

# Epilepsy, Stigmatization and the Publicity Imperative for Nigeria: An Assessment of NECAP-Rise Clinic Communication Initiative

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## Abstract

Stigmatization associated with health conditions is often a challenge in health management. A person is stigmatized when he or she is a carrier of a dangerous disease such as TB or Ebola. Epilepsy is an ailment that is hereditary; a brain disorder that is symptomatic of seizures. This study sought to determine patterns of media exposure on NECAP-RISE campaigns against epilepsy stigmatization; the impact of such media campaigns on health information seeking among epileptic patients; the impact of NECAP-RISE media campaigns in bettering the understanding of epilepsy as a public health concern; and, stigmatization as a burden to epileptic patients in the Nigerian socio-cultural setting. In-depth interviews were conducted among 30 epileptic patients registered with RISE Clinic NECAP program. Also, 400 non-epileptic persons were surveyed across the three senatorial zones in Nigeria's Anambra state. The study found that there was poor media publicity against epilepsy stigmatization; also, the study established that epileptic patients were usually stigmatized in the Nigerian context. The study, therefore, recommended publicity, verging on public education and enlightenment campaigns, by government and nongovernmental organizations to mitigate the burden of stigmatization faced by epileptic patients in Nigeria.

**Keywords:** Stigmatization, Epilepsy, Publicity imperative, NECAP-Rise Clinic

## 1. Introduction

“Most villagers [in African communities] believe [epilepsy] is a form of witchcraft. Epileptics are shunned by society and forbidden to marry or even hold jobs. Many people in Africa still believe that epilepsy is the result of some crime committed by their ancestors or the result of voodoo spell.” – John Obegolu (co-founder NECAP-RISE Clinic, Nigeria)

The forgoing observation reflects the prevailing ignorance about epilepsy in many African societies. Addressing this element through communication interventions, therefore, holds the key to assuaging the stigma felt by epileptics and inspiring their willingness to show up for treatment in dedicated clinics.

We have encountered epileptic patients, convulsing and shaking violently and the experience was horrible and we began to imagine the public disgrace patients pass through. The stigma associated with this ailment is as a result of the myth surrounding it. It seems some people believe that the disease is contagious through an infected person's sweat, saliva or underwear. It also appears that some people believe that epilepsy is as a result of supernatural curses from the gods and these have hampered the treatment of epilepsy in Nigeria.

Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher, Boas, Blume, Elger, Genton, Lee & Engel Jr., 2005).

Historically, epilepsy was believed to be a sacred disease and it remains a major medical and social problem. “This disease has been in existence for ages. Epileptic seizures have been known as the only symptom of epilepsy. Seizure is the synchronized electrical discharge from the brain – a normal brain function that just keeps going” (Scambler & Hopkins 2006).

Epilepsy has many causes: in some people it appears that the condition is inherited but in most it is caused by brain damage due to causes such as infections or trauma, stroke, brain tumor, head injury, meningitis or development abnormalities. In many individuals, the cause is never known. Some conditions can cause seizures that only occur until the provocation is removed: these are known as acute symptomatic seizures, and are not generally considered to be epilepsy.

Without the knowledge of modern science, epileptic patients experience frightening and strange behavioral attitude.

There have been public campaigns on epilepsy management and treatment around the world since 1997 by three organizations; International League Against Epilepsy (ILAE), International Bureau for Epilepsy (IBE) and World Health Organization (WHO). In order to pursue their aims in improving better general awareness, the collaboration among these organizations has been reinforced and reoriented by the launch of the Global Campaign Against Epilepsy (GCAE). The mission statement of the campaign is: “To improve acceptability, treatment, services and prevention of epilepsy worldwide” (ILAE/IBE/WHO Global Campaign

against Epilepsy 2004). A number of public campaign projects have so far been developed in some countries like Nigeria, Zimbabwe, Argentina, Brazil, China, Pakistan and Senegal with the aim of improving epilepsy care through national, regional and global health care systems.

Whether the Global Campaigns against Epilepsy (GCAE) launched by these organizations are successful and provide suitable approaches for other countries is yet to be seen. Their success or otherwise will be seen in terms of the decrease of the treatment gap and its consequences in the campaign region.

In order to discern whether a campaign is achieving the desired results, its performance will be specifically measured by comparing the following:

- the number of people with epilepsy who received correct diagnosis;
- the number of people who sought medical intervention;
- the social situation of people of various age groups with epilepsy
- Knowledge, attitude and practice of those interviewed at the onset.

Health campaigns are now a paramount factor in advancing health messages and to actualize positive health objectives. Communication interventions form the backbone of health campaigns. Similarly, the main thrust in the fight against epilepsy stigmatization is communication interventions. Misinformation and misconceptions about epilepsy appear to be the main issues working against the improvement of the quality of life for epileptic people (Bandstra & Camfield, 2008).

## 2. NECAP (Nigeria Epilepsy Care Advancement Program): An Overview

The Nigeria Epilepsy Care Advancement Program (NECAP) is a private initiative against epilepsy begun in 2012 by Dr. Edie Zusman, a neurosurgeon and John Obegolu, Director of Neuro Science Medical/Surgical Nursing at Eden Medical Center, Castro Valley, California. The goal was to establish epilepsy clinics across Nigeria which would provide patients and community support systems and create a network of local and international specialists for consultation and training (Bain-Haim, 2015).

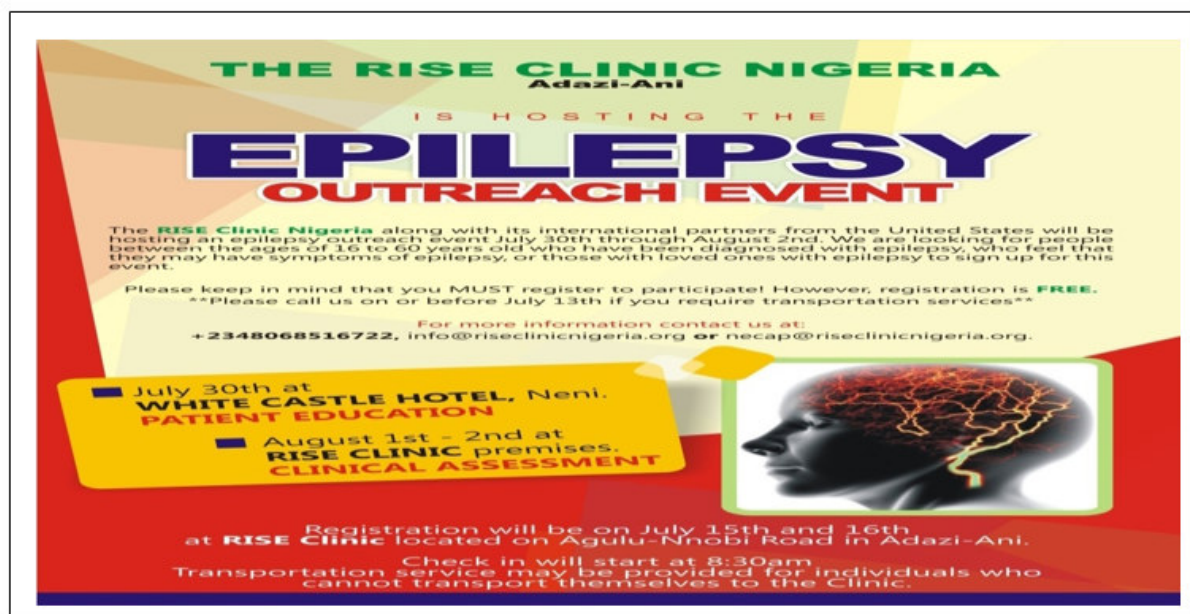


Figure 1: A sample of the handbill distributed for outreach in the NECAP-RISE Clinic campaign on epilepsy

## 3. NECAP-RISE Clinic and Epilepsy Management

In August of 2013, through the initiative of NECAP, the RISE clinic was established in Anambra State, Nigeria, as a pilot scheme to address the treatment of epilepsy in Nigeria. The clinic provided anti-epileptic medications to needy patients, followed up on them, and entered into alliance with government agencies and pharmaceutical companies to create a sustainable procurement of medications at affordable prices to patients. Volunteers from the clinic worked diligently to educate the community by speaking directly to patients and performing interviews on radio and television in order to build awareness of both the process of the disease and its manifestations; and also provide citizens in the community an avenue for assistance. The RISE clinic is now a centre of excellence in Nigeria for the evaluation and treatment of individuals with epilepsy (Bain-Haim, 2015).



Figure 2: Picture of RISE Clinic health poster on epilepsy management

#### 4. Purpose of the Study

A number of health issues are often neglected because focus appears to be on ‘killer’ epidemics like Ebola, AIDS, SARS and the like; but there are nagging health issues with as much killer impact as these epidemics. Epilepsy is not just a health condition but also a social condition demanding the attention of all stakeholders in the society.

As we have noted earlier, one way to combat stigma and assist epileptic people towards a better life, is creating awareness through communication interventions. Our study therefore sought to ascertain whether communication interventions, especially, media campaigns, have been effective in facilitating the goals of the Nigeria Epilepsy Care Advancement Program (NECAP), through the activities of RISE Clinic, Anambra State, Nigeria.

Specifically our study sought answers to the following questions:

1. How many epileptic patients are exposed to NECAP-RISE media campaigns against epilepsy?
2. Who among these epileptics seek medical help after exposure to NECAP-RISE media campaigns against epilepsy?
3. What number of non-epileptics is exposed to NECAP-RISE media campaigns against epilepsy?
4. Who among non-epileptics understands the issue of epilepsy through NECAP-RISE media campaign?
5. What number of non-epileptics engages in societal stigmatization against epileptics?

#### 5. Epilepsy in Nigeria

Epilepsy in Nigeria is seen as a source of stigma and misery for sufferers due to negative and incorrect knowledge of the disease and even occasional seizures which may have serious personal and societal consequences. This disease is associated with socioeconomic effects. Epilepsy is seen as the most common neurological disorder. The day to day consequences of epilepsy in developing countries like Nigeria include loss or change of job, a reduction in social interaction and productivity and physical effect of frequent seizures which makes it difficult to attend to school, work or social functions. Some studies have shown that epilepsy affects the intellectual abilities of PWE (Persons With Epilepsy).

Preux and Druet (2005) note that 80% of the people affected with epilepsy live in developing countries, especially the sub-Saharan African region; two thirds of these populations were children under the age of 15. Those affected by epilepsy are more likely to live in poor living conditions and have low income levels. Preux and Druet (2005) note further that only 46.4% of persons with epilepsy had access to drinking water and 55% had access to solid waste management (i.e., toilets and pit latrines). These poor living conditions make it easy for parasitic and bacterial transmission to occur.

In a study by ILAE 2004, cultural and religious beliefs were important issues in the management of epilepsy which influence the value being placed by the society on chronic disorders like Epilepsy. Local beliefs are seen as the causes of epilepsy which create the reasons why most patients seek advice from traditional rulers and healers.

In a research by Akinsulore & Adewuya (2010) psychosocial aspects of epilepsy in Nigeria with the use of PUBMED database reviewed that the prevalence of epilepsy varies from 5.3 to 37 per 1000 in Nigeria, the patients suffer social deprivation and discrimination in education, employment, housing, marital life as well as associated psychiatry morbidity which has a significant impact on the day to day functioning of persons with the disorder.

Udoh (2006) conducted a study on pattern and presentation of epilepsy in Enugu. The study revealed that most affected patients were aged from 15-34 years; 22% had childhood seizures approximately and 88% had convulsive seizures. Immunotherapy was used in 89% of patients, with 71% having good control. Alcohol use and head injury were seizure risks in 12% and 20% of patients.

### 6. Prevalence and Incidence Rate of Epilepsy in Industrialized Countries

The prevalence rate of epilepsy is lower in industrialized countries as compared to the high prevalence seen in developing countries. The prevalence rate is 3.66 per 1,000 persons in the Western Pacific, 8.3 per 1,000 persons in Europe, and 9.4 per one 1.000 persons in the Eastern Mediterranean (WHO, 2005). In some industrialized countries such as Canada, lower prevalence and incidence rates are noted in some provinces among populations with higher education, higher income, and higher socioeconomic status (Tellez-Zen ten, Pondal-Sordo, Matijevic, & Wiebe, 2004). Also, Tellez-Zen ten et al. (2004) note that the prevalence rate is high in some Canadian provinces that are close to the Atlantic Ocean and among some immigrants and non immigrants of lower socioeconomic status. The incident rate of epilepsy in Europe and North America ranges from 2.2 to 5.5 per 1,000 persons.

### 7. The Prevalence and Incidence Rates of Epilepsy in Nigeria

The prevalence rate of epilepsy in Nigeria is estimated to be around eight to 13 per 1,000 persons (Kabir, Iiyasa, Abu-Bakr, Kabir, & Farinyaro, 2005). The prevalence rate of epilepsy in the urban cities like Lagos is similar to those in rural villages, with 13 to 37 per 1,000 persons having epilepsy (Olumbini, 2006). One remedy used by traditional doctors and herbalists to treat individuals with epilepsy is to beat them with canes in an attempt to drive away evil spirits. This observation was reported by many researchers who carried out studies on epilepsy in Liberia, Ghana, and Senegal (Kabir et al., 2005). Patients and their families are isolated from other community members. This isolation caused more stigma and neglect of persons with epilepsy, thereby increasing their chance of deterioration and decreasing the possibility of improvement in their condition, adding to the risk factors that affect their daily quality of life.

Table 1: Prevalence of epilepsy in Nigeria and other African countries

COUNTRY/LOCATION	PREVALENCE RATES/1000	INVESTIGATOR
Congo	4	Piroux (1960)
South Africa	4	Bird <i>et al</i> (1962)
Ghana	4	Haddock (1973)
Uganda	4	Orley (1970)
Zimbabwe	7.4	Levy <i>et al</i> (1964)
Ethiopia (Rural)	8	Giel (1968)
Ethiopia (Urban)	5	Giel (1968)
Senegal	3 – 8	Collomb <i>et al</i> (1970)
Tanzania	1	Smartt (1959)
Tanzania	20	Jilek & Jilek (1970)
Kenya	10 – 18	Miyangi (1995)
Nigeria (Urban)	8 – 13	Dada (1970)
Nigeria (Rural)	5.3	Osuntokun(1987)
Nigeria (Rural)	6.2	Longe and Osuntokun(1989)

Source: Olubunmi (2005)



## 8. Epilepsy and Issue of Stigmatization

Stigma is a major concern that represents an overwhelming proportion of the psychosocial burden of epilepsy. Stigma knows no boundaries and occurs across all ethnic, gender, educational, and socioeconomic groups. Only by frequent, rapid, repetitive, and effective education and the recognition and reconciliation of institutionalized stigma can the downward spiral of epilepsy be reversed. Stigma and social discrimination in relation to epilepsy may be associated with a lack of knowledge and understanding about the condition.

Epilepsy is neither contagious nor infectious. Some people with epilepsy are discriminated against in education, marriages, and employment due to the belief that epilepsy is highly contagious. Some patients have reported that their wives left them with the children due to enuresis or bedwetting that occurred during seizure activity (Baskind & Brubeck, 2005). In some countries, people with epilepsy cannot eat with the same utensils as people who do not have epilepsy and some cannot be buried in the family grave (Baskind et al., 2005). The stigma often associated with epilepsy has led some people with epilepsy to conceal their disorder due to shame and to avoid being isolated from peers and close friends. This has led some adolescents with epilepsy into depressive and psychotic moods/behavior and has delayed early treatment (Paschal, Hawley, Romaine, Low, Mudguard, Sly, & Sadler, 2007).

People with disabilities are among the most vulnerable in any society. This vulnerability is even greater among those with hidden disabilities such as epilepsy and other neurological conditions and intellectual disabilities. Although, the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, all chronic medical conditions have an impact on daily life, but the impact of epilepsy is greater; the particular stigma associated with epilepsy brings some susceptibility of its own. Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures (Pahl & Bore, 2005, p.72).

## 9. Epilepsy and the Issue of Medical Assistance

Some of the known causes of epilepsy are infections, fever of unknown origin, cerebral malaria, tapeworms in the brain, injuries sustained during birth, intracranial infections of bacterial or viral origin, prenatal brain damage, toxic agents, and hereditary factors (Paschal et al., 2007). Some scholars have identified tuberous sclerosis as a cause of epilepsy noted in early stage as infantile spasm (Petrova, 2011). Acute seizures are common in severe meningitis, viral encephalitis, malaria, and neurocysticercosis, and are associated with increased mortality and morbidity (Singh, 2011).

Although research has revealed that most of the people affected with epilepsy worldwide live in developing countries, some of these individuals do not receive treatments. The negative attitude towards people with epilepsy, along with the increased stigmatization, widens the treatment gap as the affected individual hides his or her illness and does not seek adequate treatment (Meyer et al., 2010) in Maduakor-Ugo (2014).

The treatment gap in 46 developing countries originates from (a) both social and cultural factors related to cultural beliefs regarding epilepsy's causes and treatment, (b) a lack of knowledge and understanding about epilepsy, (c) lack of medical staff and access to care, and (d) economic factors such as distance to certain health facilities and supply of drugs (Chisholm, 2005) in Maduakor-Ugo (2014). Natives of developing countries may first consult traditional healers and high priests for treatment before seeking medical care due to lack of knowledge and treatment of epilepsy.

The global campaign against Epilepsy, Epilepsy Out of the Shadows, was launched as a joint effort by the International League Against Epilepsy, the WHO, and the International Bureau for Epilepsy to bridge the treatment gap (WHO, 2004). The purpose of this global campaign was to help developing countries reduce the burden of epilepsy by increasing access to care and provision of oral treatment such as phenobarbital which is the cheapest medication for seizure disorder, followed by tegretol and dilantin (WHO, 2004).

The CDC recognized epilepsy as a public health issue within the last 15 years. There are various methods of treatment for epilepsy, which include traditional, Western treatment with oral therapy, surgery Vagus nerve stimulation, and the use of the ketogenic diet (Epilepsy Foundation, 2010).

Some of these methods of treatments used in industrialized countries are available in some developing countries such as Nigeria but mostly in urban cities of Lagos, Ibadan, Enugu, and Port Harcourt. The poor in remote areas cannot afford to cover transportation to and from the interior village to urban city hospitals and pay hospital bills. More than 80% of patients with new onset of seizures in the United States are treated by general practitioners who are not likely to be aware of new diagnostic and therapeutic measures. Health care professionals, as well as teachers, patients, caregivers, and the general population, are in need of education regarding epilepsy (Schneider & Conrad, 2009, p.19).

## 10 Media Campaigns against Epilepsy and Patients' Response

The NECAP-RISE epilepsy initiative is aimed at ensuring reduced stigmatization and making available treatment for epileptic patients.



Figure 3: NECAP-RISE Clinic campaigners

People with epilepsy suffer not only from lack of appropriate care, but also stigma and discrimination resulting from widespread prejudice and ignorance. To fight this plague, reaching out to the general public is as important as educating health personnel.

Health communication has been defined as “the main currency of health care in this 21st century” (Clansey, 2004 in Schiavo, 2007, p. 7). Without communication, health care delivery will be poor and inadequate.

The mass media is pivotal to the dissemination of health information. Health media campaigns are anchored on communication protocols to ensure awareness, education and enlightenment.

According to Sparks (2012)

Mass media campaigns are widely used to expose high proportions of large populations to messages through routine use of existing media, such as television, radio, and newspapers. Exposure to such messages is, therefore, generally passive. Such campaigns are frequently competing with factors, such as pervasive product marketing, powerful social norms, and behaviours driven by addiction or habit (p. 6).

Mass media campaigns, arguably, can produce positive changes or prevent negative changes in health-related behaviours across large populations.

Sparks (2012) also affirms that “over the past few decades, media campaigns have been used in an attempt to affect various health behaviours in mass populations. Such campaigns have, notably, been aimed at tobacco use and heart disease prevention; but they have also addressed alcohol and illicit drug use, cancer screening and prevention, sex-related behaviours, child survival, and many other health-related issues” (p. 10).

Typical campaigns have placed messages in media that reach large audiences, most frequently via television or radio, but also outdoor media, such as billboards and posters, and print media, such as magazines and newspapers. Lancet (2010) similarly opines that “exposure to such messages is generally passive, resulting from an incidental effect of routine use of media” (p. 3).

However, the inceptions of new technologies that are Internet borne are now a viable tool in most campaign strategies. The NECAP-RISE epilepsy campaign did not ignore this development as ads were made available in RISE clinic websites, blogs, Facebook, twitter and Google+ accounts.

Media campaigns against epilepsy can be of short duration or may extend over long periods. They may stand alone or be linked to other organised program components, such as clinical or institutional outreach and easy access to newly available or existing services, or may complement policy changes. Multiple methods of dissemination might be used if health campaigns are part of broader social marketing programs.

According to Lancet (2010), the following are the objectives of mass media health campaigns:

- ❖ Mobilising and supporting local agencies and professionals who have direct access to individuals within the target population

- ❖ Bringing together partnerships of public, voluntary and private sector bodies and professional organisations
- ❖ Informing and educating the public, but also setting the agenda for public debate about the health topic, thereby modifying the climate of opinion surrounding it
- ❖ Encouraging local and national policy changes so as to create a supportive environment within which people are more able to change their behaviour (para. 27).

Media campaigns against epilepsy are aimed primarily to improve knowledge, awareness and attitudes of patients with epilepsy (PWE) and contribute to the goal of changing patterns of their behaviour.

### **11. Empirical Perspectives on the Burden of Epilepsy**

Maduakor-Ugo (2014) conducted a study in western Nigeria to evaluate the school performance of adolescents with epilepsy. Seventy-three subjects with epilepsy aged 12 through 18 and another 73 subjects without epilepsy aged 12 through 18 were recruited. All subjects came from different demographic backgrounds. The children were evaluated using the child's attitude illness scale instrument (CATIS) which showed how children and adolescents felt about their condition. The study revealed that adolescents without epilepsy had better school performance than those with epilepsy. The adolescents with epilepsy from the middle socioeconomic class performed better than others with epilepsy from a low socioeconomic class. The study recommended the use of education as an intervention to increase the knowledge of the community on epilepsy with the objective of eradicating the stigma attached to epilepsy.

Weiss (2006) conducted a program in East Timor to assess and address the burden of epilepsy in this community. It was found that about 95% of people with epilepsy in the communities were untreated, despite the availability of antiepileptic medications in their communities. Most children with epilepsy from the community do not go to school due to stigma and humiliation. This was related to a lack of training in the diagnosis and management of epilepsy among general health care workers, coupled with their cultural beliefs that epilepsy was caused by evil spirits or curses and was not a physical health problem.

Roux (2009) as quoted in Maduakor-Ugo (2014), carried out a study using mixed methods to investigate teachers' knowledge and attitude about children with epilepsy. Roux examined 316 teachers' knowledge and attitude by using the methodology of Persons with epilepsy Scale followed with seven open-ended questions and interviews. Findings indicated that the teachers were knowledgeable about epilepsy and had a good attitude towards PWEs. Knowledge was associated with the degree of stigmatization and attitude towards PWEs. The descriptive analysis from their response, however, indicated a gap between the teachers' knowledge related to first aid, symptoms of epilepsy, and how epilepsy affects children's learning and behavior.

Atadzhanov, Haworth, Chomba, Mbewe, Birbeck (2010) reveal that: In Zambia, several studies were done among different groups of people (teachers, clerics, policemen, traditional healers, and health workers) to describe their knowledge of epilepsy and attitude to PWEs. In general, these studies showed a lack of knowledge regarding causes and treatment.

The results of these foregoing studies suggest the need for a robust and intensive communication campaign on the epilepsy as a health and social issue.

### **12. Methodology**

This study adopted a mixed method. The first was an in-depth interview (IDI) conducted on 30 people with epilepsy, whose cases have been documented at RISE Clinic Adazi-Ani, Anambra State, Nigeria. The interviews sought to generate answers from the respondents with regard to: their exposure to media campaigns against epilepsy; their awareness of epilepsy medication and treatment; whether they are motivated to seek medical help and whether they are stigmatized because of their condition in their various communities. Also, survey method was used to collect data from non epileptics in Anambra state. Survey questions were asked in regard to: their knowledge of epilepsy as a health condition: their exposure to media campaigns against epilepsy; whether they know people with epilepsy in their communities and whether they avoid physical contact with epileptics.

According to Nigeria's 2006 population census, all non epileptic individuals in Anambra State constitute about 4,177,828 (Nigeriamasterweb.com, 2014) of the Nigerian population. For the epileptic persons, the population comprises 300 documented cases at RISE Clinic Adazi-Ani.

A sample of 400 non epileptics was drawn from the study population (4,177,828) using Taro Yamane's formula for determining sample size:  $n = N/(1+N [e]^2)$ .

Also, 30 IDIs were conducted with individuals who fall within the population of epileptic persons. These 30 IDIs were based on the principle of theoretical saturation. The sample frame for non epileptics' population is shown in respondents' distribution in Table 2.

Table 2: Respondents' questionnaire distribution

S/N	Name of Community	Number of Sample Distributed
1.	Adazi-Ani (Anambra Central)	68
2.	Alor (Anambra Central)	68
3.	Isseke (Anambra South)	67
4.	Ihiala (Anambra South)	66
5.	Awkuzu (Anambra North)	66
6.	Nnado (Anambra North)	65
<b>TOTAL</b>		<b>400</b>

Random sampling method was used in selecting the questionnaire respondents in the selected study area. This is to ensure equal probability of selecting samples for the study. Two communities in each of the 3 senatorial zones in Anambra State were randomly selected. In total, six communities were randomly selected and studied. Copies of the questionnaire were administered to people in their respective residents within the designated communities that had been randomly selected. A sample of 30 epileptic patients was purposively selected and interviewed.

Some of the variables probed for the survey are as follows:

- **Exposure to media campaigns by epileptic patients:** This was measured by asking the respondents to indicate their patterns of exposure to media campaigns on epilepsy.
- **Exposure to media campaigns by non epileptic individuals:** This was measured by asking the respondents to indicate their patterns of exposure to media campaigns on epilepsy.
- **Impact of media campaigns on epileptic patients' quest for medical help:** This was measured by asking the respondents to indicate if any media campaigns on epilepsy prompted them to seek medical assistance.
- **Impact of epilepsy media campaigns in improving the understanding and knowledge about epilepsy among non epileptic members of the public:** This was measured by asking the respondents to indicate if any media campaigns on epilepsy improved their understanding on the issue of epilepsy.
- **Patterns of societal stigmatization among epileptic patients:** This was measured by asking the respondents to indicate the forms of stigmatization against epileptics.

Data generated from our in-depth interviews were transcribed and analyzed for emerging themes that addressed research questions 1 and 2 while descriptive statistics from SPSS were used to analyze research questions 3, 4 and 5; as presented in tables and charts.

### 13. Results

We reviewed our results in both the qualitative and quantitative sense. We used the responses in the IDIs literally, so the errors that might be observed have been deliberately left unedited to maintain the integrity of the interviews.

Our in-depth interviews involved 30 epileptics, of whom nineteen are male and eleven female. These were assigned to four age groups: 16- 25 years (N = 4), 26-35 years old (N= 10), 36-45 years old (N=13), and 46 and above (N = 3).

In the first IDI, the respondent defined epilepsy as a condition whereby a person's brain undergoes what is known as neurological disorder. It affects a person's brain and neurology. He said "I don't think that the mass media has ever reported anything on epilepsy on radio, TV and newspaper." He added that when his seizure started five years ago, it was one of his uncles that referred him to see a neurologist at Nnamdi Azikiwe University Teaching Hospital, Nnewi. Anambra State, Nigeria. He had been denied access to participate in singing competition in a youth conference held at Umuahia, Abia State.

When asked about their exposure to any media campaigns on epilepsy, the second, third and fourth IDI respondents said that it is not commonly heard on the radio, and they have never seen any on TV, billboards, newspaper and health posters. The third IDI respondent said "the problem is that the fight against epilepsy is not being sensitized through the media". They further said that he was not prompted by any of these media campaigns to seek medical assistance because there was little campaigns on epilepsy and that was done by his relatives who always referred him to seek medical assistance whenever they saw his condition.

When asked whether the people living in their communities know that they have epilepsy, they said no, because it comes with a convulsive drama that is embarrassing and they are not comfortable telling people that they have epilepsy. The fourth IDI said that on several occasions, people keep away from him, especially where



there is a gathering and he experiences seizures; he becomes a form of distraction to people and a topic of discussion, too.

In the fifth IDI, the respondent was emphatic in his response to the questions. He said that “a community’s customary and cultural beliefs have an impact on the limited media campaigns about epilepsy and its treatment”; he further said he experiences barriers to care; lack of social support and willingness to seek alternative medical assistance for epilepsy.

The respondents in the Sixth, Seventh and Eighth IDIs said that they have seen a RISE Clinic health poster on epilepsy and they have also been exposed to information about epilepsy by their relatives. The Seventh IDI said that people in his community know she has epilepsy, and she has not been denied access to participate in both cultural and social activities in her community, although she is still faced with some negative remarks from people because of her health condition.

In the Ninth IDI, the respondent said, “I have never seen any media campaign on epilepsy except the health poster by RISE clinic and my brother told me about this clinic (RISE) and since then I have been receiving treatment here.” He further added that he married outside his community because he was denied access to marry in his community because of his health condition.

In the Tenth, Eleventh, Twelfth, Thirteenth and Fourteenth IDIs the interviewees said they have never come across any media campaign on epilepsy and always feel ashamed whenever they have epileptic seizures in public; people make them to feel dejected and that leads to inferiority complex. This attitude was the same for all the interviewees.

The respondent in the Fifteenth IDI defined epilepsy as a seizure that is hereditary. He narrated one of his seizure experiences on a very sunny afternoon. He further added that it was very horrible and humiliating that day but he was rescued by some people while some were afraid to come near. He agreed that he once heard a radio jingle about epilepsy and that prompted him to seek medical assistance at RISE clinic.

The Sixteenth, Seventeenth, Eighteenth IDIs said that people are uncomfortable with them because they have epilepsy and there was little or no epilepsy campaign unlike that of HIV and Ebola diseases which are seen and heard in virtually all the media outlets.

In the Nineteenth IDI, the respondent also affirmed that there was little campaign against epilepsy; he talked about his experience as a little kid whereby parents discouraged their children from playing with him, due to drooling and foaming from the mouth which is deemed to be infectious. He was referred to the clinic to seek medical assistance by his relative.

The twentieth and twenty-first IDI said that people do not believe that a person with epilepsy can be successful in their career; the twenty-first IDI affirmed “I am seen as an outcast in my community because I have epilepsy and no one wants to associate with me because they believe I am possessed by evil spirits”.

The twenty-second, twenty-third, twenty-fourth and twenty-fifth interviewees, agreed to have heard and seen media campaigns on epilepsy and these media campaigns prompted them to seek medical assistance, especially the campaign by RISE clinic. The twenty-fifth IDI added that his relatives had in the past referred him to so many native doctors and yet there was no improvement. He further said that the community he was living in before knew he had epilepsy but he was not comfortable discussing it with people now. The twenty-third IDI added that people do not avoid physical contact with him but he receives insult from them sometimes because of his health condition.

The twenty-sixth IDI responded that the last seizure he experienced was at a funeral and he attracted people’s attention and his family was embarrassed. When asked whether he had come across a radio jingle on epilepsy, he said yes, he heard the NECAP program on radio; he doesn’t have time to watch TV. He started receiving treatment in RISE clinic because it was announced on the radio. He said that people in his community knew he had epilepsy, and as a student he doesn’t receive corporal punishment like others because of his condition. He is not comfortable telling people he has epilepsy except his relatives. He also added that he had been denied access to social and cultural participation that involves physical contact in so many ways. His brother stopped him from going to visit him at Onitsha (a major commercial city in South east Nigeria) because of his health condition.

In the Twenty-seventh IDI, the respondent said that he has been maltreated and shunned from normal social interactions due to the stigma associated with epilepsy; like not being able to use the same cooking utensils as others and his marriage leading to a divorce. He suggested that there should be enough media campaign on epilepsy in order to reduce all forms of stigmatization in the society.

The Twenty-eight IDI explained that she had never heard or seen any media campaign on epilepsy and it might be because of its causative nature. She said that she sought medical assistance in RISE clinic through her relatives. She recommended that there should be increase in epilepsy public awareness to help the Nigerian society understand the etiology of epilepsy and various treatment options.

The twenty-ninth IDI emphasized on the need for epilepsy awareness campaign programs to educate the society about epilepsy and to reduce the stigma associated with epilepsy. He further went on to say that he

had encountered bitter seizures over the years.

The Thirtieth IDI said that her own seizure occurs two times in a week and because of that she isolates herself from the community, and sometimes she experiences low self-esteem and humiliation too. “I am not comfortable telling people I have epilepsy because it calls for a sober reflection.”

From the IDIs, all the patients with epilepsy felt stigma, the severity of which varied dramatically due to different factors between cases that caused the formation, enhancement or weakening of the stigma.

To determine the reasons for the media not presenting health issues about epilepsy, we sought the views of some media practitioners:

Mr. Nwabueze of Vanguard newspaper posits that the newspaper, due to its profiteering nature, will always seek to present those issues that will yield revenue. “There are so many issues bothering our society but we select stories that have prominence which can generate income for a newspaper establishment”. He said, epilepsy is a serious health issue and stigma is another problem which appropriate health communication can address but it receives less attention from the media.

In another interview with C. G Nwangene of radio Nigeria, Purity FM, Health desk, he said that he first reported the case of epilepsy during the RISE clinic epilepsy campaign. “I did a documentary in a community in Ihiala Local government, [Anambra State, Nigeria] and I discovered the psychological trauma epileptic patients are passing through. I was prompted to embark on the report due to the program”.

Also, Miss. C.J Ijeoma Health beat reporter, ABS, said that other health issues like HIV, Malaria, Tuberculosis and recently EBOLA garner more interest than epilepsy. “Epilepsy is not a life threatening ailment when compared to HIV, Malaria, Tuberculosis and EBOLA. Information about this disease is being updated regularly to create public awareness” she said.

These perspectives by media practitioners suggest that epilepsy is not receiving priority attention from the media. This might be because the media is more disposed to follow cues when individuals, government, or civil society organizations call on them to report on a particular issue. This means that the media itself needs to be sensitized on the need to report epilepsy.

Our survey data shows that 57 percent of the respondents (non epileptics) are female while 46 percent are male. The highest age range of respondents was 21 – 25 years which constitutes about 30 percent. It is followed by 26 – 40 years which represents 28 percent of the sample; 46 years and above represents 18 percent of the respondents, while 41 – 45 and 16 – 20 years represent 13 percent and 11 percent respectively. Also, our data show that 55 percent of respondents are married; 43 percent are single while 2 percent are divorced. Among our respondents, traders constitute 29 percent; Civil servants represent 28 percent; artisans are 13 percent; the clergy 3 percent; students 20 percent; and the unemployed, 7 percent. Majority of respondents have either Ordinary or Advance Senior School Leaving Certificates; 24 percent of the respondents have obtained first degree certificates; 9 percent have obtained Higher National Diploma while 10 percent of the respondents have Ordinary National Diploma. Respondents with First School Leaving Certificate and O’/A’ levels make up 30 percent, respectively; while 3 percent have Masters Degree and above.

### **13.1 Respondents’ Exposure to NECAP-RISE media campaigns against epilepsy**

We attempted to establish the respondents’ exposure to NECAP-RISE media campaigns on epilepsy. Question items 8-13 on the questionnaire were posed for this purpose. The data generated are as presented in Table 3.

Table 3: Respondents' exposure to the various NECAP-RISE media campaigns against epilepsy

Respondents' exposure to NECAP-RISE radio jingle on epilepsy			
S/N	Variable	Frequency	Percent
1	No	213	54
2	Yes	183	46
3	Total	396	100
Respondents' exposure to NECAP-RISE television publicity			
S/N	Variable	Frequency	Percent
1	No	249	63
2	Yes	149	37
	Total	398	100
Respondents' exposure to NECAP-RISE information about epilepsy on billboards			
S/N	Variable	Frequency	Percent
1	No	269	68
2	Yes	129	32
	Total	398	100
Respondents' exposure to NECAP-RISE sponsored newspaper/magazine features on epilepsy			
S/N	Variable	Frequency	Percent
1	No	229	58
2	Yes	169	42
	Total	398	100
Respondents' exposure to NECAP-RISE information about epilepsy on health posters/fliers			
S/N	Variable	Frequency	Percent
1	No	212	53
2	Yes	185	47
	Total	397	100
Respondents' knowledge about epilepsy through relatives or associates			
S/N	Variable	Frequency	Percent
1	No	137	35
2	Yes	260	65
	Total	398	100

Table 3 shows that 54 percent of the respondents indicated not being aware of NECAP-RISE radiojingles about epilepsy while 46 percent said they have heard such jingles about epilepsy. Table 3 further shows that 63 percent of the respondents indicated that they have not seen NECAP-RISE information about epilepsy on television while 37 percent said they have. Health information on billboards is usually designed for audience on transit, 32 percent of the respondents indicated that they have come across NECAP-RISE information on epilepsy on billboards while 68 percent have not.; 58 percent of the respondents admitted not to have seen NECAP-RISE information about epilepsy on newspapers or magazines while 169 (42 percent were affirmative. Bylines such as posters and flyers are one of the handy and potent ways of disseminating health information. Data in Table 3 shows that 53 percent of the respondents were not exposed to NECAP-RISE information about epilepsy on health posters/flyers while 47 percent said they were. A majority of the respondents got information about epilepsy through relatives and associates; 65 percent heard information about

epilepsy through their relatives or associates while 35 percent indicted to the contrary.

### 13.2. Better Understanding of Epilepsy through NECAP-RISE Media Campaigns

In order to determine whether NECAP-RISE media campaigns helped the non epileptic respondents to understand epilepsy better, we used question items 13-19 on the questionnaire. Data generated are represented in Table 4.

Table 4: Respondents' Inspired to a better understanding of epilepsy through NECAP-RISE media campaigns

Respondents' whose understanding of epilepsy was enhanced by NECAP-RISE radio jingles			
S/N	Variable	Frequency	Percent
1	No	284	71
2	Yes	112	28
3	Don't Know	2	1
	Total	398	100
Respondents' whose understanding of epilepsy was enhanced by NECAP-RISE television publicity			
S/N	Variable	Frequency	Percent
1	No	278	70
2	Yes	120	30
3	Don't know	0	0
	Total	398	100
Respondents' whose understanding of epilepsy was enhanced by NECAP-RISE information on billboards			
S/N	Variable	Frequency	Percent
1	No	301	76
2	Yes	94	23
3	Don't know	3	1
	Total	398	100
Respondents' whose understanding of epilepsy was enhanced by NECAP-RISE newspaper/magazine features			
S/N	Variable	Frequency	Percent
1	No	241	61
2	Yes	155	39
3	Don't know	2	0
	Total	398	100
Respondents' whose understanding of epilepsy was enhanced by NECAP-RISE health posters/flyers			
S/N	Variable	Frequency	Percent
1	No	229	58
2	Yes	165	41
3	Don't know	4	1
	Total	398	100
Respondents' whose understanding of epilepsy was enhanced through associates/relatives			
S/N	Variable	Frequency	Percent
1	No	145	36
2	Yes	253	64
	Total	398	100



Table 4 shows that non epileptic respondents whose understanding of epilepsy was enhanced by NECAP-RISE radio jingles constitute 28 percent; 71 percent said they had no enhancement of their understanding of the ailment, while 1% does not know whether they had increased understanding of the ailment or not. Most people believe and understand information when they are displayed on the television. Data in Table 4 shows that 70 percent of our respondents said exposure to NECAP-RISE TV publicity did nothing to improve their understanding of epilepsy; 30 percent indicated that they understood epilepsy better because of such exposure. For the respondents who read NECAP-RISE information about epilepsy on billboards, 76 percent claimed not to have better understood epilepsy as a result of exposure to information about epilepsy on NECAP-RISE billboards; 23 percent of the respondents were affirmative while 1 percent indicated they don't know. About 61 percent of the non epileptic respondents did not understand epilepsy better as a result of reading newspaper/magazine features on epilepsy while 39 percent of these respondents claimed they understood better. For NECAP-RISE health posters, 58 percent claimed the information on NECAP-RISE health poster/flyers did not make them to understand epilepsy better; while 41 percent among these respondents said they understood better; and 1 percent indicated they don't know. As we explained earlier, interpersonal communication can be a vital source of influence. Data in Table 4 indicates that 64 percent of our respondents claimed interactions with associates and relatives helped them to understand epilepsy better, while 36 percent held a view to the contrary. This indicates that word of mouth or face-to-face communication could be an effective way of sharing the epilepsy message in the Nigerian context.

### 13.3 Trend of Epilepsy Stigmatization

We sought to establish the trend of stigmatization among our non epileptic respondents. Question items 20-24 in the questionnaire were utilized for this purpose; results from data generated are shown in the following tables and charts.

Table 5: Respondents' perspectives on epileptics

Respondents who know someone who is epileptic			
S/N	Variable	Frequency	Percent
1	No	104	26
2	Yes	293	74
	Total	397	100
Respondents who have witnessed epileptic seizures			
S/N	Variable	Frequency	Percent
1	No	203	49
2	Yes	195	51
	Total	398	100
Respondents' attitude towards epileptics			
S/N	Variable	Frequency	Percent
1	Avoid any form of interaction epileptics	228	57
2	Do not avoid any form of interaction epileptics	169	43
	Total	397	100
Respondents' perception of society's disposition towards epileptics			
S/N	Variable	Frequency	Percent
1	Agree that epileptics are stigmatized in the society	272	68
2	Disagree that epileptics are stigmatized in the society	126	32
	Total	398	100

The data in Table 5 shows that 26 percent of the non epileptic respondents indicated that they have not seen any person suffering from epilepsy while 74 percent said they know of persons suffering from epilepsy. About 23 percent have not witnessed seizures by epileptics, while 77 percent have. Forty-three percent of the

respondents do not avoid any form of interaction with epileptics while 57 percent do. Also, 32 percent of the respondents do not agree that people with epilepsy are stigmatized in the society while 68 percent agree that epileptics are stigmatized by society.

The respondents gave some reasons why epileptics face stigmatization in the society. These reasons are represented in the accompanying chart

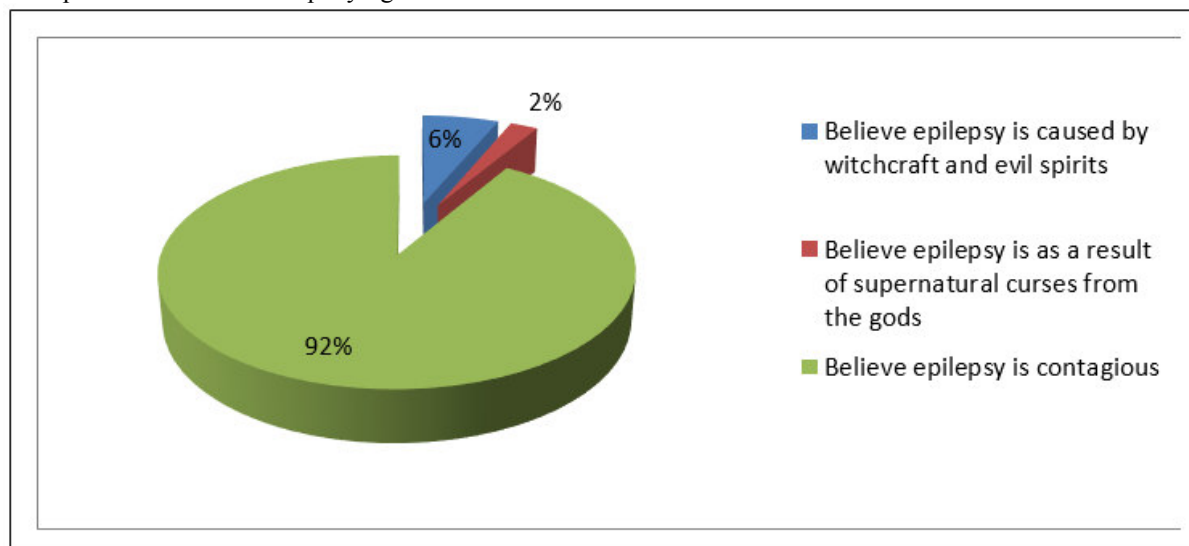


Figure 4: What the respondents believe about epilepsy

Data in Figure 4 shows that those respondents who avoided any form of interaction with epileptics did so for some reasons; 6 percent among these respondents believe that the disease is caused by the operations of witchcraft or evil spirits; 2 percent believe that it is as a result of supernatural curses from the gods; while 92 percent believe they will contact the disease when they have physical contact with epileptics.

#### 14. Findings and Implications

Our study had five specific objectives: 1) to ascertain who among epileptic patients has been exposed to NECAP-RISE media campaigns against epilepsy; 2) to determine who among non-epileptic members of the public has been exposed to NECAP-RISE media campaigns against epilepsy; 3) to establish whether exposure to NECAP-RISE media campaigns against epilepsy motivate epileptic patients to seek medical help; 4) to ascertain whether exposure to NECAP-RISE media campaigns against epilepsy improves the understanding of the disease among non-epileptic members of the public; 5) to ascertain if there is societal stigmatization against epileptic patients.

Data from our IDIs suggest the following:

- Very few epileptics, to some degree, are exposed to NECAP-RISE media communication initiative. Similarly, very few sought medical help as a result of this exposure.
- Stigmatization inhibits epileptics from seeking medical help openly.
- There is limited media sensitization on the issue of epilepsy; NECAP-RISE media campaigns appear to be just an isolated attempt at sensitization in Nigeria.
- Epileptics feel shame when they have seizures; this makes them uncomfortable to speak up on their condition because of the fear of stigmatization.
- Most epileptics seek medical help because of referral from friends and relatives who know and care about their condition.

The implication from these findings is that epilepsy as a health condition is not being given the attention that it deserves unlike health issues like AIDS, Ebola, Malaria, TB, etc which get the preeminence in media health discourses. Similarly, epileptics suffer such societal stigmatization that some would rather die in silence than tell that they are epileptic. This is what we call mum-on-epilepsy-suicidal-alternative.. NECAP-RISE communication initiative on epilepsy is gaining traction among epileptics, but the overall picture from our data would suggest that there is need for publicity campaigns in various formats, as is the case of HIV/AIDS, to help reduce stigmatization of epileptics and their integration into society's mainstream.

Survey data from non-epileptics suggest that:

- Fifty-nine percent of non-epileptics, on the average, have not been exposed to NECAP-RISE media epilepsy campaigns while; 41 percent, on the average, have been exposed to such campaigns.
- Sixty-five percent of these non epileptics got to know about epilepsy through friends and relatives.

- Sixty-seven percent of these non epileptics, on the average, did not understand epilepsy better because of exposure to NECAP-RISE media campaigns, while 32 percent, on the average, better understood epilepsy because of exposure to NECAP-RISE media campaigns.
- Sixty-four percent of the non epileptics, on the average, understood epilepsy better through interactions with friends and relatives.
- Stigmatization of epileptics appears an issue; 57 percent of the non epileptics, on the average, agreed that epileptics are stigmatized in the wider society while 32 percent disagreed

The implication from these findings is that, the attempt by NECAP-RISE to sensitize people on the issue of epilepsy is achieving results to some extent; but more publicity on the media and interpersonal routes have to be considered in order to achieve the overall objective of sensitization. Also, the efforts at publicity by NECAP-RISE did not achieve so much in bettering understanding of epilepsy. This might be as a result of the message contents and the research that went into conceptualizing them. Also, interpersonal communication seems to be more effective in disseminating the epilepsy message. This therefore implies that there is the need to involve health communication experts in developing communication strategies for epilepsy intervention. This would enable the right message to be developed for the right target audience in order to achieve the right results.

### 15. Conclusion and Recommendations

Generally, this study has shown that ignorance can affect society's attitude towards People With Epilepsy (PWE). And such attitudes are usually negative and stigmatizing. Therefore, to make the society a better place for people with epilepsy, there is an urgent need for public education and enlightenment through the media and through other forms of communication like the social media and interpersonal communication. .

A better understanding of epilepsy among the public would allay fears and mistrust about people with epilepsy in the community as well as lessen stigmatization towards such persons.

We recommend that the Nigerian government should launch Information Education Communication (IEC) programs to teach the community the causes, symptoms, first aids and the roles of people with epileptic health conditions in the society. Also, the government should organize outreach programs for various communities in order to reduce the level of stigmatization in the society.

PWEs should be encouraged through subsidization of medication, as is the case with anti-retroviral medication, to be compliant with their medication. This will help in seizure control, thus reducing stigma and improving the quality of life for epileptics.

Our study was limited by certain factors. First, the sample used to generalize results for the study was limited to a particular context within Nigeria. We therefore recommend that further studies be conducted in other contexts within Nigeria. Second, misconceptions on the part of the respondents about the real intention of researchers who sought their opinions through interviews and the questionnaire might have influenced some of the respondents not to be very open during interviews and to turn in partially completed and uncompleted surveys. As a result, the questionnaire was completed by 398 respondents. This was not considered appreciable enough to significantly jeopardize the outcome of the study, so we continued with the study. Third, the research was not holistic in addressing epilepsy and stigmatization of epileptics. It only sought to find answers to specific questions in relation to the communication initiative of NECAP-RISE. We therefore recommend that more studies be conducted along the line that we attempted to further consolidate any noticeable trend in media health campaigns against epilepsy.

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