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Pattern and determinants of self-reported enacted stigma among rural dwellers living with epilepsy attending a tertiary health facility in Enugu State Nigeria

Birinus A. Ezeala-Adikaibe[a,*], Justin U. Achor[b], Eddy Aneke[c], Uchenna Ijoma[a], Obinna D. Onodugo[a], Casmir Orjioke[a], Chinwe Onyekonwu[a], Oluchi Ekenze[a]

[a] *Department of Medicine, University of Nigeria Teaching Hospital, Ituku/Ozalla, Nigeria*
[b] *Federal Neuropsychiatric Hospital, Enugu, New Haven, Nigeria*
[c] *Department of Medicine, Enugu State University Teaching Hospital, Enugu, Nigeria*

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Purpose: Epilepsy related stigma is a barrier to recovery and has been linked to a broad range of psychosocial consequences and has the potential to influence the provision of care to people with epilepsy. Understanding the determinants of enacted stigma in epilepsy is relevant in the understanding of the burden of epilepsy in Nigeria.
Method: Using a semi-structured questionnaire, a cross-sectional descriptive study was conducted among rural dwellers receiving treatment for epilepsy in a tertiary referral specialist hospital in Enugu, south east Nigeria.
Results: The participants consisted of 108 patients, 63% of whom were males. Most patients 99(91.7%) reported experiencing stigma in the past. The commonest forms of enacted stigma were being regarded as having 'spiritual attack' 88(81.5%) and restraining from interacting with others 49(45.4%). Most individuals who received nonorthodox treatment 55(55.6%) experienced stigma. Severely stigmatized individuals were more likely to be females. Age of onset of epilepsy, use of non-orthodox treatment, seizures occurrence in public places and the presence of physical injuries positively correlated with enacted stigma.
Conclusions: The burden of epilepsy related enacted stigma is high among rural dwellers attending a tertiary medical outpatient clinic in Enugu, southeast Nigeria.

1. Introduction

One major contributor to the social and psychological problems in epilepsy is stigma. Jones et al [1] defined stigma as a 'mark' (attribute) that links a person to undesirable characteristics (stereotypes) which can only be applied when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold. Epilepsy stigma refers to the extent to which people with epilepsy are separated from society on the basis of the meanings that are attached to the term "epilepsy" [2]. Stigmatization of people with epilepsy (PWE) exists in all societies [3–5]. Stigma is a barrier to recovery and has been linked to a broad range of psychosocial consequences, including a loss of self-esteem, social withdrawal and isolation and has the potential to influence the provision of care to people with epilepsy [6]. Negative perceptions of epilepsy among medical professionals and social discrimination resulting from stigma can impair the service utilization, particularly when there is scarcity of resources for treatment, rehabilitation and research [5–7]. Because stigma is culturally dependent, it varies from one locality to another as well as with clinical contexts and social status of the individual [4,5,8–11].

Reports on gender differences in the pattern of stigma in the sub Saharan Africa (SSA) continent are conflicting [5,9,12–14]. Higher burden among females have been associated with factors such as strict patriarchal structure of many communities, lower social status, lower level of education, and higher rates of unemployment among women. Higher levels of stigma among males may be related to higher levels of socialization among males hence greater chances of exposure to stigma. Higher rate of employment may also expose them to work related stigma.

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[*] Corresponding author.
E-mail address: birinus.ezeala-adikaibe@unn.edu.ng (B.A. Ezeala-Adikaibe).

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Stigmatizing experiences may differ with age and age of onset. This is particularly significant considering the level of awareness and practice of epilepsy in schools and the community. Earlier studies had documented that the perception of families about epilepsy and the effect of early age of onset of epilepsy in fostering stigmatization as well as contributing to the poor social outcomes associated with epilepsy [15–17].

Stigma has been grouped into felt (perceived) or enacted [11]. Enacted stigma manifests as discrimination against the stigmatized person imposed by others, whereas felt stigma is the fear of enacted stigma experienced by the stigmatized person. Although studies from Europe have reported high rates of felt (perceived) stigma, [10,18] all forms of stigma have been reported to be high in Asia and the Middle East [4,7,11,19–21]. In a survey of 243 PWE from Ecuador, although 65.8% felt stigmatized, 44% reported episodes of enacted stigma [22]. The pattern of epilepsy related stigma in Nigeria may closely resemble that from other developing countries. Patient's/caregiver's beliefs about epilepsy may expose them to stigmatizing factors and environments [23]. With a prevalence of epilepsy ranging between 4.3–6 per 1000 and low levels of knowledge and practice of epilepsy in urban and sub urban areas in south east Nigeria [24,25], enacted stigma is expected to be a common experience among PWE. Understanding of stigmatization in epilepsy and its correlates is relevant to the understanding of the burden of epilepsy in Sub Saharan Africa (SSA).

The aims of this study were 1) to determine the pattern of self-reported enacted stigma among young adults and adults living with epilepsy. 2) to determine the distribution of enacted stigma by gender, age of onset and current age of PWE and 3) to determine the correlates of self-reported enacted stigma among rural dwellers living with epilepsy who were attending a tertiary facility in south-east Nigeria.

Table 1
Socio-demographic and seizure related characteristics of the study participants.

Characteristic	
Gender	
Male	68(63)
Female	40(37)
Age	
Mean(SD), Range	33.6(15.4), 11–80
Males	34.4(16.4)
Females	32.4(13.4), p = 0.51
Marital Status	
Single	65(60.2)
Marries	27(25)
Separated, divorced or widowed	16(14.8)
Educational status	
Primary school education or none	21(19.4)
Secondary school education	56(51.9)
Tertiary level education	31(28.7)
Occupational Status	
Working	56(51.9)
Not working	25(23.1)
Student	27(25)
Seizure characteristics	
Duration of epilepsy (years)	
Mean(SD), Range	13(12), <1–64
Age of onset of epilepsy (years)	
Mean (SD), Range	20.6(16.8) <1–78
Seizure frequency in the past six months	
None	21(19.4)
1–5	67(62)
6–10	3(2.8)
>10	17(15.7)
Seizure types	
Always the same always	29(26.9)
Varies	79(73.1)
Seizure related injury[a]	
Severe bruises/lacerations	57(52.8)
Burns	13(12)
Dislocation/fractures	3(2.8)
Loss of teeth	3(2.8)
Fell on a nail	1(0.9)
Treatment of seizures	
I sometimes miss taking drugs	60(55.6)
I have used non-orthodox treatment	73(67.6)
I had unpleasant experiences while using non-orthodox treatment.	– 57(52.8)
Unpleasant Experiences while using non-orthodox treatment[β]	
"Sucking" epilepsy from my spine	7(6.5)
Working for the healing center	1(0.9)
Scarification marks	31(28.7)
Public deliverance prayers (exorcisms)	41(37.9)
Sacrifices	3(2.8)

[a] More than one experience may be reported.