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South African Adult With epilepsy: Co-occurrence of Anxiety and Depression Case Study

Universidade Fernando Pessoa
Faculty of Human and Social sciences

Porto
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I, Sebolelo Mokoena, certify that this “South African Adult with Epilepsy: Co-occurrence of Anxiety and Depression Case Study” is my original work.

Signature: S.Mokoena

Work presented to the Faculty of Human and Social Sciences of the University Fernando Pessoa, as part of the requirements for obtaining a Master's degree in Psychology, with a specialization in Clinical and Health Psychology, under the supervision of Professor RuteMeneses and Professor Marta Matos

Resumo

A epilepsia é uma condição neurológica comum na África Subsaariana. Pessoas com epilepsia podem apresentar co-ocorrência de ansiedade e depressão. Embora numerosos estudos o tenham confirmado, há poucos estudos sobre os frequentes casos na África Subsaariana. Os objetivos desta revisão sistemática são: identificar a frequência de depressão e ansiedade co-ocorrentes em pessoas com epilepsia na África Subsaariana; e a frequência dessa co-ocorrência na epilepsia focal em comparação à epilepsia generalizada.

Para identificar artigos originais, dissertações de mestrado e teses de doutoramento na África Subsaariana, realizou-se uma revisão sistemática com pesquisa manual e eletrônica do CINHALL, texto completo, PubMed, Science direct, Mednar, WorldCat e Open Access Theses and Dissertations, entre 25 de março e 15 de junho de 2020, com qualidade predefinida e critérios de inclusão. A qualidade metodológica dos estudos foi avaliada utilizando a Escala de Newcastle Ottawa (adaptada). Strengthening the reporting of Observational Studies in Epidemiology (STROBE) foi usada para avaliar os relatórios dos estudos.

A pesquisa gerou 159 estudos. Destes, 5 (4 transversais e 1 caso controle) foram elegíveis para inclusão na revisão sistemática. Todos os estudos apresentaram bons índices de qualidade metodológica. Os relatos de ansiedade e depressão coincidentemente com epilepsia na África Subsaariana variaram de 19,2% a 53,7%.

A pesquisa não produziu estudos que atendessem aos critérios de comparação entre epilepsia focal e generalizada. A co-ocorrência de ansiedade e depressão em pessoas com epilepsia é maior do que em pessoas sem epilepsia. Esses achados são consistentes com os de países ocidentais. Não foi possível comparar a co-ocorrência na epilepsia focal e generalizada. Há poucos estudos sobre o assunto, e ainda menos sobre a co-ocorrência na epilepsia focal e generalizada.

Palavras-chave: Ansiedade, Depressão, Epilepsia, Comorbilidade, África Subsaariana, Adultos

Abstract

Epilepsy is a common neurological condition in Sub-Saharan Africa. People with epilepsy may experience co-occurrence of anxiety and depression. Although numerous studies have confirmed this, there are few studies on the frequent cases in Sub-Saharan Africa. The objectives of this systematic review are: to identify the frequency of co-occurring depression and anxiety in people with epilepsy in Sub-Saharan Africa; and the frequency of this co-occurrence in focal epilepsy compared to generalized epilepsy.

In order to identify original articles, master's dissertations and doctoral theses in Sub-Saharan Africa, a systematic review was carried out with manual and electronic research of CINAHL, full text, PubMed, Science direct, Mednar, WorldCat and Open Access Theses and Dissertations, among 25 March and June 15, 2020, with predefined quality and inclusion criteria. The methodological quality of the studies was assessed using the Newcastle Ottawa Scale (adapted). Lengthening the reporting of Observational Studies in Epidemiology (STROBE) was used to assess the results of study reports.

The research generated 159 studies. Of these, 5 (4 cross sectional and 1 control case) were eligible for inclusion in the systematic review. All studies showed good indexes of methodological quality. Reports of co-occurrence of anxiety and depression in epilepsy in Sub-Saharan Africa ranged from 19.2% to 53.7%.

The search did not produce studies that met the criteria for comparing focal and generalized epilepsy. The co-occurrence of anxiety and depression in people with epilepsy is greater than in people without epilepsy. These findings are consistent with those of Western countries. It was not possible to compare the co-occurrence in focal and generalized epilepsy. There are few studies on the subject, and even less on the co-occurrence of focal and generalized epilepsy

Keywords: Anxiety, Depression, Epilepsy, Comorbidity, Sub-Saharan Africa, adults

Dedication

I dedicate this work to people with epilepsy in Sub-Saharan Africa.

Appreciation

I remain eternally grateful for the grace of God, the immense support and encouragement from my family, friends and my supervisor, Professor Rute Meneses and Professor Marta Matos.

Abbreviation index

AED- Antiepileptic drugs

DSM 5- Diagnostic and Statistical Manual of Mental Disorders 5

EEG- Electroencephalogram

HADS-Hospital and Anxiety and Depression Scale

LMIC-Low and middle income countries

NOS- Newcastle Ottawa Scale

MMAS-8- Morisky Medication Adherence Scale-8

NDDI-E -Neurological Disorders Depression Inventory for Epilepsy

OATD – Open Access Theses and Dissertations

PICO- Population Intervention Comparison & Outcome

PWE- People with epilepsy

STROBE- Strengthening the reporting of Observational Studies in Epidemiology

SUDEP- Sudden unexpected death in epilepsy

SRQ-20-Self Report Questionnaire-20

SSA-Sub-Saharan Africa

US- United States

WHO- World Health Organisation

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Part- 1: Systematic Review

Introduction

Epilepsy is one of the most common neurological conditions, affecting over 70 million people worldwide (Maes et al., 2022). It occurs as a result of excessive neuronal activity in the brain and is characterised by continuous propensity to produce epileptic seizures which cause various harmful effects on the cognitive, psychological as well as social domains (Sazgar & Young,2019).

Beghi (2019) defines epileptic seizures as being repetitive paroxysmal events that are characteristic of stereotyped behavioural alterations reflective of underlying neural mechanisms of the disease. There have been recent developments of epilepsy classification in the *International League Against Epilepsy* (Fisher et al.,2017).

Epileptic seizures are divided into different groups (focal, generalised or unknown onset) depending on three factors

1. the region in the brain where they start,
2. whether or not the individual's awareness is affected and
3. whether or not the seizure involves other symptoms, e.g., movement (Fisher et al., 2017).

The new epilepsy classification is multilevel:

1. *seizure type*: focal onset (previously called partial), generalised onset and unknown onset,
2. *epilepsy type*: focal, generalised, combined generalised and focal, and unknown,
3. *epilepsy syndrome*: which consists of a cluster of features that incorporate seizure type, electroencephalography ((EEG) as well as imaging features that often occur together (see Figure 1 in Scheffer et al., 2017).

Epilepsy syndrome often has age dependent features, such as age at onset as well as remission, seizure triggers, diurnal variation and sometimes prognosis (Scheffer et al., 2017). It may have comorbidities, like intellectual as well as psychiatric dysfunctions

inclusive of EEG and imaging studies (Scheffer et al.,2017). The most common type of seizures in people with epilepsy (PWE) are focal seizures, which are predominant in adults as well as children (Beghi, 2019).

There are many causes for seizures: epileptic seizures may occur as a result of acute central nervous system injury or insult which may be systematic, structural (e.g., malformations with regard to cortical development and mesial temporal sclerosis, etc.), toxic or metabolic (of which many are epileptic encephalopathies), genetic (e.g., juvenile myoclonic epilepsy), autoimmune (e.g., anti-NMGAR encephalitis) or unknown (Beghi, 2019; Peruca, 2017; Sazgar & Young, 2019).

Although PWE experience seizures, it is important to note that not everyone who experiences seizures has epilepsy (Beghi, 2019). What is of particular interest is that the incidence of epilepsy is slightly higher in men than in women (Beghi, 2019). This difference may be due to the different prevalence of the most common risk factors as well as the concealment of the condition in women for socio-cultural reasons in certain regions (Beghi, 2019).

Approximately 75% of epilepsy onset occurs during childhood, which reflects a heightened susceptibility of brain development to seizures (Stafstrom & Carmant, 2015). The highest occurrence of epilepsy can be seen in the youngest and oldest age groups, with estimations of 86 per 100 000 per year in a well-defined population in the first year of age, which is a trend that decreases to approximately 23-31 per 100 000 in people from the age of 30-59 and then an immense increase of up to 180 people per 100 000 from the age of 85 and above (Beghi, 2019).

Epilepsy in Sub-Saharan Africa

There is scarce published literature on the incidence of epilepsy in Sub-Saharan Africa (Ba-Diop et al., 2014), which is an indication of a need for increased research. Sub-Saharan Africa is a region that is made up of “Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Congo, Cote d’Ivoire, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Sierra Leone, Somalia, South Africa, United Republic of Tanzania, Togo, Uganda, Zaire, Zambia and Zimbabwe”(Library of congress an illustrated guide, 2020).

Research demonstrates a higher prevalence of epilepsy in less developed countries than developed ones (Birbeck, 2010a, 2010b; Carpio & Hauser, 2009;Espinosa-Jovel et al., 2018). The overall information on epilepsy in Sub-Saharan Africa suggests a high annual incidence of 81.7 per 100 000 (95% cl 28.0-239.5) in less developed countries in comparison with 45.0 per 100 000 (30.3-66.7) in more developed countries (Ba-Diop et al., 2014). Epilepsy presents with major public health problems as it is a common medical condition that can result in severe physical and psychological consequences, including premature death, traumatic injury as well as mental health disorder (Ba-Diop et al., 2014).

Epilepsy is a treatable medical condition with high rates of therapeutic response as approximately 70% of PWE control epilepsy with antiepileptic drugs (Espinosa-Jovel et al., 2018). Despite the prognosis, 73.3% of patients who have active epilepsy in rural areas or low and middle income countries don’t receive treatment or when they do it is not received properly (Espinosa-Jovel et al., 2018). This is referred to as a treatment gap, and is associated with numerous psychosocial complications that consist of impairment of quality of life, social stigma as well as labour discrimination (Espinosa-Jovel et al., 2018). The stigma related to epilepsy can be intense as epilepsy is widely thought to be associated with evil spirits and witchcraft (Preux & Druet-Cabanac, 2005).

The treatment gap in some of Africa's low and middle income countries is additionally associated with a higher rate of mortality. The standardized mortality ratio in these low and middle income countries in Africa is up to six times higher than that of developed countries (Espinosa-Jovel et al., 2018). Treatment gap is dependent on the per capita income which is inclusive of a substantial trend towards larger epilepsy treatment gaps in countries that have low incomes (Espinosa-Jovel et al., 2018).

Additionally, the treatment gap in developing countries is evident in factors such as scarcity of knowledgeable staff and investigative resources to guarantee a diagnosis, limited treatment, noncompliance and non-acceptance with care by patients and their families due to their beliefs regarding the causes of epilepsy, the high costs of drugs as well as the relative unavailability of the drugs and, lastly, the psychosocial effects of epilepsy (Diop et al., 2014; Preux & Druet-Cabanac, 2005).

A systematic review conducted by Paul et al. (2012) reported an estimation of active epilepsy affecting 4.4 million people in Sub-Saharan Africa, while the lifetime epilepsy was estimated at affecting 5.4 million people. The high prevalence of epilepsy, particularly in young adults, has imperative consequences to the community and workforce structures (Paul et al., 2012).

Epilepsy doesn't normally cause death, however, the risk of premature death in people diagnosed with epilepsy is three times higher than that of the general population (World Health Organisation [WHO], 2019). The highest rates of premature deaths are found in low- and middle-income countries as well as in rural areas (WHO, 2019). A large portion of mortality causes that are related to epilepsy, more particularly in low- and middle-income countries, are possibly preventable, e.g., falls, drowning, burns, as well as prolonged seizures (WHO, 2019).

The leading cause among people with uncontrollable epilepsy is SUDEP (sudden unexpected death in epilepsy (Epilepsy Foundation of South Africa, 2019).

South Africa has seen an immense increase in SUDEP cases, as they have increased by more than 100% since 2004 (Epilepsy Foundation of South Africa, 2019).

Evidence suggests that in PWE (particularly those that live in low income populations) psychosocial aspects such as psychological distress, stigma and loneliness, as well as

psychiatric comorbidity, may be increasingly imperative in the perception of quality of health rather than other clinical variables, for instance seizure frequency and the side effects of antiepileptic drugs (Espinosa-Jovel et al., 2018).

Psychiatric conditions are very common among PWE as they affect 30% of PWE (Kanner, Ribot & Mazarati 2018). This significantly influences their quality of life (Kanner et al., 2018). Population-based studies have identified a 35% lifetime prevalence of psychiatric comorbidities in people with epilepsy whereby mood and anxiety disorders are found to be most frequent in adults as well children (Kanner et al., 2018).

Mood disorders are considered to be the most common form of comorbidity of epilepsy, especially in temporal lobe epilepsy, previously, depressive disorders were perceived to be an expression of a reactive process to the obstacles of living with epilepsy but data obtained in previous decades have demonstrated that biochemical as well as neuropathological changes mediate the development of mood disorders (Kanner, 2008).

Additionally, depression increases the risk for suicidal thoughts and attempts (Verrotti et al., 2008). A study conducted in Ethiopia on suicide attempts in PWE, with 410 respondents with a response rate of 97%, reported 28.8% of lifetime prevalence of suicidal ideation and 14.1% lifetime prevalence of suicide attempts (Haile et al., 2018).

These findings are consistent with a US study conducted by Tian et al. (2016) that found that suicide rates for PWE was 22% higher than that of the general population (see also Gandy, Sharpe & Perry, 2012; Jackson & Turkington, 2005).

Furthermore, previous studies have revealed that people who have both epilepsy and mood disorders are inclined to have more severe seizure outcomes than those without mood disorders (Insel, Ottman & Heiman, 2018) also the total prevalence of mental disorder linked with epilepsy is significantly greater than in the general population, with a range of 25% to 50% (Fiest, Dykeman, Patten et al, 2013).

PWE tend to also show symptoms of anxiety. According to the Epilepsy Foundation (2019), after diagnosis, PWE often get anxiety due to the fear of having a seizure as well as the fear of social rejection due to their diagnosis.

This systematic review is focused on depression and anxiety in PWE as they are the most common psychiatric comorbidities in PWE (Kwon & Park, 2014). This is further

validated by several studies (see Gnanavel, 2017; Kanner, 2011, 2018; Kwon & Park, 2014) that suggest that the relationship between depression and epilepsy is not simply unidirectional but rather bidirectional as patients with depression are also at an increased risk of developing epilepsy.

Mula (2017) elaborates by stating that the relationship between epilepsy and mood disorders is complex, as numerous neurological as well as psychosocial factors play a role in the relationship between mood disorders and epilepsy.

These psychosocial factors consist of the burden of stigmatisation, social limitations as well as the discrimination that is associated with epilepsy which can result in demoralization and poor self-esteem (Mula, 2017). These findings are supported by a study on perceived stigmatisation in PWE that revealed that almost 50% of PWE in a European sample experienced stigma (Kwon & Park, 2014).

Leaffer et al. (2011) conducted a US study that reported that the frequency of perceived stigma was greater in patients with incident epilepsy who had a lifetime history of depression or were in fair/poor health. The correlation was further validated by a Korean hospital-based study conducted by Kwon and Park (2014) that also found that the frequency of perceived stigmatisation was higher in PWE than in those without epilepsy.

Although these high frequencies peak an interest into further investigation of stigmatisation and epilepsy, it is important to note that the high frequencies on the stigma scale were also found to be in correlation with factors that lowered the quality of life, such as worrying and experiencing negative feelings about life (Kwon & Park, 2014). This perceived stigma was in turn frequently associated with depression and anxiety, in relation to current seizure frequency as well as psychosocial factors in a large community-based study in the UK (Kwon & Park, 2014).

The second aspect from the findings reported by Mula (2017) is that the neurological and pathophysiology aspect of epilepsy is interlinked with mood problems, similarly, to the participation of temporal lobes as well as the psychotropic effects of AED which appear to contribute to the increased rate of mood problems in epilepsy (Mula, 2017).

According to Kanner (2017), patients with previous diagnosis of psychiatric illness prior to the onset of epilepsy and those who have recurring mood and anxiety disorders are at an increased risk of having certain antiepileptic drugs (such as phenobarbital, levetiracetam, topiramate, zonisamide, as well as perampanel) causing negative

psychiatric symptoms as these AEDs are associated with negative psychotropic properties.

Kanner (2017) reiterated that carbamazepine, oxcarbazepine, valproic acid, lamotrigine, gabapentin, and pregabalin have positive psychotropic properties, which can often yield a therapeutic effect in patients with these conditions. Additionally, several systematic reviews and meta-analysis (Ettinger, Good, Manjunath, Faught and Bancroft, 2014; Grenard et al. 2011) show findings that indicate that depressed patients may be less adherent to epilepsy treatment than those without depression. These findings are supported by a systematic review on *identifying the barriers to antiepileptic drug adherence among adults with epilepsy* conducted by O'Rourke and O'Brien (2017) which selected 8 articles which met their criteria. The studies selected made use of Neurological Disorders Depression Inventory, Centre for Epidemiologic Studies Depression Scale, Beck Depression Inventory, Beck Anxiety Inventory.

On the Beck Anxiety Inventory, 25.5% of participants had moderate to severe levels of anxiety (O'Rourke & O'Brien, 2017). Within this cohort study, 57.4% of the participants had MMAS-8 scores less than 6, indicating low adherence. This was significantly different in comparison to the group who showed no or mild anxiety as a low adherence rate of 33.6% was reported. Adults with moderate to high levels of depression also scored less than 6 on the MMAS-8, which indicates low adherence to AED (O'Rourke & O'Brien, 2017).

Ettinger, Good, Manjunath, Fraught and Bancroft (2014, as cited in O'Rourke & O'Brien, 2017) report an association between depression and elevated risk of non-adherence. In addition to the aforementioned, the systematic review found a negative correlation between Beck Depression Inventory scores and items 2, 7, and 8 on the MMAS-8 ($p < 0.05$) (O'Rourke & O'Brien, 2017). The answers to MMAS- 8 items 3 and 6–8 also revealed a negative correlation with Beck Anxiety Inventory scores, which gives an indication that patients with anxiety not only have lower confidence (item 7) but also experience more difficulties with memory, thus affecting their ability to remember to take AEDs (item 8) as well as following the prescriptions from doctors, which were items 3 and 6 (O'Rourke & O'Brien, 2017).

From the aforementioned a link can be seen between depressive and anxiety symptoms and the risk of non-drug adherence. Awareness of the aforementioned is important as it may influence the treatment approach as well as the effectiveness of the treatment selected for PWE who show signs of anxiety and depressive symptoms. According to Kanner (2017), although it's not necessary for neurologists to be familiar with subtle different mood disorders, it is essential to recognize the different expressions of symptoms of depression and anxiety while consulting with psychiatrists or other mental health professionals.

It is important to gain more information on this topic due to its multifaceted nature and its consequences. Depression and anxiety are associated with an increase in mortality rate, worsened tolerance of antiepileptic drugs (AEDs), worsening of quality of life, increased risk of psychiatric iatrogenic adverse events and adherence to AEDs (Kanner, 2017; O'Rourke & O'Brien, 2017).

Numerous research exists on depression in PWE more than the co-occurrence of anxiety and depression in epilepsy which is something to look into as anxiety and depression often occur as comorbid illnesses. Approximately 85% of patients with depression also show symptoms of anxiety (Hunt, Issakidis & Andrews, 2002). Additionally, comorbidity of depression occurs in up to 90% of patients diagnosed with anxiety disorders (Gorman, 1996).

The outcome of the comorbidity of anxiety and depressive disorder is more negative than each individual counterpart as they can have adverse effects on clinical and treatment outcomes (Spijker, Muntingh & Batelaan, 2020; Pollack, 2005). Delineation of depressive disorders and anxiety disorders is important as each disorder may require different interventions (Tiller, 2013).

A systematic review on this topic can assist in contributing to increasing knowledge concerning how widespread the co-occurrence of anxiety and depression in PWE is in Sub-Saharan Africa and can provide increased insight regarding additional health needs that PWE may have. Although the necessity of recognizing and incorporating a psychiatric history into a comprehensive treatment plan of PWE is being predicated in multiple publications, it has yet to be implemented in the daily clinical practice (Kanner,

2017). Hence the additional reason for this systematic review's focus on anxiety and depression in epilepsy.

The aforementioned demonstrate the importance of evaluating the co-occurrence of anxiety and depression in epilepsy, as well as the specific epilepsy with the highest occurrence of anxiety and depression. Although there's a vast amount of literature on the research topic in more developed continents, there are few systematic reviews focused on this topic within Sub-Saharan Africa (Dessie et al., 2019). Hence the need for more research focused on the Sub-Saharan Africa region.

Bringing together research on anxiety and depression in PWE in Sub-Saharan Africa can assist in contributing to existing knowledge base on this topic by synthesising findings from various researchers. It also affords an opportunity to present collated research findings from different settings, different sampling methods, providing a broad overview on the subject thus allowing review across all borders within Sub-Saharan Africa. It can also assist in identification of research gaps in our current comprehension of anxiety and depression in epilepsy.

Objectives

The objectives of this systematic review are to identify:

1. How frequent is co-occurring depression and anxiety in PWE in Sub-Saharan Africa;
2. How frequent is co-occurring depression and anxiety in focal epilepsy in comparison to generalized epilepsy in Sub-Saharan Africa.

Before delving the required studies, a PICO (population, intervention, comparison and outcome) was conducted. The PICO tool is frequently used in the identification of clinical evidence for systematic reviews (Methley et al., 2014).

Table 1

PICO

Population	Adult out patients (≥ 18 years of age) with epilepsy in Sub-Saharan Africa, who were diagnosed by a doctor
Intervention/Indicator	The review is based on studies focused on reporting co-occurring anxiety and depressive symptoms among PWE in Sub-Saharan Africa, through the use of internationally recognised and validated methods (e.g., instruments, questionnaire, surveys & clinical interviews).
Comparison	1. Focal & generalised epilepsy
Outcome	1. Frequency (n, %) of co-occurrence of anxiety and depression in people with epilepsy 2. Frequency (n, %) of co-occurrence of anxiety and depression in focal epilepsy vs generalised epilepsy
PICO Question:	
In adult outpatients with epilepsy in Sub-Saharan Africa, how frequent is the co-occurrence of symptoms of depression and anxiety in general and comparing focal with generalized epilepsy?	

Method

This systematic review was conducted in accordance with the *Preferred Reporting Items for Systematic reviews and Meta-Analysis* (PRISMA) guidelines (Moher et al., 2009).

The PRISMA 2009 statement is made up of a 27 items checklist as well as a flow diagram with four phases. It is aimed at assisting authors in improving the reporting of systematic reviews as well as meta-analyses (Moher et al., 2009). The PRISMA may be beneficial in critically appraising published systematic reviews but caution must be taken as it is not a quality assessment instrument to test the quality of a systematic review (Moher et al., 2009).¹

¹ Protocol Registration: This systematic review is not registered as the International prospective register of systematic reviews (2020) has specified that students who are in training or conducting mini reviews are encouraged to not register their reviews on the International prospective register of systematic reviews (Prospero) website but may use the system for creation and storage of records by only saving their records and not

Eligibility criteria

The systematic review will include studies of PWE in Sub-Saharan Africa; whose epilepsy was diagnosed by a clinician, who are outpatients without any intellectual difficulties, from the age of 18 and able to provide informed consent. The literature search was limited to English language and human subjects.

Study selection

The study designs inclusive for the systematic review are published and unpublished, population-based studies (such as case control, cross sectional, retrospective and prospective cohort) and longitudinal studies reporting on the co-occurrence of anxiety and depression.

The following studies will be excluded: studies with samples of inpatients with epilepsy; unavailable free full texts; studies that report anxiety and depressive symptoms separately and not as co-occurring symptoms will be excluded from the systematic review. Systematic reviews will also be excluded

Information sources

The primary electronic searches consisted of PubMed, CINAHLPlus and ScienceDirect, as they meet the criteria for primary search system (Gusenbauer & Haddaway, 2020). To supplement the search, a grey literature search was conducted.

Grey literature is made up of any documents that are produced by an organization at any level whose main aim is not commercial publication (Gusenbauer & Haddaway, 2020). Grey literature consists of theses, organizational reports, and white papers as well

submitting them as Prospero has limited resources (and is unable to process all systematic reviews as it takes time). In addition to the aforementioned, Prospero is currently experiencing large volumes of systematic reviews (International prospective register of systematic reviews, 2020).

consultation documents. Inclusion of grey literature in a systematic review maximizes its comprehensiveness and mitigates publication bias (Gusenbauer & Haddaway, 2020).

World Cat, Open Access Theses and Dissertations and Mednar were selected for the grey literature search. WorldCat is a great source for grey literature as it is a database that consists of dissertations and theses (OATD), book catalogues as well as other materials in libraries worldwide (King's College London, 2020).

Open Access Theses and Dissertation is aimed at being the best possible resource with regard to finding open access graduate theses as well as dissertations published throughout the world ("OATD – Open Access Theses and Dissertations", 2020). The metadata (information regarding the theses) of Open Access Theses and Dissertation comes from more than 600 million universities, colleges and research institutions. Open access indexes over 1.5 million theses and dissertations ("OATD – Open Access Theses and Dissertations", 2020).

Mednar is a web-search method with a medical focus and deep-web search engine (Paez, 2017). Deep-web search engines examine web pages that have contents that are not indexed for any reason whatsoever and as a result not searched by standard search engines (Paez, 2017). In addition to the aforementioned, Mednar has the ability to search multiple databases in real time, thus recovering relevant information from public as well as deep web resources and returning the results with the utmost relevance based on the search terms (Paez, 2017).

Additional searches were conducted by contacting organisations such as International League Against Epilepsy-Africa, Zambia League Against Epilepsy, Zimbabwe League Against Epilepsy, Epilepsy South Africa and the website of National Postgraduate Medical College of Nigeria Faculty of psychiatry were consulted.

Advanced searching was conducted and employed MeSH (medical subject headings) terms, subject headings, and Boolean operators. The keywords for the electronic searches were “anxiety” AND “depression” AND “epilepsy” AND “Sub-Saharan Africa” OR “Africa South of Sahara”. MeSH terms were applied in order to increase the efficacy of searches. MeSH terms enforce uniformity as well as consistency to the indexing of biomedical literature and are applied to citation when they are indexed for MEDLINE. Mesh terms offer three main advantages (Levy Library Guides, 2020):

1. MeSH indexing is useful in facilitating retrieving relevant articles even when authors have made use of different words as well or spellings describing the same topic;
2. MeSH indexing provides an increase in the discoverability of citations. If a citation does not have an abstract or does not effectively convey the topic(s) that are discussed in the article, the MeSH indexing permits discovery of this citation even through basic keyword searching;
3. MeSH indexing provides facilitation of searching both broad and narrow concurrently because of the existing MeSH hierarchy. The MeSH Headings, Subheadings as well as Publication Types are organized in hierarchies, or even “MeSH trees.”

Boolean operators were used in the electronic search. Boolean operators refer to “AND”, “OR”, “NOT” or “AND NOT”. The advantages of Boolean operators are that they save time through elimination of inappropriate hits that should be scanned before discarding. Making use of Boolean operator is beneficial in saving time by focusing on searches for more on target results that are appropriate for the needs of the researcher, as well as elimination of unsuitable or inappropriate search results (Sayers, 2008).

To supplement the search, a search for citation relationship was conducted. This is useful for literature on a topic that is dispersed across multiple databases/ subject areas (Hu, Rousseau & Chen, 2011). This was done through the use of backward and forward citation. Backwards citation consisted of performing a bibliography search from the selected studies, whereas forward citation was done on Google scholar. Forward citation process was conducted by copying and pasting the title of the selected study (for the systematic review) in Google scholar to see the articles or studies that have cited the included study.

The dates for data collection were from the 3rd of February until 30 June 2020. The primary search was conducted from February until 30 April 2020. The grey literature was conducted from 1st May until 15th of June 2020.

Search

The search consisted of “anxiety” AND “depression” AND “epilepsy” AND “Sub-Saharan Africa” OR “Africa South of Sahara”. MeSH terms and subject terms were used on Cinahl Plus with full text, PubMed, Science Direct, Open Access Theses and Dissertation, WorldCat and Mednar. The MeSH terms and Boolean operators used will be presented in the result section.

Data collection process

The data from the studies included were extracted by the first author. The citations and abstracts of the studies were uploaded to endnote which is advantageous in terms of finding duplicates, being able to keep track of the number of articles and grouping the articles in terms of the inclusion and exclusion criteria. In order to minimise the chances of some duplicates being missed, the researcher also went through the citations and abstracts manually to verify the duplicate count.

A Microsoft excel spreadsheet was used to load selected articles for full review and quality assessment. The data collection table was drawn up on an excel spreadsheet. The table of the data items of the content to be presented was tested by using 3 articles (not representative) and from there on a final decision was made regarding a need for inserting another column or deleting a column.

Data items

The review extracted sample characteristics which are author (s), year of publication, country, study design, recruitment source, sample size, mean age, Epilepsy type, study purpose, percentage of frequency of the co-occurrence of depressive and anxiety symptoms in generalized epilepsy and percentage of frequency of the co-occurrence of depressive and anxiety symptoms in focal epilepsy. As well as the Newcastle Ottawa Scale.

Quality appraisal of studies

Risk of bias is also referred to as the risk of systematic error or a deviation from the truth, in results or the inference (Viswanathan et al., 2017). It is similar with the internal validity as defined by the extent to which the research design and the manner of the study are likely to have prevented bias or the extent to which the results from the study are correct for the conditions that are being studied (Viswanathan et al., 2017).

There is currently no consensus regarding an optimal tool for conducting quality appraisal for observational studies. As a result, studies recommend that reviewers make use of a tool reflective of the study design of the chosen articles in the systematic review (Quigley, Thompson, Halfpenny & Scott, 2018).

Shamliyan, Kane, and Dickinson (2010) conducted a systematic review of 46 scales and 51 checklists to assess the quality of observational studies. They reported that checklists as well as the scales vary in their content, validity as well as their applicability to different study designs. The essential criteria of quality such as allocation concealment, the intention to treat and the sample size were hardly ever reported and no agreement was reached for individual criteria of validity as well as ranking the overall quality (Shamliyan, Kane & Dickinson, 2010).

Shamliyan et al.(2010) concluded that numerical scores were meaningless when it came to examining the quality of observational studies in systematic reviews, partly because of their lack of transparency. None of the available tools were able to discriminate poor reporting from the quality of studies and didn't provide separate conclusions about the external and internal validity.

Shamliyan et al. (2010) were not able to recommend tools which can be used for conducting quality assessments for observational studies. Lang and Kleijnen (2010) state that researchers should avoid subjective judgements during evaluation process. Numerous quality assessment tools are potentially useful for use on systematic reviews of non-randomised studies, but they, however, omitted key quality domains and therefore each are in need of refining (Lang & Kleijnen, 2010).

The risk of bias was assessed using the Newcastle-Ottawa quality assessment, as it can be used for observational studies. The Newcastle-Ottawa Scale (NOS) is a scale which

was developed by the University of Ottawa in Canada and the University of Newcastle in Australia for assessment of the quality of non-randomised studies for inclusion in systematic reviews. It's a scale that has been widely made use since 2004 and has been validated by numerous published studies (Margulis et al., 2014).

The NOS is a commonly used scale in systematic reviews for non-randomised study designs. It was developed based on validity threats in non-randomised studies. The NOS has been reported as having face and content validity and has also been tested for inter-rater reliability (Viswanathan et al., 2017).

The NOS can be used for case controls and cohort studies. It can also be adapted for cross sectional studies. The NOS adapted for cross sectional studies makes use of the star system only in the main scale. Each numbered item that's in the Selection and exposure categories can be given one star and a maximum of two stars can be given for the comparability category. The difference with the cross-sectional scale is that it has 5 stars for the selection dimension, two stars for comparability and three stars for the outcome dimension (Rostami, Younesi, Shahboulaghi, Malakouti & Foroughan, 2018).

There is currently no "gold standard" measuring quality of assessment in cross sectional designs (Moskalewicz & Oremus, 2020). Even though the NOS is endorsed by the Cochrane collaboration, it does however suggest that researchers may also want to include quality of reporting of the study in the analysis, as it is not included in the NOS (Margulis et al., 2014). Therefore, in addition to the NOS, the strengthening the reporting of Strengthening of Observational Studies in Epidemiology (STROBE) statement was used.

The STROBE consists of a checklist, the checklist doesn't evaluate the quality of the research but rather provides guidance on how to report observational studies. Inadequate reporting of research results in hindrance of the assessment of the strength and weaknesses of the studies reported. The STROBE is available for cross sectional, cohort and case-control studies (von Elm et al., 2007).

Summary of measures & Synthesis of results

The systematic review summarises the frequency of co-occurrences in percentages. Means and ranges were used to summarise the findings from the studies.

The main outcome of interest of the systematic review is a summary of the co-occurrence of depression and anxiety in PWE in Sub-Saharan Africa. The second outcome is the summary of the co-occurrence of anxiety and depression in people with focal epilepsy and people with generalized epilepsy.

Results

Identification and description of results

The search produced 159 studies. The citations of the studies were downloaded to endnote. Of the 159 studies, 47 were found on the primary electronic search on Cinahl Plus with full text, PubMed and Science Direct. The grey literature electronic search conducted on Open Access Theses and Dissertation, WorldCat, and Mednar produced 30 studies.

In addition to the aforementioned, epilepsy organizations were contacted and the contact with organizations yielded 82 studies recommended by the Zambia League Against Epilepsy and Epilepsy South Africa.

After removal of the duplicates, 135 studies were left for review of titles and abstracts. Of the 135 studies, 111 were excluded as they were not relevant for the study, as most were either not related to the topic of study or they were studies of samples not from Sub-Saharan Africa. This left 24 studies eligible for assessment of full text assessed eligibility. The 24 articles were downloaded and a full text review was performed.

Of the 24 articles reviewed, 7 articles were on children and or adolescents, 2 were not in English, 9 studies reported anxiety and depression separately and not co-occurring and 1 article was a systematic review.

This left 5 articles (Fatoye, Mosaku, Komolafe & Adewuya, 2006; Mbewe, Uys, Nkwanyana & Birbeck, 2013; M'bayo, Tomek, Kamara & Lisk, 2017; Wubie, Alebachew & Yigzaw, 2019; Tareke, Birehanu, Amare & Abate, 2020) for inclusion in the systematic review (see figure 2).

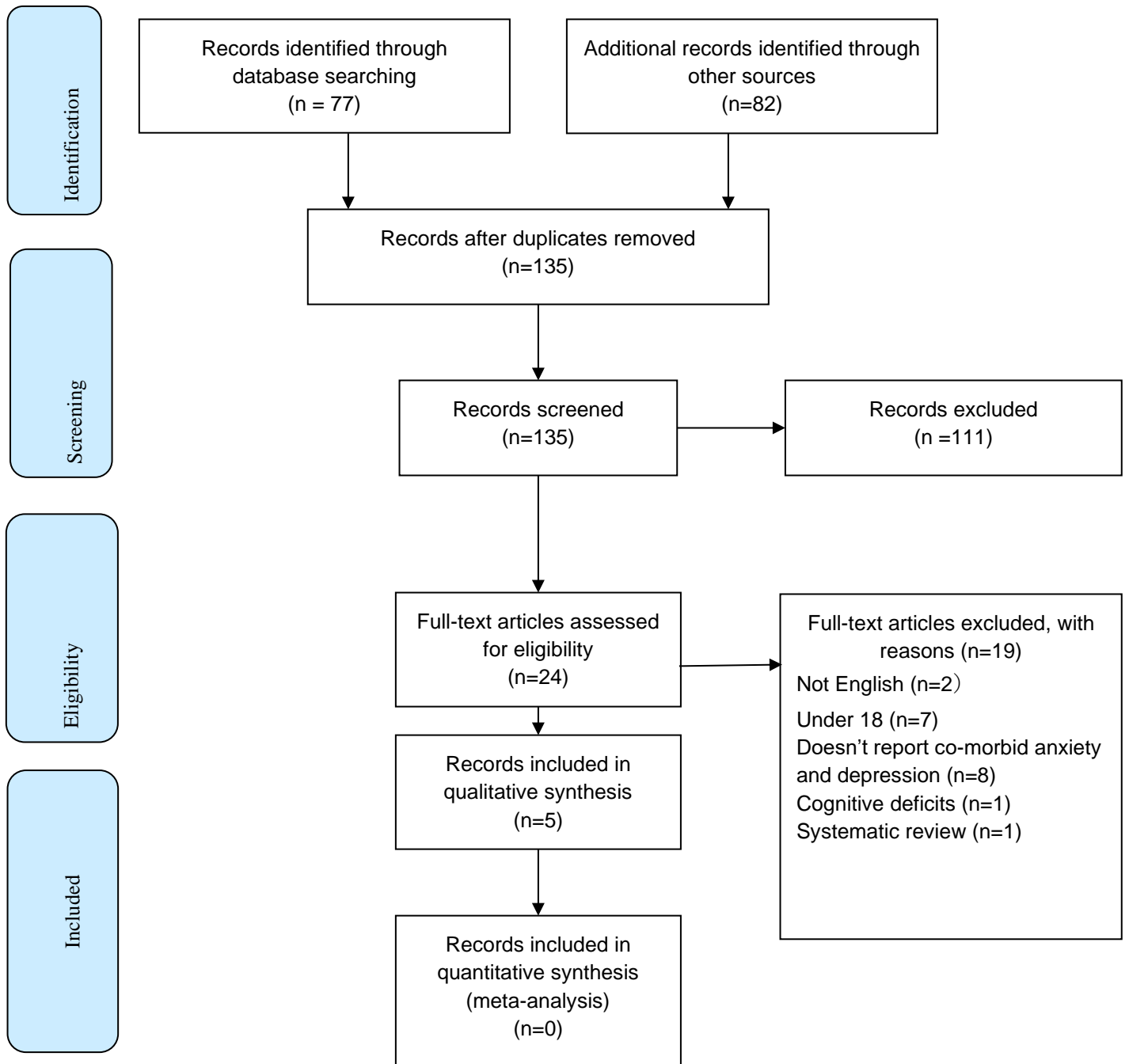
Below is a table of the strategic search outlining detail search items and the different Boolean operators and MeSH.

Databases	Search items	No. of articles identified
CINAHL Plus with Full text	((MH "Epilepsy+") OR (MH "Epilepsy, Partial, Focal") OR (MH "Epilepsy, Generalized+")) AND ((MH "Depression") OR "depressive disorders") AND ((MH "Anxiety") OR (MH "Anxiety Disorders")) AND (MH "Africa South of the Sahara+")	5
Pubmed	(((("epilepsy"[MeSH Terms] OR "epilepsy"[All Fields]) AND ("anxiety"[MeSH Terms] OR "anxiety"[All Fields])) AND ("depressive disorder"[MeSH Terms] OR ("depressive"[All Fields] AND "disorder"[All Fields]) OR "depressive disorder"[All Fields] OR "depression"[All Fields] OR "depression"[MeSH Terms])) AND ("africa south of the sahara"[MeSH Terms] OR ("africa"[All Fields] AND "south"[All Fields] AND "sahara"[All Fields]) OR "africa south of the sahara"[All Fields] OR ("sub"[All Fields] AND "saharan"[All Fields] AND "africa"[All Fields]) OR "sub saharanafrica"[All Fields])	28
ScienceDirect	Terms: "Sub-saharan Africa" AND epilepsy Title, abstract or author-specified keywords: anxiety OR anxiety disorder and Depression or depressive disorder	14
Grey literature sources		
Open Access Theses and Dissertation	(epilepsy) AND (anxiety) AND (depression) AND (africa) AND language:(en OR eng OR english)	2
WorldCat	'su: epilepsy and anxiety and depression and africa' Limiters: English	5
Mednar	epilepsy AND depression AND anxiety AND Africa *refined by: people with epilepsy	23
Zambia League Against Epilepsy	The organisation was contacted directly (by email) and they recommended studies	1
Epilepsy South Africa	The organisation was contacted directly (by email and telephone) and they sent a list of studies on the topic from their "psychiatry and epilepsy" database	81

Table 2:
Search strategy

Figure 1

Prisma 2009 flow diagram for selection of studies (Moher, Liberati, Tetzlaff, & Altman, 2009)



Each of the selected articles consisted of multiple authors. The years of publication for the articles ranged from 2006 to 2020 (see Table 3). The studies were carried out in Ethiopia, Sierra Leone, Zambia and Nigeria. The study designs consisted of case control and cross-sectional studies.

The overall sample size being 1641 PWE (see Table 3). The age of the participants ranged from 18 to 82 years.

Fatoye et.al (2006) had the smallest size (104), while Mbewe et al (2013) had the biggest sample size (575). When it comes to sex, the majority of the participants were male.

The studies made use of the Hospital Anxiety and Depression Scale (HADS), the Self-Report Questionnaire (SRQ-20) and the Zambian 10 item screening tool for anxiety and depression in Epilepsy.

Self-Rating Questionnaire 20 (SRQ-20). The SRQ-20 was developed by the World Health Organisation as an instrument to screen for mental health problems in primary health care attendants in developing countries (van der Westhuizen et al., 2016). The SRQ-20 was validated for use in African setting by several studies such as Netsereab et al.(2018),van der Westhuizen et al. (2016) and Scholte et al. (2011).

SRQ-20 reflects psychosomatic complaints, depressive symptoms and anxiety symptoms and can identify probable case of common mental illness with relative accuracy. Each of the 20 items has a score of 0 or 1, in which a score of 1 is indicative of the presence of symptoms during the past month, and a score of 0 is indicative of the absence of symptoms; the maximum score is 20 (Scholte et al., 2011).

Hospital Anxiety and Depression Scale (HADS). The HADS was developed by Zigmond and Snaith to assesses both anxiety and depression (Stern, 2014). Anxiety and depression commonly co-exist, as anxiety is often preceded by depression in response to a stressor (Stern, 2014). The HADS has been validated for use as a screening instrument for mental morbidity in hospital and community settings in Nigeria and other African countries (Fatoye et al., 2006). An individual scoring of more than 8 on either depression or anxiety subscale is classified as having clinically significant anxiety and depression symptoms (Fatoye et al., 2006). The maximum score that indicates severe anxiety and depressive symptoms is 15-21 (Stern, 2014).

10 item screening tool for anxiety and depression. This tool was developed by Mbewe et al. (2013) for primary health care settings in Zambia. It has been validated as a short screening tool for depression and anxiety among PWE. The screening tool was designed for use within a routine medical review process by existing primary health care workers without additional/more highly qualified staff (Mbewe et al., 2013).

In order to make up the 10 items, 5 items were selected from the Shona Symptom questionnaire, 1 item from NDDI-E (Neurological Disorders Depression Inventory for Epilepsy), and 2 questions from Arol et al. (cited in Mbewe et al., 2013). Based on their experience of caring for PWE and comorbid anxiety and depression disorders, Mbewe et al. (2013) also included 1 item each on heart palpitations and less desire for food. This resulted in the 10 items in the screening tool. A score of 18 is considered significant for detecting anxiety and depression (Mbewe et al., 2013).

The 10 item screening tool was validated with the use of Diagnostic and Statistical Manual version 3. It consists of 10 items, each scoring from 1 to 4 in accordance with symptom frequency, providing a total score that ranges from 10-40. Its brevity makes it an ideal tool for use in a busy primary care setting (Sweetland, Belkin & Verdeli, 2014). The importance and uniqueness of the 10 item screening tool is that it takes into consideration linguistic equivalence of measures of anxiety and depression due to the fact that in African languages there is no equivalent to words like depression and anxiety (Mbewe et al., 2013; Sweetland, Belkin & Verdeli, 2014).

In South Africa numerous words are used to describe depression, which translate to “the spirit is down”, “the body is down” and also the heart is down and not feeling well. The vocabulary or questions may differ in connotation, relevance or even salience in one culture to another. In Lesotho, there are two to three words used for “depression” that vary depending on the context (Sweetland, Belkin & Verdeli, 2014).

In numerous African settings, distress is normally described behaviourally rather than cognitively, and expressed or experienced somatically. Another factor is that worries and emotions are normally thought as relating to the heart rather than the head, which may result in misinterpretation of related questions (Sweetland, Belkin & Verdeli, 2014).

Numerous evidence suggests that lay providers can be trained in providing the basic mental health services at community level (Sweetland et al., 2014). Brief screening instruments play a vital role in care models by serving as clinical tools to be used in facilitation of case detection, monitoring symptoms as well as triage to a higher level of care as required (Sweetland et al., 2014).

Table 3.
Characteristics of the selected studies

Author(s)	Fatoye et al.(2006)	Mbewe et al.(2013)	M' bayo et al.	Wubie et	Tareke et al. (2020)
Source type	Journal	Journal	Journal	Journal	Journal
Study design	case control	Cross sectional	cross-sectional	cross sectional	Cross-sectional study
Recruitment Source	Medical, psychiatric & outpatient	Zambian clinics	Connaught Hospital &	Felegehiwot Referral Hospital	public health institutions Bahir
Country	Nigeria	Zambia	Sierra Leone	Bahirdar,	Ethiopia
Mean Age	27.6 (SD = 9.7)	Not Reported	29.7 (SD ±12.6)	59 (SD 13.37)	28.6 (SD ±10.5)
Sample size	104	575	142	422	398
Sex of sample	36.5% Female 63.5% Male	Female 48.7% Male 51.3%	41.5% Female 54.9% Male	35.5% Female 64.5% Male	41% Female 59% Male
Epilepsy type	57.7% focal seizure 42.3% Generalized seizure	Not Reported	Not Reported	Not Reported	Not Reported
Study purpose	Comparing symptoms of anxiety & depression between PWE & healthy control group & determining the factors associated with anxiety &	Developing & validating a screening tool for depression and/or anxiety disorders in PWE	Investigation of the prevalence & determinants of depression & anxiety in PWE	Assessing prevalence & associated factors of common mental	Assessing the magnitude & factors associated with common mental disorders in PWE attending government
Measures	HADS	10 Item screening questionnaire	10-item screening questionnaire	SRQ-20	SRQ-20
Percentage	19.2%	53.7%	28%	35.8%	35.4%
Frequency per epilepsy	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported
NOS	6	8	7	8	8

Table 4. Newcastle Ottawa Scale

Study author	Study design	Selection (MAX 5*****)				Comparability (MAX 2**)	Outcome (MAX 3***)			Total stars
		Representativeness of sample	Sample size	Non-respondents	Ascertainment of exposure		Based on design analysis	Assessment of outcome (Anxiety & depressive symptoms)	Statistical test	
M'bayo et al.(2016)	Cross sectional	a*	B	a*	b*	ab*	b*	a*		7
Mbewe et al.(2013)	Cross sectional	a*	a*	a*	b*	ab**	a*	a*		8
Tareke et al.(2020)	Cross sectional	a*	a*	a*	b*	a*	a*	a*		8
Wubie et al.(2019)	Cross sectional	a*	a*	a*	b*	ab**	c*	a*		8
Author	Study design	Selection				Comparability	Exposure			
		Case definition adequate	Representativeness of case	Selection of control	Definition of controls	Based on design and analysis (Control for confounders)	Ascertainment of exposure Measurement of anxiety & depressive symptoms	Same method for cases and controls	Non-response rate	
Fatoye et al(2006)	Case control	a*	B	a*	a*	ab**	D	a*	b	6

A methodological quality of six and above was considered good (Dessie et.al, 2019; Farsad-Naeimi et al., 2020).

The selected studies were consistent with the STROBE checklist items that should be reported in case control studies as well as cross sectional studies. The only items which were not included in the studies were flow diagrams (See appendix A-G).

Case control study summary

Fatoye et al. (2006) conducted a controlled study using HADS; the authors applied backtranslation method to produce Yoruba version of the instrument. The control subjects used for the study were healthy relatives of PWE who presented to the hospital for minor ailments. These subjects were screened for psychiatric disorders and only those without psychiatric disorders were allowed as controls (Fatoye et al., 2006).

The study by Fatoye et al. (2006) consisted of a sample of 57.7% patients with focal seizures and 42.3% with generalized seizures, with the mean age being 27.6 (SD=9.7). The mean score of the patient group were higher on the two subscales of the HADS than with the control group. At the recommended cut-of of > 8, 16(30.8%) PWE had clinically significant anxiety symptoms in comparison to the control group, which had 7(13.5%). Additionally, PWE also had statistically higher depression symptoms at 30.8%, in comparison with the control subjects (9.6%).

The study reported a 19.2% co-occurrence of anxiety and depression in PWE and 11.5% occurrence of either depression or anxiety symptoms in the control group. The study didn't report the co-occurrence per epilepsy type or co-occurrence in the control group (Fatoye et al., 2006).

Cross sectional studies summary

Tareke et al.(2020) surveyed 398 PWE at all public health institutions found in Bahir Dar city, Ethiopia. Using the SRQ-20, Tareke et al. (2020) reported a 35.4% co-occurrence of anxiety and depression.

The symptoms that were most prevalent were tension, headache and unhappy feelings whereas the least common symptoms were found to be sleeping badly and hands shaking (Tareke et al.,2020).

Mbewe et al. (2013) using a sample of 575 participants from Zambia primary healthcare clinics Mbewe et al. (2013) reported a 53.7% co-occurrence of anxiety and depression in people with epilepsy.

M'bayo et al.(2017) conducted a study at outpatient's clinics in cities of Freetown and Kenema with a sample of 142 patients. The age range of the sample was between 18-82 years with a mean age of 29.7 years (SD=12.6). The authors reported a 28% co-occurrence of anxiety and depression. The score considered for significant detection of anxiety and depression on the screening tool is 18.

Wubie et al. (2019) conducted a study in Ethiopia assessing for common mental disorders among PWE. A sample of 422 PWE was selected at Felegehiwot Referral Hospital and had a response rate of 100 %. The sample had a higher number of males than females, as there were 64.5% males. The mean age of the participants was 59years. The study reported a co-occurrence of 35.8% among its participants. In addition to the aforementioned, the study found association between variables such as divorce, comorbidity of medical condition, non-adherence to medication, substance dependence and abuse to be risk factors for mental disorders.

The web based and grey literature search did not produce results that could be used to make a comparison of the frequency of anxiety and depression in epilepsy in Sub-Saharan Africa. Although there are numerous studies on this topic worldwide, research in sub-Saharan Africa on the topic is not widespread.

Only one study (Fatoye et al., 2006) classified the different epilepsy types, but didn't provide the frequency of the co-occurrence of anxiety and depression per epilepsy type. The rest didn't make a distinction between the different types of epilepsy and the frequency of anxiety and depression according to the different epilepsy types, so no deductions could be made regarding an epilepsy type with the most frequent of co-occurrence.

Discussion

The co-occurrence of anxiety and depression ranged from 19.2% to 53.7%. The differences in frequency may be due to differences in the methodologies used, differences

in sampling method, sample size, as well as the different diagnostic instruments or assessment measures.

Studies by Wubie et al. (2019) and Tareke et al. (2020) reported almost identical findings: 35.8% and 35.4% of co-occurrence of anxiety and depression. The reason for similarities may be due to the fact that both studies used SRQ-20 and conducted their study in the same city (Bahir Dar City in Ethiopia) and only three years apart from one another. Wubie et al. (2019) collected their data in 2019 and Tareke et al. (2020) collected theirs in 2016.

The mean co-occurrence of anxiety and depression in PWE in Sub-Saharan Africa, based on the selected studies was found to be 34.42%.

The mean percentage frequency of the co-occurrence of anxiety and depression in PWE in Sub-Saharan Africa reported in this study is higher than that reported in non-epilepsy population in Africa. There is scant research on this topic in SSA but the WHO global report (2017) reported a 9% frequency of depression and 10% frequency of anxiety, which is a much lower frequency in comparison to that found in PWE.

A review conducted by Kwon and Park (2014) reported a frequency/prevalence of the co-occurrence in adults with epilepsy that ranged from 14.4% to 36.5% (from studies conducted in USA, UK, Canada & Korea), whereas a systematic review assessing the prevalence and predictors of anxiety in an African sample of recent stroke survivors reported a 14.1% prevalence of comorbid anxiety and depression (Ojagbemi et al., 2017).

The findings from this study demonstrated a high co-occurrence of anxiety and depression in PWE. These findings are consistent with the findings from a USA systematic review conducted by Quintas et al.(2012) on the psychosocial difficulties in PWE, which reported depressive symptoms and anxiety as being among the most frequent emotional problems experienced by PWE.

The gender of the participants may have also influenced the findings of the studies as the majority of the studies had more males than females. However, Tareke et al. (2020) reported a higher frequency of anxiety and depression in females with epilepsy (39.9%) compared to males (32.3%).

Limitations of the study

This systematic review has its limitations. The articles that were not in English were excluded from the study. The exclusion of articles that are not in English reduced the number of articles available on the topic. Sub-Saharan Africa consists of numerous languages besides English.

Exclusion of studies with samples of inpatients with epilepsy also limited the study. In addition to the aforementioned exclusion of unavailable free full texts was a limitation in the systematic review.

The study made use of the NOS to assess the methodological quality of studies. This scale has been criticised for not including the quality of reporting of the study in the analysis. As a result, the STROBE was used in addition to the NOS to counter this limitation. The selected studies scored 6 and above on the NOS scale, proving that they have good methodological quality. Majority of the studies were in line with the strobe checklists.

Mbayo et al.2016 was the only case control study. They didn't explain how the study size was arrived at and also didn't indicate number of participants with missing data for each variable of interest.

With regards to the cross-sectional studies, Wubie et al. (2019) was the only cross-sectional study that reported how missing data were addressed. None of the cross-sectional studies used of a flow diagram.

In addition to the aforementioned, Mbewe (2013) didn't indicate the number of participants with missing data for each variable of interest. Lastly, in terms of generalisability (external and internal validity) all cross-sectional studies reported except Mbewe (2013).

Majority of the studies did not mention the co-occurrence in terms of the different epilepsy types, therefore a comparison of the co-occurrence of epilepsy types comorbidities wasn't possible. Lastly, the samples from the studies consisted mainly of males than females. This could have influenced the findings from the studies.

Conclusion

This systematic review examined the co-occurrence of anxiety and depression in PWE in Sub-Saharan Africa. Although there is a high co-occurrence of anxiety and depression in PWE in Sub-Saharan Africa, literature on the matter is still scarce. More research needs to be done concerning the comparison between the different types of epilepsies and the mental health co-occurrence.

The frequency of co-occurring anxiety and depression in PWE in SSA ranged from 19.2% to 53.7%. The systematic search didn't produce studies that met the criteria for the comparison between focal and generalised epilepsy. As a result, this systematic review was unsuccessful in comparing the co-occurrence in focal and generalised epilepsy. There seems to be little literature on this topic, even less literature reporting on the co-occurrence in focal and generalised epilepsy.

The systematic review summarised the frequency of co-occurring anxiety and depression in epilepsy, which was found to be higher than in people without epilepsy. These findings are consistent with those reported in Western and Eastern countries (Quintas et al.2012; Kwon & Park, 2014).

Although there is vast amount of research on this topic in western and eastern countries, there is little research on this topic in Sub-Saharan Africa. This review will assist in contributing to the knowledge of the co-occurrence of anxiety and depression in epilepsy. These findings can also help in confirming the additional health needs that PWE in Sub-Saharan Africa may have and also contribute to the area of psychoeducation of epilepsy and mental health.

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Conflict of interest

The authors declare no conflict of interest.

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*South African Adult With Epilepsy: Co-occurrence of anxiety and
Depression Case Study*

Part II: Empirical Study

Resumo

Este estudo de caso envolve explorar a co-ocorrência de ansiedade e depressão em um adulto com epilepsia do lobo temporal. A fenomenologia hermenêutica e o modelo de funcionamento executivo autorregulatório foram utilizados como referenciais teóricos e conceituais. O estudo de caso foi analisado através da análise temática em que emergiram 4 temas 12 subtemas; gravidade da depressão e ansiedade (ideação suicida, dissociação e despersonalização, transtorno do pânico com agorafobia), influência na qualidade de vida (retraimento social, preferência por trabalhos remotos em vez de trabalhos presenciais, relacionamentos interpessoais e intrapessoais, dificuldades físicas e cognitivas), gerenciamento de ELT, ansiedade e depressão (relutância em tomar medicamentos, dependência de álcool e trabalho, apoio da irmã, amigos e colegas, exercícios de aterramento, comparação descendente), perspectiva de ansiedade e depressão.

Os achados deste estudo de caso indicaram a ocorrência concomitante de ansiedade e depressão no participante com ELT.

Pal chave

Epilepsia do lobo temporal, depressão, ansiedade, África do Sul, estudo de caso

Abstract

This case study involves exploring the co-occurrence of anxiety and depression on an adult with temporal lobe epilepsy. Hermeneutic phenomenology and self-regulatory executive functioning model were used as theoretical and conceptual frameworks. The case study was analysed using thematic analysis in which 6 themes 18 sub-themes emerged; childhood & adolescence experiences, experience of anxiety and depression related to TLE, influence of temporal lobe on the different areas of life & development, Management of TLE, anxiety and depression, Healthcare and social support for people with TLE, influence on quality of life (socially withdrawn, preference for remote jobs over in person jobs, interpersonal and intrapersonal relationships, physical & cognitive difficulties), management of TLE, anxiety and depression (reluctance to take medication, alcohol dependence and work, support from sister, friends and colleagues, grounding exercises, downward comparison), perspective of anxiety and depression.

The findings from this case study indicated con-occurrence of anxiety and depression in the participant with TLE.

Key-words

Temporal lobe epilepsy, depression, anxiety, south Africa, case study

Introduction

The empirical case study will be focused on a South African participant with temporal lobe epilepsy and the co-occurrence of anxiety and depression. This is a topic that has fascinated many researchers, and although there are numerous studies on this topic in the western and eastern world. There's still scant research on this topic on Sub-Saharan Africa, especially South African participants.

Temporal lobe epilepsy, formerly known as partial complex seizure/epilepsy originates in the temporal lobe, the exact cause of TLE remains unknown; it has, however, been linked to structural abnormal electrical activities such as hippocampal sclerosis or tumours, traumatic brain injuries, genetics, infections, cryptogenic etc. Temporal lobe epilepsy results in seizures that can manifest as altered consciousness, sensory changes, or motor symptoms (Maes et al., 2022).

There are two types of temporal lobe epilepsy, mesial temporal lobe epilepsy (MTE) and neocortical or lateral epilepsy (Epilepsy Foundation, n/a). MTE consists of the internal or medial structures of the temporal lobe. The onset of seizures of MTE occurs in the hippocampus or the surrounding area. 80% of all the seizures of temporal lobe epilepsy are accounted for by MTE. Neocortical or lateral temporal epilepsy however, entails the external parts of the temporal lobe.

Although it can occur at any age, medial temporal lobe epilepsy often starts between the ages of 10 and 20. Typically, a person has experienced a feverish seizure or a brain damage in their early years.

Types of seizures

TLE is characterized by "focal onset seizures." The person's level of consciousness during a seizure and whether they remain awake and alert are used to characterize focal seizures. This characterization consists of focal aware seizure and focal impaired awareness seizures. With the latter being the most common in people with epilepsy.

- Focal impaired seizure: Patients with TLE frequently experience focal seizures with reduced awareness, which are primarily distinguished by a loss of consciousness accompanied by stereotypical automatisms, linguistic changes, and unilateral dystonic posture (Vinti, Dell'Isola, Tascini, Mencaroni, Cara, Striano & Verrotti, 2021).
- Focal aware seizures: Previously called “auras”, focal aware seizures consist of special sensory symptoms that occur in auditory, gustatory, olfactory as well as visceral systems. The manifestation of automatic, cognitive and somatosensory events like “déjà vu” as well as “jamais vu” is also possible. Additionally, emotional symptoms may also occur like anxiety (Maes et al., 2022).
- Focal seizures: These seizures may extend to include both the cerebral hemispheres as well as regularly manifesting with bilateral tonic-clonic convulsions (Maes et al., 2022).

Focal aware seizure and focal seizure may be associated with post-ictal period which can entail amnesia, aphasia or/and confusion (Maes et al., 2022).

Problem statement & importance of the research

People with temporal lobe epilepsy are at a higher risk of developing psychiatric condition than those with general epilepsy (Gaitatzis, Trimble & Sander, 2004). Although this is a common phenomenon, there is still scarce literature and studies on this phenomenon on South African participants. Hence the motivation for conducting the study on South African, an attempt to increase the studies on this topic on south African participants.

A study by Hermann, Seidenberg, Bell, Woodard, Rutecki & Sheth (2000) found comorbid interictal psychiatric symptoms elevated amongst temporal lobe epilepsy patients in comparison to the healthy controls and they also appear to be modestly associated with cumulative chronicity (duration) of epilepsy.

Epilepsy results in the risk of developing increasing irreversible neurocognitive decline with the duration as well as frequency of the epileptic seizures. Additionally, memory

impairment, anxiety, depression, neurocognitive disorders are subsequent comorbidities in people with epilepsy (Tramoni-Negre, Lambert, Bartolomei & Felician, 2017).

A study on premature mortality in epilepsy and the role of psychiatric comorbidity found that Psychiatric comorbidity is associated with premature mortality in people with epilepsy (Fazel, Wolf, Långström, Newton & Lichtenstein, 2013). These findings are supported by Tao et.al who found that PWE and comorbid psychiatric illness had a higher mortality in comparison to PWE without psychiatric comorbidity as well as the general population.

It is also worth noting that epilepsy and psychiatric comorbidity can put individuals at an increased risk of alcohol or substance abuse, injury, suicide and lack of adherence to medication. (Fazel, Wolf, Långström, Newton & Lichtenstein, 2013). The above-mentioned indicate the importance of identification of psychiatric disorders in people with epilepsy, especially temporal lobe epilepsy.

Scientific & Social importance

The comorbidity of mood disorders in PWE can contribute to lack of adherence in regards to taking medication. Ettinger, Good, Manjunath, Fraught and Bancroft (2014, as cited in O'Rourke & O'Brien, 2017) report an association between depression and elevated risk of non-adherence. Depression in PWE complicates treatment as well as quality of life (Dessie, Mulugeta, Leshargie, Wagnew & Burrowes, 2019) and also strains the health systems, especially in low income countries.

This is due to the fact that PWE with untreated depression are more likely to significantly use more health resources (Dessie et al., 2019). This is because epilepsy and comorbid anxiety and depression/psychiatric disorders can worsen the seizures and seizure frequency which causes more impact on the hospitals and health care (Insel, Ottman & Heiman, 2018).

Poor seizure control can have negative effect on psychosocial aspects as well. A study found that epilepsy sufferers had higher rates of underemployment and unemployment. The findings indicated that poor seizure control was is the reason for employment issues,

but other psychological and societal variables also contribute, such as stigma, discrimination, passive coping mechanisms, poor self-esteem, mood disorders and cognitive challenges (Thompson & O'Toole, 2009).

From the aforementioned a deduction can be made that epilepsy and comorbid psychiatric conditions not only have an affect on the individual but the health and society as whole. Additionally, there's scant literature on this topic in South Africa and this study can assist in contributing to scientific research. Thus, accentuating the importance of increased investigation.

Awareness of the aforementioned is important as it may influence the treatment approach as well as the effectiveness of the treatment selected for PWE who show signs of anxiety and depression symptoms.

Personal importance

Research regarding the temporal lobe epilepsy and comorbid anxiety and depression can assist me in terms of developing more knowledge with regard to the many aspects of epilepsy so as to better prepare me for assisting clients with epilepsy in need of therapeutic intervention.

In summary of the aforementioned, it is essential to comprehend the possible comorbidities associated with epilepsy as this can provide insight regarding additional health needs that PWE may have. Comprehension of the extent of anxiety and depressive symptoms in temporal lobe epilepsy can be useful towards a multimodal treatment in PWE. Increased collaboration of a multidisciplinary team in the treatment of PWE can assist in improving the quality of health of PWE.

Theoretical Framework for the Case Study: Hermeneutic phenomenology and Self-Regulatory Executive Functioning Model

This study will be exploring the co-occurrence of anxiety and depression in epilepsy through a framework consisting of two approaches; the hermeneutic phenomenology and the self-regulatory executive functioning model (S-REF).

Hermeneutic Phenomenological framework

The study of philosophical and psychological approaches has greatly influenced our understanding of human perception and cognition. Among these approaches, the phenomenological approach holds a significant place.

Phenomenology has been practiced for millennia under numerous names, but it truly found its place in the writings of Husserl, Heidegger, Sartre, Merleau-Ponty, and others in the beginning of the 20th century (Mabaquiao, 2005).

There are generally thought to be two basic phenomenological approaches: interpretative (also known as hermeneutic) and transcendental (also known as descriptive phenomenology). Edmund Husserl is considered the father of phenomenology with his transcendental phenomenology. Transcendental phenomenology can be defined as the scientific study focused on the appearance of things in the manner in which they are viewed and appear on an individual's consciousness. Husserl's aim was to shift the focus of philosophy from metaphysical speculation to a more rigorous and systematic study of human experience. By investigating the structures of consciousness, Husserl believed it was possible to grasp the essence of phenomena unaffected by theories or assumptions (Moran, 2018).

Husserl's stipulated key principles of phenomenology: 1) *Intentionality*; the intentional nature of human experience, meaning that individuals are actively engaged in their experiences and have a purpose or intention behind their actions and perceptions (Mabaquiao, 2005). 2) *Epoche or bracketing*; critical principle in phenomenology where the researcher suspends their preconceived beliefs and biases in order to approach the

research with a fresh and open mindset. 3) *Reduction*; the intentional consciousness of making use of bracketing process (Rasi,2015); 4) *Noesis*; “giving stratum of experience” (Rasi,2015), belonging to thinking as well as thoughts; 5) *Noema*: the meaning of an act (Husserl 2003 as cited in Rasi,2015); 6) *Horizon*; presentation of experiences that cannot be bracketed (Mabaquiao, 2005).

Martin Heidegger (1889-1976), a student of Husserl, branched out from Husserl to create his own philosophy called hermeneutic phenomenology. Heidegger disagreed with bracketing and believed that it is impossible to bracket one’s experiences because we are constantly in the world with others in the circumstances of existence. According to Heidegger, separation of oneself from being within the world is not possible. Heidegger coined the term *dasein*, to describe the state of being in the world which literally means “being there” (Larsen & Adu, Philip,2021).

Important concepts in hermeneutic phenomenology consist of: *dasein*; fore-sight/fore-conception (preconceived knowledge about phenomenon); and hermeneutic circle (a term introduced by Dilthey and introduced by Schleiermacher, this term is described in detail, below in the motivation part of the dissertation).

Hermeneutic phenomenology was selected as a framework for this study because it is best suited for exploring the lived experience of the participant.

This study will be applying hermeneutic phenomenology as a framework to explore and understand the psychological traits of the individual as a whole in a way to put in perspective the signs of suffering, the manner in which he is responding to these signs. The positive parts to deal with the negative parts. A comprehensive picture of the individual, the resilience and overcoming. This framework allows for a deep exploration of the participant’s subjective experiences, perceptions, and meanings attached to the anxiety, depression and temporal lobe epilepsy.

The added advantage of Phenomenological framework is that it provides an inductive approach to the research study and the addition of another theory. Through the inductive approach the study found the Self-Regulatory Function Model (S-REF) to be applicable for further exploration of the topic of anxiety and depression in epilepsy.

Phenomenology of anxiety and depression in epilepsy

Although it is well acknowledged that the phenomenology of depression in epilepsy varies from depression in other neurological illnesses, confirmatory studies determining this are few and far between. The phenomenology is frequently muddled by the potential adverse effects of anti-epileptic drugs (Seethalakshmi & Krishnamoorthy, 2007).

Self-Regulatory Executive Function Model (S REF)

The Self-Regulatory Executive Functioning model (S-REF) was developed by Adrian Wells and Gerald Matthews (Wells & Matthews, 1994 as cited in Wells & Matthews, 1996). S-REF comes from the metacognitive theory (Wells, 1995 as cited in Ryum et al.).

The concept of "metacognition" refers to the stable understanding of one's own cognitive system and the elements influencing its operation, the management and awareness of the current state of cognition, and the evaluation of the relevance of ideas and memories (Wells, 1995 as cited in Ryum et al.).

S-REF is a transdiagnostic model of emotional disorder, specifying Cognitive Attentional Syndrome (CAS), which refers to an unhealthy manner of thinking as well as reacting to unfavourable and feelings which in turn lead to increased severity and protracted emotional suffering (Fisher & Noble, 2017).

CAS is made up of persistent thoughts e.g. worry, ruminating, overanalyses; Attentional strategies e.g. screening for unpleasant thoughts and feelings; unhelpful coping strategies e.g. oversleeping or avoidance of activities (Fisher & Noble, 2017). The selection and implementation of CAS in response to the occurrence of negative thoughts or perception of illness is determined by the metacognitive beliefs. S-REF specifies multiple metacognitive beliefs which can be categorised as *positive beliefs* as well as *negative beliefs* regarding uncontrollable as well as danger of worry.

Positive metacognitive beliefs refer to beliefs that are thought to improve coping, which include worrying about potential future threats (e.g., If I worry, awful things won't happen), ruminating (e.g., I need to review the event to make sense of it), and focusing on memories and filling in any memory gaps e.g., I need to remember everything to feel normal (Hett, 2017: Ryum et al.).

Negative metacognitive beliefs are centred on the inability to control and unfavourable assessment of thoughts (for example, *I can't stop worrying*). These kinds of ideas constitute an attempt to control emotion, combined with the repeated use of unhelpful mind control techniques, but instead they serve to perpetuate a feeling of threat which can lead to increased anxiety (Hett, 2017: Ryum et al.).

According to the S-REF the emergence and persistence of emotional distress, including anxiety and depression, depend on maladaptive metacognitive beliefs and processes (Reiley, 2017). PWE is characterized by a variety of negative thoughts, worries, or doubts, including worries about potential future seizures and worries about how having epilepsy can affect one's familial, social, or professional responsibilities.

Many PWE do not experience prolonged concern or rumination, however those who experience depression or anxiety may (Fisher & Noble, 2017). These individuals may continuously ruminate or worry about future events or how their actions will affect their family (Fisher & Noble, 2017).

The use of S-REF for studying anxiety and depression in PWE has been supported by Fisher & Noble (2016), Reiley (2017). Making it a useful model for investigation and exploration of the topic.

Motivation for using both the hermeneutic phenomenology and the S-REF approaches

A renowned contribution of hermeneutic phenomenology is the hermeneutic circle. The absence of bracketing allows the researcher to get to the essence of the phenomenon through the use of hermeneutic circle which is a revisionary process. Heidegger termed preconceived knowledge force-sight/fore-conception.

As one starts to comprehend and interpret something, one's foresights which consists of comprehensions, biases as well as judgements are revised. It is worth noting that hermeneutic circle is not a technique but rather a description of the comprehension process. It is a philosophy on comprehension and interpretation focused on how people make sense of the world.

When analyzing data there is a comprehension of the whole (the entire transcript) and analyzing the whole while reading the transcript (which in thematic analyses is considered "familiarizing yourself with the text" (Braun & Clark,2006), after familiarizing oneself with the text there is an understanding of the parts (codes and themes). As the data is analyzed, the researcher breaks down the information into parts and then synthesizes and looks at the whole again (the entire transcript). Which is the *new understanding*. As the researcher moves through it again in analysis, the parts make sense of the whole and the whole makes part of the sense of parts and the hermeneutic circle continues until there's an emergence of a new comprehension.

Some scholars consider the process of hermeneutic circle to be better comprehended as being spiral and not circular as circular might imply that one's understanding doesn't change since a circle gets to the same point. Which is not what the Hermeneutic circle is about. In the spiral process, comprehension increases by moving from the comprehension of parts to comprehension of a whole and again back to the parts, continually changing as new data is introduced. It is well known that thematic analysis is an ongoing process which can be simultaneously done with data collection. During this process, the moving back from parts and whole's is quite evident.

Interpretation is a constant revision, because as the researcher is interpreting something, the researcher has pre-understanding of the phenomenon, and as the researcher obtains new information, there's a revision of that understanding. The researcher began the study with pre-understanding of the topic through the systematic review. As a researcher the whole text is seized in individual parts and as a whole again and again in a circle until there is full comprehension.

According to Heidegger (1971) there is constantly a moving from the object that is to be comprehended to the personal comprehension of the researcher.

Heidegger's hermeneutic circle is beneficial because it allows for the researcher to look through these changing lenses (new comprehensions) in order to be able to comprehend the phenomenon. Each lens is created as the process continues and this is beneficial because it allows for the addition of another framework or theory, one of the lenses created through the data analysis was the self-regulatory executive functioning model that was able to describe the participant's experience of TLE, anxiety and depression. The hermeneutic circle allows for the enrichment of information and investigation.

The self-regulatory model was applied to further interpret the findings of the study. Both of these methods are focused on individual's experience, with S-REF elaborating further regarding the interpretation of these experience and how the participant maintains the depressive and anxiety symptoms.

The fact that this dissertation commenced with a systematic review, had already motivated for hermeneutic phenomenology as opposed to Husserl's transcendent phenomenology. The findings from the systematic review served as fore-sight /fore-conception as they provided the researcher with information regarding anxiety and depression in epilepsy patients in Sub-Saharan Africa and the case study served to revise the researcher's fore-sight.

Methodology of the Empirical Study: A Mixed Methodology

This empirical research employed a mixed methodology. Mixed methods research design refers to a method for gathering, analysing, and combining quantitative and qualitative research and methods in a single study for better comprehension of a research problem (Creswell, 2008).

Qualitative research consists of exploration and provision of deeper insights regarding problems, assists in the generation of hypothesis, additional investigation and comprehension in comparison to quantitative data that consists of collection of numerical data that can be statistically analysed (Tenny, Brannan & Brannan,2022).

This study was conducted through an exploratory case study. A case study is an empirical investigation that investigates a contemporary phenomenon within its real-life context, particularly when the boundaries between phenomenon and context are unclear (Kohlbacher,2006).

The exploratory case study consists of quantitative instruments (Demographic questionnaire, PHQ-9, GAD-7 as well as qualitative semi-structured interviews. Multiple methods allow the different research objectives and questions to be fully explored. The case study was conducted electronically with a South African adult with epilepsy. The exploratory case study data collection method is frequently supplemented by other data collection methods such as interviews, questionnaires, experiments, and so on (Kohlbacher,2006). This study addresses the how and what questions through in depth interviews with the participant about his diagnosis as well as a questionnaire.

Justification for Methodology

Using mixed method is highly valuable as it strengthens the study. Each methodology has its strengths and weaknesses. Combining qualitative and quantitative components can be an effective way to investigate research questions more thoroughly.

For instance, qualitative research methodology is beneficial as it entails increased research design flexibility, the ability to avoid reliance on the researcher's predetermined

assumptions, the ability to provide greater depth and detail in a researcher's findings, the ability to simulate participants' unique individual experiences, to focus on the meanings of key issues for participants, particularly any contradictions or inconsistencies in their responses (Griffin, 2004; Prasad, 2005 as cited in Griffin, 2004).

Additionally, anxiety and depression are very sensitive matters which makes qualitative research ideal as it allows researchers to address more sensitive issues, appreciate the larger context of people's experiences and make connections across different aspects of participants' lives (Griffin, 2004 as cited in Derek & Wu, 2018).

Main Research Questions

The study's main research questions are to explore:

1. What is the participant's experience in his childhood and adolescence that informed or put in perspective the understanding of the emotional and personality traits as the psychic resources to deal with temporal lobe epilepsy after the diagnosis?
2. How does the participant deal with the diagnosis information and with the clinical afflictions of the symptoms of temporal lobe epilepsy?
3. Can we observe the anxiety and depression symptoms in the person related to epilepsy diagnosis?
4. What is the influence of epilepsy in the different areas of the participant's life (individual, family, social, work life)?

Objectives

The exploratory case study aligns with the objective of the study. The study's philosophical approach has been guided by the research questions that aim to explore:

1. The participant's experience in his childhood and adolescence that informed or put in perspective the understanding of the emotional and personality traits as the psychic resources to deal with temporal lobe epilepsy after the diagnosis
2. Observation of anxiety and depression symptoms in the participant related to epilepsy diagnosis
3. The influence of temporal lobe epilepsy in the different areas of the participant's life (individual, family, social, work life)
4. The manner in which the participant deals with the psychological experience of the clinical symptoms of epilepsy and the diagnosis information

Procedures of Collecting Clinical Data

The study employed purposeful sampling. As the case study has a defined criterion for the sample. The case study consisted of one participant. The sample criteria consisted of South African adult outpatient diagnosed with epilepsy, who has no intellectual difficulties and is able to provide consent. The population selected is in alignment with the study purpose as it is focused on exploring anxiety and depression in adult with temporal lobe epilepsy.

Gaining access to the participant

The researcher contacted South Africans residing in Portugal (through the use of social media platforms e.g. facebook), informing them about the research and enquiring as to whether they knew any South African adults diagnosed with epilepsy. One person got in touch with the researcher and referred a potential participant. This person informed the potential participant about the researcher's interest for conducting research on a South African adult with epilepsy.

The potential participant provided the individual with his contact number and consented to be contacted by the researcher. The initial contact with the participant was by cell phone. The initial contact consisted of introduction and providing the participant with the research objectives and conditions. The researcher received a favorable response from the participant as he agreed to take part in the study.

As the study was conducted electronically (through zoom), certain steps were also taken. Zoom was downloaded and an account specifically for the research study was created. A meeting was scheduled and an invitation sent to the participant.

The first part of the first interview over zoom, entailed, emailing the participant with information sheet and consent form while on the zoom. He was provided with the opportunity to ask questions and he was provided with the necessary information required. Once that was completed, the interview begun.

At the beginning of each interview, (post the initial interview) the researcher informed the participant when she was about to start recording. The researcher made use of two recording devices. The recordings were saved and stored on the external hard drive. In the last interview the participant was provided with electronic study pack that contains demographic survey, the GAD-7 & the PHQ-9.

Inclusion and exclusion criteria

The inclusion criteria consisted of; 18 years and older, diagnosed with epilepsy by a clinician able to provide informed consent.

Whereas the exclusion criteria are intellectual difficulties, being under the age of 18, inability to provide consent and in-patient.

Population and characteristics of the participant

The population is south Africa people that has temporal epilepsy diagnosis, above the age of 18, residing in Portugal.

The participant (Henry, fictional name) is a 30-year-old male South African citizen. He lived in a cosmopolitan city of South Africa until he was 25 years old, and moved to Portugal in 2018. Henry resides with his sister in north city of Portugal. He speaks English, Afrikaans and Portuguese.

Henry was diagnosed with temporal lobe epilepsy in 2011 when he was 19. The participant's temporal lobe epilepsy causes focally impaired awareness seizures. There is no history of epilepsy in the family. With regards to the participant speech, he has mild stutter but has good communication skills. Henry was previously prescribed anti-epileptic drugs, mood stabilizers and antipsychotics.

The participant initially came to study but ended up working since he arrived in Portugal as a junior programmer and a technical support engineer.

Instrument Tools

The study used 3 instrument tools as follow:

Quantitative that was administrated in one session on-line:

- Generalized Anxiety Disorder-7 (GAD-7)
- Primary Health Questionnaire-9 (PHQ-9)
- sociodemographic biographical questionnaire.

Qualitative that was collected in 3 on-line sessions:

- 3 semi-structured interviews concerning the life experience in different areas following the objectives of the research.

Generalized Anxiety Disorder 7, Patient Health Questionnaire

9 & Biographical survey

The GAD-7 was selected to assess for anxiety symptoms and the PHQ-9 for depression symptoms. The biographical questionnaire served to provide biographical data about the participant (age, epilepsy type, duration of diagnosis, medication information).

The GAD-7 & PHQ-9 are considered to be screening instruments and have been validated for use on patients with epilepsy by numerous researchers such as Seo et al., (2014); Rathore et al. (2014) & Budikayanti et al. (2019).

The study pack was available electronically. Conducting the study online is beneficial as several factors can hinder participant from attending the study in person for instance, if they have clinical or personal concerns (e.g. personal pandemic risks or other health conditions, traveling distance, etc.). Online screening of anxiety and depression provides a substitute method to paper-based screening (Cronly, Duff, Riekert, Perry, Fitzgerald & Horgan, 2018). GAD-7 is a self-reporting instrument made up of short questions that can be completed in less than 3 minutes (Beidas et al., 2015).

All PHQ-9, GAD-7 screeners and translations are downloadable from the Patient Health Questionnaire Screeners and no permission is required for reproduction, translation, displaying or their distribution (Patient Health Questionnaire Screeners (Spitzer, Williams & Kroenke, n.d.). The PHQ-9 was designed for utilization in primary care populations (Rathore et al., 2014).

The PHQ-9 It consists of nine items pertaining to the DSM (33) criteria for Major Depressive Disorder (Rathore et al., 2014). The individual is asked to rate the severity of his/her depression during the previous 2 weeks. Each of the items on the measure is rated on a 4-point scale (Kroenke, Spitzer & Williams, 2001). 0=Not at all; 1=Several days; 2=More than half the days; 3=Nearly every day (Kroenke, Spitzer & Williams, 2001).

The Generalized Anxiety Disorder scale (GAD-7) is a commonly used diagnostic self-report scale for screening, diagnosis as well as severity assessment of anxiety disorder (Kroenke, Spitzer, Williams, Monahan & Löwe, 2007). It is representative of an anxiety measure based on the seven items which are scored from zero to three (Kroenke, Spitzer, Williams, Monahan & Löwe, 2007). The scale score ranges from 0 to 21 with cut-off scores for mild, moderate as well as severe anxiety symptoms, scores that are above 10 are considered to be in the clinical range (Kroenke, Spitzer, Williams, Monahan & Löwe, 2007).

Semi-structured interview

The qualitative part of the methodology was applied in the form of semi-structured interview over zoom. Interview guide was created to guide the interview (see Attachment) In a semi-structured interview, the interviewer's job is to assist and provide guidance

rather than to predetermine every detail of the conversation (Smith & Osborn,2007). In semi-structured interviews, the investigator has a list of questions and an interview guide for the interview, but the interview is directed rather than controlled by the interview guide (Smith & Osborn, 2007).

The goals of the interview are to gain a better understanding of the participants mental health with regards to anxiety and depressive symptoms. To discover if he feels anxious/depressed and how he relates to his condition and if he makes a link between his diagnosis and his self-esteem and self-perception. It provides additional information regarding his diagnosis in relation to his relationships e.g. (possible fear of having a seizure when he is dating, his experience with stigmatisation. The interview consists of open-ended questions to allow richer information.

Case study concerning the participant

The study consisted of 4 interviews, complementing the 2 scales. The duration the interviews was flexible, ideally between 60min- 75min., but also dependent on the dynamic of the interview as well, notably the involved level of the participant in the interview.

❖ Session 1 by videoconference:

The first contact by videoconference served to provide more detailed information concerning the purpose of the study, consent form, interviews, establishing a rapport and sincere and trusting environment between the researcher and the participant that enables the participant to be motivated to share his personal life story, the influence of epilepsy on the participant's quality of life (his feelings, perceptions, memories, ideas, beliefs etc. concerning the experience of the epilepsy).

❖ Session 2 by video conference:

This session started with a summary from the previous session and member checking done. It was focused on going deeper with the participant with regards to the manner in

which the participant deals with the psychological experience of the clinical symptoms of epilepsy and the diagnosis information.

❖ Session 3 by video conference:

The beginning of the session started with a summary from the previous session and member checking done. This session was focused on exploring the co-occurrence of depression and anxiety symptoms in epilepsy as well as the participant's experience with anxiety and depression symptoms in his childhood and adulthood, prior to the diagnosis of epilepsy and after the diagnosis. During the session Henry felt an epileptic episode coming on and the interview had to be stopped.

❖ Session 4 by video conference

The session started with a summary from the previous session and member checking. This session was dedicated to going through anything that may have been missed or make up for any distractions or delays that may have occurred during the other sessions as well as providing the participant with an opportunity to provide feedback. In addition to the aforementioned, debriefing will be done. The researcher sent the link (from google drive) of the questionnaire containing the GAD7 and PHQ 9 to Henry to complete it.

Conducting a case study using video conference on zoom

The case study was conducted through video conference of zoom. Zoom is an interactive, cloud-based videoconferencing service that incorporates elements such as online meetings, group messaging, as well as secure session recording (Zoom Video Communications Inc., 2016). It enables real-time communication with geographically diverse individuals via computer, tablet, or mobile device. Nevertheless, unlike many other VoIP technologies, Zoom has a number of additional benefits that increase its research utility (Zoom Video Communications Inc., 2016).

Zoom's ability to securely record and store sessions without the use of third-party software is a significant advantage. This feature is especially important in research, where highly

sensitive data must be protected. Other critical security features include user-specific authentication, real-time meeting encryption, and the capacity to backup recordings to online remote server networks ("the cloud" or google drive) or local drives, that can then be securely shared for collaboration purposes (Zoom Video Communications Inc., 2016).

The Role of the Researcher in the Data Collection

The researcher is a south African, the commonness of nationality assisted in establishing rapport and understanding the slang that the participant used during the interview. It facilitated to build trust and confidence. However, as noted by Minichiello et al., 1995 as cited in Ajjawi & Higgs (2007) this familiarity might be a drawback if the researcher assigns participants different interpretations for various terms or jargon, actions, and conclusions.

To counter this Ajjawi & Higgs (2007) suggest the use of van Manen's (1997) hermeneutic alertness, which happens when researchers take a step back and consider the meanings of occurrences as opposed to taking their initial assumptions and interpretations at face value.

The researcher therefore adapted hermeneutics' alertness as well as alertness to the context. Which is also an essential hermeneutic concept because comprehension is always reliant on existing assumptions, which can lead back into acquired traditions and ways of seeing (McCaffrey, Wilson, Jonatansdottir, Zimmer, Zimmer, Graham, Snadden & MacLeod, 2022).

The multiple interviews were advantageous to the interviewer as they allowed the researcher to apply hermeneutic circle through the process of journaling as well as asking follow up questions in the next interview as a means to record and revise experiences and assumptions about the phenomenon being studied.

Data Analysis of the Case Study

The data analysis of the case study is focused on two types of sources of information and clinical material.

Quantitative Approach

The Quantitative part of the study was analysed manually using the manuals of the PHQ 9 and GAD-7.

Regarding the psychometric tools, this study made use of descriptive analysis. Descriptive statistics are used to convey quantitative information in an understandable manner. The American Psychological Association dictionary (2023) defines descriptive analysis as techniques for showing the major features of sample data without necessarily extrapolating to a broader population.

It often contains the mean, median, and mode to illustrate central tendency, as well as the range and standard deviation, which illustrates how evenly distributed the scores are within the sample. Charts and graphs, such as a frequency distribution or histogram, are examples of descriptive statistics (APA,2023).

The results of the research will be in the form of figures and narrative deductions gleaned from explorations of the subject under study (hence the use of both qualitative and quantitative methods).

Qualitative Approach

The sessions were recorded and the recording transcribed verbatim through the use of transcription software (Descript Software). The participant's real name was not included in the recording. Descript was used to transcribe the audio recordings.

Data analysis in phenomenological research entails interpretation of the findings. The data is analyzed with the aim of finding the patterns, themes and insights regarding the

lived experience of the participant. This process commences with the researcher reading and re-reading the data collected.

The study followed the hermeneutic data analysis which consists of application of hermeneutic circle by modification regarding the nature and comprehension through a constant process of renewed comprehension of the phenomenon. The data analysis was conducted in accordance with the six stages of Ajjawi & Higgs (2007) of hermeneutic analysis. These steps consist of:

Stage 1: Immersion

In the initial step of analysis, the researcher listened to the recordings attentively, transcribed the recordings verbatim using descript. Then went through the recordings and the transcript to verify if the transcriptions were accurately transcribed.

This process was followed by re-reading the transcripts all over again to familiarise oneself with the text. Followed by the removal of repeated words and filler words. The thoughts and comments that appeared significant were highlighted and notes were made on the margins.

Stage 2: Understanding

This entails generating meanings into units, which is often referred to as identifying the participant's interpretation or identifying the first order constructs (Ajjawi & Higgs,2007). A detailed understanding of the participants interpretation was achieved by going through the transcription with a fine-tooth comb and manually creating codes on the margins of the transcript in order to identify first order constructs.

In addition to the aforementioned, in order to understand comprehensively the participant's interpretation, follow up questions and probing was done. The multiple interview sessions provided the researcher with an opportunity to start the next

interview session with follow up questioning regarding what may have been discussed previously and needed clarification. Where possible the participant exact words were used. This stage was followed by abstraction.

Stage 3: Abstraction

The stage entails the researchers' theoretical and experiential information being used to create second order constructs, which are abstractions of the first order constructs (Arraji & Higgs,2007). Abstraction consists of the researcher identifying the second order of constructs as well as grouping them into the sub-themes (Ajjari & Higgs,2007).

The researcher applied her theoretical knowledge on co-occurrence of anxiety and epilepsy from the systematic review conducted, personal knowledge as well as notes taken of observations made during the interview sessions. A combination of the aforementioned and the first-order constructs were used to create second order constructs. The second order constructs were then grouped in themes

Stage 4: Synthesis and theme development

The researcher engaged in organizing sub-themes into themes; expanding on themes; and contrasting themes among sub-discipline groupings the sub-themes into themes.

Themes and sub-themes were developed through the use of the second order constructs. The researcher applied the hermeneutic circle to move back and forth reviewing the transcripts, the analysis from the prior stages as well as theoretical background. Observing the aforementioned as a whole and as parts of a whole, searching for links or relationship to the whole.

Stage 5: Illumination and Illustration of Phenomena:

This stage entails connecting the literature to the themes that have been identified and reconstructing the interpretations into narratives (Ajjawi & Higgs,2007).

Stage 6: Integration

This stage consists of critiquing the themes and reporting the research findings' final interpretation (Ajjawi & Higgs,2007). The researcher reviewed the identified themes and grouped them into 5 themes.

Validity & Reliability of Quantitative Instruments

Generalized Anxiety Disorder-7 (GAD-7) is a reliable and valid screening tool for use in in patients with epilepsy (Seo et al.,2014). PHQ-9 has been validated by numerous authors such as Rathore et al. (2014) & Budikayanti et al. (2019). A study conducted by Budikayanti et al. (2019) found the Patient Health Questionnaire-9 to be an efficient & non-proprietary depression screening instrument consisting of excellent accuracy validated for use in adult epilepsy patients.

Ethical clearance

As the study involves interaction with humans, ethical clearance is mandatory. Application for ethical clearance was sought and received through Fernando Pessoa University. Signed consent was obtained from the participant. The participant was provided with a consent form to sign and provided with the opportunity to ask questions before signing it.

Presentation of the results

The findings are presented in two parts, quantitative and qualitative part. The findings of the quantitative part of the study will be presented first and then followed by the qualitative part.

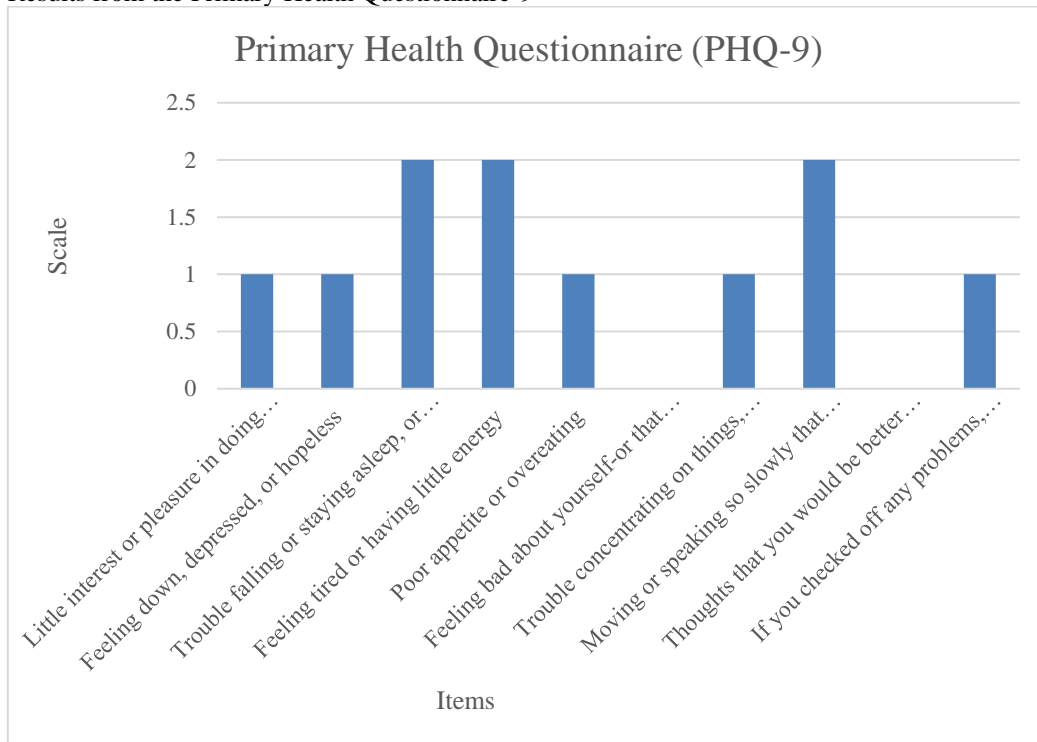
Quantitative Part: Demographic questionnaire, Patient Health Questionnaire 9 & Generalized Anxiety Disorder-7

Table 1
Demographical Questionnaire

Demographical data	
Questions	Response
Age	18-35
Marital status	Single
What is the highest level of education that you have successfully completed?	Matric
How long have you been diagnosed with epilepsy?	12 years
What type of epilepsy were you diagnosed with?	Focal
Are you taking anti-epileptic medication?	No
Have you undergone epilepsy surgery?	No

The demographic data illustrates the demographic data of the respondent. The respondent is between the ages of 18-35 and is single. He was has had focal epilepsy diagnosis for 12 years. Meaning he was diagnosed in 2011. He is not on any ant-epileptic medication and hasn't undergone any epilepsy related surgery.

Figure 2
Results from the Primary Health Questionnaire-9



As seen from the figure above, Henry's answered scored level 2 for each of the following:

- trouble falling or staying asleep,
- feeling tired or having little energy, Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

PHQ-9 assesses for depression by asking the respondent if they have been bothered by the aforementioned, over the last two weeks.

- 0- Not at all
- 1- Several days
- 2- More than half the days
- 3- Nearly every day

Henry selected 1 for “Little interest or pleasure in doing things”, “Feeling down, depressed, or hopeless,” Poor appetite or overeating, “Trouble concentrating on things, such as reading the newspaper or watching television”, “If you checked off any problems,

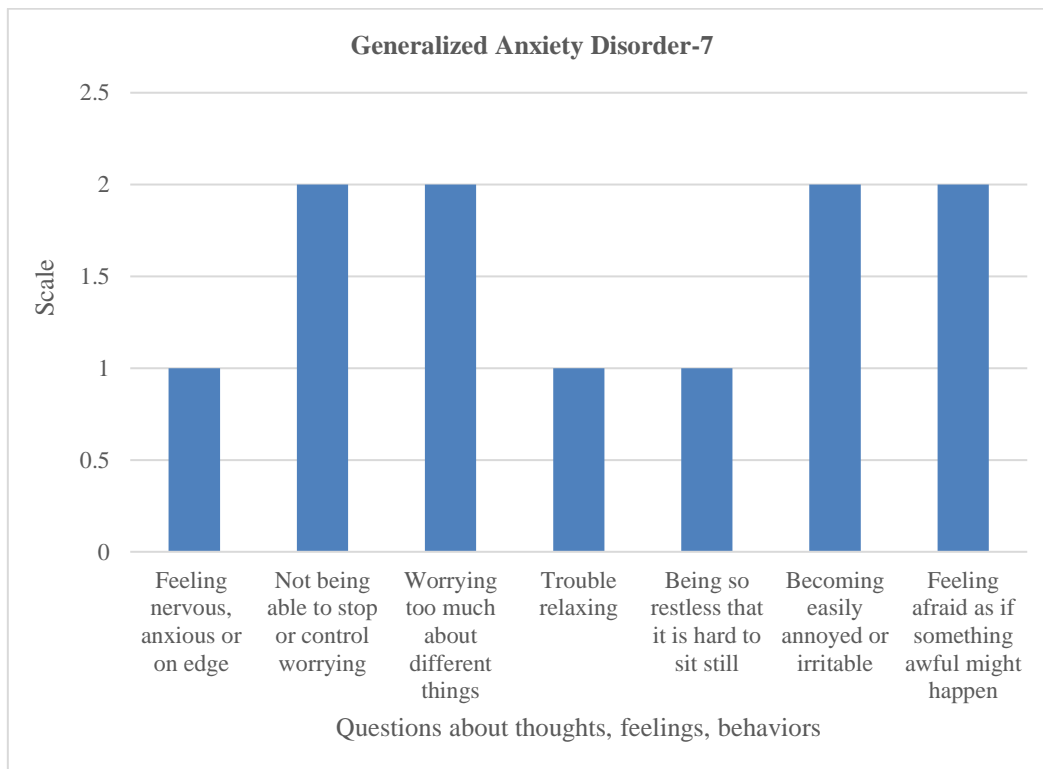
how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?” which is indicative of several days.

“Thoughts that you would be better off dead or of hurting yourself in some way” and “Feeling bad about yourself-or that you are a failure or have let yourself or your family down” were scored a zero (0)

Henry scored an 11 on the PHQ 9. A score of 10-14 is indicative of which is indicative of moderate depression. The total score ranges from 0 up to 27. The higher scores are indicative of a greater severity of depression (Rathore et al.,2014). The interpretation of the scores of levels of depressive symptoms is as follows; 0-4=none, 5-9= Mild depression, 10-14=Moderate depression, 15-19=Moderately severe depression & 20-27= Severe depression (Rathore et al.,2014).

Figure 3

Results from the responses of Henry from the “Generalized Anxiety Disorder-7”



As seen above, Henry reported experiencing ‘not being able to stop or control worrying’, ‘worrying too much about different things’, ‘becoming easily annoyed or irritable’ and ‘feeling afraid as if something awful might happen’ more than half the days.

Unlike ‘Feeling nervous, anxious or on edge’, ‘trouble relaxing’ and ‘being so restless that it is hard to sit still’ which he reported as experiencing several days.

On the GAD-7, Henry scored a total of 11, a score of 10-14 is indicative of moderate anxiety. The aforementioned results demonstrate the co-occurrence of anxiety and depression in temporal lobe epilepsy. The GAD-7 scale score ranges from 0 to 21 with cut-off scores for mild, moderate as well as severe anxiety symptoms, scores that are above 10 are considered to be in the clinical range (Kroenke, Spitzer, Williams, Monahan & Löwe, 2007).

Qualitative Part: Findings of the clinical semi-structured interviews

Six broad themes and twenty sub-themes were identified through the of hermeneutic phenomenology. Each theme is followed by a quote from Henry. The presentation of the findings from the semi-structured interviews is done thematically, using narrative format. The participant was given the pseudonym of Henry. In the following part of the chapter, Temporal Lobe Epilepsy (TLE) will be referred to as Epilepsy

Figure 2

Diagram representation of themes and sub-themes identified

Main Themes	Sub-themes
Theme 1: Childhood & adolescence experiences	<ul style="list-style-type: none"> • Childhood abandonment • Intellectual capacity as protective factor • Onset of TLE since early adolescence • family beliefs and patterns
Theme 2: Experience of anxiety & depression related to TLE	<ul style="list-style-type: none"> • Depressed mood & suicidal ideation during TLE episode • Depersonalization & Dissociation • Symptoms of panic disorder with agoraphobia • Suicidal ideation during seizure
Theme 3: Impact of Epilepsy on different areas of & development	<ul style="list-style-type: none"> • Socially withdrawn • Interpersonal & intrapersonal relationships • Preference for remote jobs over in-person jobs • Physical & cognitive challenges affecting functioning
Theme 4: Management of TLE, anxiety, & depression	<ul style="list-style-type: none"> • Reluctance to take medication: fear losing drive & ambition • Using alcohol to ease anxiety • Grounding exercises
Theme 5: Protective factors	<ul style="list-style-type: none"> • Support from sister & close friends • Inclusive work environment supportive of people with TLE
Theme 6: Healthcare and social support for people with TLE	<ul style="list-style-type: none"> • Need for increased psycho-education

Theme 1: Childhood & adolescence experiences

Childhood abandonment: development of hyper independence. Henry lived in Mozambique with his paternal grandparents and father up until his father died when he was 4. After the death of his father, Henry's mother, who had been residing in South Africa, fetched Henry and took him with her to South Africa. While in South Africa Henry experienced a lot of childhood neglect growing up, often being left home alone with his younger brother from the age of 5.

it was just wild because my mother was young, so it was like a child raising a child. It was wild. I had to learn how to cook when I was like five years old, and I basically raised my brother when I was six and he was two. yeah, I don't know. That's weird.

my mother would leave for work at like four o'clock in the morning and then only come home at like, around midnight. So it was up to me to just like do things, you know? And then on the weekends, because she was still young, like. on Friday when she goes to work she'd pack a bag and then she'd just go out the whole weekend and come back on Sunday, like afternoon

Intellectual capacity serving as a protective factor. Although Henry's childhood consisted of childhood trauma and child neglect. There is a protective factor that was apparent. His intellectual capacity.

During the interview, Henry's description of his childhood involved a lot of independence from a young age. When asked about this he stated that:

I've had to be independent from a young age. As I told you I had to raise myself and my brother. And for some parts my sister as well. So, I've had to be independent for a long time. I actually started living alone.

I think I was. 15 or 16. I was kicked out of the house, so I was living alone, not alone, like on my own at the school because I was always top five academics and I was the only person of colour who was top five academics. They needed me there. So, when they

found out that I had nowhere to stay, they basically gave me somewhere to stay. So, I had to do that. And then, from there, I went to university on my own. And that's when my family started talking to me. I just, I was like, I don't need you anymore.

Onset TLE since early adolescence. Henry stated that although he had a difficult childhood, he only started experiencing mental health problems during his adolescence. When asked about his mental health during his childhood Henry stated that:

“it was fine up until like 15. Afterwards it was a bit up and down cause I was on medication that basically took me on a trip of my life. So I just, I didn't wanna do anything..”

When asked about the onset of temporal lobe epilepsy, Henry stated that:

it started when I was 16, but I think, the actual diagnosis happened when I was 19.

at first, they thought it was just depression. And then they booked me into this place. I think the first time I went there, I was 16. And they did some tests and then they said it was bipolar one.

Henry was booked into psychiatric ward several times over the years before he received a diagnosis for epilepsy. He only received his diagnosis at the age of 19.

they did more tests and said its temporal lobe epilepsy. So, I was a bit scared when they said epilepsy. but then they explained that it, it's not the kinda epilepsy where I have seizures and stuff, it's that my brain has a seizure and then it induces a sort of like depression, anxiety, or some sort of bipolar mood disorder effect.

When asked what his initial symptoms were when he was 16 years old, he stated that:

“I randomly felt like I wasn't myself, like I would have out of body experiences and dissociation”

When asked “what significant life events would you say led up to your diagnosis?” Henry stated:

what led me to actually get the diagnosis was seeking for help for dissociation and finding out that I tried to kill myself so many times, that was not nice. So that's why I went to actually get help.

A link was made between the influence that traumatic childhood experience can have on epilepsy diagnosis. Traumatic childhood experience was viewed as a factor that can bring TLE symptoms to the surface. To elaborate on the aforementioned question, Henry stated that:

I wouldn't say that this is what caused, but I think this is what put it [epilepsy] out. just not having a normal childhood and seeing like other people, you know, like, seeing my friends, have a normal childhood. And then, looking at my life and being like this could be better. But that's not what caused, I think that's what just made it worse, if that makes sense.

Family Beliefs/ Attitudes. Henry’s childhood consisted of him witnessing concerning mental health instance within his family, either being ignored or being interpreted as spiritual attacks and the treatment being prayer. He deviated from that and took it upon himself to learn more about mental health. When asked about his experience of his family’s history of mental health, (if there’s anyone who has anxiety and or depression?). He stated that:

my sister does and, I'm pretty sure that my mother and my grandmother do too, but they'll never admit it. because they're always in denial. I would just always tell them like, “this is what it is. Are you experiencing this? because, this is an anxiety attack.” They're like, “no”, you know, those people, they just wanna pray. So they're like, “no, I'm just gonna pray and I'll be fine.”

When asked how living with a family with individuals that he experienced as showing signs of mental illness affected him, he stated:

I don't think growing up around that affected me so. I think that it may affect other people. If they were living in my family and they like actually chose to follow what the family does because the family didn't want to actually acknowledge any of it. So, I feel like if I was that kind of person, I would've suffered more, but I just chose. Basically, I told my family to fuck off. I sought help for myself.

Theme 2: Experience of anxiety and depression in relation to TLE

The sub-themes identified here are suicidal ideation, depersonalization and dissociation and panic disorder with agoraphobia.

Depressive Mood & Suicidal Ideation During Pre-Ictal & Ictal Phase of Seizure. Henry stated that he sometimes experiences suicidal ideation particularly prior to his seizures and during the seizure. When asked to describe his experience he states that:

“when it happens to me, sometimes I get depressed. sometimes I get manic.”

“emotionally, I just don't wanna be here like, on the planet. Mentally I can't function unless it's doing something that I want to do. Like, like I said, like work. Like I can't focus on anything. I can't, I can't speak to people. I can't hold a conversation. I can't, I can't do anything. I just don't want to be anywhere. except in a dark room or just dead.”

Dissociation and Depersonalization. Another recurring theme during the interview was Henry's experience with dissociation and depersonalization. Henry's worst incident of dissociation was when he was a varsity student.

I think the worst time it ever happened or the longest and the worst time, I forgot where I was. I was at home getting ready to go to university. And then I blinked and all of a sudden, I was in this field. I was wearing the same clothes but I wasn't wearing shoes. It was like, three weeks later and I'm somewhere else. So, it was like I became someone else, for three weeks. And then, I find out that I tried to kill myself a few times and then I, sometimes I woke up in the hospital”

sometimes I, I just zone out unnecessarily

I become fidgety and stuff, and I keep repeating the same thing. Like in my mind, I keep repeating the same thoughts over and over until actually I understand it. So weird.

Panic Disorder with Agoraphobia. Henry experiences chronic fear of leaving the house. He stated that he has a fear of leaving the house.

“sometimes I just have so much anxiety I can't leave my apartment. Like to the point where even when I open the door, like I just throw up.”

Theme 3: Influence of TLE on the different areas of life

When asked about the influence epilepsy has on his quality of life Henry stated that:

“I don't think epilepsy affected the, quality. I, I think it just affected like, the way that I, that I have to live, you know?...not necessarily. the quality.”

Even though Henry reported that TLE didn't influence his quality of life, it does influence the way that he has to live. Henry reported that TLE can cause him to have a panic attack, unprovoked. That he sometimes wakes up with a panic attack. The occurrence of the panic attacks has led to him developing a fear of leaving the house due to fear of having a panic attack in public. This has led to him being socially withdrawn.

Socially withdrawn. Henry's fear of leaving the house influences many facets of his life such as his work preference, social life, interpersonal and intrapersonal life.

When asked to describe his social life Henry stated that:

“I have a few friends. I have a few friends, but this is a, a very small town, so I feel like I know almost everyone. I don't go out. I only go out like when I've had like a few drinks.”

When asked if his reservations to go out and socialise with others was linked to the fear of having a panic attack Henry responded by saying:

“yeah, I mean that's why I always, I think about it first.”

During the interview, Henry stated that he had experienced a panic attack a few days prior. When asked what might have triggered it he stated:

“ I don't know. I just, it happened like when I woke up. Nothing in particular happened. immediate after, like, sometime after, nothing in particular happened. Just, just that, it just happened. “

Henry's condition influences his social interaction with others because prior to getting a seizure, during a seizure and post seizure he states:

“I can't speak to people. I can't hold a conversation. I can't, I can't do anything. I just don't want to be anywhere. except in a dark room or just dead.”

Preference for remote jobs over in-person jobs. Henry's condition poses a challenge for jobs that require in- person work and a lot of verbal communication. As a result, Henry finds solace in remote jobs that have limited verbal interactions. Henry works online as a junior programmer. When asked about the influence that epilepsy has on his work life, he stated that:

“sometimes I don't want to go anywhere. So I don't want to leave the house. And my job now, I, I can still work without having to go anywhere. So that, uh, that makes it easier.”

Interpersonal and intrapersonal relationships. When asked how his condition had influenced his interpersonal and intrapersonal relationship Henry stated:

I feel like, in the beginning, because it was a bit confusing, um, it, it wasn't easy for everyone else, but then that also was a good thing because, I feel like the people who were supposed to leave left.

And the ones who stayed, actually I'm still very close with them now. So, well, it was difficult and confusing for them and for me in the beginning.

When asked about how his diagnosis influenced his romantic relationships, Henry responded by stated that:

“Well, the first one, my first real romantic relationship was when I was figuring it out. for the most part. she was there for me, but then it got too much. and she left. So I, I think that was the only, romantic relationship it affected. And then in the time I was, I was figuring it out. I didn't really date.”

Physical & cognitive difficulties pre-episode, during and after episode. Temporal lobe epilepsy also presents physical and cognitive challenges for Henry. When asked to describe his experience with his seizures he stated that:

my mind usually works like, okay. If you think about my mind, like a Porsche, on the freeway in the fast lane. It's always moving fast and it's doing what it needs to do. But now I feel that like, at times like this, I feel like I'm driving, uh, a yaris and I'm trying to do the same speed as a Ferrari, but it's not happening. my mind is still trying to work the same way it does, but things aren't, things aren't connecting.

He further stated that:

“Like, like I try, but I can't. I can't, like, I can't, I can only wake up for like five seconds and then, um, like, yeah. So, uh, physically, yeah, I, I can't wake up. I can't move. And if I do move it's like, it's like a pain. All of my everywhere.”

Theme 4: Management of TLE, Anxiety & Depression

The sub-themes identified were *reluctance to take medication: fear of losing autonomy & drive*, alcohol use to ease anxiety, grounding exercises and downward comparison.

Reluctance to Take Medication: Fear of Losing Autonomy and Drive.

Although AEDs have been shown to be effective in the treatment of epilepsy, Henry stated that he stopped taking medication from the age of 23. Henry was prescribed AED's, Mood stabilizers and antipsychotics. He stated that the AED'S weren't that helpful. Henry reported bad experience with previous medication that was prescribed to him.

The only things that did stuff were the antidepressants and the antipsychotics. The antidepressants made me wanna sleep and antipsychotics, made me not able to sleep.

So it was very weird, very weird time.

I think it was only after I turned like 23. when I decided to just stop taking the medication. I just, I deal with it on my own. That's when it became better

that medication makes me like not want to do anything. I lose my, my drive and my patience,

Henry reported that he opted to manage his condition without medication.

I basically learned how my mind works. even though I'm still unsure now, I learned how to deal with it without needing to take medication. Even though sometimes it makes living, difficult. It's worth it. As I said before, because that medication makes me like not want to do anything. I lose my, my drive and my patience, so, that's what I learned.

It's like the sacrifice of that one week where you're not okay is better than the side effects of the medication. Now that I know how to handle it better, and also like I have a job that I enjoy, which keeps my mind off everything. Even if I'm going through a bad phase, I just work. Before it used to happen, very frequently, like at least once a month. Like for at least like five days a month, I'm not okay. But now it's once every few months. So it's better to handle, but I still prefer not taking the medication. it's still not worthwhile for me.

Henry is open to therapy but very reluctant to taking medication. Henry stated that since his arrival in Portugal in 2017, he has been struggling to find a psychiatrist/psychologist that speaks english. Even though he does speak Portuguese, he stated he prefers to see

psychiatrist/psychologist that speaks English as he will be able to express his emotions and feelings better in English than in Portuguese.

Alcohol consumption to ease anxiety symptoms. Alcohol consumption came up quite frequently during the interview as a means of dealing with anxiety. Henry experiences difficulty being around people and at times is unable to leave the house without first having a drink to calm his nerves.

I don't go out. I only go out like when I've had like a few drinks.

Grounding exercises. Henry researches his condition to gain better understanding of what he is experiencing. When Henry experiences an aura (Feeling of onset of epilepsy episode) he uses grounding exercises to help him deal better with it.

I'm smart enough to know, okay. this is a depressive episode. Don't take it in too much. Just go. Or, you are not yourself right now. So don't be too impulsive. Okay. Think twice, you know, not dumb.

Theme 5: Protective factors

The interview revealed Henry's protective factors. Henry has a support system consisting of his sister, close friends & colleagues.

Support From Sister and Close Friends. As Henry fears leaving the house, in the past he has had to rely on online shopping but now he has his sister to assist him with errands e.g. shopping. The presence of the sister also provides him emotional support.

"I'm just glad that my sister moved in with me a few months ago. Cause now I don't have to go and do shopping. Like I just give her the money and like, yeah, go buy this."

Inclusive Work Environment Supportive of People With Epilepsy. Henry works remotely as a junior tech. The company that he works for is inclusive and fosters

an environment that is supportive of people with epilepsy. When he is experiencing epilepsy episodes the company and colleagues provide him with an opportunity to rest. When asked what he does when he has a seizure and how it influences his work he stated:

“I basically just, I push through it. There's nothing else I can do. I just push through it. And that's another reason why I love my job now because everyone has a very, I wanna say intimate relationships with each other.”

“I can just tell my team, like, listen, it's one of those days and they're like, “oh, no, cool. Just, if you wanna go, go”. And I'm like, oh no, I'll work, but I'm just gonna take it easy. “

Theme 6: Healthcare and social support for People With TLE

Henry explained the frustration that comes with TLE, anxiety and depression, is the lack of explanations from the health providers when diagnosing and prescribing medication. That there's not enough information or awareness provided to PWE and mental illness. When asked if he felt that psychoeducation was needed, he stated:

Yeah. Honestly speaking, I think that would be beneficial for everyone and not just people with temporal epilepsy. I feel like. Everyone, like people who suffer from anxiety, depression bipolar, like if it's explained to you in that way, like other way that not only like other stuff that you read online.

But if people tell you exactly what's happening, then I feel like yeah, that would be, beneficial for everyone, everyone.

Instead of just diagnosing people and then telling them, okay take two of these pills every morning and then one of these in the afternoon. Just explain why take two of these, “it helps with this. It does this to you then, then you're taking this one for this”, you know? Yeah. It would, that's, that's for me, that's, that's what I would do. That's a common sense to let people know why you're doing stuff.

Henry described the complexities involved in providing assistance to people with TLE when they are experiencing anxiety and depressive episodes. Stating that the support in the social sense was complicated and tricky.

I feel like okay. When it comes to support, obviously, support from the health industry Yes. Is the same, I think. But the support, like from friends and family or just like normal people, I feel like that is very different because obviously if someone's having a seizure[convulsions], everyone's gonna panic in a public place, everyone's gonna panic and they're gonna help.

But if someone basically, is dissociating or having an anxiety attack or anything like that because of temporal epilepsy. Like no one's gonna understand that unless they know you. So I feel like, other support in that sense is different.

Discussion of Results About the Case study

The findings indicated a co-occurrence of anxiety and depression in temporal lobe epilepsy in this case study.

Discussions of the psychometric tools

Regarding the psychometric tools, the study made use of descriptive analysis. Descriptive statistics are used to convey quantitative information in an understandable manner. The American Psychological Association dictionary (2023) define descriptive analysis as techniques for showing the major features of sample data without necessarily extrapolating to a broader population.

It often contains the mean, median, and mode to illustrate central tendency, as well as the range and standard deviation, which show how evenly distributed the scores are within the sample. Charts and graphs, such as a frequency distribution or histogram, are examples of descriptive statistics (APA,2023). The mode found in the study was “2”

There were symptoms that Henry rated higher (2) which is indicative of experiencing the symptom more than half of the week. These consisted of:

PHQ-9

- Feeling tired or having little energy
- Having trouble falling asleep/sleeping too much
- Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

GAD-7

- Not being able to stop or control worrying
- Worrying too much about different things
- Becoming easily annoyed or irritable
- Feeling afraid as if something awful might happen

Discussion of interpretation of findings, using Hermeneutic phenomenology and S-REF model

Through the phenomenological framework and self-regulatory executive functioning model, this case study observed several aspects:

The hermeneutic circle was evident in the participant's life experience regarding mental health. As he stated that in his childhood, he witnessed behaviour that was indicative of mental illness but in his family, mental illnesses were considered to be a spiritual attack. His interpretation was revised in that he stated that he chose to not follow the family's belief regarding mental illnesses and instead chose to seek help when he started experiencing depressive symptoms.

Temporal lobe epilepsy affected many aspects of Henry's life, one of these aspects is relationships. Henry experienced challenges in his romantic relationship, he opted to stop dating while he was learning about his diagnosis, as he noticed that his condition presented a lot of confusion within him as well as his relationships and therefore opted to take a break from the relationship which led to him having renewed understanding of

his condition. Henry revised his interpretation and understanding of his diagnosis through researching temporal lobe epilepsy, attending therapy and group sessions.

These findings support the S-REF model in that Henry's experience with temporal lobe epilepsy has led to avoidance behaviours such as social avoidance. Henry avoids social events as a method of preventing the possibility of having a panic attack in public. He has even opted to work remotely as a result.

Cognitive attentional syndrome (CAS) is evident in the case of Henry. His selection of the CAS is a response to the occurrence of negative thoughts or perception about temporal lobe epilepsy, focal impaired seizures and panic attack. Henry's positive metacognitive beliefs consist of ruminating about the possible occurrence of panic attack while he is in public.

When asked if his reservations for socializing were related to his fear of having a panic attack, he stated that *"yeah, I mean that's why I always, I think about it first."* In Henry's case, CAS manifests in attentional strategies such as screening for unhealthy coping strategies such as drinking before going out or avoiding be in public.

The case study indicated the presence of depression and panic disorder with agoraphobia. Fear of public spaces is a common occurrence in people with epilepsy. Henry's symptoms of panic disorder with agoraphobia elicits his self-medication of excessive consumption of alcohol in an attempt to reduce his anxiety and prevent a panic attack from occurring. As he is incapable of leaving his house without first drinking alcohol.

Alcohol dependence is commonly linked to anxiety disorders in both community-based epidemiological research as well as clinical population studies (Mariani & Levin, 2008). Alcohol bingeing or withdrawal is considered a trigger for seizures which can potentially worsen Henry's condition. The negative metacognitive belief Henry experiences is reflective in the aforementioned results from GAD-7 *Not being able to stop or control the worry*

Final Discussion

Henry was misdiagnosed with bipolar when he was 16 and only received the diagnosis for Temporal lobe epilepsy when he was 19. It is common for people with temporal lobe epilepsy to be misdiagnosed as was the case in the case study conducted on a woman who had 9 years of unprovoked anxiety and dyspnea attached associated with symptoms of depersonalization and derealization (Deutsch, Rosse, Richard, Burket, 2009).

The attacks experienced by the woman were associated with suicidal ideation, derogatory voices, frightening images that led to emergency psychiatric hospitalization. The woman had been treated for panic disorder without agoraphobia which was unsuccessful. The diagnosis for temporal lobe epilepsy was only considered when she responded positively to carbamazepine (Deutsch, Rosse, Richard, Burket, 2009).

This unfortunately was also Henry's experience as he would find himself in hospital without any recollection of what might have happened, being informed that he had attempted suicide. The commonness for temporal lobe patients to be diagnosed with bipolar or depression, anxiety as temporal lobe epilepsy can be attributed to fact that TLE may result in the manifestation of many of the depressive/bipolar symptoms. Epilepsy is often associated with affective disorders (Kang, Park, Lee., Kwon & Kim, 2019). The affective disorders seldom occur concurrently with the seizure occurrence which can often lead to a misdiagnosis (Kang, Park, Lee., Kwon & Kim, 2019).

Henry's experience with anxiety and depression was apparent from his adolescence by the age of 16. After the diagnosis Henry stated that his psychologically distressing symptoms were worsened as a side effect of the medication he was prescribed. The psychological distress experienced by Henry consists of suicidal ideation, depersonalization, dissociation, panic disorder with agoraphobia.

Temporal lobe epilepsy diagnosis's pose many challenges as its symptoms can be very similar to other mental illnesses. It is not possible to state whether the psychological symptoms that Henry experienced were solely temporal lobe epilepsy symptoms or comorbid anxiety and depression. There is disagreement over the types of anxiety that are unique to people with epilepsy, their pathological importance, and the way they should be cognitively categorized (Rauh, Domschke, Hirsch, & Schulze-Bonhage, 2023).

It is not uncommon for people with temporal lobe epilepsy to experience panic attack. It is worth noting that numerous studies have alluded to numerous occasions of misdiagnosis of panic attack for temporal lobe epilepsy and confusion between the two as they share overlapping features.

Distinction between temporal lobe epilepsy and panic can be made by observing the following. Panic attacks typically last longer than seizures. Ictal episodes are more stereotypical, whereas panic episodes are more prone to manifest differently (Hurley, Fisher & Taber,2006). Even though seizure disorders may begin with fear or anxiety, they might proceed to more typical symptoms (e.g., olfactory auras, aphasias, amnesic characteristics, motionless state, visceral automatisms). The presence of these basic epileptic traits at the onset (prior to the fear/panic sensations) implies seizures. Panic disorder is 50% more likely to be connected with agoraphobia (Hurley, Fisher & Taber,2006).

There is evidence that suggests familial links associated with developing panic disorder, and being emotionally distressed can increase panic disorder; the appearance of temporal lobe lesions on imaging can imply epilepsy; and some panic disorder medications (e.g., tricyclic antidepressants) might worsen seizures. It is evident from the findings that Henry has panic disorder with agoraphobia.

The co-occurrence of panic disorder with agoraphobia is prevalent among people living with epilepsy. Patients who develop panic disorder often experience palpitations, sweating, trembling or shaking sensations during seizure attacks or anticipation of a seizure attack. The exact causes for this co-morbidity are not well understood but may be attributed to anxiety symptoms presenting as an aura to seizures.

Henry's epileptic episodes resulted in him experiencing ictal fear, amnesic features, motionless state, visceral aura as well as aphasias. These symptoms have an adverse effect on his daily functioning, although at times he may attempt to push through the symptoms by working, these symptoms can bring his work productivity to a halt. Depressive symptoms provide a challenge for Henry. He stated that during his seizures he experiences suicidal ideation which further enforces his agoraphobia because it makes

him isolate himself as he described it as making him feel like just sitting in the dark corner alone and away from everyone.

His other concerning symptom is inability to communicate with others when he is having his seizures and after having a seizure. This posed challenges with his previous jobs; the current job is advantageous for him because it doesn't require constant verbal communication.

Henry stated that he experiences an aura before the onset of his episodes which is basically a warning that he is going to experience an episode. When this occurs, he either attempts to push through it or he informs his colleagues and superiors of what is about to happen. He is fortunate enough to work for a company that is very inclusive and accommodative of his condition which makes it better for him to balance his work and the demands of his condition. His job, colleagues and supervisors serve as his protective factors as they provide him with the necessary support. Henry's agoraphobia doesn't interfere with his finances as he works from home.

Although AEDs, mood stabilizers are considered affective in treating temporal lobe epilepsy, Henry is reluctant to take medication, stating that he felt that the medication made his condition worse and made him lack ambition and drive. Even though the doctors would make changes to the dosages and so forth trying to find what would work best for him, he felt the efforts were futile.

As stated above there are some medications (tricyclic antidepressants) that can worsen seizures. This may have been a possibility. It is not uncommon for people with epilepsy, anxiety and depression to stop taking medication (O'Rourke & O'Brien, 2017).

Niriayo, Mamo, Gidey & Demoz (2019) conducted a study on medication adherence of people with epilepsy, they found that more than one third of the epileptic patients had a negative medication belief, and the majority of them were nonadherent to their medications. Predictors of medication nonadherence included comorbidity, a seizure experience, low belief in the necessity of taking a medication, high belief in the concern of taking a medication, and negative belief in taking a medication (Niriayo, Mamo, Gidey & Demoz, 2019).

The psychopathology and epileptic symptoms that Henry experiences interferes with his daily functioning, although he expresses that he doesn't perceive it as affecting his quality of life but just the manner in which he does things. It requires him to take extra measures just to be able to cope with the daily functioning.

It is worth noting that when all of Henry's symptoms are taken into consideration collectively, they can be considered to also be indicative of interictal dysphoric disorder. A condition that has been proposed in people with epilepsy (Conforti, Maekawa, Lisboa & Filho, 2023). The proposed diagnosis for interictal dysphoric disorder entails the presence of 3 out of 8 symptoms (Conforti, Maekawa, Lisboa & Filho, 2023).

The symptoms are grouped in clusters of *labile depressive symptoms* (depressed mood, insomnia, pain & anergia), *labile affective symptoms* (fear and anxiety) and lastly *specific symptoms* (paroxysmal irritability and euphoric moods).

Based on the proposed diagnosis for interictal dysphoric disorder Henry's symptoms of pain all over his body, panic attack with agoraphobia, suicidal ideation, irritability, and moments of euphoric mood make him a possible candidate for IDD.

One of Henry's frustrations was regarding the lack of detailed information provided to people with epilepsy by the healthcare and the need for increased psychoeducation. Psychoeducational programs for PWE is still lacking. There is frequently little to no information provided on the theoretical framework governing interventions, teaching techniques and methodological approach of the programs (May & Pfäfflin, 2005).

Limitations of the study

Given the fact that Henry was found to suffer from agoraphobia, the online delivery of the interviews was very beneficial. It is worth considering when dealing with people with epilepsy who are likely to experience some concerns about leaving their house. Particularly to be involved in a discussion about their conditions and challenges that could possibly trigger a seizure. This possibility can pose as an obstacle and possibly discourage

participation. The online method however allows the individual to be interviewed in the comfort of their home providing them with the needed security.

The online method has its downside in the sense that you don't have full view of the participant and therefore can only make limited observations about the participants behaviour during the interview. E.g. it is hard to determine during the online interview if the participant avoids eye contact or not, is tapping his foot etc. When dealing with online studies, technical difficulties should be anticipated.

Conclusion

The case study on South African adult with temporal lobe epilepsy- Co-occurring Anxiety and Depression provides valuable insights into the complex interplay between temporal lobe epilepsy and comorbid anxiety and depression.

This case study provides valuable insights into the challenges faced by patient (in this case study) with comorbid epilepsy, anxiety and depression. It highlights the importance of a comprehensive treatment approach that addresses both neurological symptoms and mental health concerns.

This study has highlighted the participant's experience in his childhood and adolescence that informed or put in perspective the understanding of the emotional and personality traits as the psychic resources to deal with temporal lobe epilepsy after the diagnosis; perspective and personal feelings of the participant concerning anxiety and depression symptoms related to epilepsy diagnosis, the influence of temporal lobe epilepsy in the different areas of the participant's life (individual, family, social, work life); the manner in which the participant deals with the psychological experience of the clinical symptoms of epilepsy and the diagnosis information.

Comprehension of the aforementioned is vital when treating patients with epilepsy as clinicians need to assess for the possibility of comorbid psychiatric conditions, in order to offer comprehensive treatment outcomes. Future research should focus on developing more accurate diagnostic tools and therapies that can cater to patients' specific needs living with these conditions. In order to improve medication adherence and overall treatment outcome, healthcare providers should develop educational programs that strengthen patients' beliefs about their medications.

Temporal lobe epilepsy, depression and anxiety have a complex relationship that can have an impact on the quality of life of the individual. It is common to miss panic disorder with agoraphobia diagnosis during routine examination as the general anxiety scales do not indicate the presence of panic disorder or agoraphobia. The addition of qualitative interview is beneficial in getting a comprehensive picture of the conditions that the person/persons with epilepsy are dealing with. The findings from the study allude to the importance of the continued need for multi-modal treatment when it comes to temporal lobe epilepsy.

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