1-1-2011

Effect of Education on Stigma of Epilepsy in South Eastern Nigeria

Augustina Chinyelu Maduakor-Ugo
Walden University

Walden University

College of Health Sciences

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Augustina Ugo

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Dr. Ji Shen, Committee Member, Public Health Faculty
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Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2014

Abstract

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by

Augustina Chinyelu Maduakor-Ugo

BS, Metropolitan State College, Denver, Colorado, 1982

MSN, Lehman College, State University of New York, 1995

Dissertation Submitted in Partial Fulfillment

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Doctor of Philosophy

Public Health

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Abstract

There is a need for epilepsy-based health education programs to enlighten Nigerian

communities and reduce the stigma associated with epilepsy. Epilepsy in Nigeria is

viewed by some as a contagious and an infectious disease or a condition imposed from

the gods, possessed by demons, as the work of witchcraft, or punishment from ancestral

spirits, which are all related to a lack of knowledge about epilepsy leading to

stigmatization of persons with epilepsy. Guided by the stigma theory, the purpose of this

community-based, cross sectional study was to quantitatively examine the effect of an

educational program on interpersonal, internalized, and institutional stigma of epilepsy in

terms of knowledge, attitude, and treatment gained. Two hundred and fifty participants

completed a general domain instrument which had been used in different countries,

including South Eastern Nigeria, and revised for greater validity via a pilot study. Chi-

square tests were used to examine any significant differences in participants' responses

between pre- and post-test surveys regarding knowledge, attitude, and treatment gained

of all 3 identified stigma levels. According to study results, the educational program

reduced all 3 stigma levels in terms of attitude, knowledge, and treatment gained of

epilepsy ($p< 0.001$). This study contributed to positive social change by providing

information to public health workers on how to increase the knowledge and awareness of

the South Eastern Nigerian community that epilepsy is not contagious or infectious and

there is no need to isolate persons with epilepsy from their societies.

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UMI Number: 3619197

UMI

Dissertation Publishing

UMI 3619197

ProQuest®

Dedication

This study is dedicated to my beloved, deceased, parents Sir Clement I. Maduakor of Knight of Saint John and Mrs. Veronica Maduakor. I love you both for giving me life and teaching me perseverance in life.

Acknowledgments

My first thanks and acknowledgment goes to the Holy Trinity in one God, the Father, Son, Holy Ghost, our blessed Mother Mary Queen of Nigeria, and the World. To my beautiful three children Zandra Ugo, Millicent Ugo, and Bosa Ugo, his wife Anulika and Destiny my granddaughter for their support and encouragement to complete the course even through desperate times. To my wonderful brother Chief Nnamdi Madakor who constantly supported me with words of encouragement especially when I was sick for 4 months and lost my father. My special thanks goes to my friends at work especially Nechelle James Dorbu, R.N., Eileen Hardly R.N., M.S.N, Lori fields R.N. who edited my proposal, Mrs. Rosa Paris R.N, M.S.N. A.D.N who constantly reminded me that anything worth started must be completed. I also thank Mrs. Ruth Shinar who is always willing to help, and to Mrs. Patricia Nwosu-Abata (Otolibem). A special thanks goes to the Chairman of my committee Dr. Danawi for his constant supervision, correction, advice and guidance. I also would like to acknowledge Dr. ShenJi.

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Chapter 1: Introduction to the Study

Introduction

Epilepsy is a neurological brain disorder common among minorities and those

with poor social economic status in developing and developed countries. Epilepsy is one

of the more frequent brain disorders seen among these populations (Blackwell, 2010;

World Health Organization [WHO], 2004). Epilepsy s one of the first recognized

neurological disorders, with approximately 50 million people worldwide diagnosed with

epilepsy (WHO, 2004). Precut and Duets (2005) noted 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.

Precut and Duets claimed 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.

Epilepsy is characterized by a recurrent seizure disorder caused by abnormal

electrical activity in the brain which causes involuntary changes in the body's movement,

physical sensations, awareness, and/or behavior. These abnormal electrical activities in

the brain are sometimes accompanied with incontinence of bowel or bladder movement,

or both (Meyer, Duo, Ma, Shepherd, & Gretchen, 2010). A diagnosis of epilepsy could be

made with two unprovoked seizures that are 24 hours apart without any known medical

condition; one single seizure could be seen as a warning sign (Epilepsy Foundation,

2010). When the electrical activity occurs in one part of the brain, it is called partial complex seizures and when it occurs in all parts of the brain, it is called generalized seizures (Epilepsy Foundation, 2010; Fisher et al., 2005).

Disruption of brain waves activities caused by physical changes in the brain may cause epilepsy seizures. Epilepsy and epileptic seizures are often interchangeably used with seizure disorders (Epilepsy Foundation, 2008). It is important to have a general definition of epilepsy for effective communication and understanding among all involved in the care and treatment of people with epilepsy such as physicians and policy decision-makers involved in legislation, disability pension, driving regulations, and workplace safety (Fisher et al., 2005).

Epilepsy varies in its presentation and it is diagnosed with a measuring tool called an electroencephalogram by neurologists and general practitioners (Epilepsy Foundation, 2010). Computed tomography (CT) scans of the brain and magnetic resonance imaging (MRI) of the brain are also used in the diagnosis of epilepsy. The most accurate diagnosis of epilepsy depends on an accurate clinical history of the occurrence of seizures from a reliable witness. The description of the onset helps in establishing whether the seizure is a partial complex or generalized seizure (Lavin, 2006). The treatment of epilepsy both in the developed world and Nigeria are discussed in Chapter 2, Chapter 2 will discuss how the literature was searched and words used, the causes of epilepsy, risk factors, and the prevalence/incidence rates in developing and developed countries.

Problem Statement

Epilepsy in Nigeria is viewed by some as a contagious and an infectious disease.

Some even consider the condition as being imposed from the gods, or possession by demons, the work of witchcraft, or punishment from ancestral spirits, which are all related to a lack of knowledge about epilepsy; this ignorance can lead to a stigmatization of persons with epilepsy (Columbine, 2006). People with epilepsy can be 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 or not being able to be buried in family graves). Some children with epilepsy are dispelled from school if they have seizure activity to avoid infecting others. Some teachers are also ignorant of epilepsy disorder and are not willing to assist or take care of children with epilepsy (Ojinnaka, 2002). An educational paradigm must be created to dispel the stigma associated with epilepsy on the individual and the community level. The researcher used education as an intervention on the Ozubulu community in the south east Nigeria by measuring knowledge of epilepsy, attitude, and information gained, if any, on treatment options. The domain epilepsy instrument scale was used in the pretest/posttest on the Ozubulu community to measure stigma in terms of knowledge, attitude, and treatment (Le Quang, C., Allebecl, P., Nguyen, Thi K, C& Torbjorn, T (2007). In (2012) Nuhu, T.A., Yusuf, T.H., Shelch, E.E, & Eseigbe conducted a study to assess the academic performance of adolescent with epilepsy in Nigeria and the factors associated with poor performance in this population. .Le Quang et al recruited 77 adolescents (aged 12 - 17 years) with epilepsy attending the Child and Adolescent Clinic of Federal Neuropsychiatric Hospital, Kaduna, North-West, between March 2008 and September 2010, and the socio-demographic characteristics of 76 controls (matched for age and sex) were recorded (Le

Quang et al, 2012). The overall result showed that the mean ages of the subjects and the

controls were 15.1 (standard deviation (SD) 2.1) and 14.7 (SD 1.7) years, respectively

(p>0.05), the mean duration of illness was 6.1 (SD 4.6) years, the mean seizure-free

period was 16.8 (SD 15.6) weeks, and 64.9% of the subjects and 57.9% of the controls

were males. Forty-six subjects (59.7%) and 12 controls (15.8%) had poor academic

performance (p<0.001). Long duration of illness, short seizure-free periods and irregular

school attendance were significantly associated with poor academic performance

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(59.7%) and 12 controls (15.8%) had poor academic performance (p<0.001). Long

duration of illness, short seizure-free periods and irregular school attendance were

significantly associated with poor academic performanceance (p<0.05).he authors

recommended the use of education to increase the knowledge and awareness of epilepsy

in this population (Le Quang et al, 2012).. Recommendations and suggestions to

increase public awareness to help the Nigerian society understand the etiology of

epilepsy, various treatment options, and rehabilitative measures available to them were

made by previous scholars ((Folorunsho,Fawole,Obafemi, Ayilare &Suleeiman, 2010).

There is a need for epilepsy awareness campaign programs to educate the society about

epilepsy and to reduce the stigma associated with epilepsy (Folorunsho, Fawole,

Obafemi, Ayilare, & Suleiman, 2010). In this study, I quantitatively examined the effect

that an education program would have on the reduction of stigma associated with epilepsy in terms of knowledge, attitude, and treatment gained.

Purpose of the Study

The call to develop interventional educational programs to reduce the stigma associated with the disease of epilepsy has become a priority. The continuous education of the public on the definition, causes, symptoms, and avenues of treatment for epilepsy will increase awareness and reduce the stigma associated with the disease (Diop, DeBorer, Mandlhate, Prilipko, & Meinardi, 2003). It is essential that members of Nigerian communities recognize the positive benefits of public health education about epilepsy.

Dependent and Independent Variables:

The independent variable was education as an intervention. The dependent variable was the outcome of the education on the south eastern community in this study. The variables were evaluated with respect to epilepsy in terms of knowledge, attitude, and treatment options as they relate to stigma reduction.

Research Questions and Hypotheses

The overarching research questions related to the following: What were the impacts of the education program which would be designed as an intervention program to reduce the stigma of epilepsy in the Ozubulu community? This study was guided by the stigma theory and the three constructs of stigma listed as follows: (a) internalized, (b) interpersonal, and (c) institutional stigma. These three constructs are discussed in the theoretical framework in this chapter with further discussion documented in Chapter 3.

Every construct was measured in terms of any difference in (a) knowledge, (b) attitudes, and (c) information gained, if any, on the treatment options available between the pretest and posttest questionnaire instrument used. The goal of this study was to help in the reduction of stigma associated with epilepsy disorder.

1. What is the effect of an education program on the interpersonal stigma of epilepsy on the Ozubulu community in terms of knowledge of epilepsy?

$H_0 1$: There is no significant difference between the pre/posttest surveys following the educational program on the interpersonal stigma on the Ozubulu community in terms of knowledge.

$H_1 1$: There is a significant difference between the pre/posttest surveys following the educational program on the interpersonal stigma on the Ozubulu community in terms of knowledge.

2. What is the effect of a health education program on the interpersonal stigma of epilepsy on the south eastern community in terms of attitude?

$H_0 2$: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy on the south eastern community in terms of attitude.

$H_1 2$: There is a significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy in the in terms of attitudes and knowledge in the south East.

3. What is the effect of a health education program on the interpersonal stigma of epilepsy on the south east in terms of information gained, if any,

on treatment options of epilepsy?

$H_0$3: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma in terms of information, if any, regarding the treatment options of epilepsy.

$H_1$3: There is a significant difference between the pre/posttest surveys following the educational intervention program of interpersonal stigma in the south east in terms of information gained, if any, regarding the treatment options of epilepsy.

4.   What are the effects of a health education program on the internalized stigma of epilepsy in the south East in terms of knowledge of epilepsy?

$H_0$4: There is no significant difference between the pre/posttest surveys following the educational program on internalized stigma on the south east in terms of knowledge on epilepsy.

$H_1$4: There is a significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma in the south east in terms of knowledge.

5.   What is the effect of a health education program on the internalized stigma of epilepsy on the South East in terms of attitude on epilepsy?

$H_0$5: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the southeast in terms of attitude on epilepsy.

$H_1$5: There is a significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the sound east community

in terms of attitude.

6.   What is the effect of a health education program on the internalized stigma of epilepsy on the south east in terms of information gained, if any, regarding the treatment options of epilepsy?

H_06: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma in terms of information gained, if any, regarding treatment options on the south east.

H_16: There is a significant difference between the pre/posttest survey following educational intervention program on internalized stigma in terms of information gained, if any regarding treatment options.

7.   What is the effect of a health education program on institutional stigma of epilepsy on the south east towards people with epilepsy and their caregivers?

H_07: There is no significant difference between the pre/posttest surveys following the educational intervention program on institutional stigma on the south east in terms of knowledge on epilepsy.

H_17: There is a significant difference between the pre/posttest survey following the educational intervention program on institutional stigma on the south east in terms of attitude.

8.   What is the effect of a health education program on institutional stigma on the south east in terms attitude?

H_08: There is no significant difference between the pre/posttest surveys following

an educational program on institutional stigma on people with epilepsy in terms of

attitude in the south east of Nigeria.

$H_1 8$: There is a significant difference between the pre/posttest surveys following

an educational program on institutional stigma in terms of attitude.

9. What is the effect of a health education program on the institutional stigma

of epilepsy in the south east towards people with epilepsy in terms of

information gained, if any, regarding treatment options of epilepsy?

$H_0 9$: There is no significant difference between the pre/posttest surveys following

an educational program on institutional stigma on the south east of Nigeria in terms of

information gained, if any, regarding treatment options of epilepsy.

$H_1 9$: There is a significant difference between the pre/posttest survey following an

educational program on institutional stigma on the South east in terms of information

gained, if any, regarding treatment options of epilepsy.

All of the null hypotheses were rejected if the desired effects are to be achieved.

The null hypotheses were retained, however, if it had no effect on the participants.

Theoretical Framework

This study was guided by the social stigma theory. The stigma theory is defined

as an attribute, unhealthy behavior, or reputation which is socially discriminating and

causes an individual to be mentally tortured, rejected, and shunned by communities

(Goffman, 1963). Stigma is also described as felt and enacted stigma (Becky, 2010;

Jacoby & Austin, 2007). Felt stigma are the stigma felt by an individual due to fear of

discrimination. This person isolates him or herself from the community, and may

experience low self-esteem and humiliation. Enacted stigmas are the stigma felt by the stigmatized due to people's reaction and negative behavior towards them (Jacoby et al., 2004). Stigma is also divided into three levels: internalized, interpersonal, and institutional stigma (Mihlbauer, 2002). When a person internalizes stigma, he or she may feel hurt and accepts the guilt and discrimination (Mihlbauer, 2002). Interpersonal stigma is stigma felt by a person through his or her interactions or communication with people in the community. Institutional stigma is described as stigma exhibited by companies, such as discrimination in a job interview, health insurance, housing, or other organizations (Mihlbauer, 2002). Epilepsy-associated stigmas are common in developing countries, especially in Sub-Saharan regions of Africa (Baskind & Birkbeck, 2005).

I chose to use the three levels of stigma because it provided more explanatory types of stigmatization experienced by the individual as opposed to felt and enacted stigma. The three levels of stigma assisted me in gathering an accurate analysis following the pretest and posttest survey. In order to effectively deal with the problem of stigma, all three of the different levels of stigma should be addressed systematically (Jacoby & Austin, 2002). Education was the tool used to teach the study population who did not know the reality, causes, treatment options, or side effects or epilepsy.

Theoretical constructs are the foundational elements that underpin a field's core theories, models, assumptions, methodologies, and evaluation metrics. They can be fundamental elements that drive a field's research (Jansen, 2009). Creswell (2009) indicated that constructs are concepts from which researchers build theories, develop models, evaluate results, and measure impact of the research study. A theoretical

construct is unobservable. It is believed to exist based on reasoning from observation.

There are constructs used to explain an observational phenomenon such as stigma, which

is observed through people's discrimination and negative attitudes against people with

some health issues such as HIV/AIDS, leprosy, and epilepsy. Researchers could "unlock"

their research problem with the use of hypotheses in a quantitative study through

theoretical constructs (Creswell, 2009).

This study was guided by the stigma theory and its related three levels or

constructs as discussed below. The levels/constructs of stigma (Muhbauer, 2002) are

listed below:

- Internalized stigma is felt within the person with the condition and reflects
  their feelings, thoughts, beliefs, and fears about being different.

- Interpersonal stigma occurs in interactions with others both within and
  external to the family system; in these interactions, the person with the
  illness is treated differently and negatively because of the health condition.

- Institutionalized stigma reflects indirect expressions of different treatment
  of persons with an illness as a group in the larger society (e.g.,
  discrimination of persons with epilepsy by policies of insurance_.

Definition of Terms

Akwukwu: This is the Southern Nigerian term for epilepsy used by the Igbos of

Nigeria.

Attitude: A manner, disposition, feeling, position, and so on with regard to a person or thing, tendency, or orientation. Attitude was measured with attitude scale and questionnaires. Paschal et al 2007.

Awareness: Awareness means being aware of the environment. People need to be aware of the manifestation of epilepsy to know that something is missing. This could be one reason people do not seek attention on time because some symptoms are minute and difficult to dictate that something is wrong (Paschal et al, 2007).

Epilepsy: A neurological disorder marked by sudden recurrent episodes of sensory disturbance, loss of consciousness, or convulsions associated with abnormal electrical activity in the brain (Epilepsy Foundation, 2010).

Generalised tonic clonic seizure: These are the types of seizures that most people associate with the terms seizure, convulsion, or epilepsy. They occur in people of any age, as a single episode, or as part of a repeated, chronic condition (epilepsy). Some experience a loss of muscle tone or generalized body shaking. This is generally called grand mal seizure (Epilepsy Foundation, 2010).

Incidence: The number of new cases per year of epilepsy or conditions in a specified time period, which is usually a year.(Olumbuni, O, 2006)

Internalized stigma: When the individual is ashamed of his or her condition and isolates him or herself due to discrimination. This is said to be worse than enacted stigma **(**Muhbauer, 2002).

Interpersonal stigma: When an individual is discriminated against by someone through the process of interaction or conversation (Muhbauer, 2002).

Institutional stigma: This type of stigma occurs in churches, institutions, and schools (Muhbauer, 2002).

Ketogenic Diet: The ketogenic diet is the use of fat, eliminating carbohydrates and sugar, thereby letting the body use its own fat for energy. It has been successful in epilepsy treatment for children (Epilepsy Foundation, 2010).

Knowledge: Knowing is when a person has knowledge of something, something learned, or being familiar with a topic based on study. The trainers were taught things that helped to dispel the misconception of epilepsy such as the causes, manifestation, and things on what to do in a first aid emergency. Knowledge was measured using the AKA scale questionnaire.

Partial complex seizures: Partial complex seizures affect a larger area of the brain than simple partial seizures and affect an individual's consciousness. During a partial complex seizure, a person cannot interact normally with other people. He/she is not in control of his or her movements, speech, actions, and does not know what he or she is doing. He/she cannot remember upon completion of the epileptic episode what happened during the seizure (Epilepsy Foundation, 2010).

Prevalence: The total number of cases at a particular point in time. These are usually expressed as a percentage.(Olumbuni,O,,2006).

Stigma: Any behavior or reputation which is socially "discriminating," and causes an individual to be mentally tortured, rejected, and not accepted by some communities (Goffman, 1963). Stigma was measured with a stigma scale/questionnaire such as the AKP, AKA, and QOL.

Assumptions

There were several assumptions regarding this study. I assumed that the participants would freely give their honest response on the pretest questionnaire, which was used in the assessment of what they knew and what they needed to know. The pretest was a tool that assisted me in planning an intervention program. I also assumed that the study would bring a positive social change within the adults of the south eastern community. I assumed that the study would produce better awareness on epilepsy and stigma and reduce stigma constructs. I assumed that the study would reduce misconception and stigma associated with epilepsy patients and their caregivers. I assumed that various stakeholders, including policy-makers, would be interested in carrying on continuous education programs and also introduce the subject of epilepsy in schools from primary to graduate school. I assumed that they would work with other communities to enhance and increase their knowledge on epilepsy, thereby reducing stigma. I assumed that there was limited bias and threats to validity and that I would measure what I was supposed to measure (Creswell, 2007).

Limitations

One of the possible limitations of the study was the selection of participants from one group which did not reflect a true representation of the adult population. Interested people who might have wanted to participate in the study might have decided to withdraw or drop out if they were already recruited in the study. Selection bias may have occurred because the participants might have chosen to avoid communication with people with epilepsy and caregivers. Cultural factors could affect the outcome of a study in

epilepsy due to stigma (Paschal et al., 2007). The study might have been affected when cultural factors became an issue, leading to absence or withdrawal of participants without epilepsy and the ones who had epilepsy patients in their families. Another source of limitation was when participants failed to express their view. They could respond to questions in a way that was pleasing to the research group, which will affect the result of the study.

Scope and Delimitation

In some Nigerian south eastern communities and in some developing countries, epilepsy is thought to be infectious and contagious. Some believe that epilepsy is due to witchcraft or punishment from the gods and, as such, they treat people with epilepsy as outcasts in the community. This is a cultural belief and many researchers from Nigeria and other parts of the world have called for the use of education to enlighten people about epilepsy by increasing epilepsy awareness to decrease stigma (Kabir, 2005; Ogunbini, 2006; Ojinnaka, 2002; Onwueke, 2009). In this study, I excluded the Ozubulu indigenes living in urban cities of Nigeria such as Lagos and Port Harcourt. Some of the theoretical framework not investigated was the social belief model and the cognitive theory.

Significance of the Study

The stigma of epilepsy is common in Nigeria, including the south eastern community. Developing health education program sessions and family support would be significant. Various recommendations can be disseminated based on the findings of the study. These recommendations include (a) media campaign, (b) epilepsy education in school curriculum, (c) in-service on first aid on epilepsy to teachers, (d) stakeholders and

other organizations hiring people with epilepsy, and (e) compliance in medication regime.

Positive Social Change as an Anticipated Outcome of this Study:

Social change is defined as an alteration in the social behavior of a community due to their cultural beliefs, values, or norms (Walden University, 2005). My intent was to reduce stigma on people with epilepsy and caregivers by changing their superstitious and cultural belief that epilepsy was contagious and caused by an evil spirit. The educational program is expected to reduce stigma by increasing their knowledge and awareness of epilepsy, leading to improved attitude toward people with epilepsy and increased knowledge of other treatments options available. I hoped to bring dignity and enlightenment to this community through a positive social change (Walden University, 2005).

Summary and Transition

Epilepsy is a neurological disorder associated with stigmatization in both developed and developing countries, especially of the Sub-Saharan regions of Africa. Many studies have been done in Nigeria and other countries on the topic of epilepsy. Researchers have emphasized the need to develop educational training materials. These tools should be directed towards the health care professionals, as well as patients and caregivers to increase awareness and decrease stigma. The prevalence of epilepsy is higher in developing countries as compared to developed countries.

In Chapter 2, I include a review of the existing literature. Researchers have suggested health education as an intervention to decrease stigma on people with epilepsy

and their caregivers. The stigma theory, which was the theoretical framework for this study, will be discussed in detail, including how it affects the quality of life of people with epilepsy and their caregivers in Nigeria. Literature related to the different methodologies to investigate the outcomes of interest is reviewed. In Chapter 3, I discuss the methodology used in the study to answer the research question and related hypotheses being tested. I discuss the use of the chi-square test as a valid means to analyze the possibility of a relationship between health education and stigma reduction. It also includes a description of the population, sample size, procedures, measures, and analysis of data and other ethical issues. In Chapter 4, I present the results of the study. In Chapter 5, I include the recommendation for future study and implications for positive social change. : Epilepsy is a brain disorder seen more among the poor countries due to poor living condition of the affected people, and 80% live in sub Saharan Africa,

Chapter 2: Literature Review

Introduction

There is a need for public health education as an intervention to increase general public awareness related to epilepsy knowledge, attitude, and information on treatment options, thereby reducing the level of stigma associated with epilepsy. Cultural and ethnic misconceptions of epilepsy have resulted in increased stigma perceived by people with epilepsy (Olumbini,O, 2006). Researchers have examined the effect of stigmatization on the quality of the lives of people with epilepsy in relation to education, employment, socialization, and other aspects of their daily living. A review of past interventions and educational programs to improve the quality of life for people with epilepsy is included and compared with current research.

A search of literature was conducted digitally through electronic nursing, allied health science medical, and psychological databases such as PsyINFO, MEDLINE, CINAHL, Thoreau, Dissertation, WHO, and Medscape, as well as through Albert Einstein University library databases. The list of search terms used to conduct the literature search included stigma, epilepsy, education, attitudes, Sub-Saharan Africa, Nigeria, industrialized and developing countries, and quality of life. The sources of articles obtained and reviewed for this study were obtained digitally as well as through existing print versions of professional journals. Websites such as www.epilepsyfoundation.org, www.epilepsy.com, and www.newstudyinfo.com provided overviews and the history of epilepsy. Sixty-five articles were reviewed from the 16th century through the 21st century.

In this literature review, I compare and contrast different points of view related to previous research on epilepsy stigma. The stigma theory guiding the study is discussed as well as the literature-based description of the research variables such as education, knowledge, attitude, treatment options, and ethical issues. Literature related to quantitative design and other methodologies is reviewed. The implication of past research is addressed in this chapter. The chapter ends with a review on the quality of life of people with epilepsy in Nigeria and methods of traditional treatment.

Research Related to Problem Statement, Research Question, and Hypothesis

Epilepsy is neither contagious nor infectious, but 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 (Buskin, Gretchen, & 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 (Buskin et al., 2005). The stigma of 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 et al., 2007). Education as an intervention tool is designed to engage in the mitigation of stigma. Nigerian communities must proactively reduce the stigma associated with epilepsy as a disorder (Ogunbini, 2006; Ojinnaka, 2002). In this study, I investigated if there was a relationship between the three levels of stigma and education in a pre/post survey in

terms of knowledge, attitude, and information gained, if any, regarding the treatment options of epilepsy.

Literature Review on Variables Used in this Study

The independent variable in this study was used to describe and quantify the level or the values of the dependent variable. The independent variable in this study was education as an intervention, and the dependent variables were the outcome of the education in the south eastern community on people with epilepsy and their caregivers in stigma reduction. These variables were (a) knowledge, (b) attitude, (c) information gained regarding the treatment options of epilepsy, and (d) stigma. Education was used as an intervention to reduce the stigma of epilepsy within this community.

Education as an Intervention

The Nnamdi Azikiwe University Hospital provided personnel from Anambra State who provided the community with an educational program for 3 to 4 days on what epilepsy is; causes of epilepsy, treatment options, and safety. A simple video was used to demonstrate the first aid for epilepsy and what people were expected to do to ensure safety during seizure activity. The video helped to decrease the three levels of stigma associated with epilepsy in terms of increasing the knowledge, attitude, and information gained from treatment options of epilepsy on the adults of the Ozubulu.

Many people have fears of not wanting to associate with people with epilepsy because they fear not knowing what to do when a person has a seizure. Austin (2002) suggested first aid training as a tool in empowering people and eliminating the fear factor associated with epilepsy. The Center for Disease Control and Prevention (CDC; 2011)

created a first aid video for seizures, explaining what care is expected when someone is having seizure activity, to remain calm, to take control, to ease the person to the floor if needed, and to remove dangerous elements for safety. In the video, testimonials were given by people with epilepsy. This video was used to demonstrate that epilepsy should not affect a person's quality of life. First Aid Video training was one of the educational interventions used in this study to increase people's awareness of epilepsy, to learn of treatment methods, and to decrease stigma.

Education had been the major weapon in fighting any type of stigma, and as such Hills (2010) used educational strategies to convince the population of New Zealand that direct contact with people with epilepsy alleviated fear and was proven to be successful. Most of the families including teenagers, children of people with epilepsy, and those who did not have epilepsy bonded well during outings. Activities such as biking, barbecuing, and kiting on National Kite Day helped to change the way people perceived epilepsy (Hills, 2010). Oared and Aghedo (2010) organized self-help groups that engaged in organizing outdoor activities like moonlight dances in some of the village squares in which interested villagers were encouraged to participate in addition to the teaching programs. Activities such as storytelling, roasting corn, and watching masquerades with people diagnosed with epilepsy and those without epilepsy joined with their families would encourage and increase bonding and direct contact (Oared & Aghedo, 2010). The best way to fight stigma both in developed and developing countries is through educational intervention.

Many studies used education as intervention in stigma related strategies, and as such, Austin (2002) suggested that education was needed to fight the stigma related to epilepsy. Austin stated that, in the past, there was a stigma attached to asthma but through education, the myths were dispelled. Austin believed that the same principle should be applied to epilepsy. One of the most important ways to counteract stigma is by having direct contact with the afflicted individual(s). This type of interaction will humanize the condition in addition to educating the public so that the stigmatized person will be seen as an individual and not as a sick person (Austin, 2002).

A pilot study is an initial study carried out before the main study to evaluate the effectiveness of the research questions or questionnaires, Paschal et al. (2007) conducted a community-based study with 165 participants in which a pilot study was done with three participants. The patient perceptions gathered provided a step in determining means for overcoming stigma related to epilepsy in this community (Paschal et al., 2007). A 48-item questionnaire was used and divided into sections. The three patients involved in the pilot study suggested using epilepsy letterhead and envelopes because patients would respond more to their physician's survey compared to a survey by other groups or researchers (Paschal et al., 2007). Paschal et al. found that that 59% of the participants indicated that information in doctors' offices would be the best method to increase awareness of epilepsy among people with epilepsy and their caregivers. Forty-two percent of the participants indicated using educational pamphlets and television advertisements, 29% indicated using a community epilepsy nurse, 24% indicated using radio announcements, and 21% indicated using extension services or agents as the best

way to increase awareness among epilepsy patients. The use of television ads was ranked as the best way to educate the general public and information in doctors' offices was the second most commonly indicated choice. The reverse was chosen for educating patients. Information in doctors' offices was most commonly indicated as the best educational method and television campaigns were the second most commonly indicated choice (Paschal et al., 2007). In this study, I used some of the results of the Paschal et al. study to increase awareness of epilepsy by distributing small pamphlets on epilepsy in the health care centers, schools, churches, and traditional healing centers. Word-of-mouth was also used where possible. The media helped in disseminating information faster to the public. First aid information was posted on billboards in schools with authorization from the principal or head of school authorities.

Educational plans to increase awareness of epilepsy have been somewhat effective in decreasing stigma (Jacoby, 2002). This could be attributed to an aggressive global campaign against epilepsy stigma by the WHO to reduce the burden of those affected by epilepsy worldwide (Stuart, 2008; WHO, 2004). In my study, I recommended a continuous word-of-mouth and media campaign to enlighten the community on stigma reduction. I encouraged the stakeholders to sponsor the media campaign, which is a faster means to disseminate information to the public.

Knowledge of Epilepsy

Knowledge is an act of knowing something, something learned, or being familiar with a topic based on study (Paschal et al, 2007). Health trainers must be taught tools to dispel the misconceptions of epilepsy such as the possible causes and manifestation

epilepsy, and what to do in a first aid emergency. Paschal et al. (2007) studied the types of information that should be promoted in an epilepsy campaign for the general public and confirmed that "information about reactions to seizures" was top-ranked by 59% of respondents. Paschal et al. claimed that 58% of participants top-ranked ''general information about epilepsy,'' and 43% indicated the same for ''information about reactions to epilepsy''; 42% of respondents ranked ''information about supporting epilepsy patients'' as the most important type of information (p. 322). Thirty-two percent of respondents indicated that ''information about origins of epilepsy" was the most important type of information to promote in an epilepsy awareness campaign for the general public (Paschal et al., 2007, p.332). The public should be provided with information on the causes of epilepsy, manifestation, complications, and treatment options to increase epilepsy awareness and stigma reduction.

Many people from countries in Sub-Saharan Africa and other developing countries believe that epilepsy is due to the effect of witch-craft, possession by evil spirits, or angered ancestral spirits. Some believe that the act of foaming or drooling (side effects of epilepsy) are contagious and results in families being shunned and excommunicated from the society (Chisholm, 2005; Kabir et al., 2005). Most African families believe that traditional healers communicate and have the spiritual power to mediate witchcraft. Sometimes, these traditional healers give false explanations on the cause of epilepsy and this makes the whole family become victims of stigma (Baskind & Brubeck, 2005). Witchcraft is commonly believed to be a result of malice by wronging an individual's enemy and people with epilepsy are blamed for their ill health through

wrong doing (Baskind & Brubeck, 2005). The attribution of being responsible for their disorder is one of the key elements in Goffman's (1963) stigma theory. Goffman stated that greater stigma occurs when the individual is blamed for being responsible for his or her disorder. Some communities also believe that breaking taboos by doing something against the gods or community may have caused seizures which induced angered ancestors to punish the individual for misbehaving (Buskind &Birbeck, 2005). The Ozubulu community must become aware of the causes of epilepsy to dispel their misconception of epilepsy, thereby reducing stigmatization through educational programs

To assess the knowledge and attitude of adolescence related to epilepsy, Austin et al. (2002) conducted a study in the United Kingdom to survey the knowledge and attitudes of adolescents on epilepsy by administering a 37item questionnaire. The focus of the study was to measure teenagers' familiarity, knowledge, and perceptions of epilepsy. Austin et al. found that few adolescents in the general population were familiar with epilepsy; the majority of the participants were not sure about seven out of the 12 knowledge items in the questionnaire. Adolescents with epilepsy were being isolated from socializing with their peers due to ignorance as people believed that epilepsy was/is contagious (Austin et al., 2002). Austin et al. aimed to increase epilepsy awareness through education as an intervention within the target audience. The adolescents' stage in life is the period when teenagers are in the process of identifying who they really are. The stigma of epilepsy at this stage is due to ignorance and would be traumatic for adolescents. This could be one reason why adolescents with epilepsy are prone to anxiety and depression (Austin et al., 2002; Olumbini, 2006; Paschal et al., 2005).

Teachers in Nigeria had poor and negative attitude against people with epilepsy including school children (Ojinnaka, 2002): Austin et al. (2011) also conducted a study in the United States with 189,000 teenagers and found that many had negative perceptions of epilepsy. Austin et al. showed that 52the participants had never heard of epilepsy, 46% were not sure if epilepsy was contagious 46% were not sure if people with epilepsy were dangerous; only 31% stated that they would consider dating someone with epilepsy, and 75% of the teenagers without epilepsy believed that most of the teenagers with epilepsy are mostly or often bullied or picked on compared to those teenagers without epilepsy..

Attitude towards Epilepsy

People from different countries have shown negative attitudes against people with epilepsy and their caregivers. Ojinnaka (2002) also noted the negative attitudes of teachers of people with epilepsy. Ojinnaka examined the negative attitude of teachers in a Nigerian urban community of Enugu and called for the use of health education to enlighten the teachers to increase awareness and decrease stigma attached to epilepsy. Many teachers were never educated on epilepsy and they were not willing to care for anyone with this disorder, despite the level of education of these teachers (Ojinnaka, 2002). Attending a mandatory epilepsy course to maintain their teaching license was one of the recommendations from this study.

Researchers who have studied public awareness, knowledge, and attitudes towards epilepsy among the Chinese found higher levels of discrimination against people with epilepsy in China and Taiwan as compared to the United States (Neni, Latif, Wong, & Lau, 2010). This might be related to the inherent feature of Chinese cultures,

regardless of their location in Asia (Neni, 2010). Neni et al. (2010) concentrated more on

school teachers in Thailand and patients in Pakistan. Neni et al. (2010) found that the

negative attitude and stigmatization are more often in developing countries such as

Nigeria as compared to the developed countries such as United States of America, United

Kingdom.

Gradually, positive changes among teachers was observed by researchers. .

Bishop & Boag (2006) found some improvement in teachers' attitude, knowledge, and

belief of epilepsy in the United States. Bishop & Boag (2006) conducted a large data

collection on teacher's attitudes and knowledge about epilepsy in the United States.

Bishop & Boag (2006) found some improvement in the knowledge of the study

participants about epilepsy, but education was still recommended to decrease stigma and

increase positive attitudes among the teachers in the communities. The goal of my study

was to decrease stigma by increased knowledge, decrease negative attitude, and increase

information gained on treatment options of epilepsy. I suggested courses on epilepsy in

all grade levels in schools to educate children on the disorder of epilepsy from a younger

age.

Poor knowledge and negative attitude against people with epilepsy is observed in

many countries. Neni et al. (2007) conducted a study on the East Coast of Peninsular

Malaysia to determine the attitude, knowledge, and stigma of epilepsy on the rural

communities on the East Coast of Peninsular Malaysia. This was a 3-month, cross

sectional study that lasted from June to August 2009 among three states: Terengganu,

Kelantan, and Pahang. Neni et al. (2007) sampled 588 inhabitants (both male and

female) age 18 to 95; marital status included married, single, widowed, and divorced; religion included Muslims, Christians, Buddhists, Hindu, and others; education included primary school education, high school, and diploma to postgraduates. Neni et al. found out that people epilepsy are not accepted like those without epilepsy and maltreatment and isolation increased stigma against people with epilepsy in this community.

Epilepsy is labeled as "Bibi-maten" or dead goat and "Manu-marten" or dead chicken in East Timor. These terms were extracted from the abnormal movements made by these animals when they were being slaughtered (Weiss et al., 2006). Inhabitants of East Timor demonstrated their degree of stigmatization and dehumanization attributed to epilepsy by equating humans to animals (Weiss et al,). The use of education as an intervention was recommended to decrease stigma related to epilepsy. In this study, I used education to impact an effect on the Ozubulu community by increased knowledge of epilepsy, change of attitude, and more information on treatment options.

Treatment of Epilepsy

There are different types of treatment now available for people with epilepsy both in industrialized countries and developing countries. Oral therapy is used to administer the most common used medications such as phenobarbital and Dilantin (Epilepsy Foundation, 2010). Other methods of treatment include Vagus Nerve Stimulation implant (VNS), partial/total lobectomy, or craniotomy for removal of tumor when it is identified as the main cause of seizure (Epilepsy Foundation, 2010). Some individuals believe the use of herbs is beneficial in treatment of epilepsy; these herbs are available from health food stores. The Ketogenic diet is used in treatment of epilepsy, especially on children.

The use of the Ketogenic diet worked in the treatment of epilepsy (Beniczky, José Miranda, & Povlan, 2009).The Ketogenic diet consists of high fat and low carbohydrates and it is prescribed by doctors to treat intractable epilepsy, especially in children (Epilepsy.com). Normally the body uses carbohydrates as fuel in the body, but with the Ketogenic diet, it uses body fats to produce ketones which could be detected in the blood and urine. Dieticians teach and guide parents with the calculation of appropriate fat and carbohydrates which is a four to one ratio. Although it is effective in children with intractable epilepsy, it is physically stressful to convert from a regular diet to a Ketogenic diet and the exact mechanism of the Ketogenic diet is unknown (Beniczky, Miranda, & Polar, 2009). The individual becomes seizure free when the underlying causation is treated in most situations.

Paschal (2005) described the attitude variable on the use of modern medicine in treatment of epilepsy as opposed to previous responses in the same communities who believed more in use of traditional medicine. The three rural communities were among the poorest and most timid. The rural inhabitants of these villages believed in obtaining information from their physician and education through the media was ranked second. They preferred transporting their family members to the hospital to avoid delay by ambulance services as most families had a car or bicycle (Paschal, 2005). Paschal recommended continued education to decrease stigma, mostly among the youth, the illiterates, and the elderly. Continuous education and training would enhance knowledge, decrease stigma, and produce positive change in every community, including the south eastern community in South Eastern Nigeria in West Africa.

Some methods of treatments used in industrialized countries are available in some developing countries, such as Nigeria, and in the 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 the hospital bills (Birbeck, 2010, Kabir et al., 2005; Olumbini, 2006). In this study, I emphasized the need of a health care center in the south eastern community. I recommended that the Nigerian National Youth Coppers should be sent to interior villages for their youth service with some incentives. I recommended that the Ministry of Health should provide epilepsy medication free of charge to the poor in the south eastern community and elsewhere in Nigeria.

More than 80% of patients in the United States with new onset of seizures are treated by general practitioners who are not likely to be aware of new diagnostic and therapeutic measures (Elliot & Seeker, 2008). Health care professionals, as well as teachers, patients, caregivers, and the general populations, are in need of education regarding epilepsy (Elliot & Seeker, 2008). Elliot and Seeker (2008) encouraged epilepsy in-service education not only for teachers, but for all health care providers and to the general public.

Medication treatment in developed countries for epilepsy is cost-effective. A majority of the people have access to medication and to care with insurance, Medicare, or Medicaid coverage. This type of payment coverage could reduce the burden of disability adjusted life years (DALY) that is estimated at 7 million for epilepsy in 2000 (Chisholm 2005). Most developing countries such as Nigeria have poor access to care in the remote

villages and hospitalization costs are the responsibility of the individuals because there was neither insurance nor government assistant program for the poor.

Stigma Towards Epilepsy

Stigma was first described as a shameful attribute or taboo due to some physical condition (Goffman, 1963). The sudden convulsive activities of epilepsy can make people uncomfortable, in addition to their cultural belief that epilepsy is contagious. This dehumanizing label had been noted in research studies was also noted by researchers in Nigeria who called for training and retraining to decrease stigma in Nigerians by increasing epilepsy awareness due to ignorance and cultural beliefs. In this study, I used education as an intervention to decrease stigma of epilepsy and increase peoples' awareness of epilepsy.

Bonding with people who have epilepsy decreases stigma and isolation, and can produce a positive social change in the communities (Hills, 2010). The condition of epilepsy is not hereditary and could be controlled by medication, just as hypertension could be controlled by diet, exercise, and medication (Hills, 2010; Kabir et al, 2005; Ogunbini, 2006). Hills (2010) demonstrated how to decrease stigma and increase the communities' awareness on epilepsy. Hills also demonstrated how research could be transformed into policy. In this study, I hoped to decrease stigma by increased awareness of epilepsy in the community, which was reflected in the participants' responses following the pretest, intervention, and posttest survey with the domain epilepsy scale instrument with education as an intervention.

Weiss et al. (2006) conducted a program in East Timor to address and access the burden of epilepsy in this community. Weiss et al. found out 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 (Weiss et al., 2006).

The Stigma Theory

Stigma was used as a mark of shame in the 16th and 17th century. Symbols or tattoo marks were placed on people to mark stigmatized individuals, such as criminals or slaves to be easily identified (Stuart, 2008). The theoretical framework for stigma is grounded in sociological and psychological theoretical traditions in the modern understanding of stigma (Martin, 2007; Stuart, 2008). Weiss (2006) defined epilepsy stigma as a social process which is related to the individual's experience characterized by exclusion, rejection, blame, or devaluation that resulted from experience or anticipation of an adverse social judgment about a person or group identified with epilepsy. Maubhaur (2002) classified stigma as internalized, interpersonal, and institutional. Other researchers classified stigma into felt and enacted stigma. Felt stigma is the same as perceived or internalized stigma. Internalized stigma occurs when the affected individual feels the condition, thinks about it, believes in it, and entertains fear about the isolation or stigma (Maubhaur, 2002).

Interpersonal stigma occurs in interactions with others in the community when the person is treated differently due to his or her condition (Maubhaur, 2002). Institutionalized stigma occurs when a person experiences discrimination in a public, private, or group setting such as on a job interview, at a health care center, or at an institution (Jacoby & Austin, 2007). Questions included in this study's instruments which relate to the three levels of the stigma identified above are discussed below. This will conform to the constructs of the stigma theory guiding this study (see Appendix B).

Stigma associated with epilepsy can be traced back many centuries. Many cultures associated people with epilepsy as demons, mentally deranged, lunatics, persons with abnormal personality disorder, and the mentally retarded (Jacoby & Austin, 2007). These misconceptions about epilepsy had been rooted in people's minds and worsened the stigma related to epilepsy (Jacoby & Austin 2007). In this study, I educated the southeastern community on the actual causes of epilepsy and dispelled the misconception of epilepsy and reduce stigmatization through education.

Internalized Stigma

The word epilepsy and its diagnosis are discouraging to parents and their children for fear of discrimination, rejection, and humiliation. Internalized stigmas are defined as the fear and shame an individual experiences of having a seizure disorder and knowing how the community discriminates and isolates people with epilepsy (Bauer, 2002; Jacoby & Austin, 2004, Westbrook et al., 1992).

Interpersonal Stigma

Interpersonal stigma is experienced by a stigmatized person through the interaction with people within or outside the family.

Institutionalized Stigma

Institutionalized stigma is discrimination against people with epilepsy by institutions such as schools, housing, hospitals, and governments. Institutionalized stigma can include restriction from marriages, fertility, and immigration (Jacoby & Austin, 2007). People with epilepsy in the United Kingdom are still banned by statutory legislation from being admitted into the armed forces and may face restrictions if they want to go into careers such as teaching, medicine, police force, fire brigade, or prison servicing (Jacoby & Austin, 2007). In some countries, people with epilepsy are restricted from driving for a fixed period of being seizure free or are banned completely from driving (Jacoby & Austin, 2007).

Literature Related to Pre/Posttest Survey

Hills and McKenzie (2002) conducted community-based surveys to evaluate New Zealand's knowledge and attitude among different districts on epilepsy. A telephone interview was conducted on 400 random participants from age 17 and above, consisting of 180 males and 220 females. This longitudinal study was conducted from 1949 to 1979. Questions were drawn from a longitudinal study of U.S. attitudes carried out by Cravenness and Gallup in 5 year intervals (Hills & McKenzie, 2002). Hills and McKenzie found improved attitudes in public opinions about epilepsy. The materials

used consisted of 6 to 8 minute questionnaires and totaled nine questions; Questions 1

through 3 were on the familiarity of epilepsy, 4 through 6 were on the attitude of

epilepsy, and Questions 7 through 9 were on knowledge. Hills and McKenzie indicated

that the participants were familiar with epilepsy; 96% of the respondents had heard of

epilepsy, 91% were willing to have their children marry someone with epilepsy, and 96%

knew that epilepsy is not due to insanity. Only 67%, however, had actually seen a seizure

activity. More than 76% of respondents had known someone with epilepsy, and 28% of

respondents were either unsure of employment opportunities for individuals with epilepsy

or thought this would depend on the type of job (Hills & McKenzie, 2002). Overall, the

people of New Zealand were well-informed about epilepsy and this could be attributed to

frequent education and campaigns used by trained field officers to increase public

awareness and decrease stigma (Hills & McKenzie, 2002).

Hills (2010) compared the results of the Hills and McKenzie (2002) study to other

countries. Three studies were conducted from the United States, one in Denmark, Italy,

and Germany. Hills found that New Zealand was significantly more aware of epilepsy

and were proportionately knowledgeable compared to the six international studies (Hills,

2010). Only 1% of the New Zealand participants said that epilepsy was associated with

insanity, while 9% of the participants from the United States and Denmark and 7% of

participants from Germany believed that epilepsy was associated with insanity. The use

of education, however, was recommended in all countries including New Zealand. Some

portions of these populations are not fully aware of epilepsy, especially the youth, the less

educated, and some elderly (Hills & Mackenzie, 2002).

Adowa, Ocean, and Okeniyi (2006) conducted a study in western Nigeria to evaluate the school performance of adolescents with epilepsy. Adowa et al. recruited 73 subjects with epilepsy aged 12 through 18 and another 73 subjects without epilepsy aged 12 through 18. 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. Adowa et al. found 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 (Adowa et al. 2006). Adowa et al. called for 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.

Literature Relating to Differing Methodologies

Researchers have used different research methods depending on the purpose and objectives of their research studies. Quantitative researchers use questionnaires as an instrument scale in which closed-ended questions and open interview guides are used. Experimental, quasi, and non-quasi designs are used in a quantitative study survey design. Assessments based on qualitative methods are used such as key informant interviews, focus group discussions, participant observation, and open-ended questions. The mixed method includes both quantitative and qualitative methods. In most studies on epilepsy, researchers have used the quantitative method (Weiss et al., 2001). Quantitative research methods have allowed other researchers to explore the association between

epilepsy and social stigma experienced by the people with epilepsy and its effect on their health outcome (Weiss et al., 2001).

Quantitative Method

Frank-Briggs and Alikor (2001) conducted a quantitative study in Port Harcourt, Nigeria in which 280 parents who attended the neurological clinic with their children were recruited to evaluate the knowledge and attitudes of themselves towards children with epilepsy. Out of the 280 participants, 220 were female and 60 were male with an age range from 22 years to 53 years of age. Informed consent was obtained from parents and a questionnaire was administered with closed-ended questions which were comprised of a yes/no and do not know responses only. The parents who could not read or write were assisted by the researcher as this study was conducted at the clinic and this was a convenience sample method. Frank-Briggs and Alikor found that parents were not against having a child with epilepsy, despite the discrimination and stigmatization by the public. About 49 or 17.50% of the participants believed that epilepsy can be cured. One hundred sixty-six of the participants in the study or 52.14% did not know what to do when someone is having seizure activity, and a majority of the 263 or 93.93% did not know of the causes of epilepsy, while 188 or 67.14 % of them were not aware of the manifestation of this disorder. Frank-Briggs and Alikor suggested the need of epilepsy education to inform and increase the general public awareness on the knowledge and attitude of epilepsy, including parents.

Qualitative Method

Bo hour et al. (2009) conducted a qualitative study on improving patient's quality of care in a chronic condition like epilepsy. Bo hour et al. organized six focus groups in which they identified 10 identifiers with an investigator as the mentor. Open-ended questions were used to enable the subjects to discuss their views as related to their perceptions to increase the quality of care in chronic health conditions. Bo hour et al. used focus groups as some interview questions were sensitive and were best discussed in focus groups. The participants were selected through neurology clinics and over the telephone. Consent was obtained from the subjects who volunteered to participate and a gift certificate $50.00 was given to each participant. The interview was transcribed and coded into themes. Bo hour et al.'s suggestions were effective at improving patients' quality of care.

Epilepsy has been related to superstitious beliefs in Sub-Saharan Africa, including the south eastern community in Nigeria. Baskind and Barrack (2005) conducted a qualitative study in Zambia to better understand epilepsy care rendered by traditional healers. Baskind and Barrack conducted focus group discussions with a well-known traditional healer. An in-depth, semi structured interview was conducted at the traditional healer's healing place and they also had multiple informal interviews with health care providers in rural Zambia. Baskind and Barrack found that traditional healers can diagnose epilepsy like medical doctors, especially people with jerking movements who had experienced funny smells or visual or auditory hallucinations. Baskind and Barrack also noted that traditional healers believed that epilepsy was caused by the effect of

witch-craft, possession by evil spirits, and punishment from the gods. Treatment was initiated following the first seizure activity with herbs, plants/animal products, and incantations, and when the seizure activity temporarily stopped, they considered it cured with no further follow-up. Baskind and Barrack noted from the health care providers that the most common reason for referral to a hospital was when the ill health was uncontrollable. The local Epilepsy Care Team developed a more collaborative relationship with traditional healers in the region from their findings.

Mixed Method

Roux (2009) 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. Roux indicated that the teachers are knowledgeable on epilepsy with a good attitude. Knowledge was associated with the degree of stigmatization and attitude towards people with epilepsy. 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 (Roux, 2009).

Death as an Outcome of Epilepsy/Retrospective Research Study

Research had been conducted on epilepsy and the stigma attached to epilepsy but knowledge on the sudden unexpected death in epilepsy (SUDEP) remains limited (Lear-Kabul et al., 2005). No single common risk factor has been identified for SUDEP, but predisposing factors have been suggested (Lear-Kabul, Coughlin, & Doreen, 2005).

SUDEP envelops sudden, unexpected death through witness, unfitness, non-traumatic, and nondrinking deaths in people with epilepsy. The post mortem exam shows no sign of toxic effect or any anatomic cause of death with or without evidences of seizures excluding documented status of epileptic (Lear-Kabul et al., 2005).

People with epilepsy have higher mortality rates than the general population and the cause of death can be due to the progression of an existing brain tumor or other diseases of the brain and drowning due to seizure disorder resulting in aspiration, respiratory arrest, or cardiac arrest mostly see in SUDEP (Lear-Kabul et al., 2005). Lear-Kabul et al. (2005) conducted a retrospective study on SUDEP and the purpose of their study was to review the relationship between several variables and SUDEP improve patient education and reduce mortality (Lear-Kabul et al., 2005). Lear-Kabul et al. reviewed old cases of charts, death certificates, and autopsies from Arapahoe County from January 1993 to 2000 and from Denver's coroner's office from January 1996 to December 2000. The collected data included age at time of death, duration/frequency of seizure disorder, past medical history, medications used including anti-epileptics, and alcohol and drug usage. Postmortem information that was recorded was on circumstances surrounding the scene of event, autopsy findings, and postmortem toxicological studies. Lear-Kabul et al. found that 67 cases were identified which were comprised of 48 males and 19 females who ranged in age from 2 to 58 years of age. Two cases only were less than 13 years of age and the rest were from 13 years and older. Fifty four cases out of 67 were on antiepileptic medications which included Dilantin, Tegretol, Phenobarbital, Gabapentin, and Topamax. The postmortem drug level showed that only 12 cases were

therapeutic, 36 cases were sub therapeutic, nothing was found in 4 cases, and 10 cases were not being treated. Lear-Kabul et al. reported that 58 cases out of the 67 were found either lying in bed or on the couch in a prone/dorsal position with lacerations of the tongue indicative of having had seizure activity with tongue biting. This could be an evidence of respiratory aspiration or arrest. Lear-Kabul et al. noted that out of the 67 cases, only four were documented as SUDEP on the death certificate as a cause of death. Failure by physicians to document the real cause of death of patients with SUDEP has made it difficult to identify and hard for researchers who are interested in researching the topic due to limited findings.

Lear-Kabul et al.'s (2005) retrospective study on SUDEP is essential to this study. It would help in the teachings of epilepsy to both the self-support groups and the community in understanding what epilepsy is, the importance of being a person's guide, and the safety precautions with epilepsy patients. People with epilepsy have indicated their interest of teaching both the causes of epilepsy to the public and the patient's perception on epilepsy (Paschal et al., 2007).

In this study, I addressed the mortality rate of epilepsy. Death in epilepsy has been common through mostly upper respiratory arrest or asphyxiation from drooling. Observation and safety precautions are important with people with epilepsy, especially among children.

Ethnical Issues Related to Epilepsy

Ethnicity is defined as a community's norm, beliefs, and method of practice in their cultural belief. Research concerning racial/ethnic differences in epilepsy treatment

was scarce and limited by methodology. A community's racial and cultural beliefs have an impact on the limited knowledge about epilepsy and its treatment; those with epilepsy may experience barriers to care, a lack social support, and the willingness to seek alternative therapies for epilepsy (Szaflarski, Heckler, & Homer, 2007). Ethnic and cultural beliefs are one of the causes of treatment gaps in the treatment of epilepsy, especially among the poor recourse countries of the world (WHO, 2004).

Ethnic beliefs are one of the fundamental causes of a treatment gap identified in the literature as people from different cultures believe that either epilepsy was due to manifestation of witchcraft, possession by the demons, or punishment by angered ancestral spirits (Olumbini, 2006; Paschal et al., 2007; WHO, 2004). A child born with a physical abnormality /disability or having a seizure disorder is believed to be sacred due to culture and ethnic beliefs such as in India. There are some afflicted that are even worshiped by individuals within the community. Some believe that he/she is having direct communication with God when the person is in a trance as seen in the post-ictal stage which is sleeping after the seizures. These are all the effect of ethnic beliefs related to the increase in treatment gaps, decreased knowledge/awareness about epilepsy, and increased stigma related to epilepsy. In this study, I increased the knowledge and awareness of the population on epilepsy in the south eastern communities in Nigeria through training and intervention. The establishment of health education programs to decrease stigma of epilepsy in this community and other communities was one of the long-term goals of this study. The goal of this study was to use education as an

intervention to reduce the stigma of epilepsy as recommended by previous researchers

(Ojinnaka, 2002; Onwuekwe et al., 2007).

Implications of Past Research on Present Study

Epilepsy has been in existence for over 3,000 years (Sidiropoulous, Diamantes, &

Magiorkinis, 2010). The 19th century, known as the beginning of Renaissance,

progressed to enlightenment which was known as a period of "golden era." This period

marked the beginning of epilepsy research by some doctors from Germany, France, and

Britain (Sidiropoulous et al., 2010). The pathos physiology of epilepsy was first made

known in the 19th century through the work of Jackson, neurologist who proposed that

seizures were a sudden, brief electrical discharge of the brain and that the type of seizure

depends on which side of the brain was affected (Sidoropoulous et al., 2010; WHO,

2005).

The main medication used today for the treatment of epilepsy called

phenobarbital was first used in 1912 and phenytoin or dilantin was first used in 1938

(Meridian Research, 2009). Researchers, however, have been successful in discovering

some new and noninvasive treatments for epilepsy, along with oral medication therapy.

Dilantin and phenobarbital have been the oldest medication prescribed, but many types of

antiepileptic medications are in use now such as Vigabatrin and ACTH steroids used

mostly for infantile spasms (Chudomelova et al., 2010).

Previous researchers have emphasized traditional methods in the treatment of

epilepsy. However, Xu and Xu (2009) indicated that since 1990, China has been using

many types of surgical procedures in the treatment of epilepsy. Many patients do not

have access to epilepsy surgery such as a partial or total lobectomy due to the unbalanced distribution of economic resources in China. Epilepsy surgery is presently booming in most Chinese provinces and has become a well-accepted treatment option for people suffering from surgically remediable epilepsy syndromes (Xu & Xu, 2009).

In China, the WHO (2004) is trying to ensure that the poor are receiving treatment to reduce the burden of epilepsy in their community. The poor who need these medications in Nigeria do not have access to them. It is essential that this common medication gets made available for the poor to help break the untreated cycle of epilepsy and to unify the gap of epilepsy in poor resource countries. The availability of this medication to the south eastern community would contribute to the significance of this study because informing the community on medical care as a better option would be meaningless if there were no accesses to medical treatment or health care. This would help in the reduction of stigmatization in the south eastern community because some seizures are controlled with medication.

Major Risk Factors of Epilepsy

Some of the contributing risk factors associated with epilepsy are (a) traumatic head injuries due to poor transportation infrastructures leading to motor vehicle accidents, (b) a lack of transportation for patients to get to health care centers, (c) limited neurologists, and (d) a lack of antiepileptic drugs (Brubeck, 2010). Tuberous sclerosis complex syndrome has been associated with epilepsy and is noted mostly in the early stage of life mostly as infantile spasms (Petrova, 2011). Tuberous sclerosis syndrome is

identified both as a risk factor and a cause for epilepsy, mostly in children (Petrova, 2011).

Stress is a risk factor of epilepsy and other diseases in the body. Stress has been identified as a predictor of seizure disorder and it enables distrust issues in family function (Hills, 2007). Stress is beneficial, according to the CDC (2011), as it acts as a motivator to an individual in achieving his or her objectives in life. It becomes a risk factor to different diseases such as epilepsy and cancer, including mental and emotional disturbances when stress becomes overwhelming and uncontrollable, however.

Causes of Epilepsy

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; Senanaya & Rima, 1993). 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 researchers have 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). The treatment gap in

developing countries originates from (a) both social and cultural factors related to cultural beliefs regarding epilepsy's causes and treatment, (a) a lack of knowledge and understanding about epilepsy, (c) a 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). Natives of developing countries may first consult traditional healers and high priests for treatment before seeking medical care due to a lack of knowledge and treatment of epilepsy (Oguntola, 2010).

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 provide oral treatment such as phenobarbital which is the cheapest medication for seizure disorder, followed by tegretol and dilantin (WHO, 2004). Cham (2010) stated that providing access to care in developing countries would reduce epilepsy risk factors and be helpful in reducing the burden of epilepsy.

Epilepsy affects people of all ages, gender, and social classes and has no geographical boundary. The CDC recognized epilepsy as a public health issue within the last 15 years (as cited in Elliot & Sheer, 2008). 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 (Birbeck,

2010, Kabir et al., 2009; Olubinim, 2006).

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 (Elliot & Sheneker, 2008). Health care professionals, as well as

teachers, patients, caregivers, and the general population, are in need of education

regarding epilepsy (Elliot &Sheneker, 2008).

<div align="center">**Epilepsy in Developed and Developing Countries**</div>

The prevalence rates of active epilepsy are lower in infancy and increases with

age, especially in the elderly in industrialized countries (WHO, 2005). It is equally higher

in male than females from both developing and industrialized countries due to stress and

socioeconomic backgrounds. These two factors contribute to increased frequency in

seizure activities and are seen more in rural areas compared to urban cities (Brubeck,

2010; WHO, 2005).

The Prevalence and Incidence Rates of Epilepsy in Developing Countries

The prevalence rate of epilepsy is high in Latin America and in several African

countries such as Liberia, Nigeria, and the United Republic of Tanzania as compared to

low prevalence rates seen amongst industrialized countries (Columbine, 2006). The

prevalence rates are 49 per 1,000 persons in Liberia (Senanayae & Romaine, 1993), 13.8

per 1,000 persons in Nigeria,(Columbine, 2006), 13.9 per 1,000 persons in the United

Republic of Tanzania (Winkler et al., 2009), 12.59 to 19.5 per 1,000 persons in Ecuador

(Foyaca-Sibat, Rio-Romero, & Ibanez-Valdes, 2005), and 7.9 per 1,000 in South Africa

(WHO, 2005). The prevalence rates presented by WHO (2005) were as follows: 83 per

1,000 persons in Burkina Faso, 64 1,000 persons in Ethiopia, 73 per 1,000 persons in

Tanzania, 119 per 1,000 persons in Togo, and 156 per 1,000 persons in Uganda, with the

lowest rate reported for South Africa of 35 per 1,000 persons. The incidence rates range

between 2.5 to 8.4 per 1,000 persons in Africa, including South America. The high

incidence rates seen in developing countries can be associated with risk factors and

treatment gaps observed in these countries (Peddle & Riccardo, 2008; WHO, 2005).

Some researchers have reported high incidence of 11.4 per 1,000 persons in Chile, and

7.7 per 1,000 persons in Tanzania (Pedley & Aricardi, 2008). The WHO stated that the

onset of epilepsy in Sub-Saharan African countries is due mostly to poor prenatal care.

The 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). Tellez-Zen ten et al. (2004)

also noted that the prevalence rate is high in some Canadian provinces that are close to

the Atlantic Ocean and among some immigrants and nonimmigrants 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.

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, lliyasa, 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). A Nigerian community called Aimee with approximately 2,000 inhabitants located 100 kilometers south west of Ibadan had an average of 37 per 1,000 persons while another Nigerian town Igbo-Oar in Oyo State situated 80 kilometers north of Lagos with a population of 60,000 inhabitants had a rate of 5.3 per 1,000 persons using the same WHO protocol (Senanayae & Romaine, 1993). This lower rate was due to the improved access to care, antenatal clinics made available to the Oar-Igbo community, and the emphasis on a childhood prevention program such as an immunization program (Senanayae & Romaine, 1993).

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 (Devi, Singh, & Bala, 2010).

Factors Affecting Quality of Life of People with Epilepsy

The quality of life of people with epilepsy has been documented in Western countries. There is a dearth of information and studies done in developing countries, including Nigeria, however. Previous researchers have documented that, despite the stigma attached to epilepsy, there were other factors that affect the quality of life of people with epilepsy in Nigeria such as (a) age at onset of the seizure disorder, (b) the severity and frequency of seizure activities, (c) duration of ill health, (d) socioeconomic status, and (e) side effects of different types of antiepileptic medication and its toxicity (Adewuya, 2006).

Epilepsy affects people's physical and mental health and their activities of daily living (Akins, Lore, & Adewuya, 2009). Most villagers consult traditional healers first before looking for medical care if seizures become out of control due to a lack of availability of financial resources (Akinslore & Adewuya, 2009). Stress is another factor that affects the quality of life of people with epilepsy. Stress has been identified as a predictor of seizure disorder and it affects both the patient and family function (Hills, 2007). According to the CDC (2011), stress is beneficial to a point as it acts as a motivator to an individual in achieving his or her objective in life. It becomes a risk factor for different diseases such as epilepsy, cancer, and mental and emotional disturbances when stress becomes overwhelming, however. Increased stress can lead to a decreased ability to cope as evidenced by increased stress levels, negative mood states, and impaired family functioning when parents or caregivers are faced with a constant feeling of uncertainty about their child's condition (Duff, 2011).

Stress as a Risk Factor Affecting Quality of Life

Stress can be attributed to physical factors and the environment. Mortimer (2010) noted that the basic components of stress treatment are observation, psychological intervention, or/and medication. Families of children with epilepsy report dissatisfaction with restrictions in their social and recreational activities such as playing soccer, dining out, and other social activities (Hills, 2010). Stress and the disruption in families due to the onset of epilepsy in a family affect other siblings due to neglect and increased divorce rate among parents. Parents of children with epilepsy spend more time with the affected child and may neglect other siblings, which increases the stress threshold in the family (Modi, 2008). Hill (2010) also reported emotional disturbances such as insomnia and frequent nightmares.

The initial diagnosis of epilepsy can lead to shock, grief, anger, anxiety, denial, mourning, and many psychological difficulties. At the realization of being disabled, people can experience stages of mourning, depression, internalized anger, externalized anger, frustration, acknowledgement, and finally acceptance, adjustment, and jealousy (Hills, 2007). Parents who do not know how to control or adjust to stress can display all types of ill health, including cancer, depression, and anxiety disorder which worsens the condition of people with epilepsy.

It is essential to know how the body responds to stress to be able to know when it is necessary to seek help to avoid adverse reactions to stress. Stress hormones release into the body increase, such as the adrenaline and cortisones, preparing the body for action either to defend self or flight from the situation. This increases the heart rate, blood

pressure, and other systems of the body. Mortimer (2010) demonstrated that the American Red Cross has created a 4-hour training course that presents the framework of psychological first aid and also provides education and training exercises to increase psychological first aid competence in stress management.

Treatment of Epilepsy in Nigeria

There are different methods of treatment for epilepsy which depend mostly on the underlying causes. These types of treatment are associated most often with Western medicine. Approximately 70% of the country's population in Nigeria resides in the rural areas where facilities are lacking. Children 15 years of age or younger constitute half of Nigeria's total population (Francesca, 1999; Puja, 1996).

Traditional therapy for epilepsy is common among the Nigerian society. Spirituality invoking the ancestors, the use of herbs/different types of plant bathing, and animal sacrifice has been offered during treatment (Olumbini, 2006). There are different types of traditional healers in Nigeria such as the herbalists, bone setters, and traditional birth attendants, as well as those who deal with simple surgery, mental diseases, and therapeutic occultism. Nigerian traditional healers use various techniques for diagnosis, which include searching with cowries, stones, amulets, coins, animal sacrifices, and consultation with the supernatural. The direction of the tail and the side facing upwards or downwards has meanings that aid them in diagnosis when cowries are thrown on the floor, for example.

Treatments for epilepsy vary from the use of different animals, vegetables, herbs, dancing, and incantations. Healers sometimes inscribe marks on a patient's forehead,

chest, back, and chin to let bad blood to flow out (Engel, Pedley, & Aicardi, 2003). In a survey conducted in Western Nigeria, Engle, Pedley & Aicardi, 2003, found that only 3.9% of the people with epilepsy were using herbal ant seizure medication, despite the availability of antiepileptic medication in this village. The traditional healers used a mixture of different herbal remedies for epilepsy. They usually used mixtures of plants having an anti-seizure, antipyretic, or antibacterial effect. One remedy used in Western Nigeria contains the fruits of Tetra pleura TetrapteraTab and the leaves of NicotianaTabacum Linn with the addition of local dry gin or an African hot drink called "ekpetechi" which is 100% alcohol. Some researchers reported that this concoction resulted in permanent brain damage (Puja, 1996). Spiritual healers may believe that epilepsy is related to witchcraft and visitation by the devil and evil spirits. Affected people are engaged in ritual dances, incantations, propitiatory rites, and exorcism to rid the patient of the disorder (Puja, 1996).

The communities not only believe that epilepsy is contagious, but they also believe that epilepsy is a disease that blocks the heart, with foam restricting circulation and resulting in a seizure activity (Awaritefe, 1989). It is assumed to be a male type of seizure when the victims fall and have a violent jerking, and if it is a gentle fall with mild shaking, it is assumed to be a female type of seizure (Awaritefe, 1989). Some treatments used in this community include throwing the patient's limbs into a fire, rubbing pepper into their eyes/face, or making an unconscious person drink a cow's urine (Puja, 1996). This type of treatment has the tendency of predisposing the individual to aspiration pneumonia.

Muazu and Karta (2008) conducted a study in Northern Nigeria among the Hausas and Fulani tribes. Five prescriptions were used in the treatment of epilepsy and the researchers collected them from the traditional healers for evaluation (Muazu & Karta, 2008). *Securidaca longipedunculata* (Polygalaceace) was found to contain anti-convulsion qualities which were useful for the treatment epilepsy; Methyl Salicylate was also a useful medication or agent for anti-rheumatoid arthritis and contained an antimicrobial agent containing an extract to inhibit HIV replication due to the presence of alkaloid caffeolyquinic acid (Muazu & Katia, 2008). The Mitragynainermis herb/plant belonged to the family Rubiaceace and it contained an alkaloid which was a useful agent for treatment as an anticonvulsant and also contained astragaglin which was a good inhibitor against malaria parasites (Muazu, & Katia, 2008). The Celtic belonged to the Ulmaceae family which was reported to have gamma amino butyric acid (GABA) which was a deficiency in lead convulsion. Gabapentin is one of the antiepileptic medications used by Western medicine today (Maua & Katia, 2008). The rest of the plants were helpful in alleviating epilepsy except one in the family of Asteraceae. This was reported to contain neurotic substances that could worsen the epilepsy disorder (Muazu & Katia, 2008). The Paprika clappertonianna plant was composed of mostly amino acids and phenol substances which contained antimicrobial agents useful in combating bacterial infections. The Centauries Praecox contained niacin, repine, and traces of zinc, copper, aspartic acids, and glutamic acids. The Acacia sepal contains niacin and the epin contained traces of zinc elements and copper with amino acids. The plant can worsen the

condition of an epileptic patient with hypoglycemia. Researchers, however, suggested further study on this plant for treatment of diabetes (Masha & Katia, 2008).

In this study, I provided training to reduce the stigma of epilepsy in the south eastern communities by the use of education as an intervention. A better understanding was established to determine if there was a relationship between education and the three levels of stigma in terms of knowledge, attitude, and information gained, if any, on treatment options.

Summary and Transition

In the literature review, I explored research in epilepsy stigma, discrimination, and the treatment gap associated with it. Stress was identified as a cause of many illnesses including epilepsy because of its psychological, physical, and emotional effects on human beings. I reviewed the past and present research methodologies related to epilepsy including death as an outcome of epilepsy. Many outcomes from other researchers were used as an educational tool and as an intervention in this study such as the bonding technique from (Hills, 2010). In Chapter 3, I will present the methodology used for the study.

Chapter 3: Research Method

Introduction

In Chapter 3, I discuss the study design, the sample, instrumentation, data analysis, and the ethical consideration. An overview of the study's design includes a rationale of why this particular research design was selected. The sample characteristics and size is presented as well a description of the instrumentation. The data collection process and analysis is also addressed.

Epilepsy is a stigmatized disorder and some people have the misconception that epilepsy is due to demonic possession, an effect of witchcraft, or punishment from the Gods/ancestral spirits. Previous researchers have indicated the need of education as an intervention to decrease the stigma and treatment gap related to epilepsy (WHO, 2005) . The purpose of this study was to examine potential associations or relationships with education as an intervention to decrease stigma related to epilepsy. A cross sectional pretest/posttest survey research method and descriptive design was used for this study.

Research Design and Rationale

In this study, I sought to better understand whether there were any associations between an educational program designed to increase awareness of epilepsy and the outcome regarding decreased associated stigma in relation to people's knowledge, attitude, and treatment options through the three levels of stigma. I implemented an educational intervention and a pre/posttest survey.

The purpose of the survey design was to gather information and generalize findings from a sample of a population so that inferences can be made about the

characteristics on attitude, knowledge, and treatment options of epilepsy in the Ozubulu population of Nigeria (Bobbie, 1990). Some of the advantages of a survey are the usefulness in describing the characteristics of a large population of which no other method of observation can provide this general capability (Creswell, 2009). Surveys can be administered from remote locations using mail, e-mail, or telephone. Large samples are feasible, making the results statistically significant even when analyzing multiple variables (Creswell, 2009). In quantitative research, the researcher is ideally an observer who neither participates in the study nor influences what is being studied. The students were actively involved in this study but did not influence what was been studied.

The use of the cross sectional survey using a validated instrument was more beneficial to the study. It assisted me in gaining some insight and information from the large samples by responding to open/close-ended questions, yes/no questions, or agreed/not agreed questions. The results of this questionnaire were used to understand the attitudes, knowledge of stigma, and treatment options of the south eastern community in a pre/posttest which was used for data analysis. I used domain instruments used by some researchers in many other countries including Nigeria. The institutional review board (IRB) approval was obtained from Walden University before the commencement of the study; I also obtained written permission from Ann Jacoby.

Quantitative research is commonly used to investigate research questions in the physical sciences that are designed to ensure objectivity, generalized ability, and reliability. These techniques cover the ways research participants are selected randomly from the study population in an unbiased manner. The researcher is considered external

to the actual research and the results are expected to be replicable, no matter who conducts the research and how many times it is conducted (Creswell, 2009).The cross sectional design for this study was approximated to last 14 to 21 days, starting with a pretest and concluding with a posttest with an intervention in between. The sample was drawn from a random selection of participants taken from the population at large. Sampling is the process of selecting units from a population of interest so that by studying the sample, the results can be generalized back to the population from which they were chosen (Trochim, 2006). Large samples are feasible, making the results statistically significant even when analyzing multiple variables (Creswell, 2009).

In this study, I used public advertisement such as radio announcements and word-of-mouth advertisements. Fliers were distributed by organizations at doctors' offices, health care centers, clinics, spiritual healers, and churches. People were notified of the intent and the need for their participation. The purpose of the study was made known which helped people to decide if they wanted to participate in the study. I explained in English and the Igbo dialect that a person could drop out of the study at any time without penalty. Both females and males aged 21- to 65-years-old were qualified as long as they could read, write, and were indigenes of Ozubulu living in one of the four villages. Even and odd numbers were mixed in a hat to obtain the sample through simple random selection. All potential participants who picked even numbers were qualified to participate in the study. The independent variable was education as an intervention. The dependent variables were the outcomes of the education taking place within the south

eastern Nigeria community on people with epilepsy and their caregivers in stigma reduction.

<div align="center">**Setting and Sample**</div>

Sampling is the process of using a smaller group of individuals to determine conclusions that can be applied to the whole population. Sampling is the method of choice for many research projects because it is not feasible to survey every person in the whole target population. The surveying of an entire population would not only be costly, but also not time effective. It would take years to contact the entire population to poll them on a certain issue. The small degree of additional accuracy would not be worth the extra money or time if a researcher were to study the entire population as opposed to a representative sample.

Sample Size/Power Calculations

This showed how the participant sample size was calculated following Cohen D method.. Cohen (1988) stated that the accepted power of analysis to detect effect on a study with .80 statistical level at alpha = .05 was at least 64 participants needed from each village totaling 292 participants from the four villages of the Ozubulu community. Effect size = Means Difference/Standard deviation. Cohen specified the use of > .80 for large effect size. The degree to reject the null hypotheses is alpha=.05 (Cohen, 1988). An additional 15% for expected drop out was 38 and the overall needed for this study was 294 participants. Table 1 showed how the sample size was calculated and came up with the required number following Cohen's method of calculation

Table 1

Cohen d Sample Size Calculation Table

1-B				
.50	.20	.30	.40	.50
.55	194	87	50	32
.60129	98	56	36	
.65	247	110	63	41
.70	310	139	70	51
.75	349	156	88	57
.80	394	176	100	64*
.85	450	201	144	73
.90	527	235	133	86

Note. *T-test* table for two tail independent samples (Cohen d, 1988). Sample size (alpha = .05, two tailed test). Cohen *d*'s $Z=Z^2$ (1.96 for 95% confidence level). *P*=% of population picking a choice express as decimal; *C*=Confidence Interval = .05 =+/- 5(%); *SS*=1.96^2 X .5 X (1-*p*)/ .05 or 5% 3.92 X .5 X (1-*p*) / 0.0025; Population is 1,200 people

The population was 1,200 and 25% was needed for the study. The Ekwusigo local

government of Anambra State, which includes the Ozubulu, had many people with

undocumented prevalence of epilepsy. Epilepsy in this part of the country was stressed in

the literature on its stereotype, its superstitious belief, and the degree of its stigmatization.

Families usually send an epileptic patient back to their village once they have been

diagnosed with it in the urban city. Families and caregivers of people with epilepsy may

be anxious to participate in such a study to learn on how to take care or get relief from the

burden of epilepsy. Another alternative was to use the snow ball technique by negotiating

with gatekeepers who knew the community members well. They could help in recruiting

participants within the inclusion criteria until the desired number of participants was

recruited. This might be less time consuming and less expensive but enough participants

may not be guaranteed. The next option would be a convenience study in a neurological

clinic with parents or care givers who came to the clinic with their children could be selected.

Sample Frame

A sample frame is the source material or device from which a sample is drawn and it is a list of all households or institutions within the community (Swenson & Wretman, 2003). Possible sampling frames include the telephone directory, employment records, school class lists, patient files in a hospital, or by using organizations within the population through which sampling would be drawn for example. In this study, I used a simple random sampling, which was a subset of individuals chosen from a larger group. Each individual was chosen at random and entirely by chance such that each individual had the same probability of being chosen at any stage during the sampling process. Each subset of individuals had the same probability of being chosen for the sample as any other subset of individuals (Creswell, 2009; Swanson &Wireman, 2003). The table below showed the sample frame from which participants were selected for this survey.

The Flow Diagram
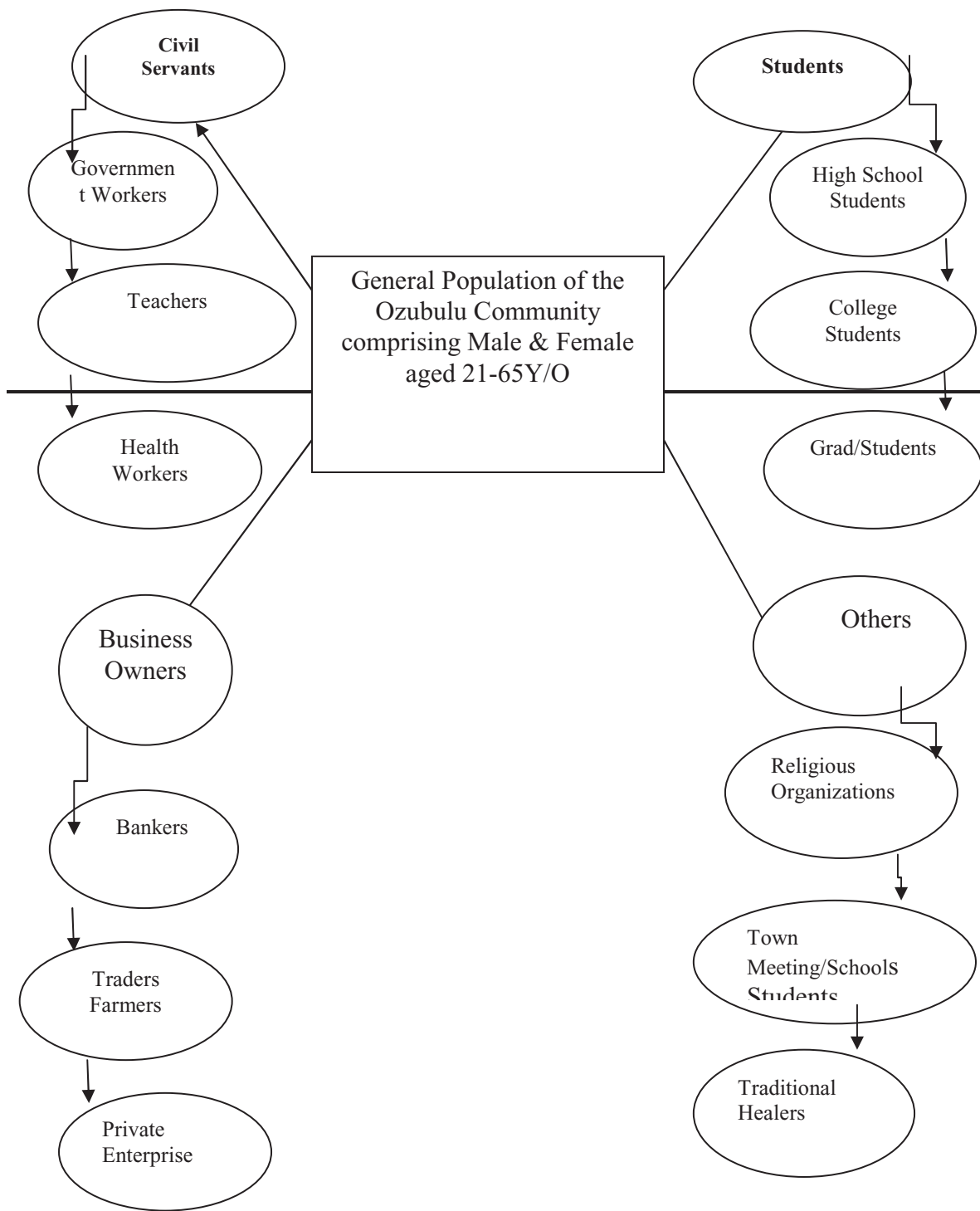
Figure 1. Flow diagram for participant's selection

Inclusion Criteria

- Must be representative of the community comprising of the groups in the flow diagram

- Must be a resident of the Ozubulu Community

- Must be aged 21- to 65-years -ld and mentally able to give consent

- Must have the necessary reading comprehension skills to complete questionnaires either in English, Broken/Pidgin English, or the Igbo dialect

- Must be one participant for every 40 households who willingly volunteered to be part of the study

Exclusion Criteria

- The person is an indigene of the Ozubulu but lives outside of the four villages within Ozubulu town

- The person was less than 21 years of age

- The person cannot speak, read, or write English, broken English, or Igbo

- The person is not mentally capable of making a decision or giving his /her consent

Procedure

From the power size calculation, it was established that the study required 292 participants from the Ozubulu community. Information introducing the background and purpose of the study was disseminated through churches, schools, traditional healer places, health care centers, and market places by word-of-mouth. This included the

procedure for participation and recruitment into the study, voluntary nature of the study, confidentiality, and other ethical concerns. The informed consent form is in Appendix A and the same consent forms were used in the posttest following the intervention. Those selected from picking of even numbers from the hat were encouraged to come back to the site on a specific date and time. I reviewed the requirements once more selected participants showed that he or she was they were willing to participate in the study. The participants were made aware that they could drop out at any time without penalty. Those who were selected from the counting of houses were encouraged to come to the site on a specific date and time. A brief demographic questionnaire was designed to collect data such as age, sex, gender, occupation, and educational level (Appendix B). Interested participants were recruited for the pretest/posttest survey as well as obtaining a signed consent form.

A pilot study was conducted to ensure clarity and understanding of the questionnaires before using it on the participants. It was translated back to the English language from Igbo to avoid mistakes, misunderstandings, or any misinterpretations. The research team was taught or reminded to be polite and respectful to the participants. Enough time was given to respond to questions and the participants were to be reassured of their confidentiality. All documents were safely locked up by me.

I explained to the subjects the intent of the study. Honesty was essential as this would help the participants to determine if he/she wanted to participate in the process. Things need to be explained to them in the language/dialect that they would understand. They had to be aware that they could change their mind at any time without penalty and

consent would need to be obtained both orally and written. A copy was given to the participant indicating how to contact the research group if necessary. No one was exposed to any harm.

Intervention

Epilepsy is one of the stigmatized health conditions that remains a public health issue, especially in the Sub-Saharan African countries including the Ozubulu community in Nigeria in West Africa. In this study, education was designed as an intervention in the reduction of stigma related to epilepsy in the Ozubulu community. The education program helped to inform the general public and health professionals by replacing false assumptions with accurate information (Van deer Mejia & Hinder, 2004). The lecture was provided by health care professionals employed at area teaching hospitals on the following topics:

- Seizure types/classification of seizure

- Causes of epilepsy and risk factors

- Medication and compliance/Ketogenic diet

- Driving and employment

- Unexpected Sudden Death of People with Epilepsy

- Different types of treatment (oral, surgery, Vagus nerve stimulation, and so on).

- Contact. Contact refers to physical interaction with the affected person and the community. Personal contact help dispel myths about the disease and generate empathy and understanding (WHO, 2002). Hills (2011)

demonstrated the effective use of contact in mitigating epilepsy stigma in New Zealand by organizing outdoor activities such as biking, barbecuing, and kiting with both families with epilepsy and those without epilepsy which increased bonding in that community.

- Teacher and education. Teachers should attend yearly in-service education on epilepsy to enable them to attend to children in their care and to maintain their license. Information about epilepsy should also be incorporated in schools to increase awareness and to stop the fear of helping people with epilepsy when they are in need. Many teachers in Nigeria are still not willing to either take, harbor, or care for a child with epilepsy in their class

- School nurses can be trained to ensure that children get their medication while in school if the need arises

- Advocacy: Advocacy interventions go beyond education and include support commitment/recognition from policy/decision-makers and the general public

- Family support system

- Infection control (hand washing)

- The First Aid Seizure Video for Safety

Instrumentation and Materials

A demographic questionnaire was designed to inquire about personal data such as age, sex, marital status, educational level, and skills. The Stigma Scale for Epilepsy (SSE) instrument was created by Fernandez, Salgado, Noronha, and Li (2007). The SSE has satisfactory content validity and high internal consistency that allows for the quantifying of the perception of stigma by patients and people from communities (Fernandez et al., 2007). The SSE can also be used to evaluate an intervention campaign and cross cultural effects of the community. It can be used in interventional studies to mitigate the stigma of epilepsy (Fernandez et al., 2007). Fernandez et al. concluded that the internal consistency of the SSE showed a Cranach's coefficient point 0.88 for the patients with epilepsy and 0.81 for the community. Cranach's coefficient for reliability and internal consistency was used for validation and verification of the consistency of the instrument. The coefficient is used to verify the accuracy of instrument items. The overall mean scores of the SSE formula were 46 (SD=18.22) for patients and 49 (SD=13.25) for the community where a score of 0 suggests that there is no stigma and the maximum score of 100 maximum showed the maximum degree of stigma (Fernandez et al., 2007).

The Scales of Social Rejection questionnaire was replicated from a study in Greece where a survey was conducted to understand the attitude towards epilepsy in Greece (Diamantopoulos, Kaleyias, Meropi, & Charillaoas, 2006). The 19 questionnaires were replicated (with permission) in their originality from the study conducted by Cravenness and Gallup (1980). Questions 1 to 4 were on the familiarity of epilepsy; Q5 through Q11 were on knowledge and understanding of epilepsy; Q12 to Q19 was on

attitude towards people with epilepsy and some of the responses were yes/no. Points were scored on attitude related to Questions 13 to 19 (1 point for answer 1, 2 points for answer 2, 3 points for answer 3, and so on) and by adding them up, a number was obtained that reflected the overall or mean attitude of each participant toward epileptic people. The scale is used to help the investigator to measure the knowledge and attitude of stigma associated with epilepsy within the community (Diamantopoulos et al., 2006). The participant was allowed to ask the research assistants questions for clarification of anything that was confusing in the questionnaire but did not lure them to correct answers.

Cravenness and Gallup (1980) found a favorable difference in public opinions about epilepsy and they used questionnaires totaling nine questions; Questions 1 to 3 on familiarity of epilepsy; Questions 4 to 6 on attitude of epilepsy; Questions 7 to9 were on knowledge. I conducted a pilot study to evaluate the general domain instrument that has been previously used in many countries including Zambia, Ghana, and Nigeria. The instrument was translated to the Igbo dialect and was re =translated back to English to ensure accuracy and consistency in meaning.

The Jacoby Stigma scale (1994) has been a popular instrument to measure stigma related to epilepsy. This 3-item scale listed below has been used in both developed and Sub-Saharan African nations including Zambia and Nigeria. Convergent validity (refers to the degree to which scores on a test correlate with scores on other tests and determines if they are actually related) and internal consistency was found to be satisfactory (Jacoby, 1994) The percentage was not indicated.

1.   Will you be uncomfortable with someone because he/she has epilepsy?

2.   Will you treat someone like an inferior person because he/she has epilepsy?

3.   Would you avoid someone because the person has epilepsy?

I gave the subjects 39 minutes to complete the questions; one translator and I supervised the completion of the survey. The generic stigma scale was used for the study which consisted of a yes/no/I don't know response.

Validity refers to the extent a researcher is measuring what he or she hoped to measure and what he or she thought she/he was measuring; reliability is concerned with the questions of stability and consistency by asking if the same measurement tool yields stable and consistent results when repeated over time (Gravette & Wallnau, 2004).

Data Collection and Analysis

A structured questionnaire was used to evaluate stigma on epilepsy in terms of knowledge, attitudes, and treatment options of the adults of the Ozubulu with closed-ended questions. The student researcher and a translator responded to participants' questions as needed. The aforementioned questionnaire was part of the instrument focusing on the participants' demographic data such as sex, age, marital status, and occupation, followed by the completion on the epilepsy stigma instruments. Informed consents were signed and kept away safely before the initiation of this study.

The student researcher collected the data by herself and the instrument included closed-ended questions with a yes/no/I do not know responses The questionnaire was hand-coded such as yes/no, *no*=0, *yes*=1, and all collected data were analyzed using the SPSS statistical software. Descriptive and inferential statistics were conducted using the

SPSS software. The chi-square test was used to determine the significance of such a difference, if any, between pretest and posttest indicators, which are factors associated with negative attitudes, knowledge, stigma, and treatment of epilepsy among the Ozubulu population using simple percentages and numbers. Hypothesis testing neither supports nor refutes the test result with a 5% confidence level.

Research Questions and Hypotheses

1. What is the effect of an education program on the interpersonal stigma of epilepsy on the Ozubulu community in terms of knowledge of epilepsy?

   $H_0 1$: There is no significant difference between the pre/posttest surveys following the educational program on the interpersonal stigma on the Ozubulu community in terms of knowledge.

   $H_1 1$: There is a significant difference between the pre/posttest surveys following the educational program on the interpersonal stigma on the Ozubulu community in terms of knowledge.

2. What is the effect of a health education program on the interpersonal stigma of epilepsy on the south eastern community in terms of attitude?

   $H_0 2$: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy on the south eastern community in terms of attitude.

   $H_1 2$: There is a significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy in the in terms of attitudes and knowledge in the south East.

3.   What is the effect of a health education program on the interpersonal stigma of epilepsy on the south east in terms of information gained, if any, on treatment options of epilepsy?

$H_0$3: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma in terms of information, if any, regarding the treatment options of epilepsy.

$H_1$3: There is a significant difference between the pre/posttest surveys following the educational intervention program of interpersonal stigma in the south east in terms of information gained, if any, regarding the treatment options of epilepsy.

4.   What are the effects of a health education program on the internalized stigma of epilepsy in the south East in terms of knowledge of epilepsy?

$H_0$4: There is no significant difference between the pre/posttest surveys following the educational program on internalized stigma on the south east in terms of knowledge on epilepsy.

$H_1$4: There is a significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma in the south east in terms of knowledge.

5.   What is the effect of a health education program on the internalized stigma of epilepsy on the South East in terms of attitude on epilepsy?

$H_0$5: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the southeast in terms of attitude on epilepsy.

$H_1$5: There is a significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the sound east community in terms of attitude.

6.   What is the effect of a health education program on the internalized stigma of epilepsy on the south east in terms of information gained, if any, regarding the treatment options of epilepsy?

$H_0$6: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma in terms of information gained, if any, regarding treatment options on the south east.

$H_1$6: There is a significant difference between the pre/posttest survey following educational intervention program on internalized stigma in terms of information gained, if any regarding treatment options.

7.   What is the effect of a health education program on institutional stigma of epilepsy on the south east towards people with epilepsy and their caregivers?

$H_0$7: There is no significant difference between the pre/posttest surveys following the educational intervention program on institutional stigma on the south east in terms of knowledge on epilepsy.

$H_1$7: There is a significant difference between the pre/posttest survey following the educational intervention program on institutional stigma on the south east in terms of attitude.

8.   What is the effect of a health education program on institutional stigma on

the south east in terms attitude?

$H_0$8: There is no significant difference between the pre/posttest survey following

an educational program on institutional stigma on people with epilepsy in terms of

attitude in the south east of Nigeria.

$H_1$8: There is a significant difference between the pre/posttest survey following an

educational program on institutional stigma in terms of attitude.

9.   What is the effect of a health education program on the institutional stigma

of epilepsy in the south east towards people with epilepsy in terms of

information gained, if any, regarding treatment options of epilepsy?

$H_0$9: There is no significant difference between the pre/posttest survey following

an educational program on institutional stigma on the south east of Nigeria in terms of

information gained, if any, regarding treatment options of epilepsy.

$H_1$9: There is a significant difference between the pre/posttest survey following an

educational program on institutional stigma on the South east in terms of information

gained, if any, regarding treatment options of epilepsy.

Ethical Consideration and Protection Rights

I was careful in meeting all requirements for carrying out a study involving

human participants. IRB approval was obtained from Walden University and the Nigerian

Ministry of Health. Informed consent was obtained from participants indicating that they

volunteered to participate in the study on their own. In the consent form, I also indicated

that a participant can quit the study at any time without any penalty from his or her job or

community members. They were not obliged to respond to any question that made them

uncomfortable. All documents were locked up under the care of the student researcher and their confidentiality was highly respected and considered in this study. The study did not involve in any invasive procedure and the participants were not exposed to any clinical experiment. Every participant was reassured of their safety and no one's name was disclosed in any situation, thereby maintaining confidentiality. The study and activities were carried out during daylight hours considering the potentially negative environment in and surrounding the southeastern part of Nigeria.

Participant's Protection

The participants were protected by maintaining confidentiality of their responses in participation. he study was conducted in a safe environment and night activities were avoided as much as possible. All records and instruments were safe-guarded by the student researcher.

Chapter 4: Results

Introduction

The purpose of the study was to quantitatively examine the effect of education on

the stigma of epilepsy in terms of knowledge, attitude, and knowledge of treatment

options, if any, which was acquired among this community. In this chapter, I summarize

the results and provide a description of the participants sampled in this study.

Research Questions and Hypotheses

Nine hypotheses were tested on the internalized, interpersonal, and institutional

stigma of epilepsy using descriptive and inferential statistics including the chi-square test.

The chi-square test was used to analyze the relationship between the demographical

variables such as age, sex, marital status, education, skills, and the responses by the

participants to these questions. The nine research questions and hypotheses tested and

analyzed were

1. What is the effect of an education program on the interpersonal stigma of

epilepsy on the Ozubulu community in terms of knowledge of epilepsy?

$H_0 1$: There is no significant difference between the pre/posttest surveys following

the educational program on the interpersonal stigma on the Ozubulu community in terms

of knowledge.

$H_1 1$: There is a significant difference between the pre/posttest surveys following

the educational program on the interpersonal stigma on the Ozubulu community in terms

of knowledge.

2. What is the effect of a health education program on the interpersonal

stigma of epilepsy on the south eastern community in terms of attitude?

$H_0 2$: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy on the south eastern community in terms of attitude.

$H_1 2$: There is a significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma of epilepsy in the in terms of attitudes and knowledge in the south East.

3. What is the effect of a health education program on the interpersonal stigma of epilepsy on the south east in terms of information gained, if any, on treatment options of epilepsy?

$H_0 3$: There is no significant difference between the pre/posttest surveys following the educational intervention program on interpersonal stigma in terms of information, if any, regarding the treatment options of epilepsy.

$H_1 3$: There is a significant difference between the pre/posttest surveys following the educational intervention program of interpersonal stigma in the south east in terms of information gained, if any, regarding the treatment options of epilepsy.

4. What are the effects of a health education program on the internalized stigma of epilepsy in the south East in terms of knowledge of epilepsy?

$H_0 4$: There is no significant difference between the pre/posttest surveys following the educational program on internalized stigma on the south east in terms of knowledge on epilepsy.

$H_1 4$: There is a significant difference between the pre/posttest surveys following

the educational intervention program on internalized stigma in the south east in terms of knowledge.

     5.   What is the effect of a health education program on the internalized stigma of epilepsy on the South East in terms of attitude on epilepsy?

$H_0$5: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the southeast in terms of attitude on epilepsy.

$H_1$5: There is a significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma on the sound east community in terms of attitude.

     6.   What is the effect of a health education program on the internalized stigma of epilepsy on the south east in terms of information gained, if any, regarding the treatment options of epilepsy?

$H_0$6: There is no significant difference between the pre/posttest surveys following the educational intervention program on internalized stigma in terms of information gained, if any, regarding treatment options on the south east.

$H_1$6: There is a significant difference between the pre/posttest survey following educational intervention program on internalized stigma in terms of information gained, if any regarding treatment options.

     7.   What is the effect of a health education program on institutional stigma of epilepsy on the south east towards people with epilepsy and their caregivers?

$H_0 7$: There is no significant difference between the pre/posttest surveys following the educational intervention program on institutional stigma on the south east in terms of knowledge on epilepsy.

$H_1 7$: There is a significant difference between the pre/posttest survey following the educational intervention program on institutional stigma on the south east in terms of attitude.

8.　　What is the effect of a health education program on institutional stigma on the south east in terms attitude?

$H_0 8$: There is no significant difference between the pre/posttest survey following an educational program on institutional stigma on people with epilepsy in terms of attitude in the south east of Nigeria.

$H_1 8$: There is a significant difference between the pre/posttest survey following an educational program on institutional stigma in terms of attitude.

9.　　What is the effect of a health education program on the institutional stigma of epilepsy in the south east towards people with epilepsy in terms of information gained, if any, regarding treatment options of epilepsy?

$H_0 9$: There is no significant difference between the pre/posttest survey following an educational program on institutional stigma on the south east of Nigeria in terms of information gained, if any, regarding treatment options of epilepsy.

$H_1 9$: There is a significant difference between the pre/posttest survey following an educational program on institutional stigma on the South east in terms of information gained, if any, regarding treatment options of epilepsy.

Pilot Study

I decided to conduct a pilot study before the actual survey because a pilot study ensures that the questionnaire, consent form, and method of data collection are appropriate before use on participants, ensuring its validity and reliability.   A pilot study is a small scale study to evaluate the questionnaire and the research questions.to be used in the main study. The pilot study helped this study to ensure that the questionnaire was clear and that everyone understood the questions. An announcement was made at St Joseph's Catholic Church in south eastern Nigeria (Ozubulu) appealing to the congregation for the need for volunteers for the initial study before the main survey study (pilot study). Interested volunteers were told to report at C.W.O. hall premises at Amakwa at 10:00am on a specific date (Eke day). Some were on time and others were late, and I gave an extra 2 hours to have enough people. At 12:00, the entrance door was locked and the study began. I welcomed the people for their time and effort for responding to the call. The purpose of the preliminary study was explained to them. I recruited eligible volunteers aged between 21- and 65-years-old. The participants were randomly selected by means of even and odd numbers folded individually and mixed in a hat. Those who picked even numbers and met the inclusion criteria and wanted to participate in the pilot study were recruited, and they were 30 people in number. They were representative of the community, comprising the groups in the flow diagram; they were male or female and residents of the southeastern community, mentally able to give their own consent, and had the necessary reading comprehension skills to complete questionnaires either in English, Broken/Pidgin English, or the Igbo dialect.

I explained the informed consent form and obtained a signed consent from the volunteers; they were informed that they could drop out without any penalty, and they were also assured of their confidentiality. A pretest questionnaire and writing material (e.g., pen) were distributed to the participant, and a 30-minute time frame was provided to complete the questionnaire. An intervention was provided by hospital personnel in English and Igbo without any interruption, as there was a big sign written on the black board "Do not disturb, study is in session." This was written in both English and Igbo. The same questionnaire was used for the posttest. Descriptive statistics were performed using SPSS software, and, in order for me to understand whether the questions in this questionnaire were understood and had same meaning to all the participants, a Cronbach alpha was run which was 0.80: this indicated a high level of internal consistency. The questionnaire did not require any modification, and I proceeded to participant recruitment for the survey.

Data Collection for Main Survey

Two hundred fifty participants were selected through random sampling. Those who picked the even numbers and met the inclusion criteria took part in the survey. They were reminded that they could drop out at any time without penalty. The pretest and posttest were 30 minutes each.

The questionnaires were collected and counted by me before being locked away in a brief case. A posttest questionnaire was distributed to the participants who were willing to continue, and another consent form was also signed to that effect after the 3-day intervention by the hospital. I ensured that this population understood what epilepsy

was. An individual needs to understand and accept teachings or concepts before expecting them to practice seizure reduction. Both men and women were ignorant of epilepsy in this community, and as such, children were being brainwashed that epilepsy was an infectious and contagious disease and people must avoid communicating with other children with epilepsy. Some educated teachers were not willing to accept a child with epilepsy in school to avoid infecting other children. Medical personnel also discriminated against people with epilepsy. This is a why everyone in this community, both young and old, should be encouraged to be involved in stigma reduction through public health.

Sample Demographics

Of the 250 participants, 157 (62.8%) were male and 93 (37.2%) were female with a mean age of 44. 8. Thirty people were disqualified because they were not able to read nor write in Igbo, nor were they able to write in English, although they understood both Igbo and broken English. The intended sample size calculated for this study was 294 participants, and 250 (85%) were recruited, which was short of 44 people (15%).

Results

Descriptive Statistics

A total of 250 participants took part in the study, ranging in age from 21- to 70-years-old. The average age of the participants was 44.87 years old ($SD = 13.00$). One hundred fifty-seven (63%) of the participants were male, and 93 (37%) were female, with a ratio of 1:2. One hundred ninety-five (78%) were Christian, 37 (15%) were Muslim, while 18 (7%) were pagans. One hundred one (40%) of the participants had either a

primary or secondary education level, while nine participants had a bachelor's degree and one had a master's degree. One hundred thirty-eight (55%) of the participants were skilled, and 101 (36%) were unskilled, while 161 or 64% were married and 36% were single. Thirty eight (15%), predominantly men, had a teachers certificate. The skilled participants consisted of teachers, farmers, and traders. Frequencies and percentages for participant demographics are presented in Table 2. Table 2 showed the age range of the participants, gender, skills, marital status, education level, religion

Table 2

Frequencies and Percentages for Participant Demographics

Demographic	*n*	%
Age		
21 – 30	49	20
31 – 40	44	18
41 – 50	67	27
51 – 60	58	23
61 – 70	32	13
Gender		
Male	157	63
Female	93	37
Religion		
Christian	195	78
Muslim	37	15
Pagan	18	7

Education level		
Primary	101	40
Secondary	101	40
Teachers college	38	15
Bachelor's	9	4
12	1	0
Skill level		
Skilled	138	55
Not skilled	111	44
4	1	0
Marital status		
Married	161	64
Single	89	36

Note. Percentages may not total 100 due to rounding error.
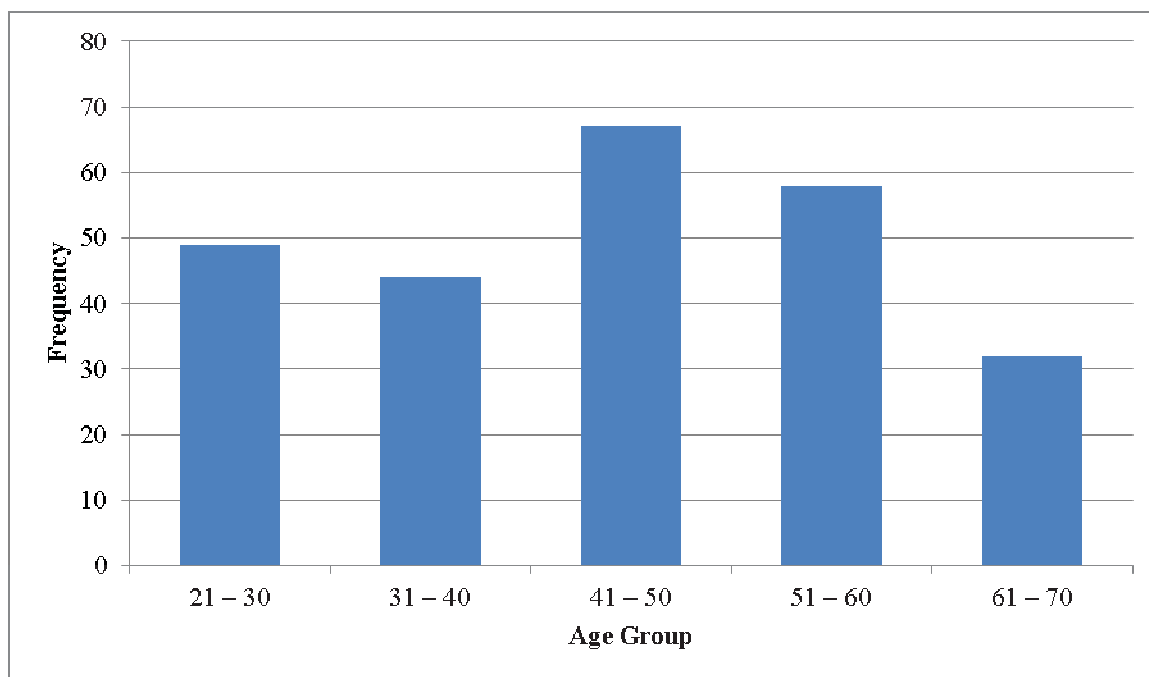
Figure 2. Age group frequencies of participants

In this study, age and gender were not adjusted. The study was based on a simple

random sampling and I recruited participants from age 21 to 65+ years old. I recruited

those that met the inclusion and exclusion criteria, and had 250 participants, which was

enough sample size for the study in this community. Women from this remote area do not

participate in decision-making in the presence of their husbands and elders. For this, it

was impressive that a good number of females volunteered for the study. Similar results

occurred with other researchers in Nigeria and from other West African countries in the

pretesting stage. The study went further with the posttest after the intervention, and I

noted that the intervention was effective. As such, I recommended continuous education

interventions and campaigns among the south eastern community of Nigeria to increase

their knowledge and awareness of epilepsy to reduce stigma and promote positive social change in their community. This included all ages.

Research Question 1

1. What will be the effect of health education on the interpersonal stigma of epilepsy on adults of a southeastern community in terms of knowledge of epilepsy?

Three chi squares were conducted to assess if there was a difference between pre/posttest answers to survey questions on the interpersonal knowledge questions to assess Research Question 1. The questions included "Do you have any prior knowledge about a disease called epilepsy?" "Do you know of anyone who has epilepsy?" and "Have you ever seen anyone having an epileptic seizure?" The chi square between having prior knowledge pre versus posttest was significant, $\chi^2 (2) = 250.00$, $p < .001$. Results of the first chi square are presented in Table 3. The null hypotheses are rejected because some participants changed their responses following the educational program. Some of the participants indicated that they know what epilepsy is, had seen someone who had seizure activity, and had some previous knowledge on epilepsy following an educational intervention; but it was noted that some of the participants could not differentiate the difference between epilepsy and convulsion (Epilepsy Foundation, 2010). People often use the words seizure and convulsion as synonyms, but they do not mean exactly the same thing. Abnormal electrical activity in the brain causes a seizure and the symptoms of a seizure vary. Seizures can trigger convulsions, or uncontrollable shaking of the body.

The education helped the participants to differentiate between both. I explained that one

seizure activity or two seen within 24 hours could be seen as an onset of seizure.

Table 3

Pre and Posttest Answers to Have You Ever Heard of or Read about the Disease Called

Epilepsy

Response	Pretest		Posttest	
	n	%	*n*	%
Yes	240	96	250	100
No	9	4	-	-
I don't know	1	0		0

Note. χ^2 (2) = 250.00, $p < .001$, null hypothesis is rejected.

The chi square between knowing anyone who has epilepsy pre versus posttest was

significant, χ^2 (4) = 500.00, $p < .001$. Few participants changed their responses from

pretest to posttest, however. Results of the first chi square are presented in Table 4.

Table 4

Pre and Posttest Answers to Have You Ever Heard of or Read about the Disease Called

Epilepsy

	Pretest		Posttest	
Response	*n*	%	*n*	%
Yes	240	96	249	100
No	9	4	-	-
I don't know	1	0	1	0

Note. χ^2 (4) = 500.00, $p < .001$, null hypothesis was rejected.

The chi square between seeing anyone having an epileptic seizure pre versus post was significant, χ^2 (4) = 500.00, $p < .001$. However, there were no changes in participants' responses from pretest to the posttest. The education did not have any effect on the participants. The null hypothesis was retained. Results of the first chi square are presented in Table 5. The null hypotheses were rejected because some changed their responses from pre to posttest.

Table 5

Pre and Posttest Answers to Have You Ever Seen Anyone Who Had a Seizure

	Pretest		Posttest	
Response	n	%	n	%
Yes	128	51	128	51
No	109	44	109	44
I don't know	13	5	13	5

Note. χ^2 (4) = 500.00, $p < .001$. The null hypothesis is retained.

Research Question 2

2.   What will be the effect of health education on the interpersonal stigma of

epilepsy on the adults of southeast Nigeria in terms of the attitude on

epilepsy?

Epilepsy is seen as an infectious disease and as being contagious. Most people

will not encourage their children to play with someone with epilepsy, due to drooling and

foaming from the mouth which is deemed to be infectious. Educated teachers and

medical personnel discriminate against people with epilepsy. Therefore, a chi square was

conducted to assess if there was a difference between pre/posttest answers to survey

question on the interpersonal attitude questions to assess Research Question 2. The

question asked, "Would you object to having any of your children in school or at play

associate with a person who has epilepsy." The results of the chi square for objecting to their child playing with someone who had epilepsy were significant, χ^2 (2) = 52.71, $p<$ .001. There were fewer participants who selected yes for objecting at posttest compared to those who selected yes at the pretest. Many participants switched from a yes response at pretest to a no response at posttest. Results of the chi square are presented in Table 6.

Table 6

Pre and Posttest Answers to Would You Object to Having Any of Your Children in a School or at Play Associate with a Person Who Has Epilepsy

	Pretest		Posttest	
Response	*n*	%	*n*	%
Yes	187	75	101	40
No	50	20.0	149	60
I don't know	13	5	-	-

Note. χ^2 (2) = 52.71, $p < .001$; the null hypothesis was rejected.

Research Question 3

3. What will be the effect of health education on the interpersonal stigma of epilepsy within the southeastern community in terms of knowledge gained, if any, about available treatment options of epilepsy?

The general communities were not aware that epilepsy could be treated and would visit a traditional herbalist or religious priest to cast out the demon which is believed to be one of the causes of epilepsy. A chi square was used to assess if there was a difference between pre/posttest answers to the interpersonal knowledge question to assess Research Question 3. The question asked: "Which of the following do you think are the main causes of epilepsy?" The chi square between the main cause pre versus post was significant, χ^2 (25) = 535.33, $p < .001$. As presented in Table 7, the null hypothesis was rejected due to changes in response following the educational program. This indicates that education is important and effective,

Table 7

Pre and Posttest Answers to What Do You Think are the Cause of Epilepsy

	Pretest		Posttest	
Response	*n*	%	*n*	%
Mental Illness	137	55	74	30
Stroke	20	8	34	14
Motor Vehicle Accident	12	5	66	26
Witchcraft	32	13	20	8
Evil Spirit	31	12	19	8
Injury to Birth Canal	18	7	37	15

Note. χ^2 (25) = 535.33, $p < .001$; the null hypothesis was rejected.

Research Question 4

    4.   What will be the effect of health education on the internalized stigma of

        epilepsy within the southeastern community in terms of the knowledge

        about epilepsy?

The question was the following: Do you believe that a person with epilepsy can

be successful in his or her carrier? Many changed their response from the pretest to

positive response at the posttest. In the south eastern community and other parts of

Nigerian except Northern Nigeria, once a person is diagnosed with epilepsy, the

individual and caregivers are seen and treated as outcasts. No one in the community

wants to associate with such people who were believed to be possessed by evil spirits.

But, in the Northern Nigeria, the people embrace them and treat them like one of them.

The chi square pre/post was significant $\chi2$ (2) = 52.71, $p < .001$

Table 8

Pre and Posttest Answers to Do You Believe that People with Epilepsy Can be Successful

in Their Career

Response	Pre-test		Post-test	
	n	%	*n*	%
Yes	34	14	163	66
No	201	80	84	34
I don't know	15	6	1	0

Note. χ^2 (2) = 52.71, $p < .001$; null hypothecs-s was rejected

Research Question 5

5. What will be the effect of the health education program on internalized stigma of epilepsy within the community in terms of the attitude about epilepsy?

A chi square was conducted to assess if there was a difference between pre/posttest answers to the internalized question to assess Research Question 5. The question asked: "Would you object to your son or daughter marrying a person who sometimes has seizures?" The results of the chi square for objecting to marriage were significant, χ^2 (6) = 82.79, $p < .001$. There were fewer participants who selected yes for objecting to marriage at posttest compared to those who selected yes at pretest. The

discrimination is worst in the eastern part of Nigeria as opposed to people from Northern

Nigeria, who are willing to associate with people with epilepsy and eat and use same

cooking utensils. Many participants switched from a yes response at pretest to a no

response at post. With this response, the null hypothesis was rejected, but there was a

difference in change in play response following the intervention compared to changes in

response on play. Results of the chi square are presented in Table 9.

Table 9

Pre and Posttest Answers to Would You Object to Your Son or Daughter Marrying a

Person Who Sometimes Has Seizures

	Pretest		Posttest	
Response	*n*	%	*n*	%
Yes	233	93	186	74
No	10	4	63	25
I don't know	6	2	1	0
Other (33.0)	1	0	-	-

Note. χ^2 (6) = 82.79, $p < .001$; the null hypothesis was rejected.

Research Question 6

      6.   What will be the effect of education program on internalized stigma of

epilepsy within the southeastern community in terms of the knowledge, if

any, of treatment options of epilepsy?

A chi square was conducted to assess if there was a difference between

pre/posttest answers to the internalized knowledge question to assess Research Question

6. The question asked: "What kind of treatment would you suggest if your relatives or

friends have epilepsy?" The chi square between suggested treatment pre versus post was

significant, χ^2 (20) = 410.11, p < .001. There were a larger number of people who

answered go to the hospital at posttest for suggested treatment compared to those who

answered go to the hospital at pretest. The results of the chi square are presented in Table

10.The null hypotheses was rejected. The rich may take their children to the hospital.

Table 10

Pre and Posttest Answers to If Your Relatives or Friends Have Epilepsy, What Kind of Treatment Would You Suggest

	Pretest		Posttest	
Response	*n*	%	*n*	%
Go to the hospital	84	34	153	61
Spiritual prayer house	59	24	32	13
Give them cow's urine	10	4	4	2
Traditional herbalist	86	34	57	23
I don't know	11	4	3	1
Other (41.0)	-	-	1	0

Note. $\chi^2 (20) = 410.11, p < .001$; the null hypothesis was rejected.

Not many in this community will initially visit the hospital for treatment. Finances could also be attributed to opting to visit a herbalist who may give them an option to pay as

they receive treatment. Medical hospital pay is out of pocket and many cannot afford the bill.

Research Question 7

> 7.   What will be the effect of education program on the institutional stigma of epilepsy within the community like employers in terms of knowledge of epilepsy?

A chi square was conducted to assess if there was a difference between pre/posttest answers to the institutional knowledge question to assess Research Question 7. The question asked: "Do you think people with epilepsy should be employed in jobs like other people?" The chi square between employment pre versus post was significant, χ^2 (4) = 36.63, $p < .001$. There were far more people who said yes at posttest for employment compared to those who said yes at pre-test. Many of the participants changed their responses from no at pretest to yes at posttest. The results of the first chi square are presented in Table 11. The null hypothesis was rejected. The participants do not know that epilepsy is not infectious and, as such, would initially oppose to working with them. But when they understood that epilepsy was not infectious and could occur to anyone at any time in life, they changed the responses to a more positive response,.

Table 11

Pre and Posttest Answers to Do You Think People with Epilepsy Should Be Employed in

Jobs like Other People

	Pretest		Posttest	
Response	*n*	%	*n*	%
Yes	49	20	160	64
No	190	76	90	36
I don't know	11	4	-	-

Note. χ^2 (4) = 36.63, *p* < .001; the null hypothesis was rejected.

Research Question 8

8. What will be the effect of health education programs on the institutional

stigma of epilepsy within the south eastern community in terms of

attitude?

To assess Research Question 8, a chi square was conducted between

pretest/posttest responses to the question "Should a person with epilepsy disclose his/her

condition to a prospective employer if they have had seizures in the past but have been

seizure free for 2 years? The chi square between disclosing his/her condition to a

prospective employer in a pre versus posttest was significant, χ^2 (4) = 500.00, *p* < .001.

There were few participants who changed their responses from pretest to posttest. This

rejects the null hypothesis, and the results of the chi square are presented in Table 12.

People with epilepsy, especially after being seizure free for 2 years, are not expected to

disclose the condition to a potential employer unless they want to.

Table 12

Chi Square between Pre and Posttest on Disclosure of Epilepsy to Employer

Pre-test				Post-test	
Response	n	%	n	%	
Yes	185	74	190	76	
No	60	24	60	24	
I don't know	5	2	0		

Note. χ^2 (4) = 500.00, $p < .001$; the null hypotheses were rejected

Research Question 9

9. What will be the effect of the health education program on the institutional

stigma of epilepsy within the southeast community among employers,

business owners, and so on, in terms of knowledge gained, if any, on

treatment options?

To assess Research Question 9, a chi square was conducted between

pretest/posttest responses to the question "Do you think that people with epilepsy are

treated different from others by society?" The chi square between pre/posttest on

treatment on people with epilepsy was significant, χ^2 (4) = 500.00, $p < .001$. Many

changed their response to yes on the posttest as opposed to no at the pretest. They were

honest because many of them knew nothing about epilepsy other than it is an infectious

disease. They failed to see how badly they treat and discriminate this group of people and

their family by maltreating them as outcasts.

Table 13

Chi Square Between Pre and Post on Treating People with Epilepsy Differently:

			Post	
Response	n	%	n	%
Yes	60	24	180	72
No	180	72	60	24
I don't know	10	4	10	4

Note. χ^2 (4) = 500.00, $p < .001$; null hypothesis was rejected

The findings were based on discussion on the outcome of the education on the

participants. The participants were randomly selected from the community and met both

the inclusion and exclusion criteria. Researchers from Nigeria make frequent calls on

public health personnel to educate the community on epilepsy knowledge and to increase

their awareness on epilepsy. In this study, I evaluated the effect of education in this community ranging from 21- to 65-years-old.

Age and gender as a confounding variable were not adjusted in this study which may or may not alter the outcome of the study by influencing the relationship between two variables, the education intervention and the participant's responses (outcome). They can either camouflage the relationship between the two variables, making it appear as if there was no relationship when actually there is, or it could make it seem that there is a relationship when in fact there is none. This could be a Type I or Type II error, and may or may not have affected the internal validity of the study. This could have been considered from the initial designing stage of the survey.

Summary

In Chapter 4, I described the analyses of the data collection. Chapter 5 provides summaries and interpretation of the result for this study. I compare my results against previous studies. I also explain how my findings are similar to or different from other studies, offering insights that add to the existing body of knowledge. The theoretical framework, limitations, recommendations, and implication to social change related to this study were discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Epilepsy is a common neurological disorder seen in both developed and developing countries, but especially among the Sub-Saharan regions of Africa and other poor countries of the world. Previous researchers who have studied epilepsy have indicated a need for epilepsy-based health education programs to enlighten Nigerian communities with the hope to reduce the stigma associated with the disease (Ojinnaka, 2002;). Despite international efforts with global epilepsy campaigns, there remains a gap in initiating such programs in different local communities in Nigeria. The purpose of this study was to quantitatively examine the effect that an education program had on the reduction of such stigmas associated with epilepsy. Moreover, the goal of this study was to increase the communities' awareness on epilepsy to decrease its stigma in terms of knowledge, attitude, and knowledge of treatment. The study was carried out to quantitatively evaluate this community in terms of the relationship between education used as intervention on the knowledge, attitude, and treatment options using pre/post program questions. I targeted the indigenes of the south eastern Nigeria who live within the community and excluded those indigenes who lived in urban cities. Such a stigma devalues human beings and leads to stressful conditions that sometimes lead to other disease conditions such as depression (Paschal et al., 2007).

Summaries and Interpretation of Findings

The findings were based on the outcome of the education on the participants. The participants were randomly selected from the community that met the inclusion and

exclusion criteria from the community. Researchers make frequent calls on public health providers to educate the community on epilepsy knowledge and awareness. In this study, I evaluated the effect of education on this population ranging from age 21- to 65-years-old. I did not control for age or gender as a confounding variable, which could have affected the dependent variables (participant's responses) and alter the results of the study.

In the results of the pretest questionnaire, I found that the participants from southeastern Nigeria lacked the knowledge and awareness of epilepsy. For many years, people living in the developing countries, especially the Sub-Saharan Africa, have believed that epilepsy is infectious and contagious, and that it is caused by evil spirits (Olumbuni, 2006,). Most participants have heard of epilepsy and have seen someone having a seizure activity. However, there is a misunderstanding about the difference between epilepsy and a convulsion. This is unlike the study conducted in Europe evaluating the knowledge and awareness of epilepsy among 16- through 25-year-olds in which Austin et al. (2002) found that this age group did not know anything about epilepsy, and were not able to answer five out of 12 questions on epilepsy. This showed that the participants who were 25 years old in south east Nigeria are more aware, at least have heard of epilepsy and had seen someone with epilepsy. They were more likely to respond better to questions on epilepsy as compared to the adolescence in Europe.

A high proportion of the 180 participants (75%) would not allow their children nor someone they know to play with children with epilepsy, and 233 (95%) of these participants objected to their children or someone they know marrying someone with

epilepsy. This can be attributed to the belief that epilepsy is infectious. This was also reported in similar findings among participants at Enugu in Eastern Nigeria in a study reported by Ojinnaka (2002), where teachers indicated that they were not willing to take care of a child with epilepsy, despite the fact that epilepsy occurs mostly in school-aged children. This is different from the findings in Kano in Northern Nigeria where villagers were willing to share rooms with people with epilepsy, use the same cooking utensils with them, let their children play together, and marry someone with epilepsy (Kabir et al., 2005). Although the south east Nigeria and northern Nigeria are in one country Nigeria, there are differences in belief and cultural norms. The Hausas from Northern Nigeria are more accommodating to people with epilepsy and their caregivers than people from the Southern Nigeria who are predominantly Christians and the people from Northern Nigeria are mostly Moslems.

Epileptics are often viewed by society in Sub-Saharan Africa as lunatics (Ogunbini, 2006). In the pretest, 187 participants (55%) believed that epilepsy was due to mental illness, followed by witchcraft 33 (12%), evil spirits 32 (13%), stroke 13 (8%), injury to birth canal 18 (7%), or motor vehicle accident 12 (7%). This is one reason why people believed more in traditional medicine than going to hospital, for which a lack of finances is also a contributing factor. Many opted for traditional medicine 86 (34%) and hospital (84) 32% as two initial treatments. Similar results were noted in Ghana where educated subjects admitted ignorance on the causes of epilepsy (Nyman & Barium, 1997).

Due to maltreatment and isolating people with epilepsy, the participants did not believe that people with epilepsy can be successful in life; 201 (80%) of participants believed that people with epilepsy cannot be successful in life. However, according to Epilepsy.com (2006), many prominent men such as Julius Creaser and Aristotle had epilepsy. About 190 (78%) participants objected to people with epilepsy being employed in the same jobs, while 185 (78%) believed that people with epilepsy should disclose their condition before employment. Although studies in West Africa have similar findings, and it is optional for a person to disclose his/ her condition, especially having being seizure free for at least 2 years (Epilepsy.com, 2006).

The Intervention Program

The intervention program had some effect on the southeastern Nigerians who participated in the survey. Many changed their response from being negative to a more positive response as indicated in Tables 3 to 13. This study had results similar to other researchers from West Africa and Nigeria on the poor knowledge of and negative attitude toward people with epilepsy in terms of all research questions. However, I also evaluated the effects of education as an intervention, as well as noted some positive effects of an educational program. As such, I recommend continuous campaign and education program all in southeastern Nigeria provinces, irrespective of people's locations.

Many people will not allow their child nor someone they know play nor marry someone who sometimes has seizure activities. Lai et al. (1990) reported that parents will not allow their family to play nor marry someone with seizure activities. The same was reported by Tekle et al. (1991) in Ethiopia, and Ojinnaka (2002) reported the same from

the research conducted in Enugu, Nigeria. However, in surveys conducted in Europe, the United States, New Zealand, and some Asian countries, participants were less likely to have these views, ranging from less than 10% to some 30% (Dawkins et al., 1993) on marriage and allowing children play with someone who sometimes has seizures. Bishop and Boage (2006) showed improvement among teacher behavior regarding children with epilepsy. In terms of employment, similar findings were reported by Milligan and Siranyan (2004) in a study among school teachers in Bobo-Dioulasso, Burkina Faso. Today, people with epilepsy are working at hundreds of different kinds of jobs from one end of the country to the other, and many of these people have seizure control (Epilepsy.com, 2006). Not all people with epilepsy are being treated differently, especially in the developed countries. People with epilepsy should not inform their employers of their condition at the time of employment, this is optional as employers do not ask of an employee's health condition on a job interview especially after being seizure for two years (Epilepsy.com, 2006).

This study had results similar to other researchers in Nigeria and other West African countries, indicative of people's lack of knowledge and negative attitude towards people with epilepsy. I found that education is effective as an intervention with the participants' positive changes in their responses.

Although I failed to control for age or gender, it may or may not have affected the results. I failed to show how many people in each age group who responded to yes or no to the questions. The same applied to the number of male or female responses to each question with a Yes or no. However, I ensured that this population understood what

epilepsy was. An individual needs to understand and accept teachings before expecting them to practice seizure reduction. Both men and women are ignorant of epilepsy in this community, and as such, children are brainwashed that epilepsy is an infectious and contagious disease and must avoid communicating with other children with epilepsy. Some educated teachers are not willing accept a child with epilepsy in school to avoid infecting other children (Ojinnaka, 2002). Medical personnel also discriminate against people with epilepsy. This is a reason everyone in this community should be encouraged and be involved in education and campaign of stigma reduction.

Theoretical Framework

This study was guided by the social stigma theory. The stigma theory was initially defined as an attribute, unhealthy behavior, or reputation which was socially discriminating and caused an individual to be mentally tortured, rejected, and shunned by communities (Goffman, 1963). Epilepsy-associated stigmas were common in developing countries, especially in Sub-Saharan regions of Africa (Baskind & Birkbeck, 2005). Goffman (1963) indicated that stigma reduces an individual from a whole person, to nothing, and emphasized that people with epilepsy are often categorized as lunatics. Stigma leads to isolation and treating one like an outcast, and the south eastern Nigerian group people with epilepsy as mentally deranged or mad people.

Other theories such as the cognitive theory could also be used to explain human behavior by understanding the thought processes. Humans are logical beings who make choices that make the most sense to them. Cognitive theorists rejects behaviorism on the basis that behaviorism reduces complex human behavior to simple cause and effect.

However, the trend has been towards merging the two into a comprehensive cognitive and behavioral theory. This allows therapists and educators to use techniques from both schools of thought to help clients achieve their goals. This will help people with stigma as they need to learn how to help themselves and not believe that the world is against them

Limitations

In this study, I did not control for age or gender, which many have affected the true result. I failed to show how many people in each age group who responded to yes or no to the questions. The same applied to the number of male or female responses to each question with a yes or no.

Other major limitations were that the quantitative method of the study used only included closed-ended questions. I did not give the participants the opportunity to express themselves or share how they felt about epilepsy. The responses the participants gave following the posttest could be a social response, and this might lead to inaccurate findings. Another limitation was eliminating the potential participants who were eager to participate, but were handicapped by speaking the Igbo dialect, but were unable to either read or write neither in Igbo nor in English. The study would improve if it was conducted using the qualitative method approach. The time frame for the study was short. The participants showed interest and were anxious to know more about this disorder, but a 2-week study without a follow-up in educational campaign defeated the purpose

Recommendations

I would recommend (a) a media campaign, (b) epilepsy education in the school curriculum, (c) on-service on first aid on epilepsy to teachers, (d) stakeholders and other

organizations hiring people with epilepsy, and (e) compliance in medication regimes. Educating trainers would be beneficial in that they can be taught techniques on supervising children during school hours. People with epilepsy should be encouraged to be compliant with their medication because this will help in seizure control, thus reducing stigma and improving their quality of life.

Further research should use both open- and closed-ended questions with a mixed-methods approach to allow more of an in-depth interview process, discussion, and verbalization of their feelings.

It is recommended that the Nigerian government, including the Department of Transportation, ensure that the roads have fewer potholes and create an information campaign on driving while under the influence of alcohol as there are many motor vehicle accidents leading to head trauma. Heath care centers for people with stigmatized conditions should be made available with more incentives to encourage young doctors to work in such remote areas. To achieve the above recommendations, continuous education and campaign on epilepsy are a must.

Positive Social Change

Social positive change could be viewed as an alteration in change of behavior or attitude, changing from a negative norm and belief to a more positive and realistic behavior towards an individual's neighbor, family, or community, which will be achieved through a change of thought process in human beings. Epilepsy is a stigmatized disorder in the southeastern community and other parts of Nigeria due to ignorance and superstitious beliefs from their ancestral fathers. An aggressive and continuous education

campaign to increase epilepsy awareness among the southeastern community would help them embrace positive social change. Such change ought to increase trust and love within their communities; children will be free to attend school without fear of discrimination and humiliation. Young men and women will be able to marry their chosen partner without fear. A successful campaign to train the trainers will help instill ideas, strategies, and actions to reduce the stigma associated with epilepsy and promote the dignity and social change of these southeastern communities.

Conclusion

My findings would have been different if I had controlled for age, which may or may not reduce the number of errors. It may reduce camouflaging the relationship between the two variables, making it appear as if there were no relationship, when actually, there is; or it could make it seem that there is a relationship when in fact there is none. Controlling for age will be easier to determine how many of the participants in specific age and gender groups responded to the yes or no questions for easy comparison with other studies. I ensured that the participant understood what epilepsy is. Both men and women of all ages in this community are ignorant of epilepsy. Educated teachers and some medical provider even discriminate against people with epilepsy in the hospital and other parts of Nigeria continue to participate in continuous education program. Although I did not adjust for age, I recruited those who met the inclusion and exclusion criteria through the process of simple random sampling; and had 250 participants, which is enough sample size for the study in this community. Women from this remote area do not participate in decision-making in the presence of their husbands and elders. For this, it

was impressive that good number of females volunteered for the study. The study had

similar results with other researchers in Nigeria and from other West African countries in

the pretesting stage, despite not adjusting for age. I noted that the intervention was

effective, and as such, I recommended continuous education interventions and campaigns

among the south eastern community of Nigeria. A study on knowledge, practice, and

attitude toward epilepsy among primary and secondary school teachers in South Gezira

locality, Gezira State, Sudan did not adjust for age or gender (Haydar, Babikar, Islam, &

Abbas, 2011). Not all researchers adjust for age or gender in their study.

In this study, I responded to calls to educate Nigerian society on an awareness of

epilepsy to decrease the stigmatization related to epilepsy; the low level of knowledge,

coupled with the ancestral beliefs and misconception noted among the subjects, indicates

that there is a need for educational programs aimed at mitigating the stigma of epilepsy in

this community through education programs on epilepsy and other diseases.

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    649.

Appendix A: Permission to Conduct the Study

From : "Jacoby, Ann"
[ajacoby@liverpool.ac.uk]

Date : 07/10/2012 04:38 AM

To : 'Augustina Ugo'
[augustina.ugo@waldenu.edu]

Subject : RE: permission to use your
instrument

Dear Augustina
Thanks for your email. Your proposed
research sounds very interesting and I
wish you success in carrying it out. I'm
more than happy for you to use the
questionnaire you refer to. I've attached
two things – the paper on carers' attitudes,
which has the questions incorporated; and
the questionnaire we used with employers.
I hope this helps.
BW
Ann Jacoby

Appendix B: Informed Consent

Evaluation of educational program to increase Epilepsy Awareness in the South East

Ozubulu Anambra State

Consent Form

You are invited to participate in a survey about epilepsy awareness program in the

Ozubulu Community. You must be from age 21 years old to 65+ years old, and must be

a resident and indigene of the community to be recruited into this program. This form is

part of a process that is called informed consent which will help you to fully understand

the survey study before deciding whether to be a participant. The study is being

conducted by a student researcher at Walden University in the school of Health Sciences

named Augustina Ugo.

Procedure:

I will collect the pre-test questionnaire information from participants who are willing and

meet the inclusion criteria for this study. Health professionals will provide the education

program on epilepsy from University Teaching Hospital. I will then ask: Have you ever

heard of or learned of a disease called epilepsy?

Response: Yes/No

Would you object to having any of your children in school or at play associate with a

person who sometimes has epileptic seizures?

Response: Yes/No

If you agree to participate in the program and meet the study's inclusion criteria you will be asked to arrive to the C.W.O. premises at Amakwa two hours earlier for consent and pre questionnaire data collection.

Nature of the Survey:

The survey is voluntary and you can stop the study at any time without any negative Consequences.

Benefits and Risks:

There is no risk anticipated in this study. The community can benefit if the study permits us to learn about the effectiveness of the educational program.

Compensation:

No compensation will be given.

Privacy:

I will make sure that names and responses given by the participants will not be seen, disclosed, or discussed outside the study. Collected data will be safely stored away in a locked cabinet and will be stored in a computer database with no access to anyone except me. I will keep the data for 5 years as per the school policy (Walden University). You will be given a copy to keep for your record.

Contact Information:

You can ask any question you have and if any question comes to your mind, then call the student researcher at ▮▮▮▮▮▮ or you can email ne at ▮▮▮▮▮▮▮▮▮▮. Should you wish to talk to someone at my university about your privacy or your rights as a participant you can email IRB@waldenu.edu or call 00-16123121210. Walden

University's approval number for this study is **05-13-13-0131752** and it expires on **May 12, 2014.**

Statement of Consent:

I have read the information related to the study and I have decided to participate freely. By signing this form I state that I understand the terms and conditions related to this study.

Participant Initial/signature/ink pad fingerprint:

Date:

Researcher's Signature:

Data:

Appendix C: Demographic Questionnaire

1. Age_____

2. Sex

Male_____

Female_____

3. Religion_____

4. Educational Level

Primary_____

Secondary_____

Tertiary_____

5. Occupation

Skilled

Non-Skilled

Others_____

Appendix D: Questionnaire

1. Do you have any prior knowledge about a disease called epilepsy?

2. Do you know of anyone who has epilepsy?

3. Have you ever seen anyone having seizure activity

4. Would you object to having any of your children in school or at play associate with a person who has epilepsy?   Response: Yes/No/I don't know

5. Which of the following do you think are the main causes of epilepsy?

    Please check all that apply:

    Head injury,

    Injury sustained through the birth canal,

    Mental illness,

    Infections to the brain or central nervous system.

    Evil Spirit

    Witchcraft

6. Do you believe that a person with epilepsy can be a successful person in their carrier?   Response: Yes / No /I don't know

7. Would you object to your son or daughter marrying a person who sometimes has seizures?   Response: Yes / No /I don't know

8. Would you object to your son or daughter marrying a person who sometimes has seizures?   Response: Yes / No /I don't know

9. Do you think people with epilepsy should be employed in jobs like other people?

Response: Yes/No/I don't know

10. Should a person with epilepsy disclose his/her condition to a prospective employer if they have had seizures in the past but have been <u>seizure free</u> for two years?

Response: Yes / No /I don't know

11. Do you think that people with epilepsy are treated differently from others by society?   Response: Yes / No /I don't know

Appendix E: Permission to use Instrument

Subject : **permission to use your instrument**

Date : Mon, Jul 09, 2012 01:58 PM CDT

From : **"Augustina Ugo" <augustina.ugo@waldenu.edu>**

To : ajacoby@liv.ac.uk

Dear Dr. Ann Jacoby,

My name is Augustina Maduakor-Ugo and I am a PH D student in public health sciences with concentration in community education at Walden University. I have an associate degree in nursing from the school of nursing University of Nigeria Teaching Hospital Enugu in 1976, a bachelor's degree in aviation and business management from metropolitan state college Denver Colorado in 1982, and worked for the aviation industry from 1984 to 1988. And finally a Master's degree in nursing and my background is pediatric neurology and has been with the epilepsy comprehensive unit at Children's hospital at Montefiore for 22years. Having read some of your publications on epilepsy and the use of education to enlighten the public on epilepsy awareness, I have decided to choose a similar topic for my dissertation which is on the effect of health education on the stigma of epilepsy on the adult of Ozubulu of South East Nigeria. I am wondering if I can use your questionnaire although I need to alter few words where your mention children to community. I intend using education as an intervention and a lecture need to be given to the community before the posttest. Thank you very much and I am look forward to hearing from you. I am at the point of filling out the IRB for as my proposal and oral defense has been approved. I can be reached at ████████████████████████ . This is the article on epilepsy in the United Kingdom and Implications for Stigma

Sincerely,

A. Ugo

Curriculum Vitae

Augustina C Maduakor-Ugo

Education

1972 – 1975: School of Nursing
University of Nigeria Teaching Hospital Enugu
Nigeria- West Africa
R.N. Program

1979 – 1982:   Metropolitan State College
Denver, Colorado, Aurora Campus
B.Sc.   Aviation and Business Management

1993 – 1995 Lehman College
State University College, Bronx New York
M. Sc. Nursing

Professional

1975- 1976: Staff Nurse
University of Benin Teaching Hospital, OB & GYN Department.
Benin City, Bendel State,
Nigeria West Africa

1983 – 1986: Operation Officer
Federal Ministry of Aviation
Abuja Airport and Lagos

1990– 2013 (present) Professional Registered Nurse
Epilepsy Monitoring Unit
Children's Hospital at Montefiore
Bronx, New York

1994 – 1996 Nurse Managers
Village Nursing Home
Manhattan, New York

2002-2003; Per Dem R.N, Case Manager
Upper Manhattan Mental Health Care Center
New York, New York

2003 -2004. Charge Nurse
Bronx Lebanon Special Care Center
HIV/AIDS Unit
Bronx, New York

2006- 2007 Nursing Supervisor
Workman Circle Rehabilitation and Nursing Home
Grace Avenue, Bronx New York

Harlem Dialysis Center
Registered Nurse.
18 outpatients
Harlem, New York

ALL Care Nursing Registries
Riskers Island Maximum Security Prison
Registered Nurse per Diem

Columbia Presbyterian Hospital
Registered Nurse per Diem
Milstein Building

Bronx Psychiatric hospital
Waters place
Bronx, New York