PSYCHOSOCIAL EFFECTS OF LIVING WITH EPILEPSY: CASE STUDY IN A TERTIARY HOSPITAL IN NORTH WEST NIGERIA

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Abstract

People with epilepsy (PWE) experience not only the physical signs and symptoms that manifest mainly as seizures or epileptic fits but also psychosocial effects. The psychosocial problems negatively affect all facets of the PWE life that include; anxiety associated with fears of seizures, depression with risk of suicide, personality changes and psychoses. They also experience anger/frustration, lower self-esteem, lack of confidence, feeling of humiliation/embarrassment, social withdrawal, neurodevelopmental disorders, cognitive deficits, educational attainment and achievement problems. PWE also experience family and marital relationships problems causing family dysfunction, child bearing/rearing problems, higher divorce rates, difficulty getting married and sexual dysfunction. They also have work input and employment opportunity problems leading to under employment, unemployment, and dismissal from work. PWE are also stigmatized as being possessed by devil or evil spirits and also face isolation, discrimination, ostracism, and reduced quality of life. However, this clinical paper is on anxiety, depression, specific phobia and stigma. Case study of twenty-eight (28) year old client attending neurology clinic of a tertiary hospital and diagnosed of epilepsy (focal impaired awareness seizures) by consultant neurologist and then referred him to clinical psychologist for clinical assessment and therapy was presented in this paper. A comprehensive psychodiagnostic assessment that comprised clinical interview, administration of psychological tests, and behavioural observations were conducted and the client benefitted from therapeutic interventions with good outcome. There is the need for psychologists to be employed and included as members of the interdisciplinary team of healthcare professionals managing PWE to treat the psychosocial effects.

***Keywords*:** Case study, Living with epilepsy, Psychosocial effects, Seizures, Tertiary hospital, North West Nigeria

INTRODUCTION

The task force of the International League against Epilepsy (ILAE) in 2005 conceptually defined Epilepsy "as a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition" (Fisher et al., 2014). While "an epileptic seizure is a

transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain" (Fisher, 2014). These imply that a seizure is an event and epilepsy is the disease involving recurrent unprovoked seizures (Fisher et al., 2014, p.476). However, another ILAE task force formulated the practical (clinical) definition of Epilepsy that was adopted in December, 2013 and which stated that:

> Epilepsy is a disease of the brain defined by any of the following conditions; At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart; One unprovoked (or reflex) seizure and probability of further seizures similar to general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; Diagnosis of epilepsy syndrome (Fisher et al., 2014, p.477).

Furthermore, Epilepsy is also defined "as a chronic disease of the brain characterized by recurrent seizures, and is sometimes accompanied by loss of consciousness and control of bowel or bladder function" (World Health Organization [WHO], 2024a, Overview section, para.1). The "seizure episodes are as a result of excessive electrical discharges in a group of brain cell and seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions" (WHO, 2024a, Overview section, para.2).

PWE experiences the psychosocial effects of epilepsy such as anxiety associated with fears of seizures, depression with risk of suicide, personality changes and psychoses. They also experience anger/frustration, lower self-esteem, lack of confidence, feeling of humiliation/embarrassment, social withdrawal, neurodevelopmental disorders, cognitive deficits, educational attainment and achievement problems. PWE also experience family and marital relationships problems causing family dysfunction, child bearing/rearing problems, higher divorce rates, difficulty getting married and sexual dysfunction. They also have work input and employment opportunity problems leading to under employment, unemployment, and dismissal from work. PWE are also stigmatized as being possessed by devil or evil spirits and also face isolation, discrimination, ostracism, and reduced quality of life which could negatively affect their various psychosocial lives and exacerbate the physical symptoms.

"Epilepsy is associated with stigma, psychological, social, cognitive and economic repercussions" (Fisher et al., 2014, p.479). Epilepsy is a chronic neurological condition that is greatly vulnerable to different mental health problems due to its enormous biological, social and psychological burden (Wubie, Alebachew, & Yigzaw, 2019).

However, this case study is on anxiety, depression, specific phobia, and stigma. Anxiety is defined "as an emotion characterized by feelings of tension, worried thoughts, and

physical changes" (American Psychological Association [APA], 2024a, Anxiety section, para.1). Specific phobia is defined "as an intense, persistent, irrational fear of a specific object, situation, or activity, or person. People with phobia will frequently go to great lengths to avoid the object or situation in question e.g. fear of blood" (Penn Psychiatry, 2023, Specific phobia section, para.1). Depression is defined "as extreme sadness or despair that lasts more than days. It interferes with the activities of daily life and can cause physical symptoms such as pain, weight loss or gain, sleeping pattern disruptions, or lack of energy" (APA, 2024b, Depression section, para.1).

Stigma is classically defined "as an attribute that is deeply discrediting. A discredited attribute could be readily visible, such as one's skin color or body size, or could be hidden but nonetheless discreditable if revealed, such as struggles with mental illness" (Goffman 1963 as cited in Clair, 2018, p.1). "Stigma reduces someone from a whole and usual person to a tainted, discounted one, thus, the stigmatized are perceived as having a spoiled identity" (Goffman, 1963 as cited in Ahmedani, 2011, p.2). Stigma results in the stigmatized person becoming tainted or discounted, the effects of stigma on the individual include isolation, low self-esteem, depression, self-harm, employment deprivation, poor academic achievement and social relationships, and suicide (Liamputtong & Rice, 2021). Stigmatizing processes can affect many spheres of people's lives in such areas as earnings, housing and health (Link & Phlen, 2001). The stigmatized faces discrimination, stereotype, and threats to personal and social identity (Major & O'Brien, 2005).

"People with epilepsy and their families frequently suffer from stigma and discrimination. In many parts of the world the true nature of epilepsy has also long been distorted by myths, fear and mistaken notions about the disorder" (WHO, 2024b, Overview section, para.3). In Nigeria, epilepsy is a stigmatizing disorder which has a negative effect on the day to day activities of those with the condition (Akinsulore & Adewuya, 2010). Also, the stigma associated with epilepsy in Nigeria, is at times more severe than the side effects of antiepileptic drugs (Akinsulore & Adewuya, 2010).

LITERATURE REVIEW

The social theories of stigma discussed below were the theoretical framework of this case study because stigma is the bases of the anxiety and depression in the client:

The social psychological and cognitive theory of Stigma is the latest line of research that is more general in nature, and not confined to the specific of mental illness or illness in general. It analyzes any situation in which the self is threatened (Martin, Lang, & Olafsdottir, 2008).

Social psychologists have studied the intentions, motives, and emotions of those who may stigmatize as well as those who are potential victims of stigma. This theory suggests that stigmatizing attitudes are hidden in motivation, and unknown by individuals (Banaji & Greenwald, 1994 as cited in Martin, Lang, & Olafsdottir, 2008). However, other social psychologists were of the view that conscious motivations and emotions drive stigma. For example, anxiety in interacting with people with stigmatized conditions can occur in individuals who hold very detrimental feelings and in those attempting to override known social prejudices. In both instances, the level of anxiety is likely to be expressed in words and actions (Haslam, 2006; Stephan & Stephan, 1985 as cited in Martin, Lang, & Olafsdottir, 2008). Similarly, through a distinguishing psychological process, individuals stigmatized by others due to a certain circumstance may experience negative self-stigma (Crocker, Cornwell, & Major, 1993 as cited in Martin, Lang, & Olafsdottir, 2008). Furthermore, the victim's knowledge of having a diminished social identity can also influence the perception and response to the social slights and to the acts of discrimination (Blaine & Crocker, 1993 as cited in Martin et al., 2008). Finally, understanding the pervasive nature of the over generalized belief held by others about them in the society set up a stereotype threat that can negatively affect the stigmatized ability, particularly in situations where the stereotypes apply and also strengthen the stereotype, and the prejudice and discrimination that follow from it (Steele & Aronson, 1995 as cited in Martin et al., 2008). This theory relates to this case study because the entrenched social pressures against PWE will cause anxiety and depression in the client.

The Bruce Link and Jo Phelan theory argue that stigma is the co-occurrence of several components that includes labeling, stereotype, separation, status loss, and discrimination (Link & Phelan, 2001 as cited in Ahmedani, 2011). First, labeling develops as a result of a social selection process to determine which differences matter in society. Differences such as race are easily identifiable and allow society to classify people into groups. The same situation may occur when society reacts to the untreated outward symptoms of several severe mental illnesses. Labels connect a person, or group of people, to a set of undesirable characteristics, which can then be stereotyped. This labeling and stereotyping process gives rise to separation. Society does not want to be associated with unattractive characteristics, thus hierarchical categories are created. Once these categories develop, the groups who have the most undesirable characteristics may become victims of status loss and discrimination. The entire process is accompanied by significant embarrassment by the individuals themselves and by those associated with them (Link & Phelan, 2001 as cited in Ahmedani,

2011). This theory also relates to this case study because the social discrimination, ostracism and out caste of PWE will result to anxiety and depression in the client.

Constantinou (2020) conducted a study on CBT for temporal lobe epilepsy and presented the case report revealing improvement in cognition, quality of life, medical needs, and psychological functioning. The case report was of 15-year-old boy diagnosed with medial temporal lobe epilepsy. CBT interventions were provided in the following, stigma and self-image relating to epilepsy, low self-esteem, fears about potential seizures at school, stress and tensions at home. After the 12 weeks of CBT, the client, his parents and his school advisor all reported qualitative and quantitative improvements in the above mentioned psychosocial problems.

Kim et al. (2023) conducted a study on the effect of CBT on depression of PWE. The study comprised 16 PWE with depression who received CBT and 30 PWE with depression that serve as control and did not receive CBT. The mean number of CBT sessions per client was 7.2 in the CBT group. Beck Depression Inventory-II (BDI-II) and Patient Health Questionnaire-9 (PHQ-9) were administered before and after the CBT sessions in the CBT group, while the PHQ-9 was administered at baseline and follow-up in the control group. The difference in PHQ-9 and BDI-II scores were analyzed between the pre- and post-CBT periods in the CBT group and the difference between baseline and follow-up PHQ-9 scores was compared in the control group. The interpreted statistical results demonstrated a significant improvement of depression in PWE.

Willems et al. (2019) conducted a cross sectional multicenter study on counselling and social work for PWE, demand, frequent content, patient satisfaction, and burden of disease. A total number of 435 patients were registered at six ECS sites. The most common reasons for counselling were general information needs, administrative help, problems with education or work and recreational activities. In addition, 6.2% reported epilepsy-related questions on family planning as a specific reason for desiring counselling. Referrals by the treating physicians was the most frequent reason for receiving counselling through ECS (62.5%), and most clients preferred to receive a personal consultation (73.1%). Client satisfaction as measured by the ZUF-8 client satisfaction score was high and 83.9% of clients stated they would recommend ECS. Disease related job loss or change in school was avoided in 72% of 82 clients. It was concluded that epilepsy counselling services are necessary, valued, and effective institutions for PWE complementing outpatient and inpatient care.

CASE STUDY

Client A.A is a twenty-eight (28) year old male job applicant attending the neurology clinic of a tertiary hospital in North West Nigeria and diagnosed of epilepsy (focal impaired awareness seizures) by the consultant neurologist. The client was subsequently referred to the clinical psychologist by the consultant neurologist for clinical assessment and therapy inside the teaching hospital folder of the client after adequately discussing and informing the client about the need to see a clinical psychologist.

After receiving the client folder with the written referral (consult form) in it, the client sat comfortably in one of the quite consulting room of the neurology clinic. The clinical psychologist introduced himself to client A.A, ensures him of confidentiality, right to conservation of time, and obtained the informed consent of the client for the clinical assessments and the subsequent therapies.

A comprehensive psychodiagnostic assessment that comprised clinical interview, administration of psychological tests, and behavioural observations were conducted. These were documented in the client hospital folder without violating confidentiality.

Clinical interview revealed that the client fell down in a hospital and became unconscious after seeing blood and blood stained bandage and therefore decided to seek for medical attention. Client stated that he fainted ten times within a span of ten years whenever he went to hospital for various reasons and sees blood. Also, the client stated that he usually fell down and faint whenever something frightened him. The family history of the client indicated that he is the eighteenth child of his polygamous father. Client mother is the fourth wife of his father and client is the second among the four children of his mother. The father of the client died when the client was very young. Client stated that there were no relationship problems in their polygamous family, that he had cordial relationship with all family members. Client stated that he was born in a hospital and was not told of any problem experienced by his mother before and after his delivery. Client also stated that he has no history of a major childhood illness.

Client had primary, secondary, and university education and describes his performance as very good and his feelings as very nice in the primary and secondary schools, and good and nice respectively in the university. About his occupation, client graduated not long ago from the university and is a job applicant which he mentioned as becoming difficult to get. Client is not married and hopes to do so after getting a job. Client stated that he does not abuse drugs. Furthermore, client mentioned that the most important person in his life is his mother and his life's goal is to get married and have children. The hobby of the client is playing and watching football but it has been long that he played.

Tests Administered

Based on the clinical interview, the following psychological tests were administered to the client; Symptom Distress Checklist-90 (SCL)-90 (D-depression; E-anxiety and G-phobic anxiety scales (Derogatis, Lipman, & Covi, 1973); State Trait Anxiety Inventory (STAI) Form Y-1 and Form Y-2 (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1977a, 1997b); Incomplete Sentences Blank (ISB)-Adult Form (Rotter & Willehmann, 1947).

Test Results

Below are the test results of the administered tests.

Tests Results of the SCL-90

The SCL-90 scores of the client showed the following; D-Depression = 21/11.85; E-Anxiety = 16/9.10; G-Phobic Anxiety = 7/5.75. Based on these scores the client scored higher than the adult norms (Nigerian) in the depression, anxiety, and phobic anxiety scales of the SCL-90 as such the client manifested symptoms of those scales (Omoluabi, 1997c).

Tests Results of STAI Y-1 and Y-2

The STAI Form Y-1 test score of the client indicated a score of 49/33.59 and the STAI Form Y-2 indicated a score of 49/37.54. These showed that the client had state anxiety, which is a momentary or transitory or situation specific anxiety and trait anxiety, which is the relatively stable predisposition of an individual to being anxious respectively (Omoluabi, 1997d).

Incomplete Sentences Blank (ISB)-Adult Form-Interpretation

The ISB is a projective test and the qualitative (clinical) interpretation done semantically indicates that the client has anxiety and depression manifestations (Rotter, & Willehmann, 1947).

Behavioural Observations

Client was anxious, sad, worried and fearful of blood or blood stained bandage.

Therapy

Client A.A benefitted from client centered therapy of Carl Rogers, imaginal flooding, cognitive behaviour therapy (CBT) and relaxation techniques. The client was adequately informed about all the therapies from the onset and his consent obtained.

Objectives of Psychotherapy

The objectives of the psychotherapy were to:

1. Reduce the feeling of stigma
2. Extinguish the client specific phobia (fear of blood).

3. Eliminate the anxiety of the client.
4. Change the negative thinking of the client with the positive and dispute his irrational thoughts.

The course of psychotherapy

The course of psychotherapy lasted for seven weeks and took the form of 45 minutes session daily during the week days. Each psychotherapy technique takes seven sessions. The therapy was carried out in line with the objectives.

Therapy for Stigma

Stigma is a general problem experienced by PWE. Client centered therapy of Carl Rogers was applied to help client A.A to reduce his feelings of being stigmatized. This therapy is a nondirective therapy in which the therapist let alone leading the client toward certain goals but create a warm, attentive and receptive therapeutic atmosphere for the client to assert himself, and also the therapist exhibits empathy, active listening, unconditional acceptance (unconditional positive regard) and genuineness to the client (Rogers 1951, Rogers 1961 as cited in Davison & Neale, 2001; Rogers 1961, Rogers 1980 as cited in Myers, 2008). During the therapeutic interactions that lasted seven sessions all the tenets of client centered therapy mentioned above were applied on client A.A with a view to reducing the feeling of stigma in him. The client also benefitted extensively from information and psychoeducation about epilepsy and seizures to reduce the feeling of stigma.

Therapy for specific phobia (fear of blood)

Imaginal flooding was the first technique oriented therapy that the client benefitted. Imaginal flooding is a procedure of fear extinction (Rimm & Masters, 1979). It is a procedure in which a phobic client is exposed through imagination to the feared situation over a period of time (ShareYrHeart, 2022). Client A.A had specific phobia (fear of blood) and imaginal flooding was used to eliminate his fear of blood. The client was told to visualize objects and events around the hospital in imagination such as blood donor room, laboratory, blood stained bandages, syringes and needles stained with blood, and people donating blood in the donor room and after seven sessions, the fear of the blood was extinguished from the client.

Therapy for Anxiety and Depression

Client A.A also benefitted from seven sessions of cognitive behaviour therapy (CBT) and includes Aaron Beck cognitive therapy and Ellis's rational emotive therapy (RET) (Davison & Neale, 2001; Rimm & Masters, 1979). The Ellis's RET was renamed rational emotive

behaviour therapy (REBT) (Davison & Neale, 2001). CBT is a therapy that changes the thinking and act of the client (Myers, 2008; Rimm & Masters, 1979). It can help alleviate anxiety and depression (Cherry, 2024). The notion behind CBT is that the individual thoughts about situations affect how he/she feels emotionally and physically and how he/she behaves (Anxiety BC, 2014). CBT is evidence (scientific) based psychological treatment that has been demonstrated to be useful particularly for depression and anxiety (Anxiety BC, 2014; APA, 2024c). CBT make individuals to be aware of their irrational, faulty, unhelpful, negative ways of thinking and replace it with new ways of thinking and positive ways of life (APA, 2024c; Myers, 2008). Aaron Beck pinpointed many instances in which individuals suffering from psychological disorders manifest distortions in thinking (Beck, 1976 as cited in Rimm & Masters, 1979). The main notion of Ellis's RET/ REBT is that sustained emotional reactions are caused by internal statements that individuals tell themselves about what is significant or meaningful life which sometimes turn out to be irrational beliefs (Davidson & Neale, 2001; Ellis, 1977 as cited in Rimm & Masters, 1979).

The cognitive therapy of Aaron Beck was applied on client A.A because the client stated that after graduating from the University life became difficult for him with no job and the future look bleak for him. Client A. A also stated that getting married is going to be difficult for him because of financial problems, he no longer had the pleasure of playing football, and he has fear of going out and also fear of going to the hospital. During the therapeutic interactions with Client A.A, he was persuaded to change his negative (faulty) thinking and develop positive thinking about the future, develop hope of getting a job and marriage. Client was also encouraged to be happy with life and continue with his hobby. By and large the client had cognitive restructuring by way of therapeutic persuasion, discussion, explanation and support, thus eliminating his anxiety and depression and also changed his negative way of thinking. Anxious and depressed individuals may harbour irrational beliefs

The RET/REBT of Albert Ellis was also applied on client A.A by using A-B-C-D-E paradigms. Where A-stands for activating experience, which refers to some real external event that the client is exposed; B-stands for belief, the series of thoughts or self-statements the client goes through in response to A; C-refers to consequence, the emotions and behaviours that result from B; D-the therapist and the client disputing the irrational beliefs and E-the effect of appropriately confronting the irrational beliefs that is the client feels better and functions effectively by changing faulty and irrational ideas.

From the clinical interview, the completed ISB and behavioural observations of client A.A, it was deduced that the client harbour some irrational beliefs or thoughts such as the

beliefs that things were bad for him, there is much hassles in life. In his completed ISB, the client stated that sometimes he felt worthless, he also felt sad and lonely at home, the client also stated that people in the environment are hostile, wicked, noisy, not kind, not friendly, he cannot stop hating people that cheated him and he gets annoyed and suffered when deprive of his right. These negative self-verbalizations of the client were disputed by applying A-B-C-D-E paradigms of RET and also the irrational beliefs or thoughts of the client were disputed using REBT by empathically telling the client that they are irrational, thus changing his behaviours.

Also, Client A.A benefitted from various relaxation techniques which involve breathing exercises, guided imagery and progressive (deep) muscle relaxation. Relaxation techniques are therapeutic exercises designed to assist individuals to decrease physical and psychological tension and anxiety (Norelli, Long, & Krepps, 2023; Rimm & Masters, 1979). They are used as complementary therapies to treat anxiety, depression among others (Norelli, Long, & Krepps, 2023). Client A.A was taught the relaxation techniques and was observed practicing them for the period of seven sessions and these treated his anxiety and depression.

Outcome of Therapies

The outcomes of therapies were good because Client A.A feelings of the stigma associated with having epilepsy are reduced. Also, the client fear of blood was extinguished and his anxiety eliminated. The negative (faulty) thinking and irrational ideas of the client were changed and disputed, and client no longer had depression. Behavioural observations indicated no anxiety and depression symptoms. The client self-reported reduction of feeling stigma, no fear of blood, no symptoms of anxiety and depression, and also the consultant neurologist that referred the client confirmed the good psychological health of the client after the therapies.

DISCUSSION

Constantinou (2020) case report stated that following weeks of CBT offered to 15-year-old client diagnosed of medial temporal lobe epilepsy for stigma, fears, low self-esteem, tension. The client, his parents and school advisor reported qualitative and quantitative improvements in all his identified psychosocial problems. This is in line with this case study which stated that after weeks of CBT applied on a 28-year-old client with epilepsy, the client and the referring neurologist reported marked improvements in his anxiety and depression but stigma was treated with client centered therapy in this case study.

Kim et al. (2023) applied CBT in 16 PWE with depression but did not apply CBT in 30 PWE that were the control. The researchers reported significant improvement in depression in the PWE that received CBT based on the differences between the pre and post BDI II and PHQ-9 in the CBT group and their control. This is an individual case study that reported improvement in anxiety and depression after applying CBT based on the client self-verbal report, the report of the referring neurologist and behavioural observations done by the clinical psychologist.

Willems et al. (2019) applied specialized epilepsy counselling services (ECS) to treat the psychosocial problems presented by PWE. The clients that benefitted from ECS expressed their satisfaction with it and even stated that they would recommend ECS to other PWE. However, the client with epilepsy in this case was treated with psychotherapy techniques.

Implications of the Findings

The theoretical implications were that the client would experience anxiety and depression symptoms. The practical implication was that psychologists should be employed and be involved as members of the team of interdisciplinary healthcare specialists treating PWE to professionally treat the psychosocial problems of the PWE. This will result in a good psychosocial wellbeing for the PWE.

Limitations of the Study

The limitations of the study were that only one case study was presented.

Conclusion

PWE experience psychosocial problems that negatively affect their mental, educational, occupational, social, and economic life and also worsen the physical signs and symptoms of their epilepsy. The psychosocial effects are as disturbing as the seizures and equally require attention. The psychosocial effects also have the potentiality of negatively affecting the outcome of the medical management of epilepsy and even reduced antiepileptic medications taking compliance. However, a clinical psychologist when employed and included as a member of the team of specialists treating PWE will professionally handle the psychosocial problems that drugs treatment alone cannot solve.

Recommendations

The following recommendations will help the PWE:

1. PWE should be assessed or screened for psychosocial problems in the neurology clinic and other centers that provide management for PWE.
2. Psychotherapy will be of paramount importance to the PWE. Therefore, psychologists should be employed and included among the healthcare professionals that manage PWE.
3. Altruistic help and support in the form of monetary and antiepileptic medications to PWE.
4. Generally, PWE need economic and welfare support.
5. Public enlightenment on epilepsy and on the reduction/stopping of stigma against PWE.

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