas we selected 17 rural communities (8 from the area of Gutierrez, 5 from the area of Lagunillas, and 4 from the area of Huacaya).

2.2. Study population

The ethnic group living in the study area is mainly represented by the native Guaraní people, living in poor dwellings without running water and electricity, and with a local economy based on agriculture and animal husbandry. The majority of the population speaks both Spanish and Guaraní.

A cluster sampling of the communities was performed and then a sample of the most representative community members was selected for each community. In particular, the key subjects for each community were chosen among PWE, relatives of PWE, teachers of both primary and secondary school and school directors, students of at least 12 years of age, community authorities, health personnel, and older adults (> 60 years old). The participants were identified from the census available at the health centers. The lists of PWE living in the selected areas were obtained and their treated/untreated conditions were updated by the community nurses. All the available PWE were included in the assessment.

2.3. Questionnaire to assess knowledge, attitudes, and practices about epilepsy

A questionnaire to assess the knowledge, attitudes, beliefs, and practices toward epilepsy was administered to all the key informants of the selected communities before the educational campaign and after a month to evaluate KAP at a community level. The questionnaire, in Spanish language, was developed adhoc from a previous anthropological study performed in the same area [10] (Supplement 1). It was evaluated and modified by a local anthropologist (SP) and pretested on a sample of students of the local nursing school. The questionnaire has been field-tested in a pilot study before the survey was conducted. It includes 12 questions that elicit information on demographics, personal experience with epilepsy, epilepsy care knowledge, common treatments, and social considerations toward PWE. All the questionnaires have been administered by the local nursing students already involved and trained during previous studies performed in the same area.

2.4. Questionnaire to assess stigma related to epilepsy

A validated Stigma Scale of Epilepsy (SSE) [11], previously translated, adapted, and used in this population [5] was administered to the community members prior to the educational campaign and one month after the campaign. The SSE consists of a multiple-choice questionnaire containing 24 items grouped in five domains (Supplement 2). It covers a range of topics about the perception of epilepsy in different contexts: attitudes and behaviors in relation to PWE, perception and feelings regarding seizures, and social aspects associated with having epilepsy. The SSE total score ranges from zero, which is the lowest level of stigma, to 100, which is the highest stigma level. All the questionnaires have been administered by the local nursing students.

2.5. Questionnaire to assess quality of life among PWE

The Spanish validated Quality of Life in Epilepsy Inventory-10 (QOLIE-10) [12] was administered to both treated and untreated PWE identified in rural communities included in the project prior to the educational campaign and one month after the campaign. The QOLIE-10 is a brief survey of health-related quality of life for adults with epilepsy. It comprises seven components: seizure worry, emotional wellbeing, energy/fatigue, cognitive functioning, medication effects (physical and mental), social function (work, driving, and social function) (Supplement 3), and overall quality of life. All the questionnaires have been administered by the local nursing students.

2.6. Communities education and awareness campaign

An educational program aimed at improving knowledge on epilepsy has been organized, with the support of local anthropologists, directed toward patients, their families, and community members.

Awareness and educational materials (sheets, posters) were produced. A flipchart was developed with drawings about the life of a patient with epilepsy. The drawings have been adapted to the Guarani culture by a local artist (Fig. 1).

An educational video was produced by the local nursing students on how to act when facing someone with an epileptic seizure following the recommendations of the International League Against Epilepsy.

Activities and meetings were organized and promoted through the participation of community leaders and local school teachers. The meetings, lasting about 3 h, were organized in all the selected communities with the help of the local healthcare personnel. Local GP (DR) and an anthropologist (SP) have led the events. The number of attendees has been systematically recorded.

Sessions were focused on epilepsy characteristics, causes (especially on modifiable factors), and treatment possibilities. The flipchart has been systemically used and talked through, and the educational video has been projected in all the communities.

The effectiveness of the campaign has been evaluated through the reassessment of the KAP and stigma level indicators a month after the educational event.

2.7. Statistical analysis

Demographic data have been collected for all the participants, and clinical data, such as age at onset, type of epilepsy, seizure frequency, and current treatment have been also recorded for PWE.

All the questionnaires collected have been coded, anonymized to protect confidentiality, and entered in an adhoc created database using the software EpiData version 3.1. An identified local nurse has been responsible for the data entry. Data have been double entered into the database. All errors have been checked and corrected. Data cleaning has been performed before the data analysis considering both range and consistence checks.

Data have been analyzed by the University of Catania using STATA 12 software packages (version 12.0, College Station, TX). Quantitative variables have been described using mean and standard deviation (SD), and qualitative variables using number of participants and percentages. The frequency comparisons have been done with the chi-square test. For paired data with two variables, the McNemar test has been used; for paired data with more than two variables, the exact test for symmetry has been performed. In case of not normal distribution, appropriate nonparametric tests were performed.

2.8. Ethical approval

The study was approved by the Ethical committee of the Bolivian Neurological Society. All the participants of the study signed a written informed consent. However, a verbal consent was obtained in case of illiteracy with the help of a local language speaking anthropologist, who witnessed and documented the whole procedure. Guardians gave their informed verbal consent, using the same approach than previously specified, in case of minors/children.

3. Results

3.1. Study population

A total number of 216 subjects in 17 rural communities have been involved in the program. Only 133 (61.6%) subjects were able to answer to the questionnaires performed before and a month after the educational program. Indeed, 83 subjects were not available at the time of the second interview and therefore considered lost to follow-up. Differences were found between subjects lost to follow-up and the rest of the population in terms of sex (more males than females) and areas of origin. The main characteristics of the study population are shown in Table 1. Among the total population of participants, six PWE have been involved in the program [one male (16.7%), five females (83.3%)] with a mean age of 31.3 ± 15.2 years. Three of them came from the area of Gutierrez, one from Lagunillas, and two from Huacaya. Their level of education was primary school for four (66.7%) and secondary school for two (33.3%) with four PWE being housewives and two students. All of them were suffering from generalized tonic–clonic seizures (GTCS).

LA EPILEPSIA NO IMPIDE QUE SE PUEDA RECIBIR EDUCACIÓN

Fig. 1. One of the drawings of the educational flipchart used in the study.

Table 1
Main characteristics of the study population participating in to the educational program.

	Total population N = 216 (%)	Community members with FU N = 133 (%)	Community members lost to FU N = 83 (%)	p*
Sex (M)	54 (25)	28 (21.1)	25 (30.1)	<0.01
Age (mean ± SD)	36.9 ± 16.6	37.6 ± 17.8	35.8 ± 14.4	0.45
Education				0.75
None	4 (1.9)	2 (1.5)	2 (2.4)	
Primary	84 (38.9)	53 (39.9)	31 (37.3)	
Secondary	78 (36.1)	45 (33.8)	33 (39.8)	
Higher	50 (23.1)	33 (24.8)	17 (20.5)	
Categories				0.77
People with epilepsy	6 (2.8)	5 (3.8)	1 (1.2)	
Relatives of people with epilepsy	22 (10.2)	12 (9.0)	10 (12.0)	
Teachers and school directors	37 (17.1)	23 (17.3)	14 (16.9)	
Students	32 (14.8)	21 (15.8)	11 (13.2)	
Community authorities	19 (8.8)	12 (9.0)	7 (8.4)	
Health personnel	25 (11.6)	16 (12.0)	9 (10.8)	
Older adults (>60 years old)	15 (6.9)	12 (9.0)	3 (3.6)	
Others	60 (28.8)	32 (24.1)	28 (33.7)	
Areas of origin				0.01
Santa Cruz department				
Gutierrez	110 (50.9)	74 (55.6)	36 (43.4)	
Lagunillas	54 (25)	22 (16.5)	32 (38.5)	
Chuquisaca department				
Huacaya	52 (24.1)	37 (27.9)	15 (18.1)	

N, number; SD, standard deviation; M, males; FU, follow-up.

* Statistical differences between community members available at follow-up and subjects lost to follow-up.

Their reported age at seizures onset was 17.5 ± 20 with a median age of 13.5 and a range of 0–55. They reported the presence of 2 ± 2 seizures per month (range 0–5). Four of them were taking AEDs, and one not regularly; one was not on AEDs. The drugs used were carbamazepine (CBZ) by three patients (50%), phenobarbital (PB) by one (16.7%), and valproic acid (VPA) by another one (16.7%).

3.2. Questionnaire to assess knowledge, attitudes, and practices about epilepsy

Two hundred sixteen subjects completed the KAP questionnaire before the implementation of the educational campaign. The majority of them (68.2%) already knew the right definition of epilepsy, even if for some of them (14.9%) epilepsy was considered an “illness caused by a state of nervousness and anxiety”. The doctors (63.9%) and the family (24.1%) have been considered the most important persons responsible for PWE. However, many of the community members (26.9%) thought that children should not be allowed to have contacts with PWE. Moreover, the majority of the people (64.8%) were not aware of any treatment for epilepsy, but among the ones who were aware, tablets were considered the most common (62.7%) life-long (58.8%) treatment, able to control the attacks (90.2%). There were still a high percentage of people thinking that PWE could not go to school (25.5%), go to a university (22.7%), get married (18.2%), or have children (17.1%).

A part of them (59.3%) knew that epilepsy could be “indirectly” spread by eating pork contaminated with *Taenia solium*.

Comparing different groups of subjects with the rest of the population, significant differences were found in terms of knowledge and attitudes toward epilepsy among the different community members involved in the program. In particular, significantly more health workers (89.5% vs. 29.9%; $p < 0.01$), relatives of PWE (59.1% vs. 32%; $p = 0.02$) and PWE (83.3% vs. 33.8; $p = 0.02$) were aware of the existence of a treatment for epilepsy and health workers knew that it was represented by AEDs (94.1% vs. 53.5%; $p < 0.01$). Moreover, opposite trends were recorded between students and housewives from one side and teachers and health workers from the other, regarding the possibility for PWE to go to school and university, to get married and have children ($p < 0.01$).

Only 133 participants were available to answer the questionnaire both before and one month after the educational campaign. A significant change was recorded in many items with an overall significant improvement in their KAP toward epilepsy. The answers to the questionnaire of the 133 subjects are shown in Table 2.

3.3. Questionnaires to assess stigma related to epilepsy and quality of life

Among the 216 subjects who completed the SSE questionnaire, a moderate baseline level of stigma was found with a mean total score of 38.7 ± 13.4 (minimum score zero, maximum score 100), as shown in Table 3.

Significant differences were found between different groups of subjects and the rest of the population in terms of mean SSE total score, with the highest score of stigma recorded among students (43.5 ± 14.1 vs. 37.8 ± 13.1; $p = 0.03$) and the lowest among teachers (34.4 ± 12.3 vs. 39.6 ± 13.4; $p = 0.03$) and health workers (30.9 ± 12.1 vs. 39.5 ± 13.3; $p = 0.007$). No differences were found in stigma levels between PWE (37.6 ± 12.4 vs. 38.7 ± 13.4; $p = 0.8$) or PWE relatives (38.8 ± 11.7 vs. 38.7 ± 13.5; $p = 0.9$) and the rest of the population. None of the answers of PWE to the different items of the questionnaire was significantly related to their reported number of seizures per month.

Among the 133 subjects who answered to the questionnaire before and after the educational program, a significant reduction was found in the mean SSE total score (38.3 ± 14.7 vs. 28.5 ± 12.3; $p < 0.01$), reflecting a significant reduction of stigma levels, as shown in Table 4.

Regarding the different groups of subjects, a significant reduction in the mean SSE total score was found between the scores before and after the training among housewives (37.0 ± 12.8 vs. 28.9 ± 11.5; $p < 0.01$), students (44.8 ± 13.4 vs. 29.1 ± 12.7; $p < 0.01$), and teachers (35.3 ± 13.2 vs. 23.5 ± 10.2; $p < 0.01$).

In addition, relatives of PWE had a significant change in stigma scores (37.3 ± 12.4 vs. 27.2 ± 7.6; $p = 0.04$).

At the beginning of the study, five out of six PWE completed the QOLIE-10 questionnaire. After one month, only 4 out of the 5 PWE were available, and the patient not taking AEDs was then taking CBZ. None of the answers to the different items of the questionnaire was significantly related to the number of seizures per month. Although no significant changes have been recorded after the training, patients stated to experience less depression, memory difficulties, work or social issues, and seizure worry.

Table 2
Answers to the questionnaire regarding KAP toward epilepsy.

Question	Answer	Before training N = 133	After training N = 133	p*
What is epilepsy?	• A disease of the brain that causes attacks with loss of consciousness and uncontrollable movements of the arms or legs.	89 (67.4)	119 (89.5)	<**0.01**
	• Illness caused by a state of nervousness and anxiety.	19 (14.4)	9 (6.8)	
	• A contagious disease.	8 (6.1)	1 (0.7)	
	• A sexually transmitted disease.	3 (2.3)	1 (0.7)	
	• An illness caused by noncompliance with cultural norms.	6 (4.5)	3 (2.3)	
Who are the subjects responsible for the treatment of a patient with epilepsy?	• The traditional doctor	9 (6.8)	6 (4.5)	0.21
	• The healer	2 (1.5)	7 (5.3)	
	• The doctor	89 (66.9)	78 (58.6)	
	• The family	31 (23.3)	41 (30.8)	
	• Whoever finds the way	2 (1.5)	1 (0.7)	
Who should not be allowed contact with the subject with epilepsy?	• Children	35 (26.7)	22 (16.5)	<**0.01**
	• Pregnant women	23 (17.6)	13(9.8)	
	• No one is allowed	16 (12.2)	9 (6.8)	
	• Everyone is allowed	56 (42.7)	89 (66.9)	
Do you know any kind of treatment for this disease?	• Yes	49 (37.7)	57 (43.5)	**0.05**
	• No	81 (62.3)	74 (56.5)	
Which are these treatments?	• To curse	1 (2.0)	1 (1.8)	0.25
	• Natural remedy	12 (24.5)	6 (10.7)	
	• Special diet	1 (2.0)	1 (1.8)	
	• Special bath			
	• Consider lunar movement			
	• Consider special days			
	• Secrets or prayers			
	• Tablets			
Do you believe that if a person with epilepsy takes his medications, he can control his attacks?	• Yes	119 (89.5)	127 (95.5)	<**0.01**
	• No	12 (9.0)	6 (4.5)	
Do you believe that taking an epilepsy medication is life-long?	• Yes	83 (62.4)	116 (87.2)	<**0.01**
	• No	50 (37.6)	17 (12.8)	
Do you think that people with epilepsy should go to school, if they are children?	• Yes	96 (72.2)	124 (93.2)	<**0.01**
	• No	37 (27.8)	9 (6.8)	
Do you believe that a person with epilepsy can go to university?	• Yes	101 (75.9)	127 (95.5)	<**0.01**
	• No	32 (24.1)	6 (4.5)	
Do you believe that people with epilepsy can get married?	• Yes	105 (80.1)	126 (94.7)	<**0.01**
	• No	26 (19.8)	7 (5.3)	
Do you think that people with epilepsy should have children?	• Yes	107 (80.4)	128 (96.2)	<**0.01**
	• No	24 (18.0)	5(3.8)	
Have you ever heard that epilepsy can be spread by eating pork with “trichina” (cysticercosis)?	• Yes	70 (52.6)	126 (94.7)	<**0.01**
	• No	62 (46.6)	7 (5.3)	

P-values marked in bold indicate results that are significant.

* Comparison between community members who participated to both the first and the second training module, using McNemar test and the exact symmetry test.

4. Discussion

As in many other chronic diseases, stigma highly contributes to the hidden burden of epilepsy [13]. The stigma associated with epilepsy is mainly related with misconceptions and wrong beliefs about epilepsy itself that are widespread, even if specific for each different culture, leading to important consequences in PWE lives, including limitations in social activities and restrictions in social roles such as having children, being married, or having a job [14]. These misconceptions are usually more frequent in LMIC and especially in rural areas and among people with low educational level. In fact, the highest levels of stigma have been found to be related with poor knowledge about epilepsy and consequent negative attitudes toward the disease [4,15,16]. Social stigma and the stigma perceived by PWE represent the most important contributors to the low quality of life reported by the patients, especially in LMIC [17].

In a previous investigation exploring stigma perception among the members of rural communities of the Chaco region [5], it was found that a lower level of education of the participants and the type of seizure experienced by PWE, usually represented by GTCS, are significantly associated with higher stigma levels.

During the last three years, we started an educational program in the same area, directed to different figures involved in the management of PWE: GPs, nurses, and CHWs [8,9] leading to an increase in knowledge and a change in attitudes and practices among these key figures. However, among the interventions aimed at increasing knowledge and reducing stigma in epilepsy, the most successful are community-based campaigns with the involvement of the community members, PWE, and their families. Most of these programs have been able to increase knowledge toward epilepsy and sometimes they also led to a reduction in treatment gap [6,7]. The aim of the present study was to increase knowledge and reduce stigma to consequently improve the quality of life of PWE.

The results of our study showed the effectiveness of our educational program with significant changes recorded in knowledge and stigma toward epilepsy, even without a significant improvement in quality of life, as measured by the difference between the assessments before and after the intervention. However, this could be due to the short delay between the intervention and the reassessment, good enough to record fast processes as learning new concepts and opinion changes, but not sufficient to evaluate the impact of these modifications in the everyday lives of PWE. Moreover, the results of the quality-of-life assessment were restricted to only 5 PWE, a sample too small to capture significant changes.

Regarding baseline assessment, the significant differences in terms of knowledge and attitudes toward epilepsy among the different community members should be underlined, with higher levels of knowledge among health workers, relatives of PWE, and PWE and better attitudes among school teachers and health workers. This finding is in line with previous studies showing good knowledge and lower

Table 3
Answers to the Stigma Scale of Epilepsy questionnaire before the educational program.

Total population N = 216	Not at all	A little	A lot	Totally
Do you think that people with epilepsy feel able to control their own epilepsy?	164 (76.3)	41 (19.1)	10 (4.6)	0 (0)
How would you feel when you see an epileptic seizure?				
• Scared	48 (24.9)	82 (42.5)	48 (24.9)	12 (6.2)
• Afraid	64 (33.5)	63 (33.0)	50 (26.2)	12 (6.3)
• Sad	7 (3.7)	57 (29.84)	92 (48.2)	32 (16.7)
• Pitiful	22 (11.6)	51 (27.0)	85 (45.0)	28 (14.8)
Which difficulties do you think people with epilepsy have in their daily lives?				
• Family	51 (23.8)	91 (42.5)	60 (28.0)	12 (5.6)
• Work	18 (8.4)	90 (42.1)	92 (43.0)	14 (6.5)
• School	23 (10.7)	97 (45.3)	78 (36.4)	13 (6.1)
• Friendships	70 (32.6)	73 (33.9)	56 (26.1)	13 (6.05)
• Sex	68 (32.1)	76 (35.8)	46 (21.7)	15 (7.1)
• Emotions	33 (15.3)	106 (49.3)	66 (30.7)	10 (4.6)
• Prejudice	51 (23.9)	65 (30.5)	69 (32.4)	26 (12.2)
How do you think that people with epilepsy feel?				
• Worried	12 (5.6)	41 (19.0)	115 (53.2)	47 (21.8)
• Dependent	58 (27.0)	77 (35.8)	62 (28.8)	14 (6.5)
• Unable	70 (32.9)	79 (37.1)	42 (19.7)	19 (8.9)
• Afraid	35 (16.4)	60 (28.0)	90 (42.1)	28 (13.1)
• Sad	10 (4.6)	61 (28.4)	102 (47.4)	41(19.1)
• Ashamed	69 (32.4)	68 (31.9)	59 (27.7)	15 (7.0)
• Not different	86 (40.2)	81(37.8)	33 (15.4)	13 (6.07)
In your opinion, the prejudice in epilepsy will be related to?				
• Relationship	94 (43.9)	76 (35.5)	35 (16.4)	8 (3.7)
• Marriage	100 (46.9)	81 (38.0)	24 (11.3)	5 (2.3)
• Work	61 (28.5)	91 (42.5)	52 (24.3)	9 (4.2)
• School	58 (27.1)	98 (45.8)	41 (19.2)	17 (7.9)
• Family	133 (61.8)	62 (28.8)	133 (61.9)	17 (7.9)
Total score				38.7 ± 13.4

stigma levels among teachers or others subjects with higher education and "those who know someone with epilepsy", such as health workers and relatives [5]. In a previous study performed among Guaraní communities of rural Bolivia, to analyze sociocultural beliefs about epilepsy, the same community members were interviewed about the meaning and beliefs, feelings, and practices concerning epilepsy. In this survey, conducted in 2009 [10], fewer people were aware about the causes of epilepsy with many of them (45%) indicating an unknown origin. Regarding epilepsy treatment, the majority of subjects indicated natural remedies and special baths as the most appropriate therapies for epilepsy. Moreover, nearly half of the respondents highlighted restrictions for PWE, especially regarding the relationships with other community members (children or pregnant women). Therefore, after almost 10 years, a significant improvement has been recorded, with changes in KAP toward PWE, as a result of the long-term educational activity conducted in this area.

Regarding stigma, we analyzed both the social stigma and the stigma perceived by the patients themselves. However, no significant differences were found in stigma levels between PWE and the rest of the population. Moreover, unlike other studies, their stigma perception was not related to the severity of their condition, indirectly measured by the reported number of seizures per month [18–20]. In our study, the highest baseline stigma level was found among students, an opposite result of what we found in our previous survey [5] where students had the lowest SSE questionnaire scores. Nonetheless, it should be underlined that in the previous study, the "student" category mainly included the nursing students of the Tekovekatu School, therefore, subjects already well-trained in health issues, such as epilepsy, and with a higher level of education. Conversely, in the present study, the category "student" included students of primary and secondary schools. In fact, as demonstrated in many studies, stigma and knowledge are strictly linked with the degree of schooling [21].

At any rate, in our sample a moderate baseline level of stigma was recorded (38.7 ± 13.4), comparable with the scores of the previous study (36.8 ± 12.1) [5]. We know from previous studies that stigma and quality of life are negatively correlated [17]. In our study, we were not able to correlate quality of life with stigma levels, because of the small sample of PWE involved. Possibly, also for this reason, we could not find a significant change in quality of life after the intervention, even if patients reported less depression and memory difficulties, work or social issues, and seizure worry.

Nonetheless, our educational program significantly improved knowledge and reduced stigma among community members of the rural communities of the Chaco region, representing the first important step for a subsequent improvement in quality of life of PWE. As a note, it should be underlined that, after the educational program, one of the PWE who was previously not taking any treatment, started taking AEDs.

We are aware that in order to better evaluate the possible positive effects of awareness campaigns on the level of stigma and quality of life, long-lasting programs at a community level should be performed possibly involving a larger number of PWE and considering a longer time period for the reevaluation. Nonetheless, according to our experience, the percentage of people, lost at the reevaluation after 6 months or more, is generally very high, because of the seasonal migrations for work reasons, limiting the interpretation of the results. In fact, significant differences were found with more males than females being lost to follow-up, possibly for work, and differences in the areas involved, possibly for logistical reasons.

The findings of the present study, along with the increase in awareness of GPs, nurses, and CHWs, obtained in our previous surveys, could lead to a significant change in the social perception and attitudes toward epilepsy in the rural communities of the Chaco region, with the final aim of reducing treatment gap in this area. A new evaluation of the treatment gap in this area will be implemented in order to assess the real impact of our program. Furthermore, prospective randomized controlled trials involving also a random sample of rural communities without intervention program acting as controls should be performed.

Table 4
Stigma Scale of Epilepsy questionnaire before and after the educational program.

Question	Before the training N = 133 (%)				After the training N = 133 (%)				p*
	Not at all	A little	A lot	Totally	Not at all	A little	A lot	Totally	
Do you think that people with epilepsy feel able to control their own epilepsy?	106 (79.7)	22 (16.5)	5 (3.8)		90 (67.7)	34 (25.6)	7 (5.2)	2 (1.5)	0.06
How would you feel when you see an epileptic seizure?									
• Scared	28 (23.7)	53 (44.9)	26 (22.0)	9 (7.6)	54 (42.2)	47 (36.7)	25 (19.5)	2 (1.6)	0.82
• Afraid	42 (35.9)	34 (29.1)	34 (29.1)	5 (4.3)	8 (6.2)	54 (42.2)	54 (42.2)	12 (9.4)	0.17
• Sad	1 (0.8)	38 (32.5)	58 (49.6)	18 (15.4)	15 (11.9)	46 (36.5)	55 (43.6)	10 (7.9)	0.19
• Pitiful	13 (11.2)	33 (28.4)	54 (46.5)	13 (11.2)	15 (11.9)	46 (36.5)	55 (43.6)	10 (7.9)	0.21
Which difficulties do you think people with epilepsy have in their daily lives?									
• Family	13 (11.2)	33 (28.4)	54 (46.5)	13 (11.2)	44 (33.1)	65 (48.9)	23 (17.3)	1 (0.7)	**0.01**
• Work	10 (7.6)	54 (40.9)	61 (46.2)	7 (5.3)	29 (21.8)	75 (56.4)	25 (18.8)	4 (3.0)	<**0.01**
• School	14 (10.6)	62 (47.0)	45 (34.1)	9 (6.8)	46 (34.8)	64 (48.5)	19 (14.4)	3 (2.3)	<**0.01**
• Friendships	42 (31.8)	48 (36.4)	35 (26.5)	5 (3.8)	66 (50.4)	43 (32.8)	20 (15.3)	2 (1.5)	<**0.01**
• Sex	42 (32.3)	47 (36.1)	25 (19.2)	11 (8.5)	62 (47.0)	54 (40.9)	15 (11.4)	1 (0.8)	<**0.01**
• Emotions	24 (18.2)	61 (46.2)	40 (30.3)	7 (5.3)	44 (33.3)	61 (46.2)	24 (18.2)	3 (2.3)	<**0.01**
• Prejudice	33 (25.2)	38 (29.0)	42 (32.1)	17 (13.0)	50 (38.5)	53 (40.8)	21 (16.1)	6 (4.6)	<**0.01**
In your opinion, how does a person with epilepsy feel?									
• Worried	5 (3.8)	27 (20.3)	75 (56.4)	26 (19.5)	8 (6.0)	38 (28.6)	77 (57.9)	10 (7.5)	**0.01**
• Dependent	37 (28.0)	50 (37.9)	33 (25.0)	8 (6.1)	42 (32.3)	59 (45.4)	25 (19.2)	4 (3.1)	0.19
• Unable	43 (33.1)	50 (38.5)	25 (19.2)	10 (7.7)	62 (47.0)	49 (37.1)	19 (14.4)	2 (1.5)	**0.02**
• Afraid	24 (18.3)	38 (29.0)	56 (42.7)	12 (9.2)	42 (31.6)	54 (40.6)	36 (27.1)	1 (0.7)	<**0.01**
• Ashamed	43 (33.1)	38 (29.2)	40 (30.8)	8 (6.1)	65 (48.9)	42 (31.6)	21 (15.8)	5 (3.7)	<**0.01**
• Sad	7 (5.3)	39 (29.5)	62 (47.0)	24 (18.2)	20 (15.1)	50 (37.9)	56 (42.4)	6 (4.5)	<**0.01**
• Not different	51 (38.9)	52 (39.7)	19 (14.5)	8 (6.1)	89 (67.4)	30 (22.7)	11 (8.3)	2 (1.5)	<**0.01**
In your opinion, the prejudice in epilepsy will be related to?									
• Family	86 (64.7)	35 (26.3)	9 (6.8)	3 (2.3)	96 (72.2)	30 (22.6)	7 (5.3)	0 (0)	0.40
• Relationships	63 (47.7)	43 (32.6)	21 (15.9)	4 (3.0)	73 (54.9)	47 (35.3)	12 (9.0)	1 (0.7)	0.32
• Marriage	59 (45.0)	55 (42.0)	14 (10.7)	1 (0.8)	86 (64.7)	31 (23.3)	15 (11.3)	1 (0.7)	<**0.01**
• Work	41 (31.1)	51 (38.6)	35 (26.5)	5 (3.8)	67 (50.4)	51 (38.3)	14 (10.5)	1 (0.7)	<**0.01**
• School	35 (26.5)	61 (46.2)	23 (17.4)	13 (9.8)	67 (50.4)	41 (30.8)	21 (15.8)	4 (3.0)	<**0.01**
Total score	**38.3 ± 14.7**				**28.5 ± 12.3**				<**0.01**

* Comparison between community members who participated to both the first and the second training module, using McNemar test and the exact symmetry test or paired *t*-test.

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