IFE

PSYCHOLOGIA

An International Journal.   Volume 9 No 1, 2001

ISSN: 1117 – 1421

CONTENTS

PERCEIVED STIGMA: PREVALENCE AND RELATED FACTORS AMONG CLINICALLY DIAGNOSED NIGERIAN INDIVIDUALS WITH EPILEPSY

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Abstract

The theoretical model that epilepsy is globally stigmatizing was tested among Nigerian adults. The model suggested relationships among several characteristics (seizure control, age at onset of illness, duration of epilepsy, seizure type) depression, neuroticism, social support and perceived stigma. Subjects were 264 adults, 21 to 60 years old, clinically diagnosed epilepsy.

Using both correlational analysis of variables and a hierarchical multiple regression analysis, results of the study suggest that Nigerian individuals with epilepsy felt seriously stigmatized by the illness.

Five variables: poor seizure control, duration of epilepsy, depression, neuroticism and social supports were related to stigma. However depression and social support best predicted perception of stigma.

Introduction

The concept of stigma was formulated to explain the behavior, perceptions, beliefs, and development of the social and psychological self of stigmatized persons. Stigmatized persons can be broadly defined as individuals who possess an attribute that others see as negative, unfavorable, or in some way unacceptable. Examples of such individuals may include those with physical disabilities, facial deformities, facial deformities, mental retardation, and mental illness. A contention among contemporary researchers about the social consequences of epilepsy is that, it bears a universal and devastating stigma. From a modest beginning through the work of Temkin (1971), researches and concern regarding the effects of stigma on individuals with epilepsy have grown tremendously. All these studies have maintained that the illness bears a lot of stigma (Bagley, 1973; Janzik, Schmitz, Geiger, & Mayort, 1978; Schneider & Conrad, 1983; Awaritefe, 1985; Scambler & Hopkins 1980; Arnston, Droge, Norton & Murray 1986; Hermann, Whitman, Wyler, Anton & Vanderzwagg 1990; Westbrook, Silver Coupey & Skinnar 1991; Westbrook, Bauman & Skinnar 1992; Westbrook 1995; Aziz, Akhatar & Hasan 1997; Chaplin 1998 And Amir, Roziner, Knoll, & Neufeld, 1999). Dell, (1986) documented that this stigma has resulted in the past a prohibition of mariage and adoption, mandatory sterilization and institutionalization for individuals with epilepsy. They are often a subject of prejudice and rejection (Bagley, 1973) and often less preferred compared to the psychotics (Awaritefe, 1985).

These attribute, seemingly can result in various forms of psychosocial and psychiatric complications, the relationships, which have attracted much studies among contemporary researchers. For example Janzik et al (1978) reported a relationship between subjective feelings of stigmatization in social interaction and tendency to conceal the presence of the disorder. It was also reported that perception of stigma was related to direct exposure to rejection and disapproval from others. (Schneider & Conrad, 1983) and that epileptic persons did not

disclose their disorder to their employer and majority of them thought their careers had been inhibited (Scambler & Hopkins 1980). Arnston et al (1986) found that perceived stigma was correlated with perceived helplessness, depression, anxiety, somatic symptoms, and low self-esteem. Similarly, Hermann et al (1990) found a significant association between feelings of stigma and psychiatric symptoms and Westbrook et al., (1991) found a significant difference exist between adolescents with epilepsy and adolescents with other chronic illnesses in the way they disclosed their conditions to others. Those with epilepsy told fewer teachers and fewer friends about their disorders and found talking about their epilepsy more difficult. A behavioural pattern that is consistent with what was described as selective disclosure Goffman (1963) or the revealing of disease condition to only sympathetic others. Westbrook et al (1992) tested a theoretical model that sought to explain the association of stigma to self-esteem among adolescents (12-20 years old). They found using a hierarchical multiple regression analysis, perceived stigma, seizure type, and seizure frequency as predictors of low self-esteem. In Nigeria, there is a dearth of empirical studies about the perception of stigma in individuals with epilepsy and its effects on their psychological well being. Apart from the study of Danesi (1984) who documented evidence of perceived non-acceptance in the sample of epileptics he studied, no other study has documented stigma from the perspective of the individuals with epilepsy. Result from Danesi (1984) study showed that individuals with epilepsy rated themselves lower than individuals without epilepsy with regard to employability and higher with respect to emotional problems and tendencies toward violence. Two alternative model have been postulated in literature as capable cause of stigma in individuals with epilepsy: the first model assumes a direct influence of epilepsy on stigma, meaning that perception of stigma will increase as seizure severity and lack of maintaining seizure control increases. The second model, which is psychosocial, assumes that other individual characteristics are also important and therefore have an explanatory role in the degree of stigma perceived by an individual with epilepsy. This study hypothesized that epilepsy is not globally stigmatizing and that the psychosocial factors are equally important in explaining perception of stigma among individuals with epilepsy. It foremost documents the prevalence of perceived stigma among a sample of patients with epilepsy and examined the causal factors of this stigma using some predictable variables.

Methods
Subjects
The subjects were selected from among patients on follow-up management at the clinics of two psychiatric facilities in Nigeria: the Neuro-psychiatric hospital Aro and the University College Hospital Ibadan.

Most of the patients in these clinics are either self-referred or brought by relatives. Only a few of the new patients at these clinics would have received any form of orthodox medical care for their illness before presentation.

A total of 264 subjects were interviewed over a 4 month counseling sessions at each of the clinic days. This sample size was based on the 37% cases of psychiatric morbidity found in a previous study Gureje (1991) among epileptics seen at the Neuro-psychiatric hospital Aro Nigeria.

Criteria for inclusion were: (a) epilepsy diagnosed on clinical and EEG findings, (b) adults epilepsy in the age range of 21-65 years, (c) absence of evidence of mental sub-normality or other gross diagnosable neurological disorders, (d) attendance at follow-up at the clinics for at least a period of three months prior to interview. This latter criterion is necessary so as to guarantee all vital investigations prior to clinical diagnosis.

Measures
Perceived Stigma

Due to the non-availability of an established culturally relevant instrument to determine perceived stigma among epileptics in Nigeria, it was imperative or the researcher to develop an instrument, which will help in assessing the concept. This was accomplished by employing the judgment of experts and learning directly from epileptic patients themselves Nunnally, (1978). In order to achieve this, a focus group discussion (FGD) session was conducted separately with a purposive sampling of 10 (5 men and 5 women) of epileptic patients who were on follow-up at the neurology clinic of the Neuro-psychiatric Hospital Aro, Abeokuta. The FGD was instituted due to the nature of the concept and the relative lack of background information. It was made to encourage patients to talk about what they perceived to be stigmatizing about their illness and what they perceived as their limitations as patients with epilepsy. They were asked questions on their general knowledge about their illness, the causes and the management of the illness. The researcher who also served as the moderator jotted points. A psychologist youth corper served as an observer. The subsequent scripts were reviewed, and it was possible to produce a list of 19 potential stigma items. Responses to the items were coded on a five point Likert format scale, ranging from never (score of zero) to often (score of four). The 19-item scale was pre-tested among 71 other epileptics who were also on follow-up at the same clinic. The purpose of the pre-testing was to further establish validity as well as the reliability of instrument. Internal consistency was established by obtaining a significant relationship between each item and the total score.

Correlation between each item and the total score ranged from +0.41 to +0.52 p<0.000 for all the items. Cronbach Alpha is +0.82 p<0.000. Split half reliability is +0.86 p<0.000. Factor ananlysis of the responses of 71 epileptics using principal component analysis with varimax rotation yielded a 6 factor, 7 items questionnaire, which made up the perceived stigma scale used for this study (see table 1).

The 6 factors that were yielded from the factor analysis are as follows: friendship domain, receptivity domain, fear of contamination domain, limitation domain, reproductive domain, and discrimination domain.

These six factors accounted for 64% of the variance of the entire 19 items.

Predictor variables
Neuroticism

This was measured using the Crown-Crisp Experiential Index (CCEI) formerly the Middlesex Hospital Questionnaire (HMQ) developed by Crown and Crisp (1966) as a self reported questionnaire providing information usually generated by a formal psychiatric consultation. It is used for research, screening for psychoneurotic with an overall score for emotionality or neuroticism and with further sub-scores in six clinical subscales of eight items respectively. The subscales are free-floating anxiety (A), Phobic anxiety (P), Obsessionality (O), Somatic concomitants of anxiety (S), Depression (D) and Hysterical anxiety (H).

In this questionnaire, subjects were normally requested to state how frequently they manifested the described symptoms. A score of 0, 1, 2, 3, and 4 were assigned to hte ranges of these frequencies from "not at all" (score of zero), through rarely (score of one), don't know (score of two), sometimes (i.e. three to four times – score of three) and certainly (score of four). Scoring was done in such a way that highest scores consistently indicated greater emotionality.
Depression

This was measured using the Becks Depression Inventory (BDI) (Beck; Ward;

Mendelson; Mock; & Erbough 1961), an instrument developed for the assessment of a stable-trait-like property of depression. It is a self-rating inventory and can as well be administered by interviewing. It measures severity of depression and therefore used as measure of treatment outcome. It comprises 21 items describing a specific behavior manifestation of depression. The inventory has been mainly used on psychiatric inpatients and outpatients with any diagnoses like schizophrenia, epilepsy. Internal consistency was demonstrated by obtaining a significant relationship between each item and total score. The split-half reliability is +0.78. Concurrent validity was assessed by comparing the total BDI scores with a 4-point clinical rating of the severity of depression (none, mild, moderate and severe).

Social Support

This is a self developed index, for the measurement of the number of people in the entire family knit (limited to nuclear family) that individual patients can turn to in a variety of situations such as finances and counseling and the degree of satisfaction derived from such network.

Other variables

Other variables are included in the explanatory model of perceived stigma, include age, gender, age at onset of illness, seizure type and duration of epilepsy.

Procedure

Data collection for this study extended through a period of 4 month. After the initial contact with the management of the two health facilities used as the study setting, permission was granted to create an Ad hoc Epilepsy Counseling Clinic which lasted through the duration of the study. The clinic collaborated with the consultant in charge of patient on follow-up treatment for the purpose of screening, assessing and counseling for the study.

All patients' case notes that were consecutively booked for appointment on a particular clinic day were screened for eligibility based on the inclusion criteria. Each eligible patient automatically qualified to be included as subjects for the study and none was excluded. They were then approached at the time of their visit to the clinic for informed consent and confidentiality was assured. No patient refused to participate. A Consultant Neurologist, blind to the psychological status of the subjects assessed the degree of seizure severity defined in relation to the seizure type and the frequency of attack of the seizure type Rosemary Ryna et al (1980). Both age at onset, and duration were included because of their theoretical relevance with information obtained from case notes review and patient self-reports. Age and sex were also included for their value in defining demographic characteristic of the patients.

All interviews were conducted with the translated Yoruba version of the questionnaire. The English version was administered to subjects who did not understand Yoruba.

Subjects who neither spoke nor understand English and Yoruba were excluded. All subjects had both version of the questionnaire read to them. The decision to read the questionnaire to them was informed by the fact that many of the patients could neither read English nor the Yoruba versions of the questionnaire. For consistency in the mode of interviewing however, an audio-recorded version of the translated version was done and always listened to by the researcher at the end of a particular clinic day.

A consultant neurologist who was blind to the subject's assessment status classified the seizure type and also defined seizure control. The Kappa statistic for inter-diagnostician reliability was calculated on 78 of the entire subjects. This was generally very good, ranging from 62 for a few classifications to 1 for most.

The procedure was repeated during every clinic days of the week and was done at the two health facilities for the study until the desired number of subjects were seen.

Data analysis

Two analytic procedures were utilized. First the Pearson Product Moment correlation coefficients were computed between each of the nine prediction variables and perceived stigma. The probability statistic of 5% or less was taken to indicate a significant result

Stepwise multiple regressions were computed for perceived stigma using the nine independent constructs. The assumptions underlying regression analysis (homogeneity of variance, and independence and normally of error variance) were verified statistically. For this analysis only variables, which reached the conventional level of statistical significance (P<0.05) were taken to indicate a significant result.

Results
Descriptive Data

The mean age of the 264 subjects was 32.6 years (SD 10.2), and they had a mean of 7.2 years of basic education (SD 5.0). The mean age at onset of their seizure disorder was 20.4 years (SD 10.9), and the mean duration of their seizure disorder was 14 years (SD 9.2). One hundred and fifty-four, 58.6% were males while 110 (41.1%) were females. One hundred and seventeen (44.3%) were diagnosed as having primary generalized epilepsy, four (1.5%) diagnosed as partial epilepsy with simple symptomatology, 13 (14.9%) diagnosed as partial epilepsy with complex symptomatology, 19 subjects (7.2%) were diagnosed as epilepsy of the undifferentiated type, while 111 (42.0%) received a diagnose of partial epilepsy with secondary generalization.

Majority of the subjects were on a single drug treatment regimen. Forty (15.2%) received Carbarmazepine only. One hundred and twenty-six (47.7%) received Phenobarbitone only. Twenty-four (9.1%) received phenytoin only, while fifty-two (19.7%) received both drug combination of phenobarbitone, Carbamazepine and phenytoin. Twenty-two (8.3%) received both in addition to their anticonvulsant drugs a prescription of neuroleptics. Seventy-five (75%) were of low socio-economic status. Most were employed as 166 (62.9%) indicated, 56 (21.2%) were unemployed while 42 (15.9%) were never employed.

Further distributions of the data showed that most patients appeared stigmatized by their epilepsy: 68% reported that it did affect whether people want to be friends with them, 61% reported that the illness affects whether people like them or not. 70% indicated that due to their epilepsy people around them do not want to eat with them for fear of contamination. 74% however believed that people with epilepsy could have sexual intercourse just like ordinary people. 54% believed that employers and teachers they have dealt with have treated them fairly 60% believed that most people they know are willing to be educated about epilepsy, while 38% think that if they are nervous, it can bring on an attack.

Bivariate analyses

The seizure, psychological and socio-demographic factors were compared against each other and on the perceived stigma. Increased stigma was associated with poor seizure control ($r=0.31$, p-0.004), duration of epilepsy ($r=0.34$, p=0.005), depression ($r=0.43$, p=0.001), neuroticism ($r=0.35$, p=0.005) and social support ($r=0.41$, p=0.001). Age was significantly associated with duration of epilepsy ($r=0.60$, p=0.000) and depression ($r=0.50$, p=0.000). Gender was not related to age, duration of epilepsy; seizure type, age at onset of illness and seizure control. Social support was related to depression ($r=0.44$, p=0.001), neuroticism ($r=0.34$ p=0.003), duration of epilepsy, ($r=0.40$, p=0.003) and seizure control ($r=0.37$, p=0.004).

Multivariate Analyses

From these independent variables the five significant variables associated with increased perceived stigma were entered into a stepwise multiple regression analysis, two variables remained significant. The social support two (p=0.005) and depression P = 0.019.

Discussion

This study evaluated the extent to which persons with epilepsy in Nigeria felt stigmatized by the disorder and also document the relative explanatory power of some specific seizure. psychological and demographic factors on perceived stigma. In order to measure stigma a scale was developed that quantitatively defined the concept and extent to which individuals with epilepsy feel they are the victims of prejudice. The results of this study suggest that Nigerian individuals with epilepsy feel globally stigmatized by the disorder. Among the subjects studied, the majorities felt that other people discriminated and act differently to them because of their epilepsy. This finding run contrary to earlier findings by Aziz et al (1997) and Westbrook et al (1995) who found among their samples that epilepsy is not universally stigmatizing. In this study Aziz et al (1997), which was investigated among individuals with epilepsy in Pakistan. it was concluded that educational level, difficulties in daily living activities and decisions about marriage and children was related to stigma. Rosemary Ryan et al (1980) on the order hand found that the relationship between the severity of seizure and the perception of stigma was mediated by other psychosocial characteristics. Based on stigma theory, we expected that attributes of a stigmatizing mark should be more among patients who could not maintain good seizure control, are depressed, neurotic or had history of long duration of illness. In line with this theoretical proposition, investigation of the association between seizure controls, age at onset of epilepsy, duration of illness, depression, neuroticism, gender and age on perceived stigma was done. It was found that individual adults with epilepsy who had higher elevated scores on depression, neuroticism, and those who had poor seizure control longer duration of illness and lack of social support, also reported more stigmas.

This confirm earlier report Rosemary Ryna (1980) who found that subjects with frequent tonic-clonic seizures were more likely to report feeling of stigma by their epilepsy, it further confirmed the interest of Arnston et al 1986 and Herman et al (1990) which found perceived stigma to be related to depression, somatic symptom and general psychiatric distress of the subject studies. Stigma theory in its current stage or development implies strong and direct relationship between variables. However, the results of this study suggest that such relatedness may be more subtle and indirect. In comparison with more formally developed theories from which testable model are readily derived, stigma theory is less explicit and may be more challenging to translate into discrete hypothesis. Rather than prematurely abandon what could be a useful theory for a broad range of research disciplines, it is recommended that further clarification be sought in this endeavor. As each new hypothesis is modified with empirical testing, it is believed that stigma theory will merit the continued attention of future researchers. Several new hypotheses can be proposed for future analysis of a modified stigma model. First, the attributes of a stigmatizing mark vis-à-vis visibility and unpleasantness may be mediated by other characteristics of the individual, such as personality traits and general adjustment, and the particular social context of individual.

TABLE 1: FACTOR ANALYSIS OF THE RESPONSES OF 71 ADULT EPILEPTICS TO THE PERCEIVED STIGMA SCALE

Factor Loadings	Factor	Item	Cases	Raw Mean	Score S.D.
+0.92	1	Do you think having epilepsy affects whether people want to be friends with you	71	2.41	1.20
+0.56	1	Do you think having epilepsy affects whether people like you or not	71	2.32	1.19
+0.97	2	Do you think most people you know are willing to be educated about epilepsy?	71	2.47	0.74
+0.93	3	Do you think people that know you have epilepsy will not want to eat with you for fear of contamination?	71	1.95	1.23
+0.97	4	Do you think that if you really get nervous/tense I can bring on a seizure	71	2.07	0.88
+0.98	5	Do you think that people with epilepsy can have sexual intercourse just like ordinary people?	71	2.05	1.07
+0.98	6	Do you think employers/teachers you have dealt have treated you fairly	71	2.91	1.24

TABLE 2: REGRESSION ANALYSIS OF PREDICTIONS OF STIGMA

Study Variables	Adjusted R^2	R^2 Change	Beta weight
Seizure Factors	.30	.34*	-0.32
Age at Onset of illness			-0.21
Duration of epilepsy			-0.18
Seizure type[+]			-0.04
Psychological Factors[+]	.41	.10**	
Depression			0,16
Neuroticism			0.12
Socio-demographic Factors	.11	.03*	-0.19
Age			-0.19
Sex[+]			-0.15
Social Support			0.14

+ = Converted to Dummy variable in the regression analysis.

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