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Community integration of people living with epilepsy in a Nigerian population

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ABSTRACT

Background: Epilepsy is a chronic seizure disorder that affects numerous people worldwide. Community integration (CI) is the ultimate goal of rehabilitation of any chronic condition. There seems to be a dearth of research on CI among people living with epilepsy (PLWE).
Aim: The present study was designed to investigate on the level of satisfaction with CI and its associated factors in a Nigerian PLWE.
Methodology: This was a cross-sectional survey of 70 adult PLWE (28.6% females; mean age = 34.91 ± 16.21 years) consecutively recruited from three purposively selected specialized clinics in Anambra State of South-eastern Nigeria. The Reintegration to Normal Living Index was used to assess the level of satisfaction with CI among the participants. Data was analysed using Spearman Rank Order Correlation, Mann-Whitney U and Kruskal-Wallis tests at 0.05 level of significance.
Results: The total level of satisfaction with CI among PLWE was poor (59.76 ± 23.24). PLWE were severely restricted in nine out of the fourteen CI scores but were mildly or moderately restricted in the remaining five CI scores. The participants' total level of satisfaction with CI significantly correlated with their annual ($r = -0.319$; $p = 0.007$), six-month ($r = -0.275$; $p = 0.021$) and one-month ($r = -0.221$; $p = 0.025$) episodes of seizures, and was significantly influenced by their occupational status ($k = 12.15$; $p = 0.009$) and highest educational attainment ($k = 12.39$; $p = 0.006$).
Conclusion: Generally, the total level of satisfaction with CI among PLWE was poor. There is need for interventional programmes aimed at integrating PLWE into their various communities with special emphasis laid on unemployed and less educated ones having high seizure frequency.

1. Introduction

Epilepsy is a chronic seizure disorder that affects almost 70 million people worldwide. Eighty five percent of people living with epilepsy (PLWE) live in the developing world, with 10 millions living in Africa (World Health Organization, 2003). Epilepsy is the most common non-infectious neurological disease in developing countries, and has a Nigerian prevalence of 5.3–37 per one thousand (Akinsolure and Adewuya, 2009). There is more to epilepsy than having recurrent seizures (Kabir et al., 2005). Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries (World Health Organization, 2003). Across the world and throughout history, epilepsy has been a culturally devalued condition (de Boer et al., 2008). People living with epilepsy (PLWE) are exposed to discrimination in education, employment and promotion at work (de Boer et al., 2008; Kabir et al., 2005); violence, abuse, and health insurance and marriage restrictions (Petersilia, 2000); social ostracism (de Boer et al., 2008) among others. These may negatively influence the level at which PLWE are integrated into their community.

Community integration/reintegration (CI), defined as the opportunity to live in the community and be valued for one's uniqueness and abilities like everyone else, has attracted considerable attention in rehabilitation of sufferers of chronic conditions (Marco et al., 2007; McColl et al., 2001; Salzer, 2006). The goal of rehabilitation has shifted from only mere survival and improvement in physical, psychological and social health to include how well a sufferer

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of a chronic debilitating condition is integrated into their community (Griffen et al., 2010; Marco et al., 2007; McColl et al., 2001; Pang et al., 2011). The benefits of CI are numerous and include physical, social, psychological, health, and quality of life related outcomes (Stumbo et al., 2015). CI has been conceptualized as a multidimensional construct with its constituting domains differing with authors. The domains of CI may include health status, recreation/leisure, mobility, social network or support, residential integration, employment/economic integration, employment stability, education, personal satisfaction, independent living, self-care, spirituality/religion, citizenship and civic engagement, and so on (Griffen et al., 2010; McColl et al., 2001; Pang et al., 2011; Salzer, 2006). Following an increasing emphasis laid on CI during rehabilitation of chronic disease conditions, satisfaction with community integration has been variously assessed in some chronic conditions and life situations (including stroke, head injury, spinal cord injury, dementia and old age), and has been found to be significantly influenced by some factors such as age, gender and level of social support (Baseman et al., 2010; Marco et al., 2007; McColl et al., 2001; Pang et al., 2011). However, there seems to be a dearth of research on satisfaction with CI among PLWE.

Epilepsy adversely impacts on the quality of life of the sufferers in various ways including physical hazards, psychological consequences, social exclusion and stigma, marital, academic and employment denials (England et al., 2012; World Health Organization, 2003). With the physical, psychological, social and economic burdens epilepsy can have on its sufferers, one may wonder if the sufferers' level of community integration will be negatively affected, considering the fact that some of these aspects of life are also domains of community reintegration. Studies on PLWE have generally concentrated on health and quality of life (QOL) (Birbeck et al., 2002; Canuet et al., 2009; Fawale et al., 2014; Kinyanjui et al., 2013). Hardly is there one available on CI among PLWE. In as much as QOL and CI are closely related, they represent two different constructs (Wood-Dauphinee and Williams, 1987). CI is concerned with community participation, the ability of an individual to function and be valued in his community just like everyone else, whereas quality of life can encompass all aspects of wellbeing (Marco et al., 2007; 2001; Salzer, 2006). There is a handful of instruments for assessing quality of life and CI among PLWE. The most popular QOL of scales utilized among PLWE are different versions of Quality of Life in Epilepsy Inventory (QOLIEs). For CI, most of the popular instruments (such as Community Integration Questionnaire and Community Integration Measure) are disease-specific (acquired brain injury) and cannot easily be used among other pathological groups. There is no epilepsy-specific instrument for assessing CI. The Reintegration to Normal Living Index (RNLI), unlike the previously mentioned measures of CI, is a generic scale that has wide range of application and has been validated and variously used in Nigeria (Hamzat and Peters, 2009; Obembe et al., 2010, 2013; Akosile et al., 2016).

The RNLI has some intersections with the QOLIEs. Both assess individual's self-care, daily, work, recreational and social activities. The QOLIEs further assess other aspects of wellbeing including emotional and physical health, energy, cognition, speech, general health, and so on. On the other hand, the RNLI further assesses individual's public image, ease of moving at home, inside and outside the community, functional self-efficacy and family role. In interventions targeted against stigma in epilepsy, changes in QOL and stigma have frequently been used as outcomes for ascertaining the effectiveness of such interventions (Birbeck, 2006; Heijnders and Van Der Meij, 2006). Considering the fact that stigma can alienate one from one's community, and that CI can explore additional life dimensions when compared with QOL, adding CI to the outcomes for determining the effectiveness of stigma reduction campaign in epilepsy may provide additional value. The present study was therefore designed to investigate the level of satisfaction with CI and its associated factors in a Nigerian sample of PWLE

2. Materials and methods

This was a cross-sectional survey involving 70 adults (18 years and above) PLWE consecutively recruited from three purposively selected specialized clinics (RISE Clinic at Adazi-Ani; Nnamdi Azikiwe University Teaching hospital at Ukpo; and Neuropsychiatric Hospital Nawfia) in Anambra State of South-eastern Nigeria. These clinics were selected because they were offering specialized care to PLWE. This study was approved by the Ethical Committee of Nnamdi Azikiwe University Teaching Hospital (approval number: NAUTH/CS/66/VOL.7/59). Permission was sought and obtained from the management of the various clinics before commencement of data collection. Each individual living with epilepsy gave his/her informed consent after the procedure of the study has been duly explained to him/her. All consenting individuals living with epilepsy were consecutively recruited for the study.

Information on socio-demographic (age, gender, location, marital status, occupational status, and highest educational attainment) and clinical (age at onset of epilepsy, episodes of seizure, comorbidities, presence of other therapies and usage of assistive devices) variables of the participants were obtained through interview. The Reintegration to Normal Living Index (RNLI) was used to assess the level of satisfaction with CI among the participants (Pang et al., 2007, 2011; Murtezani et al., 2009). RNLI is a generic scale developed to assess, quantitatively, the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities (Wood-Dauphinee et al., 1988). It can be used among different populations including community-dwelling older adults, individuals with arthritis and central nervous system disorders (Stroke Engine, 2008). The RNLI is an 11-item, valid and reliable instrument with eleven domains: indoor mobility, community mobility, distance mobility, self-care, daily activities (work and school), recreational activities, social activities, family roles, personal relationships, presentation of self to others, and general coping skills (Korner-Bitensky et al., 2008; Wood-Dauphinee et al., 1988). The first 8 items in the RNLI represent 'daily functioning' subscale while the remaining 3 items represent 'perceptions of self' subscale (Daneski et al., 2003). Each item is accompanied by a 10 cm visual analogue scale with 0 signifying no integration and 10 signifying full integration (May and Warren, 2002). A total score is obtained by the summation of the individual item scores. The total score is then normalized to 100 such that the minimum and maximum possible scores are 0 and 100, indicating no and full integration respectively. Hence, with the RNLI, fourteen community reintegration scores (11 domains, 2 subscales and total score) can be obtained. Scores of less than 60 indicate severe restrictions in self-perceived community reintegration whereas scores of 60 through 99 indicate mild to moderate restrictions in self-perceived CI. The English version of the RNLI was used on participants who could speak or understand English Language. An Igbo language translation was administered on individuals who could only speak and understand the native Igbo Language. Both versions were validated on people with disability (internal consistency coefficient, $\alpha = 0.84$; construct validity coefficient, $r = 0.70$; concurrent validity coefficient, $r = 0.81–0.95$) (unpublished data). The data collection for the present study took place over a period of five months (from March to July 2015).

Data was analysed using the Statistical Package for the Social Sciences (SPSS) (version 20). Descriptive statistics of frequency counts, percentages, range, mean and standard deviation were used to summarise the socio-demographic and clinical variables and the level of satisfaction with CI among the participants. Spearman rank-